Māori Women's Perspectives of Raising a Loved One Who Has Autism (Takiwātanga)

A thesis presented in partial fulfilment of the requirements for the degree of

Doctor of Philosophy

in

Psychology

Massey University

Palmerston North, Manawatū, Aotearoa New Zealand

Jeanette Louise Hastie

2025

Abstract

This thesis presents research that explored the understandings, worldviews, and approaches of eight Māori māmā (mothers) with children (tamariki) or adolescents (rangatahi) who have been diagnosed with autism (takiwātanga) in Aotearoa New Zealand. An interpretivist qualitative research design was utilised that combined methods from Western methodologies and Kaupapa Māori and Mana Wahine theory and research. The methodology was transformative (whakaahua) in nature, as the concepts behind the Western methodological tools were transformed into the concepts of te ao Māori (the Māori worldview) through the application of Kaupapa Māori and Mana Wahine theory.

Eight Māori māmā attended one of four small focus groups consisting of two māmā and the researcher, during which they were encouraged to create an artwork while telling their lived experience of takiwātanga through pūrākau (narratives). Over approximately four hours, the māmā were asked to describe how they navigated the New Zealand education and health systems, and their home and community, with their tamariki and rangatahi with takiwātanga.

The pūrākau revealed that the māmā had brought about a transformation of their own by resisting the Western deficit-based model of autism and drawing on their cultural understanding of takiwātanga to change their negative Western-based experiences into positive Indigenous-based ones. This led to the development of a model inspired by the taiaha, a Māori weapon of war, that demonstrates how a deficit-based Western ideology about autism can be transformed into a strengths-based Indigenous ideology about takiwātanga, from both the researcher's perspective and that of the participants.

The findings also identified strong connections between the māmā and those professionals and others who supported them, whom they called "game changers". Professionals who were not supportive were circumnavigated or dismissed as the māmā held onto their own expertise and developed their own knowledge about takiwātanga.

The te ao Māori concepts of whakawhanaungatanga (relationship building), manaakitanga (showing respect, generosity and care for others) and tuakana-teina (the relationship between an older [tuakana] person and a younger [teina] person) were woven throughout the pūrākau, which the māmā drew on to strengthen their mana wahine (power as women) and mātauranga wahine (female knowledge). The thesis concludes that cultural competence for registered professionals in education and health should include formal assessments of their knowledge of te ao Māori concepts such as manaakitanga, whakawhanaungatanga, and tuakana-teina in relation to takiwātanga.

Acknowledgements

I humbly acknowledge the wāhine who decided to be part of this research journey with me. You opened your hearts and trusted me with your pūrākau about the lives of your tamariki (children) and rangatahi (adolescent children) with takiwātanga (autism). There are no words to describe how much I have appreciated your awhi (support). I am blessed to have known you and to hear about the deep, unwavering aroha (love) you have for your loved ones. It is my hope that your expertise as Māori māmā, and mōhio (deep understanding) of takiwātanga is clearly seen, heard and felt in this thesis. *Ngā mihi nui.*

It is with gratitude that I acknowledge Dr Vijaya Dharan and Dr Pania Te Maro who were my supervisors for this thesis. I thank you both for your time and patience with me. You were always there to remind me what decolonising Western dominance of research really means. Your support was like a warm sunny spring morning looking over a misty lake of possibilities. Your support in terms of te ao Māori was inspiring and without your keen sense of te reo Māori and te ao Māori, I would still be struggling to understand Māori concepts in translation.

Thank you, Matua Wiremu Barrett, you were part of my journey supporting me in how to discuss each māmā in this research and the clarification and deep meaning of Māori concepts. On the surface this looked like something simple to do, however in your beautiful way you reminded me about the right way to do this. Your kind and gentle nature underpinned by a scholarly understanding of te reo and te ao Māori was a true gift. Thank you, Wiremu. Dr Tepora Emery and Dr Ramari Raureti, thank you for your early support in terms of Kaupapa Māori theory and tikanga (rules) around engagement regarding the māmā in this research. Dr Richard Smith, your short talks on the research process while at work were very informative. I also thank Paul Vincent for his careful proofreading of this thesis.

I am grateful to Te Rau Puawai, Massey University's Māori mental health workforce development programme, whose scholarship has supported my academic journey through undergraduate study, master's study, and finally this PhD. Thank you to the Board of Trustees of Te Rau Puawai for having faith in me and supporting me for all these years.

Another expression of gratitude is owed to my whānau, who have been an endless source of support over 14 years of study. Firstly, to my life partner, Daniel, you have lived with me for 22 years, are the father to my children, and have helped me in every aspect of this long academic journey. Your support has been the only reason I have been successful. Thank you, Daniel. To my older children Jessica and Marc: after you told everyone I was

going to get a PhD, I really had no choice but to complete it. Just remember that the two of you and your younger sister Bricharne will always be my greatest achievement.

My final expression of gratitude is to Bricharne, who has takiwātanga (autism), an intellectual disability, and obsessions and compulsions as part of her lived experience. No term or diagnosis really defines you, my clever, amazing tamāhine (daughter). You are the real reason I have spent weeks, months, and years studying, wondering what on earth I was doing, and stumbling through hundreds of books and thousands of academic journal articles. The brilliant white light of your spirit is undeniable and untameable.

In some small way, I hope that what I have to offer the world about the lived experience you have provided me can support another whānau in a way that is meaningful for them. I hope that this research is able to inform the understanding of those people who work for the Ministries of Education, Health, and Social Development to stop for a moment, slow down, and think about what a difference they could make in the life of a whānau with the lived experience of takiwātanga by simply trying to understand. I hope that they would consider elevating the knowledge of the whānau to the level of expertise and listen to them. They know their tamariki and rangatahi better than anyone else.

Bricharne, you have provided me with the expertise in how you see and respond to the world and given me the strength to try to change it. You are my greatest teacher. Thank you, Bricharne.

Table of Contents

Glossary

ahae	defensive posture while wielding a taiaha
ako	to learn/to teach
Aotearoa	New Zealand
arero	tongue (of a taiaha)
aroha	love, compassion
Atua/atua	God/gods
awhi	support/nurture/embrace
hapū	sub-tribe
hauora	health, wellbeing
hui	social/ceremonial gathering
Io Matua Kore	supreme/divine being
ira tangata	human element/genes
iwi	tribe or people
kai	food
kaiako	teacher
kaitiaki	guardian
kanohi ki te kanohi	meeting face to face
kanorau ā-roro	diversity
karakia	traditional prayer
kaumātua	elders
kaupapa	principle/idea/plan
kauwhau	to recite
kawa	protocol/etiquette
kete	traditional woven flax basket
koha	gift/donation
kohanga reo	Māori full-immersion early childhood education centres
kōrero	talk/discuss/have a conversation
koro	grandfather
koroua	elderly male relative(s)
koru	spiral shape of an unfurling silver fern frond
kotahitanga	unity/movement of self-government and national unity
kuia	elderly female relative(s)
kupu	word
kura kaupapa Māori	full-immersion Māori primary school

mahi tahi	collaboration
māmā	mother/primary caregiver
mana	status/power
manaakitanga	support/respect/upholding mana
mana atua	divine right given to Māori by Io Matua Kore
mana tangata	leadership/talents bestowing power and status
mana wahine	strong, powerful woman
manuhiri	visitor/guest
marae	courtyard of a Māori meeting house
māramatanga	understanding
matatau	teacher
mātauranga	knowledge
mātauranga Māori	Māori knowledge
mātauranga wāhine	women's knowledge
mihi whakatau	formal welcome
mōhio	deep, expert understanding/to truly know
mokopuna	grandchild
moteatea	lament/song of sadness/loss/grief
nga kōrero iwi	tribal stories
Ngāti Porou	iwi based in the east of the North Island
noa	ordinary
pā	hillfort/tribal fortified village
pāpā	father/father figure
pepeha	traditional oral introduction
pōwhiri	formal welcome
pūrākau	storytelling/stories, narratives
rangatahi	adolescent
rangatiratanga	self-determination
raupō	bullrush
takiwātanga	Māori term for autism
tamāhine	daughter
tamariki	child/children
tane/tāne	man/men
tangata/tāngata	person/people
tāngata whaikaha	people with a disability
tāngata whaitakiwātanga	people with autism

tāngata whenua	people of the land
taonga	socially, culturally valuable/treasure
tapu	sacredness/forbidden/potential for power
te ao Māori	the Māori worldview
Te Ao Marama	the world of light/enlightenment
Te Kore	the great nothingness/void of unlimited potential
Te Pō	the realm of perpetual night
teina	younger sibling
tikanga	customs/rules/rituals
tipuna	ancestors
tohunga	expert/to have expertise
tōku/tōna anō takiwā	my/his/her own time and space; Māori phrase for autism
tuakana	older more expert brother/sister/cousin
tūrangawaewae	standing place/a place to stand
waewae	feet/leg/a place to stand/a place we are connected to
wāhine/wāhine	woman/women
wahine toa	strong, powerful woman
wai	water
waiata	song
waiata oriori	lullabies
wairua	spirit/spiritual/spirituality
wairuatanga	distinctive Māori spirituality/spiritual dimension
whaikōrero	formal speech/oratory
whakaahua	transform/transformation/embrace/inclusive
whakapapa	ancestors/genealogy/line of descent
whakatau	welcoming ceremony
whakataukī	proverb/significant saying
whakawhanaungatanga	relationship building/relating to others as if they were whānau
whānau	family/extended family
whanaungatanga	whakapapa connections
whāngai	adoption/adopted
whare	house/home
wharekai	dining hall
whariki	woven mat to sit or sleep on
whenua	land

Chapter 1: Introduction

Pepeha (Tribal Introduction)

Ko Mauao te maunga.

- (Mauao [Mount Maunganui in Aotearoa] is my sacred mountain. Here my ancestors built an altar to offer thanks to the Atua [Gods] after their safe arrival to Aotearoa. It is my physical and spiritual connection to my tribal land and people.)

Ko Tauranga te moana.

- (The harbour my ancestors landed in is the ocean waters around Tauranga on the Northeast coast of Aotearoa.)

Ko Taakitimu te Waka.

- (The name of the waka [canoe] they travelled in from Hawaiki [the Pacific homeland of Māori] was called *Taakitimu*.)

Ko Huria te Marae.

- (The name of my whānau marae [traditional meeting whare or house] is called Huria Marae.)

Ko Ngāti Ranginui te Iwi.

- (The name of my iwi [tribe] is Ngāti Ranginui.)

Ko Jan Hastie toku ingoa.

- (My name is Jan Hastie.)

From 'Autism' to 'Takiwātanga'

The Māori word for autism is 'takiwātanga', which was coined by linguist and educator Keri Opai. It is a derivation from his phrase for describing autism, 'tōku/tōna anō takiwātanga', which means 'my/his/her own time and space' (Altogether Autism, 2020). 'Takiwātanga' affirms the person as being whole and valued and resists the understanding of being less than others. The research reported in this thesis examined the lived experiences of eight Māori māmā (mothers) raising their tamariki (child[ren]) and rangatahi (adolescents)

who had been diagnosed with ‘autism’ in relation to education, health, home and the wider community.

Throughout this thesis, my intention is to highlight te ao Māori (Māori worldview) perspectives of mana wāhine (strong women) and particularly their mātauranga wahine (Māori women’s knowledge). There are examples of reframing, rewriting, and re-storying the lived experience of autism in the literature which challenge the deficit-based Western model of autism (Colavita et al., 2014; Douglas et al., 2020; Hastie & Stephens, 2019; S. Ryan & Cole, 2009; Treffert, 2009).

This research presents positive perspectives of takiwātanga as articulated through the authentic voices of the māmā as they kōrero (talk) about how they have navigated the various systems that interact with on a daily basis. During the focus groups, the wāhine did use the word ‘autism’ in their kōrero, but it was clear that the word held no power for the wāhine, unless it was being used within the education and health systems or the home and the community as a way to access support services, funding or knowledge.

This thesis therefore seeks to re-story the phenomenon of autism and its deficit-based connotations analogy as the phenomenon of takiwātanga, which incorporates a strengths-based understanding that illuminates the whole person as valued and valuable. From Chapter 5 (Discussion) onwards, I will not use the term ‘autism’. Before Chapter 5, I use either ‘autism’ or ‘takiwātanga’, depending on whether the context is based in the Western worldview or te ao Māori.

Positionality and Reflexivity

L. T. Smith et al. (2016) highlight that in Kaupapa Māori research the researcher must always operate in an authentic way with Māori and work towards positive outcomes for Māori. The researcher must intrinsically know or seek to understand the complexities of the intersectional boundaries and liminality of those with whom they are engaging in research.

There is, therefore, a need for me to know myself as a woman, mother, sister, aunt and researcher intimately, and to acknowledge the intricacies and the aspirations of the communities in my research. Therefore, articulating who I am and where I am from serves as both whakawhanaungatanga (relationship building) and reflexivity.

According to A. Ryan and Walsh (2018), reflexivity involves a critical assessment of how the construction of knowledge is affected by the significance of the environment, power,

context and subjectivity that is delineated during this process. The absence of reflexivity on the part of the researcher simply reaffirms the practices, values and knowledge of the power elites in society by replicating the dominant research ideologies. As a researcher, it is my responsibility to acknowledge my world, where I position myself within this world. Accordingly, I position myself as a Māori woman of a tamāhine who has takiwātanga, and therefore as an insider researcher in relation to this study.

Hayfield and Huxley (2015) discuss insider and outsider perspectives in research and describe an insider researcher as someone who is a member of the group that the research participants belong to. This position provides an advantage when developing research questions, recruiting participants, and analysing the findings. It has been argued that an insider researcher has greater insight into the lives of the research participants, and therefore is well positioned to maintain ethical boundaries (Dwyer & Buckle, 2009; Gair, 2012; Labaree, 2002; Miller & Glassner, 2016). According to LaSala (2003), an insider researcher's shared identity with their participants results in the likelihood of shared interests and concerns, and this helps to ensure that the priorities of the participants are kept in the foreground.

As an insider researcher, I am keenly aware of the unique characteristics of tāngata whaitakiwātanga (people with autism), and I have purposefully organised this research around the kōrero of the wāhine as the experts in the lives of their loved ones and indeed their own lives. By working through the reflexive process, I realised that at all times during the research my focus would be on enhancing the mana of the māmā and ensuring that they and their kōrero would be treated as taonga (treasures). The knowledge that is produced by the research is owned by them, and I informed them of this before, during, and after the research.

I am a fully registered social worker and hold a current annual practising certificate. I am acutely aware of the code of ethics and code of conduct that underpins the Social Workers Registration Board, which governs social work in Aotearoa. I have worked with Māori communities during my career and believe I am culturally competent and understand what cultural safety entails.

I believe that the wāhine in this research felt listened to because I have a 26-year-old tamāhine (daughter) with the lived experience of takiwātanga, intellectual disability, and compulsions where she repeats the same behaviours over and over in the same sequence each day. Since she was born, my daily life has been centred around her and the gifts that she

brings to the world. I myself use both ‘takiwātanga’ and ‘autism’ in relation to her, depending on the situation, but one thing remains the same: no term defines her; *she* defines *us* as her whānau (family).

This provided me with a level of understanding of the participants’ lived experience, and engendered trust in relation to the more unusual experiences they disclosed. I believe that my presence was affirming and provided a space for them to be authentic about their lived experience. This of course makes me fully accountable to the women in this research, their loved ones, their whānau, hapū and iwi. The research design itself minimised oppressive aspects of traditional Western scientific research by privileging the lived experiences of the māmā as mātauranga wahine that is informed by te ao Māori.

Motivation for This Research

My inspiration for this research came from my own experiences of having a tamāhine with takiwātanga and learning to advocate for her rights. I understand how ‘silenced’ you can be by a system that only views you as a client number. Another strong motivation came from my own māmā, who supported me in my journey with her mokopuna (granddaughter) by encouraging me to speak up, ask questions, and research to increase my own understanding. She only saw perfection in my tamāhine and loved her unconditionally. Her māmā was also a wahine toa (a strong and brave woman), and so I come from a long line of strong independent wāhine as my role models. I honour them by honouring the māmā in this research and by providing a space for them to have their voices heard loud and clear as they articulate their knowledge.

Organisation of This Thesis

The thesis consists of six chapters. Chapter 1 provides an introduction to the thesis that includes my pepeha (traditional Māori oral introduction) and my experiences as a māmā of a tamāhine with takiwātanga. My career is outlined and my intentions in conducting this research. The literature review carried out in Chapter 2 outlines a brief history of autism, followed by the background relating to education and special education in Aotearoa New Zealand. The roles played by the Ministry of Health and the Ministry of Social Development in relation to people with autism are reviewed along with the avenues of disability funding available. Descriptions of the Western biomedical model of disease and illness and the social model of disability lead into a discussion of Indigenous perspectives on disability and feminism (mana wahine). Chapter 3 describes the methodology and methods used in the

study. Chapter 4 then provides the findings of the research, and Chapter 5 discusses the implications of the findings. Chapter 6 concludes the research and provides recommendations in relation to its findings.

Research Question

As developed from the findings of the literature review in Chapter 2, the question that guides this research is:

> *What are the experiences of Māori māmā with education, health, home and the community in raising a loved one with takiwātanga (autism)?*

A Note on Style

This thesis has been written in resistance to Western academic language that has a tendency to be rigid and overly complex. I have intentionally written this thesis in language that is easy to understand to ensure this work is accessible to as many people as possible, in line with a rich genre of writing associated with Indigenous feminist research (Arvin et al., 2013; J. Lee, 2009; Million, 2009; Sangster, 1994; L. T. Smith et al., 2016).

While my voice is prominent, my goal was to elevate the voices, pūrākau (stories) and knowledge of the māmā above all others. I humbly invite you to accompany me on this journey and encourage you to pause and reflect on the power of the wāhine toa who are the essence of this research.

Chapter 2: Literature Review

Introduction

The Swiss psychologist Eugene Bleuler first used the term *autism* to mean 'self' in 1912, but it is Leo Kanner and Hans Asperger who are credited with increasing awareness of autism following their work with over 400 children in 1943 and 1944 (Asperger, 1944; Feinstein, 2011; Kanner, 1943; Wolff, 2004). Kanner and Asperger described characteristics in the children that included an absence of empathy, deficits in socialisation, stereotypical patterns of behaviour, a severely limited use of language, and an aloofness coupled with an obsessive need to preserve sameness (see Rimland, 1964; Silverman, 2012). Social and emotional disturbances associated with autism relate to the difficulty of mastering the subtle nuances of social communication, including the use of intentional eye contact, making gestures to share attention with others, and making spontaneous responses to being greeted or someone saying farewell (Dawson et al., 2004; Spezio et al., 2007).

The *Diagnostic and Statistical Manual of Mental Health Disorders Fifth Edition, Text Revision* (DSM-5-TR) defines autism spectrum disorder (ASD) as having a range of persistent deficits under five criteria:

A. Persistent deficits in social communication and social interaction across multiple contexts.
B. Restricted, repetitive patterns of behavior, interests, or activities.
C. Symptoms must be present in the early developmental period.
D. Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.
E. These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay. (American Psychiatric Association, 2022, pp. 50–51)

These criteria are further complicated by their manifestations, which vary greatly depending on the severity of ASD. The lived experiences of people who have autism has often been associated with maladaptive behaviours that can include repetitive behaviours, restricted interests, and severe behavioural disturbances linked to having tantrums, becoming aggressive, and displaying self-injury alongside other psychiatric comorbidities (Attwood,

2003; Estes et al., 2009). Additionally, these symptoms can maintain impaired social functioning and can increase family stress and burden (Donaldson et al., 2019; Plumb, 2011; Sikora et al., 2013).

Caregiver burden associated with raising a child with autism features extensively in the literature and is discussed in terms of increased parental stress, marital disharmony, and dysfunctional family relationships (Bailey et al., 2007; Gerstein et al., 2009; Heywood, 2010; Landon et al., 2018; Searing et al., 2015; Shepherd et al., 2018). A study by Olson et al. (2021) suggests that the emotional and externalising behaviours of autism, including aggression and non-compliance, predict parental mental distress, and found that mothers were more likely to experience poorer overall mental health (see also Alsa et al., 2021; Asbury & Tosbeeb, 2023; Pruitt et al., 2018).

Other stressors highlighted in the literature are associated with delay in diagnosis of ASD, and various authors have shown that such delay is more common in parents with low socioeconomic status and racial minorities (C. Y. Chen et al., 2008; Mandell et al. 2009; Mazurek et al., 2014). The cost of living is higher for people with disabilities, resulting from additional expenses that are required to achieve a similar standard of living as people without a disability (Dudley & Emery, 2014; Minh et al., 2015; Tibble, 2005).

Stigma by association is an important factor for parents who have children with autism, and this is highlighted by Weastell (2017), who investigated common beliefs held by society around discriminating against and excluding children with autism. Autistic children are often not valued and discredited due to their characteristics and behaviours. Taken together, parental stress, higher financial and emotional costs, and discrimination and stigma by association are challenges that require a robust approach – one that challenges the deficit model of autism and explores ways in which autism can be evaluated differently.

Mothers of disabled children are more likely to have multiple roles, including primary caregiving and advocating for their children, and therefore tend to have multiple skills and knowledge in these areas (Good et al., 2017; S. Ryan & Cole, 2009; Traustadottir, 1999). This understanding aligns with the development of expertise, strengths and resilience by mothers through their daily care of a child who has autism. An alternative view to the deficit model of autism argues for an acceptance of autism and advocates for ‘seeing the person before seeing the disorder’ and a positive interpretation of the identity of the parent and the child (Gold, 2016; Woolfson, 2004). This approach includes appreciating life, focusing on strengths and

the unity of families, and the quality of relationships within the family unit (Cridland et al., 2014).

Overall, ASD researchers have shown little interest in the multitude of homegrown and unique approaches that mothers develop over the years when supporting their children, adolescents and adult children with autism (Morgan, 2009). Instead, researchers have tended to emphasise a gender-blind, deficit-oriented understanding of the lived experience of autism (Benjak, 2009; Durate et al., 2005; Estes et al., 2009; Falk et al., 2014; Gold, 2016). According to J. Lee (2019), around 11% of children in Aotearoa New Zealand will be impacted by disability and up to 84% of these children will be living in a single-parent home. Additionally, most of these homes will be headed by women. There is a paucity of research that focuses on the intersectionality of health, disability, and motherhood in Aotearoa, especially studies that focus on Māori mothers.

The identification of this gap in knowledge sets the foundation for this research, which aims to explore the lived experiences of Māori māmā (mothers) who have a tamariki (child) with autism (takiwātanga) through an Indigenous feminist lens. Māori have lived with takiwātanga, along with its causes and accompanying 'treatments', since early times (Robson & Harris, 2007). In terms of contemporary interpretations of autism, the theoretical and methodological approach of this thesis will challenge the dominant deficit perceptions of autism. An appreciative and positive stance will be taken that supports Māori wāhine (women) as experts about their daily lived experience of parenting a loved one with autism. It is hoped that this approach will increase our understanding of the cumulative and layered effects of culture, disability, and being a Māori wahine, with the aim of informing social policies, which are often fraught with difficulties in their design and implementation due to the complex nature of ASD (Stace, 2011). This research is important because mothers are often at the forefront of providing care and advocacy for their children, and this is heightened when a child has extra needs. This places Māori women in unique positions as advocates and activists, and as creators of knowledge and expertise in autism (Bevan-Brown et al., 2016; Stace, 2010).

There have been some key developments, both internationally and nationally, that have sought to establish and protect the rights of people with disabilities, and a range of governmental strategies that have sought more positive outcomes for people with the lived experience of autism. These are detailed in the following section, before the literature relating

to the New Zealand education, health, and social support systems and disability is reviewed individually.

Key Historical Developments Establishing the Rights of Disabled People

International Conventions on Disability

Aotearoa New Zealand is a signatory to the United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD), which is a benchmark agreement that advocates for the fundamental rights and freedoms of persons with disabilities (UN, 2006). Article 24 of the Convention states that under international law, people with disabilities are recognised as equal citizens, with the same rights as everyone else. Indeed, inclusive education is the key to achieving this and is one of the 17 Sustainable Development Goals adopted by world leaders in 2015 to tackle major global inequalities by 2030.

Aotearoa is also a signatory to the UN Convention on the Rights of the Child (CRC; UN, 1989). The CRC is a comprehensive human rights treaty that outlines the rights of children in international law. Article 23.3 of the Convention enshrines the right of children to access to, and the receipt of, an education, training, healthcare, and rehabilitation services in preparation for employment and recreation opportunities in a manner that supports the child to reach the fullest possible social integration, individual development, and spiritual development possible.

National Strategies and Disability

According to section 34 of the New Zealand Education and Training Act (2020), students with special education needs have the same rights to education at state schools as any other non-disabled student. This clearly protects the rights of students with disabilities to equal access to an education as those people without disabilities. The New Zealand Bill of Rights Act (1990) states that disabled people have the right to live with freedom from discrimination in all areas of life including education; it supports equality and disabled people's right to make decisions about ordinary aspects of life. The New Zealand Disability Strategy 2016–2026 (hereafter 'Disability Strategy') (Ministry of Social Development [MSD], 2016) reiterates that all children must be included in the education system of Aotearoa, and this principle is further supported by the National Curriculum (Ministry of Education [MoE], 2012). The vision of the Disability Strategy is that New Zealand is a non-disabling society and is a place where disabled people have an equal opportunity to achieve

their goals and aspirations by removing the barriers that restrict people with impairments (Office for Disability Issues, 2017a). The Office of Disability Issues is administered by the MSD and is responsible for the operationalisation of the Disability Strategy.

The New Zealand Education System

The School System

New Zealand provides free education to students from ages 5 and 19 at state schools throughout the country (Education and Training Act, 2020). The education system is made up of 13 levels, with primary school starting from Year 1 and going through to Year 8 and secondary school starting from Year 9, with students graduating in Year 13. Schooling is compulsory for students from six to 16 years old. For children under six, there are various types of early learning services, both teacher-led and whānau-(family-)led. There are also specific cultural early learning services, including Kohanga Reo (for Māori children) and Aoga Amata (for Pasifika children). The majority of children start school when they turn five years old (MoE, 2022).

Ka Hikitia: Accelerating Success 2013–2017 (MoE, 2013) was the first national strategy to work towards education services that support Māori students alongside their whānau, hapū and iwi (MoE, 2013). This strategy was underpinned by te Tiriti o Waitangi | Treaty of Waitangi and included five strategic outcomes:

1. Educational provision is responsive to Māori students that takes into context that they are part of their own and a wider whānau.
2. Māori education is free from racism, discrimination and stigmatisation.
3. The diversity of Māori is acknowledged that includes their diverse aspirations and lived experiences.
4. Identity, language and culture are important aspects for Māori learners.
5. Education is a space for Māori to exercise their authority and agency.

Ka Hikitia was a cross-agency strategy and included MoE, the Teaching Council of Aotearoa New Zealand, the Tertiary Education Commission, and the New Zealand School Trustees Association, which together encompassed all early learning, schooling, and tertiary education provision.

The next significant stage in the development of a national strategy for Māori education was Ka Hikitia – Ka Hāpaitia: The Māori Education Strategy 2023, which begins

by noting that the implementation of the original strategy has been successful and that Māori have been enjoying and achieving education success as Māori, learning skills to participate in te ao Māori (the Māori world) as part of their learning journey. Ka Hikitia – Ka Hāpaitia was set up to continue this success and revitalise the original strategy, emphasising the understanding that in order to create change it is important to further embed the concepts of Ka Hikitia. This requires deliberate action and passion by educators to follow through with the original concepts until the strategy is woven into everyday teaching practices (MoE, 2023).

A Brief History of Special Education in New Zealand

Exclusion of children with special needs from ordinary educational settings in Aotearoa goes back as far as the middle of the 19th century (Mitchell & Singh, 1987). Churches and voluntary organisations provided education for children with special needs through a charity model as part of their service to the community and religious values. The first institutions to open in Aotearoa included the Sumner Institute for the Deaf in 1880 and the Jubilee Institute for the Blind in 1891 (Hornby, 2014). By 1917, children with learning delays could attend special classes in some schools; however, those with sensory and physical disabilities were still denied access to an education in ordinary school settings (Mitchell & Singh, 1987). The worldwide civil rights movement worldwide in the 1960s and 1970s demanded expanded human rights alongside advocating for integrated and inclusive education. During the 1970s, special education in Aotearoa was influenced by key developments in the United States (Education of All Handicapped Children Act, 1975) and the Warnock Report on special education needs in the United Kingdom (UK) (Department of Education and Science, 1978). These developments led to a comprehensive special education system in New Zealand associated with a clear and strong vision to provide effective education for all children with special needs (Hornby, 2014).

By the late 1980s however, the special education provision had declined in Aotearoa due to the separate establishment of self-managing schools and the philosophy of inclusive education that promoted integration of children with special needs into the mainstream system (Hornby, 2014). The Education Act (1989) established the right for all children to attend their local mainstream school, and this was followed by the development of the Special Education 2000 policy (Coleman, 2011).

The Special Education 2000 Policy. This policy was based on a set of educational reforms following the Tomorrow's Schools report (Department of Education, 1988) and underpinned by the New Zealand Education Act (1989). The policy aimed to produce a world-class inclusive education system in New Zealand and to enhance the rights of children with high and very high needs to an education. It also aimed to ensure that there was support for those children with disabilities to attend their local school. The policy included a funding framework related to providing resources for students in a fair and equitable manner associated with where they lived, and what level their needs were assessed at. The policy consisted of five components:

- **Ongoing Resourcing Scheme (ORS)**. The ORS was designed for students with the highest ongoing needs of specialist support in school. According to Kearney and Kane (2006), 3% of students attracted this category of funding, which is linked to providing services such as speech-language therapists, psychologists, occupational therapists and educational support workers (ESWs). The scheme provided ongoing and guaranteed funding for students with high and complex educational needs. This included students with intellectual, physical and sensory disabilities. Funding decisions including ESW hours were decided by the school and Specialist Education Services. Similar resourcing across different settings was made available to eligible students (Coleman, 2011).
- **Severe Behaviour Difficulties**. Resource teachers: learning and behaviour (RTLB) specialists supported teachers with in-class and in-school strategies to manage students with behaviour and learning difficulties. Behaviour Specialist Support Services provided intensive in-school and off-site interventions for students with severe behaviour difficulties. The school was supported to involve parents and caregivers in the management of students with challenging behaviours and to manage crisis situations. Non-educational government and non-governmental agencies could be contacted and enlisted for further support of the school, students and their whānau (MoE, 2021).
- **Speech-Language Difficulties.** Additional funding was allocated as part of this policy to support students with speech-language difficulties. Speech-language therapists are employed by the MoE and support children with language and communications needs in education settings. This support

extends to the children's families, where they can provide advice and guidance (MoE, 2023).

- **Special Education Grant.** This grant was designed to support students with moderate special education needs and was allocated directly to the school based on its decile rating. A school decile rating measures the extent to which the students who attend the school live in poorer or low socioeconomic communities. This assessment denotes financial support from the government and determines how much funding a school may receive based on this data (Coleman, 2011).
- **Early Childhood.** Funding for coordinated specialist teaching, speech-language therapy and paraprofessional support for this sector was assigned at the same time as the Special Education 2000 policy was being implemented in the compulsory schooling sector (Coleman, 2011).

The Turn towards Inclusive Education

Sweeping changes to special education were being delivered during the social, political and cultural unrest associated with other neoliberal policies in Aotearoa New Zealand in the mid-2000s, and the term inclusive education started appearing in policy associated with the education sector. At its core, inclusive education is linked to a much wider understanding of children achieving to their full potential, and in Aotearoa it was linked to an obligation to uphold children's rights (Willis, 2009). Cathy Wylie (2000) produced a report reviewing Special Education 2000 that included more than 1,000 submissions and site visits to schools across the country. The report underscored the inequity of support for students with special needs, which was described as fragmented with gaps in accountability and inequalities of resourcing that reduced the opportunities for students with special needs.

The Special Education 2000 policy was reviewed again in 2010 by the National-led coalition government, and 2,000 submissions from groups and individuals highlighted serious concerns with a lack of compulsory teacher training and school leadership development in special education (MoE, 2010a). The review included 10 questions associated with school, transitions, funding, access to resources, and additional questions relating to accountability and what respondents signalled as the single most important change that was required in special education (MoE, 2010a). Moreover, there was a recommendation for compulsory pre-

service teacher education with evidence-based practice informing working with children with special education needs.

The 2010 review underpinned several rapidly developed initiatives that predicted all schools would demonstrate inclusive practices by 2014 (MoE, 2010b). According to Minto (2010), successive National and Labour Governments ignored the need to "sort out" the mess that was special education. Importantly, Selvaraj (2015) suggested that such policies perpetuated ableism and inequality, which was highlighted by the government being lobbied by interest groups such as CCS Disability Action and correlated with parental complaints escalating exponentially to statutory bodies, including the Office of the Ombudsman, the Human Rights Commission, and the Ministry of Justice through the court system (Gibson, 2010, 2012). This notwithstanding, further policy development tried to address the issues of special education for Māori and Pasifika students, who for the most part were invisible in educational disability policy, by including Pasifika learners, their parents, extended aiga (family), and communities into the equation. For Māori students in special education this required acknowledging the relevance of te Tiriti o Waitangi, and its principles of protection, participation, and partnership. Additionally, it was argued that there was a need to move from the Eurocentric ideology of embedded white privilege within the education system of Aotearoa (Bevan-Brown et al., 2016; Mauigo-Tekene et al., 2013).

Success for All – Every School, Every Child Policy. In October 2010, Rodney Hide, then Associate Minister of Education, launched 'Success for All – Every School, Every Child', the Government's response to the Special Education Review. This directive signalled to schools that they needed to be ready, willing and able to accept every child and, in Hide's words, give every child "a fair go" (Hide, 2010). Furthermore, a target was set for 80% of all schools in Aotearoa to become inclusive by 2014, with extra funding allocated to the sector that included 1,100 spaces for ORS-funded children to attend school. Moreover, individualised specialist support would be provided to 1,000 more children in the first three years of their schooling, particularly those who had not attended an early childhood centre prior to coming into the mainstream schooling system. For those with sensory disabilities, a more flexible service approach was to be implemented, with teaching resources allocated to the Blind and Low Vision Education Network and two Deaf Education Centres. Established special needs schools were encouraged to provide outreach services to provide specialist teacher support to children in mainstream settings (MoE, 2010b).

Special Education from 2015. In 2015, 156 forums were held around Aotearoa to gain feedback about improvements that were needed in special educational settings (MoE, 2015). The summary of engagement findings for these forums included the requirement for extra training of teachers in special education for early childhood settings and onwards. Parents wanted more involvement in decision making, with better information on the availability of support and transparency between services aligned with transitioning between schools or from primary to high school. The action plan from this report pledged to reorganise support for families and educators through the simplification of, and increased access to, timely information. Other improvements included the facilitation of collaboration between professionals, educators, students, parents and whānau.

In 2016, a select committee inquiry looking at support for children and young people with dyslexia, dyspraxia and autism emphasized increasing the capability of teachers and identifying students with learning needs as quickly as possible (MoE 2019). In 2017, a pilot of a new learning support delivery model was implemented in the Bay of Plenty, including Tauranga, Whakatane and Taupō. Six priorities were included in the action plan for 2019–2025, with Priority 1 linked to the implementation of a new Learning Support Coordinator role in schools (kura). Priorities 2 and 3 related to culturally responsive screening and strengthening early intervention processes in addition to timely information for parents. Priority 4 promoted an increase in the range and flexibility of services for neurodiverse children. Priorities 5 and 6 focused on supporting gifted children and those who are at risk of disengaging in education (MoE, 2019).

Overall, special education has evolved through various stages of development in the effort to address the learning support needs of students and their families in Aotearoa. Comprehensive changes in special education since 2008 have focused on needs assessment and well-timed information for families and whānau. By the introduction of six priorities regarding special education in 2019, it was clear that in some respects they were still trying to addressing similar concerns raised in 2010, which stressed the importance of collaboration between education, families and services.

Office of Disability Issues and Education

In 2015, the Education Review Office found that there were more schools who demonstrated inclusive practices in 2014 than in 2010. Ninety per cent of schools had enrolled one or more students with high or moderate needs. Fifty per cent had six or more

students with high needs currently enrolled. Almost all schools indicated staff had been provided with professional learning and development around supporting students with special needs. Fifty per cent of schools used other funding in addition to the Special Education Grant in supporting these students (Education Review Office, 2015).

While the above reports were targeted at schools and teachers, the Office of the Children's Commission – Mana Mokopuna undertook a survey to capture the voice of 474 disabled children and young people through a survey and face to face engagements. In 2018, the Office of the Children's Commissioner published a report called *What Makes a Good Life for Disabled Children and Young People*. The children who participated in the research behind the report wanted an education system that worked for them with flexibility and responsiveness. This included flexibility in how lessons were taught, accommodating start and finish times, and being able to choose what they wanted to wear in school. There was a request from the children and young people for a direct connection between what is being taught and what the students want to do in the future in connection with employment.

Specific Autism Services. Autism New Zealand is a non-governmental organisation that works with autistic people and the wider autism community. Its support services include outreach services, diagnostic guides, employment support, and transition services. The organisation is funded by the MoE to implement a programme called 'Tilting the Seesaw'. This is a two-day course suitable for whānau, primary schools, ESWs, learning assistants, special education needs coordinators (known as SENCos) and RTLB specialists. It provides a strengths-based approach and practical strategies to support everyday inclusion of children aged 5–12 with a diagnosis of autism and creates a connection between the school and home.

Altogether Autism is another non-governmental organisation that provides a national information and advisory service with up-to-date and evidenced-based information on autism for people who are autistic, their families, and professionals. The organisation arranges network meetings for the autistic community, sibling support that includes day events and camps for siblings aged 8–18 years, and weekends for adults. Professional development workshops run in collaboration with members of the autistic community. Journal articles, including peer-reviewed research on autism, are freely accessible on their website.

The MoH and MoE, meanwhile, published the New Zealand Autism Spectrum Disorder Guideline ('the Guideline') in 2008, a resource designed to provide an overview of autism in both children and adults in Aotearoa. This evidence-based resource covered the

identification and diagnosis of autism, ongoing assessments, interventions, and services for individuals with autism. It was published after 10 years of policy research that attempted to clarify autism from various standpoints, including lifespan implications and whole-of-government and best-practice approaches in an attempt to theoretically and practically address the complex nature of autism (Stace, 2011). The second edition of this 'living guideline' – one that is updated as new relevant evidence becomes available – was published in 2016, reflecting the latest best-practice evidence, applicable research, and the changing landscape of service user needs (Ministry of Health [MoH], 2020). The Living Guideline Group, an advisory panel of sectoral experts including individuals with lived experience of autism, educators, health professionals, and service providers – annually reviews evidence related to the original Guideline topics, reviewing and adding new guidelines and practice points as needed. The group also selects one new topic every year to review the evidence and make new recommendations when required or strengthen existing evidence (MoH, 2021). The third, and current, edition of the Guideline is named the Aotearoa New Zealand Autism Guideline: He Waka Huia Takiwātanga Rau and was published in 2022 (Whaikaha – Ministry of Disabled People & MoE, 2022). Its major innovation was a change in the language and terminology used, acknowledging that there had been a significant evolution in perspectives of autism since 2016. This was particularly marked in the rejection of the word 'disorder' and the acronym ASD to describe autism. Another notable distinction in this edition is a genuine attempt to acknowledge te Tiriti o Waitangi and an increase in the prominence of Māori perspectives, including the use of the term *takiwātanga* for the first time. Other changes include an increased use of te reo Māori (the Māori language) and the use of the health model designed by Mason Durie as a framework to promote equitable health outcomes for Māori (Whaikaha – Ministry of Disabled People, 2022).

Summary: Evaluating the History of Special Education in Aotearoa

The disparities between the education of children without special needs and the education of those with special needs are starkly apparent in the literature and date back to the 1800s. During the 19th century, policies actively excluded children with special needs from schools. What followed was nearly two centuries of marginalisation of children with special needs in an education system that has little positive regard for diversity, and even less for personal agency (Higgins et al., 2011). As noted above, Aotearoa has ratified the CRC (UN, 1989), however little attention has paid to children's rights in educational policies and ordinary practices in the classroom. Additionally, Aotearoa was criticised in the second UN

Human Rights Council Universal Periodic Review in relation to its lack of conformity to the CRC, and the government has been urged to come into line with the policies associated with this Convention (Lundy et al., 2012).

A recent independent report by the Tomorrow's Schools Independent Taskforce called *Our Schooling Futures/Stronger Together* highlighted the exclusionary practices of not enrolling disabled students in schools; if they are allowed to enrol, the students and their whānau were not always made to feel welcome (MoE, 2018). Likewise, it was reported that schools struggled to be inclusive with fragmented funding and resourcing, alongside accessing external support for students within a realistic timeframe. The report made three recommendations for disability and learning support that called for MoE to lead through a national strategy and policy. The report underscored an expectation that MoE will work collaboratively with the Education Hub, an organisation that works to bridge the gap between research and practice in education in Aotearoa (MoE, 2018). Its mission is to improve opportunities and positive outcomes for young people in education. This includes holding six-monthly forums where knowledge on practice, whānau and student experiences can be examined alongside reviewing progress and identifying priorities to improve outcomes for students with additional learning needs. The second recommendation of the Taskforce's report was every school should be supported to become inclusive and to share best practices. The final recommendation related to how the Education Hub needs to be funded appropriately to support its ongoing work to support best practice.

The history of education for Māori in Aotearoa is an important factor in this research, as it is characterised by 200 years of discrimination and oppression that have impacted the lived experience for Māori within education (Pihama, 2019). The history of education in Aotearoa has been described as a tool of colonisation that has been honed and perfected by years of imperial rule across Indigenous populations around the world by the British. Aotearoa was no different. Indeed, the colonial settler government of Aotearoa assimilated Māori through education policy and the missionary intent to support a wider agenda of separating Indigenous peoples from their land and identity (Pihama, 2019).

The third governor of New Zealand, George Grey, effected the Ordinance Act (1847) that funded missionary schools to teach English to Māori children, and this was initially eagerly accepted by Māori from the perspective of increasing their life chances (Simon, 1998). However, 20 years later, William Rolleston had become frustrated with the lack of

English being taught in missionary schools, which he saw as slowing down the assimilation process of Māori. He supported the establishment of the Native Schools Act (1867). Native schools were built close to villages and marae (courtyard of a Māori meeting house) for ease of access to Māori students. As evidenced in the *Appendices to the Journals of the House of Representatives* in 1862, one school inspector felt that "natives" (Māori) should not be offered a refined education or high mental culture. This related to the understanding that this would be inconsistent for the position that Māori were being afforded by the Crown, on the lowest rung of the societal ladder. This decisively makes education a space to control Māori as a cohort, and to control what Māori students were learning and how they were being educated for manual labour in the powerhouse that was the burgeoning Pākehā (New Zealand European) society. Indeed, this is highlighted by Native Schools Act prohibiting the speaking of te reo Māori on any school grounds funded by the government, further removing any form of self-determination for Māori within education (Walker, 1985).

For nearly 200 years, education has been a vehicle for the colonial settlers of New Zealand to assimilate Māori for what was considered a lifetime of servitude and manual labour. Building schools near Māori villages and paying the teachers to deliver lessons only in English was another way to build a workforce of compliant subjects. The Western educational lens has further created disparities for Māori in contemporary times and continues the process of colonisation through education. Adding to this history of assimilation, the lived experiences of tāngata whaitakiwātanga (people with autism) unsurprisingly are characterised by disadvantage, ableism and racism. These historical deprivations filter down into the everyday engagements of māmā with whaitakiwātanga and reinforce the underlying barriers to access to education.

The New Zealand Health System

The current New Zealand Health Strategy has an ambitious long-term vision "that honours Te Tiriti o Waitangi, is inclusive of all people, protects and promotes health, prevents illness, injury and harm throughout their lives" (MoH, 2023, p. 3). This section will focus on the support and services that are available for children and adults with a formal diagnosis of autism through the health system, specifically the MoH.

The Ministry of Health

The Ministry of Health (MoH) originated as the Department of Public Health in the early 1900s. The role of this ministry is to provide a coherent system-level leadership that

sets priorities for policy and performance in the health sector. The onus is on the MoH to achieve the health equity of the diverse communities in Aotearoa to improve people's experience of and access to health services. The MoH (2023) is also responsible for the implementation of the Government's health and disability policy ensuring the services are arranged as efficiently and effectively as possible for all New Zealanders.

The MoH is the principal advisor to the government on health and disability issues and provides coherent clinical, technical and practical advice to the Minister of Health and Associate Minister of Health. This informs the policies to improve, protect and promote health equity for all New Zealanders. One of the identified priority areas in 2020 included commissioning better health outcomes for Māori. Whāia Te Ao Mārama 2018 to 2022: The Māori Disability Action Plan worked with Māori leaders to develop initiatives to create a liberated space where tāngata whaikaha (people with a disability) can shape the direction of their own lives (MoH, 2018). The Action Plan encouraged the participation of the person with a disability in the decision-making process for their individual health plan, funding, and how services are delivered.

In order to get MOH-funded support services, a person must be assessed as having a physical, intellectual or sensory disability or a combination of these that is likely to continue for at least six months. This disability must limit your ability to function independently, and require ongoing support (MoH, 2019). Autism is identified as one of the developmental disabilities that is funded by the MOH. The full diagnostic criteria for ASD in the DSM-5-TR (American Psychiatric Association, 2022) are included in Appendix 1.

Ministry of Health Services for Autism. The MoH provides the following types of services for people with autism and their families:

- **Disability Information and Advisory Services (DIAS).** DIAS provide independent advice and information to people with disabilities, including autism, and their whānau. This includes advice about MoH and non-MoH services.
- **Autism and educational programmes for parents/caregivers.** ASD Plus: Education for Families is an educational programme for parents, whānau and caregivers of children aged 0–6 years with a diagnosis of autism. It is delivered in modules via distance learning with both group and individual sessions that can be tailored by the facilitators according to the needs of the whānau. ASD Plus is funded

jointly by the MoH and MoE. The non-governmental organisation IDEA Services is responsible for the service delivery of this programme across Aotearoa.

- **Support services for autism.** Eligibility for services is determined by the Needs Assessment Service Co-ordination Association (NASCA), the premium agency that determines the level and type of supports that are required to meet identified disability related needs and the goals of an applicant (MoH, 2018). Behaviour Support Services assist people with an intellectual disability whose behaviour requires extra support to engage in everyday settings, activities, and relationships by designing a plan to increase autonomy and community engagement (HealthCare New Zealand, n.d.) Another service is ASD Developmental Coordination, which is responsible for arranging multidisciplinary allied health teams that specialise in assessments of children and coordinate intervention and management plans with a focus on early intervention.

- **Supports in the home for autism.** Individualised Funding is a service provided through the MoH that gives disabled people a way of directly managing their disability support. They are then able to purchase contract care associated with household management and personal care that is provided by support workers. Respite funding is provided by the MoH Carer Support provision and is available for parents and caregivers to pay for services that allow them to take some time out from their ordinary daily caregiving duties of looking after someone with a disability (Te Whatu Ora, 2022).

Summary: Evaluating the Health System's Provisions for People with Autism

Interacting with the health system will become a regular part of life for families (whānau) with a child diagnosed with autism. This is partly due to it being a lifelong condition. Engagement with education will for the most part finish when the person with autism turns 21 years old. Getting a diagnosis of autism in the first instance tends to be slow and often difficult to attain (Eggleston et al., 2019; Ennis-Cole et al., 2013; Mandell et al., 2009; Searing et al., 2015). This is important because delays in a formal diagnosis that can only be made within the health system have ramifications for key types of funding including ORS funding for an ESW in early childhood, or a teacher aide at school, home carers, and personal carers for disabled persons living outside of a residential service.

P. Reid et al. (2019) notes that Māori, like other Indigenous peoples around the world, have experienced systematic health inequalities associated with inequitable access to the health system due to racism, marginalisation, and lack of cultural representation in the health workforce. It has been argued that a Western understanding of health may reinforce racism, and this can be seen in health interventions where Indigenous populations are viewed as individuals who are 'at risk' or have 'risk factors', and the focus is on changing behaviour and ignoring the social and structural inequalities that perpetuate negative health outcomes (L. T. Smith et al., 2016).

State Support of Those with Disabilities

The Ministry of Social Development

After the MoH and MoE, one of the most important support systems for families and individuals is the MSD. The MSD is dedicated to helping individuals be successful in their lives, which in turn should result in strong, healthy families and communities. One of the functions of the MSD is funding specialist services for disabled people and people with a health condition who require extra support to participate and be included in the community. The MSD works towards providing employment, income support, and superannuation services for the people of Aotearoa, and some of these services are linked to the whānau experience of autism (MSD, 2021). For the purposes of this thesis, I will explain the MSD benefit entitlements for children with a diagnosis of autism alongside those that primary caregivers may be entitled to in the day-to-day care of a child or person with autism. There are strict criteria for all benefits and allowances and the criteria is assessed by MSD staff. The MSD provides the following benefits:

- **Child Disability Allowance (CDA).** This is a fortnightly payment made to New Zealand citizens who provide primary care for a child or young person under the age of 18 years with a serious disability. The child or young person has been assessed as requiring constant care and monitoring for at least 12 months because of the seriousness of their disability. It is a payment in recognition of the extra cost, including parental attention, that is associated with the needs of a child with a disability (MSD, n.d.-a).
- **Disability Allowance.** This is a weekly payment for people who have regular and ongoing costs associated with their disability related to doctor and hospital visits, cost of medication, and other items such as clothing and travel. The criteria for this

payment include being a New Zealand citizen with a disability that is likely to last at least six months. It is, however, income-tested, meaning your income is assessed and there is an income limit beyond which you can no longer receive this allowance. It is possible to get the CDA and DA for the same child (MSD, n.d.-b).

- **Supported Living Payment.** This is a weekly payment to help recipients 16 years and over who are severely restricted from entering the workforce because of their disability. Additionally, this involve a weekly payment to a primary caregiver over the age of 18 years and who cares full time for their child, family member (other than a partner or spouse), or another member of your community who would ordinarily require hospital or residential level care. Hospital or residential level care relates to the person being cared for who fits the criteria for rest home care, residential disability care, extended care services for severely disabled children and young people, or inpatient or resident hospital care (MSD, n.d.-c).

The MSD supported each Māmā in this research with various benefits associated with autism, according to the different criteria of the benefits. Any entitlement is linked directly to a formal diagnosis of autism from a recognised and registered medical professional.

Evaluating the Ministry of Social Development's Provisions for People with Autism

There are avenues of support from MSD that are available to those who have a diagnosis of autism and their whānau, including help with the extra and ongoing costs that may arise with the lived experience of autism. In the mid-1980s, the MSD was called the Department of Social Welfare. Ann Hercus, Minister of Social Welfare from 1984 to 1987, asked a Ministerial Advisory Committee to report on a Māori perspective of the Department of Social Welfare. The seminal report that resulted was *Puao-Te-Ata-Tu (Day Break)*, and it highlighted how, since colonisation, institutional decisions have been made with little consultation with Māori and many of those decisions were made *for* Māori instead of being made *with* Māori (Ministerial Advisory Committee, 1986). The report identified structural racism in Aotearoa and particularly in the experiences of Māori who engaged with the Department of Social Welfare. In order to address this, the Committee suggested that Māori need to be included in any decisions that impact their future, and that there needs to be an investment in whānau, hapū and iwi to strengthen and maintain tribal responsibility with their own people.

The Biomedical Model of Health and Disease

The Western biomedical model of health and disease has dominated health provision for the past 200 years (Lyons & Chamberlain, 2008), and the diagnosis of autism is firmly embedded in this model. Additionally, the New Zealand health system is predicated on illness and disease originating from biological influences that include bacteria, viruses, physical injuries, or biochemical imbalances. By focusing on these areas, little attention is paid to the social and psychological factors that impact health and wellness. Therefore, the emphasis on brain structures and maladaptive and pathological behaviours informs an ableist understanding of autism that seeks to modify and medicate those people with autism whose behaviour is deemed to be outside social norms and societal expectations (Estes et al., 2009; McBride et al., 1996; Nelson & Prilleltensky, 2010).

The biomedical model assumes that the body and mind are separate entities and that all disease and physical disorders are biologically based. Looking for cures to these diseases has set medicine on a mechanistic pathway searching for biological causes of disease, and led to development of vaccines, medications and surgical procedures (Bernard & Krupat, 1994; Lyons & Chamberlain, 2008; Stroebe, 2011). The discourse of disability associated with the biomedical model began when religious leaders were replaced by doctors and scientists as the voices of authority in society, and diagnosis and treatment conceptualised disability as a biological product (Brittain, 2004; Humpage, 2007).

In the biomedical model, disability is understood as an individual problem that results from a limitation or impairment of bodily functions and structures that can include the mind. Causes of disability include disease, injury or other health conditions, and thus the biomedical model places disability alongside illness and sickness, as a deficiency or defect (Bingham et al., 2013; Forhan, 2009; Oliver & Kirk, 2015; Palmer & Harley, 2012). Viewed in this way, people with disabilities are considered to need treatment in order to ‘fix’ them so they become ‘more normal’, or to eliminate the causes of the impairment. Those who do not comply with this medical regime are considered unmotivated, supporting the belief around people not wanting to help themselves (Bingham et al., 2013; Roush & Sharby, 2011).

Disability thus becomes the defining characteristic of a person, and this shapes the beliefs of those people who are not disabled, reinforcing an ‘Us vs Them’ mentality (Oliver & Kirk, 2015). Those people whose disabilities are not ameliorated by medication are often viewed as requiring help or charity. They are reliant on medical professionals as gatekeepers

who assess the disabled person's needs and provide or withhold resources and benefits accordingly (Humpage, 2007; Roush & Sharby, 2011). This experience of gatekeeping is a common one for whānau in the education system, where a medical diagnosis like autism is the only way to provide entry into segregated educational settings (Humpage, 2007; Searing et al., 2015; Whitlock et al., 2020).

It is suggested that the prevalence of autism/takiwātanga in Aotearoa is between 1% and 2%, although this is only an estimate because no definitive data is collected on the incidence of the disorder (Drysdale & van der Meer, 2020). Therefore, any estimates on prevalence are based on overseas data. Males are diagnosed four times more often than females. Severity is based on impairments in social communication and patterns of behaviour that are restricted and repetitive. Additionally, intellectual disability and autism frequently co-occur. These characteristics are complicated further if both an intellectual disability and a language impairment accompanies the diagnosis of autism (American Psychiatric Association, 2022). Taken together, this makes it difficult for policy makers to predict the funding needs for autism in Aotearoa with any real certainty.

The research presented in this thesis will challenge the dominance of the biomedical model of illness and disease in relation to autism in Aotearoa. However, it is important to reiterate that this model is very important, because gaining any type of support and funding relates directly to a formal diagnosis of autism by an approved medical professional (Eggleston et al., 2019). As previously explained, the MoE, MoH and MSD are the primary governmental agencies that provide various types of funding for a child with a formal diagnosis, allowing extra support in school, the health system, and the home and the wider community. Having a diagnosis declined or delayed can leave whānau with few options for extra support for their children to thrive in these areas of life.

The Social Model of Disability

The social model of disability is an alternative perspective to the biomedical model of illness and disease, one that challenges societies deemed to produce and reproduce barriers for people with impairments to enjoy full participation in ordinary, everyday settings (Shakespeare, 2013). The model states that health or illness manifest at the interface between biological, social, and psychological factors that collide to influence health outcomes (Engel, 1977). Disabled researcher Tom Shakespeare (2006, 2013) states that the social model of disability differs from the medicalised, individualistic deficit approach of the biomedical

model and provides a space to identify disability as a cultural and historical distinctive phenomenon. There are nine different versions of this model: (a) the social model (UK), (b) the oppressed minority model, (c) the social constructionist version (US), (d) the impairment version, (e) the independent living version, (f) the postmodern version, (g) the continuum version, (h) the human variation version, and (i) the discrimination version (Bingham et al., 2013; Brandon & Pritchard, 2011; Haegele & Hodge, 2016; Indjov, 2007; Palmer & Harley, 2012). For the purposes of this literature review, discussion will focus on the social model of disability in general, rather than just one of these versions.

The terms *disability* and *impairment* are not synonymous in the social model of disability, which argues that it is society that imposes disability on individuals with impairments (Forhan, 2009; Goodley, 2001). Under this model, bodily experiences such as difficulty moving, seeing or hearing are described as 'impairments', while the experience of disability is considered to be disadvantage that comes from living in a society that does not take into account people's experiences of impairment and thereby restricts the rights of everyone to have full participation in society (Degener, 2016; Skarstad, 2018). This important distinction points to an unresponsive society as limiting a person's ability, rather than their physical self. It suggests that there is nothing that is disabling when a person has an impairment (Blustein, 2012). Viewed through this lens, people with impairments face barriers to their participation which society is unwilling to acknowledge and/or remove. As a consequence, disabled people experience a reduction in their wellbeing, an increase in their social isolation; socioeconomic disadvantage, and lower social status than those without disabilities (Bezyak et al., 2020; Blustein, 2012; Mitra et al., 2017; Morris & Zaid, 2020; Morris et al., 2022; Palmer & Harley, 2012).

According to Article 1 of the CRPD, people with disabilities "include those with long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society" (UN, 2006). The purpose of Article 1 is the promotion and protection of full and equal human rights with access to fundamental freedoms for all persons with disabilities, which upholds their right to respect for their inherent dignity. New Zealand is a signatory to the CRPD and therefore Article 1 protects the rights of children with autism to fully participate in society (Priestley et al., 2022).

Reducing societal barriers for people with impairments requires political and social determination to improve access to ordinary activities within the community, and to challenge the beliefs that non-disabled people have about them. To this effect, the rights of people who experience disability must be foregrounded, and in Aotearoa these rights are acknowledged by the te Tiriti o Waitangi (Office of Disabilities Issues, 2017). Te Tiriti was signed between the British Crown and Māori rangatira (chiefs) at Waitangi on February 6, 1840. Approximately 40 rangatira added their signatures at this historic meeting and eventually another 500 would sign the document. In order to fulfil its obligations as Treaty partner, the Crown recognises te Tiriti and centres this obligation on key principles that inform the foundation for the relationship between Māori and the Crown (Office of Disabilities Issues, 2017).

The development of the Disability Strategy for 2016–2026 was supported by the New Zealand Disability Strategy Revision Reference Group, of which the majority of members identify as disabled people (MSD, 2016). The stated aim of this Disability Strategy is to eliminate barriers, enabling disabled people to reach their potential and to fully participate in the wider community. The Disability Strategy identifies eight outcome areas that will contribute to achieving its overall vision, written from the perspective of disabled people: (1) education, (2) employment and economic security, (3) health and wellbeing, (4) rights, (5) protection and justice, (6) accessibility, (7) attitudes, choice and control, and (8) leadership.

Outcome 1 is associated with access to an excellent education that provides an opportunity to achieve a disabled people's full potential throughout their lifetime. Being economically secure is the objective of Outcome 2, while Outcome 3 calls for health and wellbeing to be maintained to the highest standards available. The right to be protected, feel safe, understood, and treated fairly and equitably by the justice system is the essence of Outcome 4. Outcome 5 supports accessibility to all places, services and information with ease and dignity. Being treated with dignity and respect links to Outcome 6. Disabled people having choice and control of their lives is highlighted in Outcome 7. The final outcome relates to disabled people being provided with opportunities to demonstrate their leadership.

The Disability Strategy is explicit about the rights of persons with disabilities and the goal of Aotearoa becoming a 'non-disabling society' so that disabled people will have an equal opportunity to achieve their goals and aspirations. 'Non-disabling', when articulated in this context, aligns with the removal of barriers in society that disable people with

impairments (MSD, 2016, p. 11). Therefore, the Disability Strategy is thus firmly grounded in social model of disability thinking. Taking this understanding for granted creates a space for people with disabilities to enjoy full access to living an aspirational life.

The International Classification of Functioning, Disability and Health (ICF) is also based on a social model of disability but emphasises the addition of the environment in a conceptual framework that is promoted as a 'bio-psycho-social' model of disability. This signifies a workable compromise between the biological and social experiences of disabled people. Cultural perspectives of autism align with the social model of disability where disability is reframed as a positive space that identifies strengths and an acceptance of difference (Cherrington, 2003; Kahn-John & Koithan, 2015).

There are, however, challenges associated with the social model of disability, and this is highlighted by the model focusing attention on the individual and their experiences of disability. According to Shakespeare and Watson (2001), the social model of disability created a contradiction in that there is a very fine line between disability and impairment, and a bidirectionality between disability and impairment – that is, impairment can cause disability and disability in turn can intensify an impairment. This point of view is supported by Garland-Thomson (2005), who argues that the social construction of disability correlates to the interaction of people's bodies and the environment, whilst impairment relates to the restriction of one's ability to participate fully in the social and physical activities of everyday life in society. Hickey (2017) further challenges to the suitability of the social model of disability, stating that both the biomedical and social models of disability do not explain experiences of disability from an Indigenous worldview that encompasses spiritual, relational, environmental, and holistic dimensions that relate to the whole person. Additionally, there is a need to acknowledge identity and culture and the meaning this gives to disability.

Theoretical Perspectives That Underpin This Research

Kaupapa Māori Theory and Research

Kaupapa Māori theory is associated with the affirmation of Māori cultural practices and philosophies (Pihama et al., 2002). Additionally, Kaupapa Māori theory underpins the meanings linked to the life of Māori and is derived from a conceptualisation of the word 'kaupapa': "Kau means 'to appear for the first time, to come into view, to disclose'. Papa means ground or foundation" (Royal, 2003, p. 66). Walker (2004) extends the understanding

of kaupapa as being the foundation of te ao Māori. G. H. Smith (2012) articulates this as living a culturally informed life that includes the centrality of te reo Māori me ōno tikanga (Māori language and customs). According to Sharples (1988), Kaupapa Māori theory is firmly rooted in spiritualism and traditionalism of the 'old' knowledge. The lived realities and experiences of Māori have emerged from this understanding as a theory and praxis. Culture is an essential consideration that is articulated in the work of Heshusius (2002) and L. T. Smith (2021), who state that involving Māori in research has explicit boundaries that ensures that research is safe, ethical and recognises that the culturally shared meaning of Māori knowledge is associated with rangatiratanga (self-determination) and demonstrates momentum towards liberation and wellbeing by foregrounding the systemic impacts that oppress Māori.

Historically, research in Aotearoa New Zealand has focused *on* Māori instead of being conducted *with* Māori, and this has resulted in objectives, methodologies and outcomes that have been inadequate in addressing the issues Māori face, including a lack of political power, inequality, and the validation of their own Indigenous knowledge (Atatoa-Carr et al., 2012; Walker, 2004). Kaupapa Māori research resists Western definitions and supports a range of research methodologies to achieve objectives that support accountability to Māori and legitimise Māori knowledge (Kerr, 2012; Pihama et al., 2002). Furthermore, as Māori academics have emphasised, research needs to enhance positive social, cultural and educational outcomes that support the mana (status, power, control) of Māori, and this includes researcher responsibilities regarding the cultural safety, values, beliefs, and rangatiratanga of the participants (L. T. Smith, 2021).

This is extremely important in terms of this research that involves Māori wāhine and their lived experiences of raising a loved one with takiwātanga. Therefore, this research will support valued outcomes for Māori linked to what G. H. Smith (1992) calls the philosophy and practice of being and acting Māori. This study upholds the social, political, historical, intellectual and cultural legitimacy of Māori people and accepts the validity of mātauranga Māori (Māori knowledge). While Kaupapa Māori theory is the theoretical foundation of this research, it also draws from other theories, including Western ones. Attributes of the Western research paradigms are integrated into Kaupapa Māori theory to provide a clearer picture of how the māmā in this study experienced a monocultural health system with their tamariki and how takiwātanga influences this experience. This provides a pathway to whakaahua (transformative) research in alignment with the objectives of Kaupapa Māori theory.

Bishop (1999) states that validity of Māori knowledge is located within Māori cultural practices, where what is accepted and rejected is determined and defined by the research community itself, based on whether a process is valuable for Māori. The phrase ‘taonga tuku iho’ broadly translates as ‘caring for and nurturing the treasures handed down from our ancestors’, whose ancient wisdom has been established over an expansive period of time and is valued as a guide to life today and in the future. Within these treasures are kawa (protocols) for how the process is performed. Bishop (1999) gives an example of whakawhanaungatanga (relationship building/family connections), where he describes this process as being not haphazard but one that is based on time-honoured and proven principles of a multiplicity of rituals that are protected and maintained by the tapu (sacredness) of Māori practices.

According to Good et al. (2017), organisers of the International Women’s March held in Auckland in January 2017 initially excluded disability as a women’s issue and thereby excluded some women from the need of protection in government policy. As mothers of disabled children, these authors identified a need to clarify the roles of mothers of disabled children in Aotearoa. Māori experience inequitable provision of disability services, and there is a dire need to address misperceptions of Māori mothers and their experiences of having a disabled child (Good et al., 2017; G. H. Smith, 2012). This includes valuing the skills and attributes mothers will develop through their lifelong role as an advocate for their disabled child(ren) and linking credibility to this vital role (Good et al., 2017; Robson & Harris, 2007; Stace, 2011).

Aligning with this understanding is Heshusius’s (1994) call for research that employs a ‘participatory mode of consciousness’ that foregrounds the fundamental review of the understanding of the relationship between self and other, creating a space for connectedness, and recognising the place of cultural practices. Heshusius (1994, 2002) suggests that women and ethnic groups are better suited to a research approach that is associated with reciprocity and that requires the researcher to relinquish predetermined patterns of thought, methods and formulae that divide self and other, and therefore reality. A participatory mode of consciousness is the intentional act of sharing the role of the researcher, with the researcher giving up a degree of power over the research. From this standpoint, there are opportunities to legitimise both knowledge about takiwātanga from a Māori perspective and the knowledge created by the wāhine in this research.

Critical Disability Theory

Critical disability theory (CDT) focuses on the space where the intersection of politics, theory, and practice reveals the structural foundations of oppression, and how the translation of oppression and marginalisation for disabled people is a reality faced on a daily basis (Goodley, 2013). This approach emerged when a shift that was influenced by other disciplines including psychology, feminism and queer theory emphasised a new direction of thinking about research, theory and activism (Shildrick, 2009). Moreover, the emergence of this theory links to the disability rights movements alongside the women's and Indigenous rights movements.

CDT is important to this research in terms of analysing the experiences of the māmā. To successfully influence policy requires highlighting the divergence that is associated with the legal and social parameters of human rights and equality for people with the lived experience of disability (Delvin & Pothier, 2006). Fine (2019) calls for an examination of disability as a social, political and cultural phenomenon that has ableism at its core. Ableism is supported by structural violence that is wielded as a metaphorical scientific scalpel of stratification including social, institutional and individual oppression that is so deeply embedded in our everyday life, it is undetectable in how we organise our society, public policies, educational, health and judicial systems (Harder et al., 2019; Mueller et al., 2019).

According to M. C. Hall (2019), CDT is linked to a set of interdisciplinary theoretical approaches where disability is analysed as a social, political, and cultural occurrence. Furthermore, CDT researchers are tasked with enacting social justice and working towards liberation for people who have less value, status and power than those people who are able-bodied. There are wider arguments around the concept of disability that call to resist the distinctions between disabled and non-disabled people, ignoring the reality and complexity that is disability (Sefotho & Leshota, 2020). Furthermore, Derrida's notion of deconstruction that can be applied to the hierarchy of binaries suggests that the term *disability* may be upholding meanings that it seeks to remove or flush out. The disabled, as 'the other', are less privileged and accepted than the able-bodied, generating meanings that marginalise disabled people (Sefotho & Leshota, 2020).

Rejecting the deficit-based Western biomedical word 'autism' and privileging the use of te reo Māori is one way to embrace a positive perspective of takiwātanga. Takiwātanga describes a person who livers in their own space and their own time. The person is seen first

before all other things. This research explores the meanings of takiwātanga and privileges the knowledge of māmā naming and claiming the lived experience of takiwātanga as epistemological knowledge, or mātauranga wahine. This aligns closely with CDT, which identifies the power structures in society and how this power benefits specific sectors (Meekosha & Shuttleworth, 2009).

Mana Wahine Theory

Another important theoretical foundation of this research is Mana Wahine theory (Pihama, 2001, 2020). Mana Wahine theory provides a framework that can be utilised to illuminate the multiple realities of the lived experience of Māori women by navigating away from the Western preoccupation associated with the need to have a singular universal truth (Best, 1924; Grey, 1922). The search for the female essence in pūrākau (ancestral stories) is linked to the creation of woman by Tāne, the son of Papatūānuku (Earth Mother) and Ranginui (Sky Father). Guided by Papatūānuku, Tāne fashioned Hineahuone, the first woman, from clay. During this process other atua gifted parts of the body as sacred offerings, and hence wāhine are said to be the spiritual heart and essence of the earth.

The Māori concept of mana has been discussed above, however, when ‘mana’ is combined ‘wahine’ and it should be clarified that there is no one singular translation for mana (Henare, 1998, Pere, 1991, Pihama, 2020). Mana can be viewed as supporting a collective understanding where the roles of people are linked to obligations that serve social and political influences that contribute to how Māori see themselves and are viewed by others (Marsden, 1988). In this manner, when combined with ‘wahine’, ‘mana’ relates to how wāhine position themselves in terms of their social and political understanding of who they are and what their role is.

According to Pere (1991), the most important form of mana is mana atua, or the divine right given to Māori by Io Matua (the supreme being), defining the absolute uniqueness of every person as an individual. It can be argued that this involves the responsibility of each whānau member to support this kaupapa (philosophy), and this is articulated by Durie (1998) as an obligation for whānau to support all members of the iwi from the very young to the very old. This is important for this research because it focuses on māmā and their children or loved ones who have takiwātanga.

According to this conceptualisation, the tamariki and rangatahi in this research have a divine right from Io Matua to be exactly who they are, and that their own space and time is

honoured without needing to be changed or fixed. This includes the mana of wāhine who have been defined as the simultaneous connection between atua and tangata (people), creating a space for considering the practice of mana through this understanding. Therefore, mana wahine engages the cultural, spiritual and emotional way of being that links to upholding and perpetuating the mana and sacredness of their tamariki.

The theoretical conceptualisation of mana wahine adopts the lens of Kaupapa Māori theory to examines the complexities of the landscapes and contemporary spaces that Māori wāhine engage with (Simmonds, 2014). Furthermore, this complexity exposes the possibilities that arise from wāhine taking a position of power or privileging the power of wāhine by making visible the narratives and experiences of being Māori and being a wāhine. For a māmā, this allows the exploring and reclaiming of pūrākau as *her* stories and ultimately supports these pūrākau as *her* knowledge, and finally as mātauranga wāhine. After delineating these theoretical positions that view the māmā as having legitimate authority over her own life, it is useful to review the spaces where the māmā in this research engage in their daily life that intersect with their children and loved ones who have takiwātanga.

Te Ao Māori Understanding of Disability

While there is no definitive word or description for disability in te reo Māori, Māori perspectives on disability extend beyond physical or psychological impairments. Supporting the disabled for Māori promotes a balance between spiritual and emotional wellbeing, facilitates maximal functioning, strengthens positive interdependence, and reinforces a secure cultural identity (Robson & Harris, 2007).

Disability features in the atua narratives such as Muriranga-Whenua, the blind and deaf grandmother of the demi-god Maui. Muriranga-Whenua gifted her jawbone to Maui, and he fashioned it into a fishhook that he used to pull up a giant fish from the ocean, later called Te Ika a Maui, the North Island of Aotearoa. Being disabled did not stop Muriranga-Whenua contributing to Maui's triumph over his older brothers, as he overcame his small stature with resourcefulness, cunning, and her magical karakia (prayer) that he uttered as he caught the biggest fish of all time. Maui also provided the world with fire by tricking his other grandmother, Mahuika, the Goddess of Fire, to give him her fiery fingernails after he had extinguished all fire from the world in an attempt to find out where it came from. Mahuika was a very powerful and feared deity who was also blind. Again, being blind did not make

her any less formidable as she recognised Maui firstly as a mortal through her sense of smell and secondly as her grandchild through her understanding of whakapapa (genealogy).

Positive Culturally Based Narratives about Disability

According to Cherrington (2003), the use of pūrākau about atua in a clinical setting is acknowledged as one way to build resilience and an alternative view of wellbeing that resists the pathologisation of Māori in health settings. The use of pūrākau as a culturally based narrative method in research is explored in the work of Jenny Lee (2009). Pūrākau are passed down through the generations and give insights into ancestral thoughts, feelings and actions, and can be expressed as waiata (songs), poetry, painting and illustrations. Drawing on the pūrākau about Muriranga-Whenua and Mahuika, who were fearsome and powerful deities despite being 'disabled' and who were considered both formidable and instrumental in Maui achieving his goals, we can reframe the experiences of disability for Māori and champion the potential of all people who are intrinsically part of the whānau, hapū and iwi (Durie, 1977).

Other Positive Indigenous Understandings of Disability

While the present research focuses on the lived experiences of Māori māmā, the literature includes affirmative views of disability valued by other Indigenous populations. For example, Aboriginal peoples in the remote parts of New South Wales, Australia, do not distinguish between age-related difficulties or illnesses and disabilities (Gething, 1994). Furthermore, J. Reid (1985) found that elders in the Indigenous community of Yirrkala in the Northern Territory did not class older people with impairments as disabled, and they were included in every aspect of communal life. Being labelled as disabled is considered offensive in many Indigenous communities, and even discussing a person's physical limitations conveys shame and humiliation to the person and to their family (Ariotti, 1997). The Navajo Nation of North America consider autism as a 'beautiful difference'. Family mentors guide and care for those relatives with autism inside their own communities, developing their unique strengths and reframing them as a source of social capital known as *hozho*. *Hozho* is a Navajo term relating to beauty, perfection, harmony and blessedness. Furthermore, those mothers who have an autistic child are encouraged to make changes in their life where less importance is placed on employment or materialism and more on their role as a parent (Kahn-John & Koithan, 2015).

A study by Llias et al. (2019) of 22 Malaysian parents of the Muslim faith with children of autism found that the parents felt that they had been specially chosen by God.

Furthermore, these children were *saham* (treasures) that God has sent to the parents to embellish their lives and support more *pahala* (rewards from Allah) when arriving in Jannah (Paradise). One participant reflected that God provided her with this assignment to extend her capacity to tolerate, understand, and love her child. She identified important characteristics she was lacking prior to having her child with autism. Additionally, several parents believed that a child with autism is a pure and innocent gift from God.

Feminism, Mothering, and Disability

The intersectionality of mothering and having a child or loved one with a disability provides an opportunity to consider sociopolitical space through a lens of feminism. Brock (2014) claims that research on women with the lived experience of raising a child with a disability is scarce. In her own research on mothers with disabled children, she discusses the profound effect of having a child with a disability. The societal expectation of being a "good-mother-of-a-child-with-a-disability" (p. 33) can be a burden and will have a profound impact on how the mother develops a sense of self.

Mothers of disabled children are propelled into the forefront of advocacy, which according to Nespor and Hicks (2010) involves trying to engender collective action in a structural system that is designed to preclude it. Voysey (1972) describes these specific skills as a 'crusadership' model, where mothers acquire specialist competencies in system navigation, dealing with professionals, and becoming experts on their child's disorder or disability. Moreover, this extends to challenging the medical professionals who focus on a biomedical interventionist understanding of their child's difficulties, instead of the child's unique personhood (Agmon et al., 2016; Featherstone, 1985).

Waitoki and Levy (2016) call on Māori academics to boldly claim their space in psychology and other disciplines that contribute positively to Māori in a celebration of diversity, and this includes mana wahine (Kasari & Smith, 2013; Pihama, 2020). Mana wahine is often understood as Māori feminism and is discussed as an extension of Kaupapa Māori theory. The intersectionality of being Māori and female is highly visible in traditional narratives and the contemporary experiences of Māori women. Furthermore, this understanding allows the (re)definition and (re)representation of the stories and experiences of what it means to be a Māori woman in Aotearoa (Irwin, 1992). The complexity of mana wahine is explored by Leonie Pihama (2001), who makes the point that while wahine can refer to a woman, the assumption cannot be made that it holds the same universal meaning.

Similarly, the connection between mana wahine and feminism is not straightforward because this intersecting space is entangled with mana tane (male power), a distinguishing feature that locates mana wahine in the social and political landscape of Aotearoa (Pihama, 2020). G. H. Smith (1992) argues that Māori women are defined by their differences to men, as Māori from Pākehā. This creates diverse realities for Māori women. Wāhine are recognised as the kaitiaki (guardians) of the physical and psychological wellbeing of their whānau that is underpinned by cultural understandings such as manaakitanga (support), aroha (compassion) and māramatanga (understanding), reinforcing the likelihood that Māori māmā will take the leading role in protecting, teaching, and caring for their son, daughter or whānau member with takiwātanga. This perspective positions Māori mothers as holding key knowledge about their loved one, about takiwātanga, and as being in a position to add to our understanding of takiwātanga from their own unique cultural perspective. Furthermore, it provides a strong case for privileging this knowledge, which is valued by theoretical perspectives associated with Kaupapa Māori theory and rangatiratanga (self-determination) as Māori.

According to Royal (2003), the spirit (wairua) arrives in the mind like the radiance of a rainbow on the surface of wai (water), which is a metaphor for how knowledge that belongs to the head develops. When the radiance of this spirit arrives in one's heart then one truly knows and has wisdom (mōhio). Extending this metaphor, when the radiance arrives in the heart of wāhine then they 'truly know' takiwātanga and what it means for themselves and their loved ones by listening to the soft whispers resonating in their soul. In this manner, the knowledge they develop in their head is associated with learning how the system works. Through their heart and their soul, they tap into the light of spirit to truly know their children.

Motherhood and Autism (Takiwātanga)

The controversial child psychologist Bruno Bettelheim coined the 'refrigerator mother' label for mothers of children with autism, blaming their cold emotionless parenting styles as the reason for an autistic response in their children (Dolnick, 1998; Jack, 2014; Van Patten-Walsh, 2013). Research on families with the lived experience of autism has concentrated mostly on the emotional stress levels of mothers and has found they suffer from more physical and emotional stress than fathers, which is coupled with the guilt, shame and stigmatisation (Benjak, 2009; C. P. Johnson & Meyers, 2007; Weastell, 2017). Other literature suggests that mothers of children with autism undergo significantly higher levels of

stress than those mothers who have children with developmental delay without a diagnosis of autism (Estes et al., 2009; Rivard et al., 2014). Furthermore, it is implied that these experiences of higher stress levels are closely linked to the severity of the autistic behaviours exhibited by the child with autism.

Counternarratives have been expressed as a challenge to these deficit understandings by mothers advocating for their children's strengths and human rights (Bevan-Brown, 2010; Carver & Connor-Smith, 2010; Hastie & Stephens, 2019; Kingston, 2007). Dalley (1996) claims that caring can be described as a gender divide, where women care for and about their children and men can care about their children without having to care for them. Traustadottir (1991) argues that mothers of children with disabilities expand their care through advocacy and campaigning to change systems and policies, and relates this to "an extension to her caring role for her child and of her devotion for her child" (p. 218).

Garland-Thomson (2005) delivers a poignant critique of the role that dominant theories and discourses have had in the creation of negative images of women and disabled people who have been objectified by 'science'. Feminist scholars have criticised how the experiences of women have been ignored, discounted and trivialised within research, and people with disabilities have been portrayed as tragic and unfortunate (Barnes & Mercer, 2003; Reinharz, 1992; Robertson, 2014). Integrating these ideas, feminist and disability researchers have suggested that there is a need to develop a new approach to research that include practices underpinned by equality in the research environment, and which are inclusive, emancipatory and participatory in nature (Garland-Thomson, 2005; Goodley, 2013; K. Johnson & Warmsley, 2003; Kelly, 2013; Traustadottir, 2001).

There has been a steady increase in the amount of feminist literature highlighting the experiences of motherhood and mothering with a call to include the diversity among mothers by acknowledging factors such as gender, ethnicity, class (socioeconomic status) and sexuality (Lewiecki-Wilson & Cellio-Millar, 2011; S. Ryan & Cole, 2009). This research has been produced by feminist writers who use a narrative approach with mothers as participants and apply feminist ethnographic qualitative methodologies to explore politically oriented themes of liberation, empowerment and reflexivity (Kingston, 2007). This research centralises gender to make women visible and privilege their perspectives, locating feminism as socially constructed, politically and critically oriented, but clearly dialectical (Robertson, 2014; Wilkinson, 2001). Aspects of individual identity that may contribute to sociopolitical

marginalisation associated with race, ethnicity, social class, sexual orientation and disability are embraced by feminist theory. Women's personal narratives create an ontological space where personal history and accounts of those who have experienced marginalisation can foreground their 'voice' in these experiences (Chase, 2007; Douglas et al., 2020).

Traustadottir (2006) examined how disability and gender operate together as interlocking categories, along with race, ethnicity, age and sexuality, affecting every aspect of human existence and the lived experience of this intersectionality. Following on from this argument, it is worthwhile to consider the intersectionality of a Māori mother's experience of takiwātanga and how it is negotiated in her day-to-day life, particularly considering the omnipresence of Western discourses about autism. These understandings inform the research presented in this thesis that explores gender, ethnicity and race in the context of providing a safe platform for participants where their voices as Māori mothers with children and loved ones with autism are heard. Heshusius (1994) posits that to hear this voice, the researcher must offer a state of complete attention through observation without evaluation that foregrounds an authentic relationship and the goals supporting the reality of the lived experiences of the māmā.

Research on the Lived Experience of Autism in Aotearoa

A review of the relevant literature quickly reveals the need for more research that focuses on the Māori understanding of the lived experiences of takiwātanga (autism) for whānau (families). Jill Bevan-Brown's (2004, 2010, 2013) research explores Māori perspectives of autism (takiwātanga) and examines the efficacy of professional development for kaiako (teachers) who work with ākonga (students) with takiwātanga. In addition, Tupou et al. (2021) conducted a comprehensive review of the literature and provided an overview of existing narratives linked to a Māori understanding of autism, its prevalence in the Māori population, and experiences of whānau related to diagnostic and other support services. Oades (2021), meanwhile, looks at the intersection between social work in schools and takiwātanga.

Māori Perspectives of Takiwātanga (Autism)

In 2004, Jill-Bevan Brown investigated Māori perspectives of autism (takiwātanga). Parents and whānau of 19 Māori children with takiwātanga were interviewed and invited to share their lived experiences of raising their children. The research identified an urgent need

for an increase in existing services and for personnel who were empathetic and knowledgeable in terms of resource entitlements for whānau and able to transition their children across various stages of their education. In addition, the participants wanted medical professionals to listen to and be guided by parents. The research also identified building professional capability in knowledge of takiwātanga, and te ao Māori was deemed as an important way to provide bicultural and bilingual expertise in services. Whānau considered that awareness programmes about takiwātanga would support a better understanding in the community and improve attitudes of the public. Services for adults with takiwātanga needed to be reviewed to enable them to be as independent as possible. The research covered a wide variety of experiences expressed by whānau, with delay in diagnosis and stress around this being prominent. Parents reported being devastated, stressed, confused, intimidated and frightened following a diagnosis of takiwātanga. This reinforces the need for professionals to be open, approachable and able to provide robust information to parents (Bevan-Brown, 2004).

A subsequent project undertaken by the same researcher produced DVDs about autism (Bevan-Brown, 2010). One hundred and thirty-seven parents of children with takiwātanga responded to an online questionnaire that sought parental input in the messages and content for the DVDs. Consultation to review the 10 questions included in the survey was extensive, adding to the authenticity of the research. Some of the key findings of the survey were that parents felt their children were underestimated in terms of their strengths and weaknesses. They wanted teachers to see their children for who they are rather than how they think they should be. An important finding related to the resistance teachers had around the expertise that parents have about their children, takiwātanga, and teaching approaches that might work with their children. Maintaining routines in the classroom in addition to working with student strengths was considered an important strategy. Safety for their children while at school was paramount for the survey respondents, particularly in terms of bullying. This understanding of safety underpinned messaging for peers, where teachers and teacher aides were asked to encourage and nurture friendships between students with takiwātanga and their fellow classmates. Additionally, raising awareness of takiwātanga was supported by parents visiting the class to talk about their children at the beginning of each school year. Parents also wanted open and free-flowing communication between school and home.

Messages for community members and other parents were around building awareness of the difficulties their children have accessing ordinary spaces such as the supermarket, the

doctor's surgery or getting a haircut (Bevan-Brown, 2010). Parents also voiced their frustration through the survey of having to constantly "battle" the system for respite care and other essential support. These messages from the questionnaire were collated and a set of four DVDs were made to be used across the education sector. Around 20,000 copies of the DVD titled *In My Shoes* were produced and distributed for free to schools, medical offices, social service agencies, and Māori organisations.

Aotearoa New Zealand Autism Guideline: He Waka Huia Takiwātanga Rau (Third Edition)

The Aotearoa New Zealand Autism Guideline: He Waka Huia Takiwātanga Rau (Third Edition) (Whaikaha – Ministry of Disabled People and MoE, 2022) offers the best evidence currently available to support informed decision making that may improve health, educational and social outcomes. The intended audience includes autistic people (tāngata whaitakiwātanga) and their families and whānau, primary care practitioners, educational professionals, service providers, policymakers, funders, specialists and carers. Of special interest to the current research is Part 7 of the Guideline that is associated with Māori perspectives of takiwātanga developed by Jill Bevan-Brown. It outlines recommendations linked to good practice for working with Māori with the experience of takiwātanga, which are summarised in Table 1 below.

Table 1

Key Recommendations for Māori Perspectives from the Guideline

1. Information packages in appropriate and relevant language about takiwātanga using a range of media should be developed. This information could be distributed through Māori, mainstream and community providers of health, education and disability services.	✓
2. The appointment of a kaiarahi (guide) who would work in conjunction with, and be supported across, the health, education and disabilities sectors involved with takiwātanga should be considered.	✓
3. A programme of empirical research that would provide baseline information about Māori and takiwātanga should be developed.	✓

4. Takiwātanga provisions for Māori tamariki, rangatahi, pakeke and their whānau should be culturally appropriate. This involves valuing and affirming their cultural identity by including Māori concepts, knowledge, skills, reo, processes, practices, resources, customs, attitudes, values, and beliefs.	✓
5. People who work with tāngata whaitakiwātanga should possess the knowledge, skills and attitudes needed to provide culturally responsive, friendly and effective services. This includes valuing and supporting Māoritanga and Māori expertise.	✓
6. Parents, whānau and, where appropriate, tāngata whaitakiwātanga themselves, should be consulted on an on-going basis and involved in all goal setting and decision-making relating to them. This includes consultation about their needs and aspirations; areas of importance and concern; relevance and appropriateness of provisions and the nature and extent of cultural input preferred and involvement possible.	✓
7. Takiwātanga-focused policies, reports, research, resource development and data collection should all include a Māori component.	✓

Source: Whaikaha – Ministry of Disabled People and Ministry of Education. (2022). *Aotearoa New Zealand Autism Guidelines: He Waka Huia Takiwātanga Rau* (3rd ed.), pp. 237–239.

The Guideline does include an important disclaimer that it does not serve as the absolute standard of care or practice, nor do the authors intend to override professional judgement. It is designed to support health and education professionals, service providers and individuals to make informed decisions around support, and that if the Guideline is properly implemented, research has shown that it may improve care. The recommendations are highly aspirational and ask for considerable investment both financially, professionally and personally in autism.

Poi Ngā Ākonga Kanorau Ā-roro

Poi Ngā Ākonga Kanorau Ā-roro is a literature review recently conducted by Melanie Riwai-Couch (2021) for the MoE. It provides a Māori-centric view of neurodiversity with the view

of supporting educators to work more effectively with ākonga kanorau ā-roro (Māori students who are neurodiverse) and whānau. The review features ways to work effectively with ākonga kanorau ā-roro by addressing power imbalances through kaiako being culturally responsive. Key features of this cultural responsiveness align with acknowledging te Tiriti o Waitangi Māori values, and a deliberate space for whānau to engage in decision-making processes. Riwai-Couch (2021) highlights the unequal power relationships in education and that kaiako have internalised the discourse that ākonga kanorau ā-roro are in some way defective or insufficient. Kaiako also fail to recognise how their own culture impacts on Indigenous students and tend to ignore the inherent contribution that they can offer to the learning space (Berryman & Woller, 2013). Additionally, Indigenous knowledge is treated as inferior when compared with Western knowledge (Macfarlane et al., 2015).

Solutions proposed include the inclusion of whakawhanaungatanga and upholding the mana of whānau. A move away from professional knowledge in isolation and the creation of spaces for whānau and Māori worldviews is discussed by Elder (2017). Whakawhanaungatanga (relationship building), ako (teaching) and mahi tahi (collaboration) feature as principles for achieving cultural and relational tools to address racism and prejudice experienced in this area of education (Berryman et al., 2015). This is reinforced by the cultural choices of whānau of ākonga kanorau ā-roro being respected and accepted (Crawford, 2018). Underpinning Riwai-Couch's (2021) aspirational publication is the understanding of equitable practices that ensure the application of te Tiriti o Waitangi as fundamental to special education (Macfarlane et al., 2015).

Social Justice and Autism (Takiwātanga) in Aotearoa

Along with Bevan-Brown's good practice points for decreasing discrimination and stigmatization in Part 7 of the Guideline, the contemporary mission of the social work profession is to support the most vulnerable in our communities, including individuals with takiwātanga (Bishop-Fitzpatric et al., 2019). Disparities in social and economic justice for people with autism throughout their lives are commonly experienced, setting up a trajectory of isolation, health issues and low unemployment rates (Sosnowy et al., 2018; Yingling et al., 2018). Social workers are trained to examine the social and ecological systems that maintain social and economic inequalities. Interventions are often targeted at communities and follow the Ngā Tikanga Matatika | Code of Ethics, which includes a core commitment to social justice (Brekke, 2012). Moreover, although other professions in health and education share

these values, it is social work that integrates these understandings as a framework for solving social problems. From a research perspective, social work embraces complexity without the need to isolate single variables or constructs of measurement, instead grounding inquiry in biopsychosocial and person-context perspectives.

Key contributions to research in this area include examining the factors that underpin marginalisation from a life course perspective; including family systems in research and not just individuals with autism; highlighting vulnerability during key life transitions; and developing and testing interventions across the lifespan for individuals with autism and their families (Bishop-Fitzpatrick et al., 2019). Additionally, there is a focus on the understanding that evidence-based interventions and services attempt to change the behaviour of an individual with autism to better support them to function in society. Research highlights that this may perpetuate discrimination by not addressing the need for society to change. Behaviours in individuals may alter, but the wider picture of altering societal attitudes is far more complex (Kenny et al., 2016; Pellicano et al., 2014).

Warner Parr and Cusack (2018) identify that there is a lack of readily available systems-level, community-oriented interventions for autism, and this is identified as a substantial gap in the literature. Another area that social work research highlights is associated with the likelihood of parents of children with autism having disruptions to employment and the ongoing financial impacts that this has long term (Cidav et al., 2012; Hill et al., 2015; Montes & Halterman, 2007; Shepherd et al., 2021). Oades (2021), meanwhile, suggests that there is a need for diversification in social work training and to assess the best social work practices in schools. According to Oades (2021), social workers in school (SWiSs) work with children who have autism and their families through a social-ecological perspective. This perspective addresses family isolation and stigma, and a SWiS can support families with benefit entitlements, multidisciplinary team meetings, and development of external support systems such as support groups in the context of community development.

An emerging area of social work research on autism relates to strengths-based understandings of this lived experience (Ooi te al., 2016; Salkas et al., 2016). Parents of children with autism have reported feeling more grateful for the important things in life and finding meaning in acceptance through a deeper understanding of themselves (Ooi et al.,

2016). Salkas et al. (2016) report deeper spirituality and meaning for parents from their faith in God or Allah as a way to maintain positivity about their children.

Research on Autism (Takiwātanga) and the Community

In 2021, a community development project titled 'Autistic Co-led Autism Research Priorities for Aotearoa New Zealand' adopted a partnership approach and asked people from the autistic and autism community what they considered to be worthwhile directions for future research on autism in Aotearoa (Emerson et al., 2022). Focus group sessions were held and an online survey was conducted. The focus groups concentrated on future research questions and the online survey collected the views of adults 18 years and over living in Aotearoa who were either autistic, parents, carers, whānau, professionals or researchers. The online survey presented a list of 32 potential autism research topics grouped into four broad themes and attracted 450 respondents. The four themes were needs and supports, inclusive communities, Aotearoa autism research, and autistic experience. The importance of these topics to the participants was rated on a 5-point Likert scale.

Analysis of the findings indicated 13 priorities for research that were clustered into four main research areas: determining the needs of autistic people, effective support and services, understanding the perspectives and experiences of autistic people, and creating communities that are inclusive of autistic people. It was concluded that the partnership and involvement of autistic people and autism communities are vital to develop an authentic research relationship. Such research champions their collective voice to create and sustain real changes in the current space of research. This partnership between the autistic and autism researchers must progress to become the standard not the exception in research (Emerson et al., 2022).

Rationale for This Research and Formulation of the Research Question

Many research articles reviewed in this chapter tend to be gender-blind when it comes to raising a child with autism, and there is a clear need to identify the unique experiences of Māori who parent children with autism (Bevan-Brown et al., 2016). Research in this area is scarce, which an important motivation and justification undertaking a study like the one reported in this thesis.

There are several other reasons why this study is urgently needed. The prevalence of autism is increasing globally (Centers for Disease Control, 2014), and there are nearly 93,000

people identified as being on the ‘autism spectrum’ in New Zealand (Autism New Zealand, n.d.). Families in Aotearoa New Zealand are required to navigate conflicting systems to get support services for their child with autism, and it is mostly women who are at the forefront of this negotiation space (Stace, 2011). Being Māori complicates this experience, with the literature establishing that race and gender increase the likelihood of disparities for treatment and diagnosis (C. Y. Chen et al., 2008; Ingham et al., 2022; Mandell et al., 2007; Mazurek et al., 2014; Rosenberg et al., 2011; Valicenti-McDermott et al., 2012).

The social policy being created by successive governments in New Zealand continues to ignore cultural understandings in terms of Māori knowledge and experience (Hickey & Wilson, 2017). As a result, the intersectionality of culture, gender and disability is lacking from key policies, which fail to support Māori whānau, wāhine and their tamariki and rangatahi with autism. Finally, without adequate robust knowledge on what works for Māori wāhine with tamariki and rangatahi with autism, the system will replicate policies and strategies that will continue to have negative implications for Māori (Stace, 2010).

The MoH and MoE claim to have a culturally appropriate framework to support autism, despite te Tiriti o Waitangi and the Treaty principles stating that Māori are to be part of the planning and delivery of health and educational services for Māori who are impacted by disability. Cultural values and beliefs are still ignored, with supports delivered and managed in ways that do not take te ao Māori into account (Hickey & Wilson, 2017).

As an example of how governments can be seen to take one step forward and then two steps back, the previous Labour Government adopted a ‘whole of life’ approach when it introduced Whaikaha – Ministry of Disabled People in 2021. This new ministry transformed social investment by identifying silos between different supports and services and advocating for more integrated services and supports. The plan going forward was to address these silos and to create a space for te ao Māori values to be included as a standard approach during the planning stages of support for whānau. But in 2024, the new National-led Government announced that the ministry would be restructured (R. Palmer, 2024). It has now lost responsibility for delivering support services, and the move towards the new approach of the Labour Government has been put on hold.

This review of the literature has created a space to consider how an Indigenous understanding can inform education, health, home and the community as they interact with the lived experiences of Māori māmā with a child who has autism. This research seeks to

understand how the māmā manage their daily lives and the daily lives of their loved ones with autism in a Western-based health system that largely ignores cultural and feminist understandings as they relate to disability. Given these realities faced by the participants of this research, it can be argued that by upholding te ao Māori as a legitimate framework for Māori knowledge to be privileged will support Māori whānau with their lived experiences of autism. This will require the research to be culturally sensitive and delivered in a manner that will highlight the voice, power, and advocacy of the participants as being experts in their own knowledge.

In line with the findings of this literature, and the identification of a significant knowledge gap in this area, the following research question was developed:

> *What are the experiences of Māori māmā with education, health, home and the community in raising a loved one with takiwātanga (autism)?*

Chapter 3: Methodology

To create and honour a space of wellbeing and mana for Māori wāhine with the lived experience of raising a child with autism, an interpretivist qualitative research design was utilised in this study that combined tools from Western methodologies and methods from Kaupapa Māori theory and Mana Wahine theory.

Qualitative research has been described as "an emergent, inductive, interpretive and naturalistic approach to the study of people, cases, phenomena, social situations and processes in their natural settings in order to reveal in descriptive terms the meanings that people attach to their experiences of the world" (Yilmaz, 2013, p. 312). Interpretivist qualitative research methods gather and analyse qualitative data. Positivism, which is closely associated with quantitative methods of data collection, was considered inappropriate to the nature of this research, which explores the understandings, worldviews, and approaches of eight Māori māmā (mothers) with children or adolescents who have been diagnosed and labelled as having autism. Qualitative research is therefore fitting for this topic as it comes from the epistemological philosophical tradition wherein meaning is subjective and co-constructed with participants, and causes are complex, intertwined, dynamic, and contextually dependent (Matta, 2022).

Qualitative research has a plethora of methods to capture the complex meanings and diversity associated with interpretations people use to decode the world they live in (Bradbury-Jones et al., 2017; Hammersley, 2008). According to Smythe and Giddings (2007), the design of a qualitative inquiry can capture the everyday context and should seek to uncover the understanding that already exists in the lived experiences of the participants. This approach provides a framework that responds to the values and beliefs of Indigenous people by supporting their worldviews, which include spirituality (ontology) and shared cultural knowledge (epistemology). In this way, the Western ideology behind qualitative research is transformed into an Indigenous one – specially that of te ao Māori – via a series of stepping stones using a bricolage of Western research tools.

Ontology

Ontology can be described as your way of being, what you believe is real in the world. (Carter & Little, 2007; Crotty, 1998; Gomm, 2009). Ontology includes the claims and

assumptions made about how human beings acquire and create knowledge. According to S. Wilson (2001), how people see the world is bidirectional, meaning that their ontology influences their understanding of what exists and vice versa. To expand on this concept, many Indigenous peoples acknowledge the existence of a spiritual realm that is interconnected with a physical realm, which influence each other (Meyer, 2008; B. Rice et al., 2005). Cajete (2000) argues that Indigenous science assumes a spiritual orientation where human beings have an important role in the natural processes in the world, and that these processes or actions in the world require ceremony and ritual. Ontology (What is there?) sits alongside epistemology ('What do you know?' and 'How do you know it?') and informs the theoretical lens being used in all research.

This research allows wāhine to speak for themselves as participants, researchers, and as creators of their own mātauranga wahine through privileging their kōrero as knowledge. The preferred method for human research aligns with interpretation, description, self-reflection or an approach that is critically analytic (Ahmad et al., 2019; Schwandt, 2012). This provides a space for Kaupapa Māori theory to question the taken-for-granted norms of Western theories that have labelled and pathologised autism. In this context of questioning and challenging social norms, the Gramscian concept of the 'organic intellectual' calls for the academic to reflect on their role and position in society, and to resist demands for objectivity and neutrality (Saeed, 2016). Organic intellectuals are embedded in a social class within an economic structure, and this positioning therefore allows the researcher to speak from and for a specific class or social group (Saeed, 2016).

Epistemology

This section provides epistemic justification for this research's use of a bricolage of tools from Western research methodologies to aid in translating the multiple realities of the māmā in this research. Hermeneutic phenomenology (HP) developed from the work of Edmund Husserl in the1900s, followed by that of Martin Heidegger (1962, 1975, 1982 [1975]). HP is associated with examining first-person experience of the world in order to (1) describe the world and (2) describe the nature and the structure of conscious experience itself. Human engagement with reality is from our subjective – not objective – position, where we interpret, re-interpret and make sense of reality, and this has implications for what we should, according to HP, privilege as knowledge and how we make sense of our own and other's experiences (Dreyfus, 1990).

The first stepping stone in the development of the methodology for this research therefore involved taking HP's subjective positionality and seeing similarities with how te ao Māori privileging the lived experiences of Māori, in this case māmā of children with takiwātanga.

Another stepping stone involved using the instruments of participatory action research to reinforce the status of the understandings of the māmā. PAR embraces emancipatory and sociopolitical movements by offering freedom from conventional research methods and challenging the dominant positivist position of social research as the only source of knowledge (MacDonald, 2012; McIntyre 2002). Various tools of PAR provide a space for emancipation by valuing knowledge that seeks to tackle issues caused by unequal and harmful social systems (Cornish et al., 2023). Furthermore, PAR aligns with resisting tokenisation of Indigenous groups by universities, government organisations and health institutions. Aotearoa leads the world in 'repowering Indigenous knowledge' through research by centring Māori and their knowledge, and the tools of PAR have some commonality with Indigenous traditions of knowledge production. The instruments of PAR used in this study helped to identify the social context of the māmā and their loved ones with autism and how their social, political, economic and familial experiences in the community impact their daily lives and (re)shape the knowledge that is produced. The māmā were provided with a summary of the research findings and asked for their feedback, which also aligns PAR. This feedback is provided at the end of Chapter 5.

Using these arguments, approaches and models, it becomes possible to interpret the lived experiences of Māori wāhine who are raising a tamariki or a loved one who has autism as they unfold over time and are influenced by cultural and historical ideologies in their daily activities and practices. According to Ruangjiratain and Kendall (1998), critical analysis can guide the inquiry into common and culturally based lived experiences, enabling interpretive research paradigms to include analysis of oppressive structures that perpetuate those experiences. Thus, critical analysis of the lived experiences of these māmā could reveal racial discrimination, for example, when view through the lens of critical disability theory (see Chapter 2) (M. C. Hall, 2019).

Tipene (2017) identifies HP as aligning strongly with the strengths and traditions of Māori culture, particularly as an oral culture. Māori traditionally share identity and experiences through pūrākau (stories), whaikōrero (traditional speech-making) and moteatea

(traditional song). Storytelling is associated with Kaupapa Māori theory, through which the words of the wāhine become their pūrākau, their stories, and their knowledge. The transformative nature of this research shares commonalities with transformative research, the aim of which is to contribute to solving societal problems.

Transformative Research

Transformative research has its roots in participatory, feminist and anti-racist research methodologies (Kemmis & Smith, 2008; Mertens, 2009). It strives to make a difference in the lives of people through a social justice and human rights approach that benefits marginalised communities and foregrounds the lived experience of those communities. Transformative research approaches are guided by the values of self-determination, participation and empowerment (Kemmis & Smith, 2008; Mertens, 2009; Ristock & Pennell, 1996). Its capacity for positive change for disabled people and their families make transformative research particularly pertinent to the present study. Transformative researchers employ those most marginalized to become active participants and decision makers within the research processes and often engage in the research as a participant.

The focus of this research is on how Māori wāhine create their own knowledge and understanding of takiwātanga and how, over time, they develop strategies and skills of negotiation and activism in relation to the environments they interact with on a daily basis, including the education and health systems and the home and the community. The research design allowed the wāhine in the study to be in control of the knowledge being generated by privileging them as experts in their tamariki and in takiwātanga. This created a space where knowledge was created, accepted, negated, ignored or challenged by the māmā as they integrated their experiences in the creation of mātauranga wahine. Whakaahua – or the ability, desire or action to transform, embrace or integrate – aligns with the essence of transformative research.

Transformative research aligns with PAR in that it challenges the structures of power with the goal of emancipation through empowerment of the disadvantaged and the disempowered (Nelson et al., 1998; Ochocka et al., 2002). Furthermore, using the tools of PAR supports a space for co-learning and collaboration by maintaining a strong focus on the relationship between the researcher and the participants in the research.

Transformative research also draws attention to historical and enduring inequalities caused by colonisation and patriarchy and advocates for liberal policies and empowering

communities through social and political action (Lorenzetti & Dhungel, 2020; Mertens, 2017). According to Jacobson and Rugeley (2007), transformative research focuses on the concerns of communities, privileges lived experience, and values collaboration as imperative to both the research and processes of social change.

Indeed, transformative research is associated with drawing together philosophical strands that include feminism, critical theory, Indigenous and postcolonial and disability rights theory. Therefore, this research approach is applicable for communities that experience less access to social justice and positions transformative research as an ideal tool to underpin this research conducted with Māori wāhine whose tamariki experience takiwātanga. In this study, the māmā maintained control over the direction and ultimately the outcomes of this research.

Recruitment and Participant Selection

The target population for this research were Māori māmā (mothers) or primary caregivers of children (tamariki), adolescents (rangatahi) and adults with autism. A total of eight wāhine participated in this research from across Aotearoa (see Table 2 below). Potential participants were sought through agencies associated with autism and non-governmental organisations who support families with disabilities in Aotearoa. These included Parent2Parent; CCS Disability Action; Altogether Autism, and Autism New Zealand. Another organisation that was contacted was a social media group called 'Takiwātanga: Māori Takiwātanga Support Group' on Facebook. This is a Facebook page created specifically to support Māori whānau with their experiences of takiwātanga. Initial contact was made with organisations through email (Appendix 2). I followed up with a personal phone call to discuss the research and requesting permission to use their databases to send information to prospective participants.

An electronic participant invitation letter (Appendix 3) was provided to the organisations to pass on to the prospective participants. Contact with the wāhine who responded to the participant invitation letter included emailing them, calling them by phone, or talking to them through the electronic meeting platform Microsoft Teams. This was an opportunity to explain the research to them in more detail, and if required, send another copy of the participant invitation letter electronically or by post. A pilot study was conducted to test the arts-based activity to review how it would suit the overall research plan.

Table 2

Māmā Pseudonyms and the Age of Their Child(ren) with Takiwātanga at the Time of Data Collection

Māmā	**Tangata Whaitakiwātanga**
1. Māmā Tuatahi	14-year-old son
2. Māmā Tuarua	8- and 7-year-old sons
3. Māmā Tuatoru	3-year-old son
4. Māmā Tuawhā	9- and 6-year-old sons
5. Māmā Tuarima	8-year-old son
6. Māmā Tuaono	14-year-old son
7. Māmā Tuawhitu	3-year-old son
8. Māmā Tuawaru	5-year-old daughter

Ethical Issues

This research was approved by the Massey University Human Ethics Committee: Southern A, Application 19/70 in January 2020 (see Appendix 6). There are a number of ethical considerations when conducting research with human subjects, and at a minimum these include the preservation of privacy, confidentiality, and the rights of the research participants. Ethical research is extremely important when the participants are Māori. The established principles of Te Tiriti o Waitangi – partnership, participation, and protection – must guide the processes of relationship building, control over the research processes, and rights to the intellectual ownership of the knowledge being produced (Aksoy & Tenik, 2002; Durie, 1994; Hudson, 2004; Hudson & Russell, 2009). Hudson (2004) clarifies three significant aspects of the research relationship: status (recognition of parties as equal), process (integrity of engagement) and outcomes (equity of outcomes).

All of the participants in this research were Māori wāhine, and so I followed the advice of Kaupapa Māori research advisor and researcher Tepora Emery in relation to opening each focus group with a karakia (traditional prayer), followed by a mihi whakatau

(formal welcome) and whanaungatanga (whakapapa connections) to remain within the appropriate boundaries of tikanga.

The wāhine were informed of their rights and responsibilities as participants and were asked to sign the participant consent form at the beginning of the data collection day (Appendix 4). This included the wāhine being given prior knowledge that the focus group interviews were being conducted in pairs. Other information provided to them related to revisiting the participant invitation letter (Appendix 3), and, before the start of the focus group, they were assured of the confidentiality of the information being shared within the focus group space. The focus group sessions were scheduled for around four hours, and classrooms or private room bookings were made in the town or city where the wāhine resided to support their participation.

I personally transcribed the recordings of the kōrero (discussions) during the focus group sessions and thereby protected the confidentiality of profoundly personal stories that the māmā shared with me whilst gaining a deep sense of their lived experiences with takiwātanga. At each focus group session, the wāhine created their own set of rules and one that was always non-negotiable was confidentiality. Another aspect of confidentiality was the anonymising of the identifiable information about the māmā and their loved one with a diagnosis of takiwātanga in the final thesis.

In 2020 and 2021, the worldwide COVID-19 pandemic resulted in a Level 4 countrywide lockdown, and this impacted the ethical holding of any type of focus group. Additional measures included social distancing, deep-cleaning research rooms before and after use, and the availability of hand sanitiser and face masks. All procedures and rules associated with the protocols of the COVID-19 pandemic were implemented during this research and the focus group sessions to maintain optimum safety for the participants and myself.

Reciprocity and manaakitanga (support) were important cultural factors associated with this research, I therefore provided kai (food) and other refreshments during the focus group sessions. In addition, the wāhine were provided with a small koha (gift/donation) for their time (either petrol or supermarket vouchers). I also personally made up a carry bag of chocolates, treats and specialty coffees for each wāhine as a form of personal thanks for their time.

The research was conducted in a way that was supportive, nurturing and reaffirming for the wāhine who participated in the research. However, from an emotional perspective, the wāhine occasionally discussed some sensitive and upsetting topics around their loved one with takiwātanga. When this happened, I purposefully slowed down the discussion to allow time for reflection and to awhi (support them). Having experienced overt racism and discrimination across the education and health systems and my community, I was very aware of the pain this causes and was conscious of not wanting to cause distress to the wāhine by bringing up past trauma.

Having two māmā and myself in the focus groups allowed for emotions to be expressed in a safe space because every one of us had the lived experience of takiwātanga and could be supportive on all levels of the discussion.

Methods

Pūrākau

The deliberate act of using pūrākau as a research method in this thesis aligns with a commitment to adopt a decolonising methodology that meets the needs of the wāhine in this research as the owners of the knowledge they collectively created. Reproducing their kōrero as faithfully as possible respects their kōrero as pūrākau in which they are both the protagonist in, and expert on, their lived experiences. Pūrākau are traditional oral Māori narratives that are a rich tapestry of philosophical thought, cultural nuance, and knowledge from the perspective of te ao Māori, encapsulating how Māori identify themselves both historically and in contemporary times (J. Lee, 2009). Furthermore, the use of pūrākau within a decolonising approach to research is firmly embedded in the social and political landscape of Māori rights and the potential to provide a pathway to reclaim traditional concepts and stories as authentic knowledge and culturally validated discourse that inform Indigenous theory (J. Lee, 2009; Rua et al., 2017; Sanson, 2017). Similarly, L. T. Smith (2021), claims that Indigenous research privileges self-determination and the endurance of culture that includes language, values and beliefs that support the reclamation over the collective destiny of Māori. Perhaps most relevantly for this study, Ngahuia Te Awekotuku (2003) tells her own versions of some well-known pūrākau that feature powerful women (mana wāhine) who used pūrākau to emphasise power and strength in traditional Māori society.

The māmā in this research engaged in the telling and retelling of their lived experiences and retained the power to define the truth and meaning of their story. This is a

move away from the linear process characteristic of Western research and towards a research process that moves in more like a spiral or koru (spiral shape that represents an unfurling silver fern frond). According to Bishop (1996), this spiral suggests a process of continually revisiting the research. As stated by Heshusius (1994), “Reality is no longer to be understood as truth to be interpreted, but as mutually evolving” (p. 18). She maintains that the research must adopt Indigenous relational practices that support working alongside those being researched.

Focus Groups (Ngā Rōpū Arotahi)

Bringing participants together in focus groups provided an opportunity to elicit a range of perspectives from a single session (Tolich & Davidson, 2011). Hughes and DuMont (1993) characterise focus groups as homogenous parties who provide knowledge around specific topics of interest to researchers and can support a large amount of interaction on these topics in a short period of time (Pini, 2002). A strength of the focus group method is the possibility for the research participants to collectively develop their ideas and foreground their own perspectives. Focus groups are characterised by interactions between the participant-researcher and between the participants themselves. They supports the collective ideas and understandings that advance the creation of theory that is grounded in the lived experience (Mostern, 1996; Smithson, 2000).

The focus groups were run in pairs because this gave the māmā plenty of time and opportunity for kōrero to take place in a natural and unhurried manner. The intimate environment allowed everyone to feel relaxed, connected and creative during the art activity. A group agreement was reached at the start of each focus group that identified the rules around confidentiality and participant rights. Before starting each session, I outlined the research again and asked the wāhine to sign the participant consent form (Appendix 4). The entire engagement process with the wāhine was conducted in a relaxed and informal manner.

My role required me to listen to the discussion during the art sessions and guide the māmā when necessary, with prompt questions. My aim was for the māmā to lead the discussion, and, as they spoke, I made notes and probed their answers when I needed clarification or more context. The focus groups lasted between 3.75 and 4.5 hours. Morning tea and lunch breaks were taken during the ongoing kōrero.

Art Making

During the focus groups, the māmā were provided with a large canvas measuring 55 cm × 70 cm to create a piece of artwork while answering the semi-structured focus group questions (Appendix 1a). Art resources were also provided, including suitable adhesives, acrylic paints and other artefacts such as shells, sticker sheets of letters and numbers, glitter, beads, feathers and raffia.

Bringing Māori māmā together in the storytelling environment of this research where they could create art facilitated a space for friendships to develop and for activism to be made visible through conversation and reflection about the lived experience of having a whānau member with takiwātanga. Storytelling contributes to the diversity of perspectives for Māori, and the storyteller retains the power over this story (Bishop, 1996). Collaborative storytelling within research is associated with people who can recall, reflect, and integrate their cultural context in a way that makes sense of their experiences and builds whakawhanaungatanga.

My interest in using art as an activity to collect data for this research links to the desire to bring Māori māmā together in pairs to create artwork so that this part of the research was relaxed and interactive. This made the research process less intrusive and provided the opportunity for whanaungatanga to occur between the participants and myself as the researcher. The kōrero generated from this activity set the foundations for the development of knowledge by the wāhine. It was the process of creation rather than the product that catalysed the kōrero of the māmā (Withers, 2009). Additionally, the creative process of art making involves opportunities for reflection through the participants' inner dialogue with their experience (Blomdahl et al., 2018). According to my training in Interactive Art Therapy, artworks created in this way will continue to 'speak' to the māmā long after the artwork is returned to them (Withers, 2009), providing moments of reflection and recalling the whakawhanaungatanga that enveloped the art activity and the kōrero in the focus group.

Recording and Transcription of the Pūrākau

The pūrākau of the māmā were recorded using a recording device. I personally transcribed the pūrākau, which involved revisiting the art activities and the interactions between the māmā during the focus groups. The transcription process brought recollections of the kōrero to mind and allowed me to become familiar with the intonations in the voices of the māmā, whether denoting happiness, anger or pain. Transcription, particularly for Māori,

by Māori and with Māori, is not just typing out a recording – it is reliving it. Any other way minimises the context of the spiritual nature of the event.

By transcribing the pūrākau myself, I was able to ensure Māori tikanga was followed and that the mana of the māmā was respected. Some of their kōrero was very personal and spiritual, requiring sensitivity and the application of cultural protocols associated with tikanga (L. T. Smith, 2021). I listened to the recordings and read the transcripts multiple times over multiple months and years. I am intimately familiar with the content and concepts of the pūrākau that were gifted by the māmā (Dewis & Kay, 2018).

Printed copies of the transcripts were provided to the wāhine for reviewing and to gain their consent to release them for analysis by the researcher (Appendix 5). The completed artworks were dried and sprayed with an appropriate sealer before being photographed. Hooks and wires were added so that the artworks were ready to hang, and they were returned to the māmā by courier. All the artworks were returned in December 2020, just before Christmas.

Data Analysis

Analysis of the transcripts was conducted in two phases. The first phase focused on what the māmā were doing, saying and being, and from this process emerged an analytical device in the form of a metaphorical taiaha, which is traditional Māori weapon of war. This metaphor helps to explain the eclectic nature of the methodologies I have employed in this research.

As I engaged and re-engaged with the pūrākau of the māmā, it became clear to me that in defending their unique knowledge of their tamariki with takiwātanga against opposing and deficit-based models of autism, they were symbolically wielding a taiaha to silence anyone who did not respect their mātauranga wāhine.

A taiaha is a long-handled wooden weapon used in defence or offence against an opponent. It was used to stab, slash and strike others and to block attacks from an opponent. Traditionally, the taiaha was used by Māori men during warfare, but history informs us that it was also used by Māori women in defence of their homes and their tamariki, and this is mentioned in traditional pūrākau (Sharples, 2015).

The body (tinana) of the taiaha narrows from the bottom upwards until the upoko (head) and arero (tongue) are reached at the top. The arero is often carved and ornate with a

collar of feathers and hair at its base that not only adds to the beauty of the taiaha but also distracts the opponent in confrontation when it is wielded and rotated in the air, making the feathers flutter and dance (Keane, 2012).

Figure 1 shows the Taiaha model, which includes the methodological ingredients that have contributed to the creation of the methodology for this research. From my perspective as researcher, the taiaha represents the integration of theory and praxis – both Western and te ao Māori - that guided me during the data analysis process that preserves the mana of the knowledge created by mātauranga wāhine of the māmā. The Taiaha model demonstrates how a Western ideology can be transformed into an Indigenous – specifically te ao Māori – one.

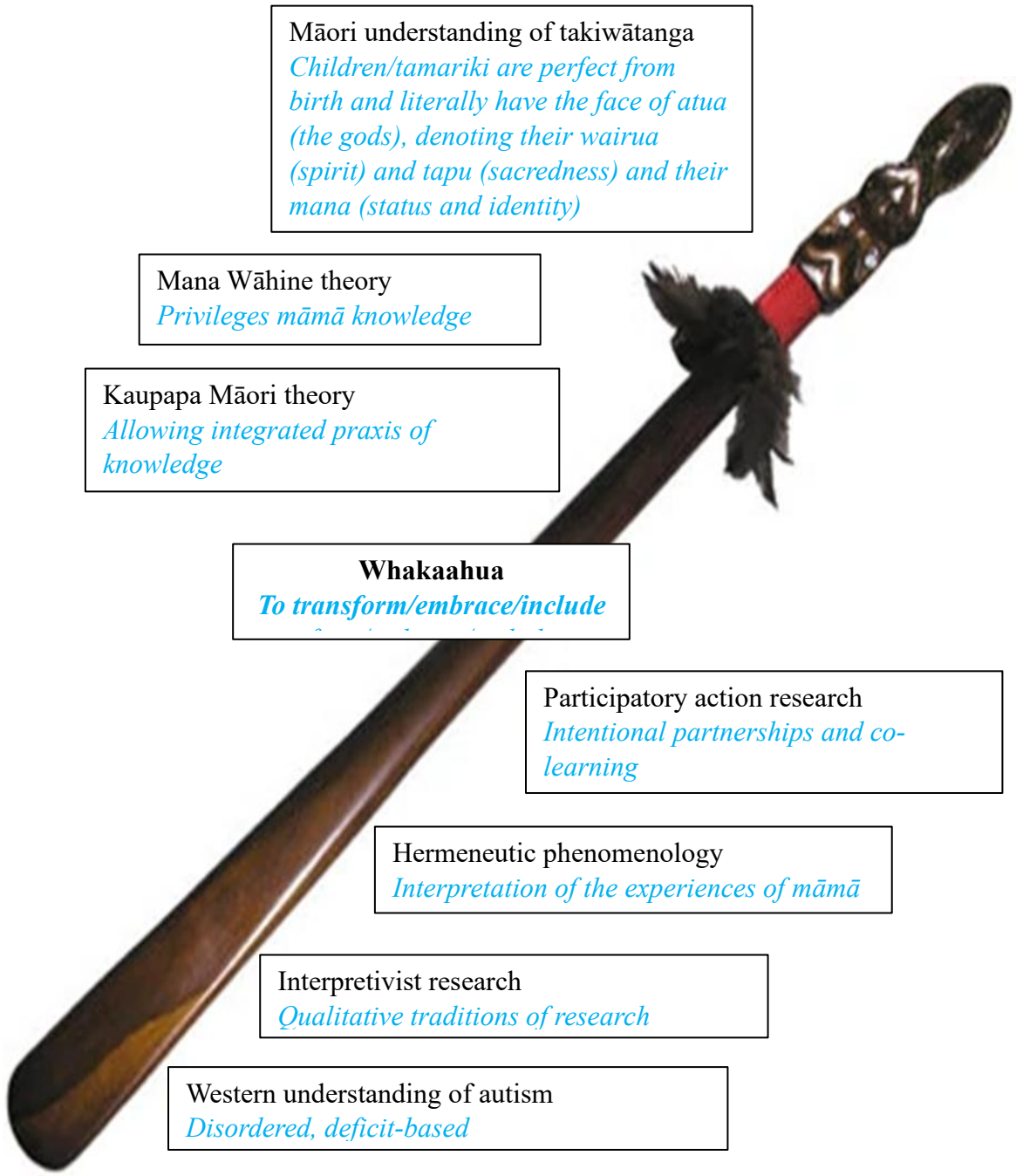
'Autism' for the māmā in this research was learned about in the first instance in the New Zealand health system after acting on their own observations or those of others, and on the desire to gain support for their child and understand their child's diversity. The māmā took the metaphorical taiaha in their grasp and through patience and practice became experts in its use. The taiaha became seasoned and hard through the intentional symbolic movements of parrying, stabbing and striking that defended their intimate knowledge of their tamariki from birth.

The taiaha is purposeful in terms of te reo o nga māmā – 'speaking' back through the carved arero (tongue) of Taiaha – declaring that the māmā will not be silenced and insisting they will be heard. The adornment of the feathers on the taiaha symbolises that the māmā will deflect and distract information that is not useful or valued by them. When applied to the transcripts, the figurative meaning of the taiaha highlights te tū toa – the strength and resilience of the māmā. When taking ahae (a defensive posture) or wielding their Taiaha, they were not coming for a battle; they were declaring their capacity for war.

The Taiaha model demonstrates how a Western deficit-based ideology of autism can be transformed into an Indigenous strengths-based ideology of takiwātanga. The development of my methodology therefore mirrors the development of knowledge by the māmā in this research.

Figure 1

Taiaha Model



The second phase of the data analysis involved thematic analysis (TA), which is the process of identifying patterns or themes within qualitative data (Braun & Clarke, 2013). This Western method was utilised to identify the key Māori concepts or themes within the kōrero. Two broad categories of TA include experiential and critical orientations (Braun & Clarke,

2013; Reicher, 2000). Experiential orientations denote what participants think, feel and do, and align with the theory that reality is reflected in language. Critical orientations, by contrast, involve cross-examinations of the dominant patterns of meaning within language, as they posit that language creates reality (Guest et al., 2012; Joffee, 2012). The recognition of patterns, repetitions of words, phrases, and concepts that can be readily identifiable as Māori through TA illuminated the experiences of Māori māmā and their tamariki with the lived experience of takiwātanga. Building a foundation for theme development for this research involves identifying concepts within a dataset that potentially link to the research question (Braun et al., 2016). Following this process, I organised concepts into themes from each pūrākau, reviewing these themes and creating a rich tapestry of te ao Māori concepts that support the understanding of raising a loved one with takiwātanga. Additionally, and to ensure the accuracy of the key Māori themes within the data, the researcher consulted with her kaumātua (elders), and with the Kaupapa Māori literature reviewed in Chapter 2.

The next chapter presents the findings of this research categorised under the three main contexts given in the research question: the education and health systems, and home and the community.

Chapter 4: Findings

The following findings are shared from the individual viewpoint of each māmā who participated in this research. Their pūrākau are presented directly from the transcripts under the three main contexts of education, health, and home and the community. A brief description is provided about each māmā and their tamariki. Analysis of the findings revealed that three main concepts from te ao Māori were interwoven within and between the pūrākau of the māmā: whakawhanaungatanga (relationship building), manaakitanga (showing respect, generosity and care for others), and tuakana-teina (the relationship between an older [tuakana] person and a younger [teina] person). These concepts will be fully explored in Chapter 5, which discusses the findings of the pūrākau in relation to the findings of the literature review conducted in Chapter 2.

Māmā Tuatahi

Māmā Tuatahi has a 16-year-old son with a diagnosis of takiwātanga who attends a mainstream high school. In addition to takiwātanga, he has a serious and ongoing respiratory condition that requires him to have long stays in hospital during the winter. This condition has at times led to him being admitted into the hospital's Intensive Care Unit (ICU). Māmā Tuatahi also has a daughter, who is a year younger than her son, whom she believes has takiwātanga too, but has received little support to have this medically recognised.

Education

Her son's schooling had been a stressful experience for Māmā Tuatahi. She believed most of his teachers had failed in their professional and ethical duty to protect his right to an education, and her right to be treated with respect as his māmā. According to Māmā Tuatahi, there was only one teacher in her son's entire schooling who was supportive:

> So [one teacher] is helping him all the way through. I met with her last week to do the term 1–3 parent/teacher classes, and she said that he will pass with endorsements this year, which is really good.

Negative Experiences at School. Māmā Tuatahi felt discriminated against when she was asked intrusive questions relating to where she lived, and by the non-verbal

communication she observed during interactions with school staff. This discrimination extended to the actions of teachers who showed a lack of empathy and awareness of takiwātanga as experienced by her son. These biases led to both māmā and her son being the target of unfair judgements:

> I have had that all the way through the kids' education … You know those questions. I hate those questions. Oh, you used to live on that side of town. The whole demographic. You know the questions and the intentions behind it.
>
> The looks up and down [from my head to my feet and back to my head again] before you even open your mouth. They have judged you before you open your mouth … Like when [my son] got stood down last year, they didn't want to listen to me. They just knew that he had been in a fight. And because his father had arrived there before me … Oh God, he has already ruined it for me. We have not been together for 15 years … I don't know why the hell they rang him first.

Māmā Tuatahi believed that a teacher's training didn't count for much when their attitude and actions were driven by ignorance:

> [The teachers] will take their privileges away … take them away from camps, take their devices away, keep them in after school. What school has taught me is that it does not matter how much training they get [about takiwātanga], it's all about their attitudes and their ignorance.
>
> It's in his high school years that he became a target for the teachers ... recently the teachers have been really hard with him, saying that he is failing English … [One supportive teacher] said to me at the end of last year, "Look, I have got this pissy email, from his English teacher, he has failed English … It is up to [your son] to communicate with her about what he needs, and you and I know that he doesn't have the language [skills for this complex discussion]."

Health

For Māmā Tuatahi, the health system provided professional opinions of her son's behaviours linked to his diagnosis and to the symptoms of takiwātanga. This enabled her to learn about the way her son perceives and responds to the world around him:

> [I go in] for the behaviour along the way, for getting a diagnosis … the tools that you need, the communication, the sensory, the things that you don't know about takiwātanga … wondering why [he is] still spinning and clapping for 16 minutes.

Not Being Heard. Māmā Tuatahi felt that her own knowledge was not valued by people working in the health system:

> [He was] 12 when he got his diagnosis. By the time he was 15 years, I just learned to nod my head … For three years I challenged [them], because I am a believer that us mums know because this is our lived experience … No one wanted to listen.

Despite there being well-known symptoms of takiwātanga, often people in the health system showed little empathy, especially when it came to her son's diet: "They said feed them vegetables and fruit, and I said, 'Good one … you try to do that with an autistic child.' Then they think you are over [protective].

First and foremost, the pride and identity of her son as Māori was very important to this māmā, and she felt that the health system could support him better:

> [My son] is somebody and he has a story … He has a whakapapa [genealogy], they all have someone at home that is waiting to wrap their arms around them … They are not just a placement, or an internship, they are not someone you have trial and error with. It's about having a lot of faith in maintaining what we have. Hence the reason why we go to our paediatrician appointments.

When interacting with the health sector, Māmā Tuatahi felt judged by the medical professionals she came into contact with. The health system in Aotearoa is characterised by seemingly endless encounters with receptionists, doctors, paediatricians and other specialists providing health care for tāngata whaitakiwātanga:

> Every time I sit down, every time I am waiting in the waiting room, every time I get the appointment … every time, oh yeah, this is just the process. I get that. But we are not a process. We are a miracle. Treat us like one. That is me. I don't want privilege … I just want them to know that we are not just

> National Health Index numbers. Getting judged, always getting judged, especially because of our skin [being Māori].

Even with an attitude of wanting to get the best out of the health system, Māmā Tuatahi felt that she and her whānau had been let down by the very system meant to support them and increase their wellbeing. This even included Māori organisations:

> I have been really let down by the health system … I look back and my husband and … how we are so lucky that [our son] got his diagnosis at all really … I struggled with his behaviour … and my husband said we are lucky because the diagnosis gave him the ability to understand [our son]. There were so many times I asked for help … asked how can I love my son … how can I parent him properly. I went to Māori organisations, and other organisations where I live. I kept getting sent away.
>
> But it's health … because people [medical professionals] are leaving all the time, you cannot get a relationship or a connection with somebody.

The manner in which health appointments were made proved to be a barrier as this māmā could not afford transport on the assigned appointment day because it did not align with income payment days. As a result, instead of health staff recognising this as a financial barrier for her, Māmā Tuatahi was painted as being a resistant mum who was deliberately avoiding appointments:

> [There was no consideration of whether I would] be able to afford to show up to the clinic [the District Health Board]. Māori health services first heard about me and I had a DNA [Did Not Attend] for two of their appointments. They asked me why … and I said I don't have gas money … it's on a Monday and I don't get paid until Tuesday.

As noted above, her son has an ongoing severe respiratory condition, which often culminates in him being admitted to ICU. He has multiple stays in hospital every year, especially during the winter. Māmā Tuatahi has been questioned by social workers about her son's multiple hospital admissions:

> You can be recorded looking like a red flag … I have social work being done on me. [My son] had just been released from hospital after a six-week stay … and he has presented back three times in resuscitation [linked to his chronic

> asthma condition] … but they have let him go home again. Now you [the hospital] are the one discharging him … The real issue is that he is not well enough to be going home.

The experiences of Māmā Tuatahi in the health system are common for parents with children whose behaviour is difficult to manage in unfamiliar environments, and this related directly to the symptoms of takiwātanga (Samsell et al., 2022):

> It's all about attitude … They can have all of the information but no compassion, no empathy, no regard because the kid might be absolutely beautiful but if you are struggling with their behaviour, and you are trying to get a needle in their arm, the security is running [to attend the disturbance] … They [the security staff] get overwhelmed, which in turn gets you overwhelmed, which has the child double overwhelmed. And this is my experience. The less I have to do with them [the health system] the better … It makes me feel better not to have anything to do with them.

Māmā Tuatahi believed her daughter is also on the takiwātanga spectrum. Obtaining an appointment for assessment and possible diagnosis, however, has proven difficult:

> They rang me during [the COVID-19] lockdown to ask if my daughter still needs to be assessed … I have been waiting for an assessment for three years now. I feel I just can't throw her there, to do it now for a label. I just wanted her to understand herself. She has presented not so much self-harm, but sadness, which is what I would suspect would go to depression.

Home and the Community

Māmā Tuatahi values the inherent strengths her son has. She also feels he plays an important role in increasing awareness of takiwātanga for people they come into contact with:

> They have so many strengths and blessings along the way … and the superpowers that they have … [My son] is always accurate, he glides, but we know that they do have empathy, they do have pain, they do have expectations, and desires, and dreams. So, [at home] it's the permission and a place for us to become better people, and if other people cannot deal with that when we step out into the world … and sprinkle our little glitter all over them

> … Our takiwātanga glitter, because it sticks, it doesn't matter how much you want to wipe it off, that glitter sticks.

Home is a place of safety where takiwātanga is celebrated for this whānau. Māmā Tuatahi describes her whare as the 'whānau marae', with its own tikanga (rules) and rituals linked to her son's lived experience of takiwātanga:

> Takiwātanga is our home. I would not want my world any other way. In this world, I am so privileged, I am so blessed, I had all of these kids, you need to be militant and structured, and you have got to be organised … If home is where the heart is, takiwātanga is our heart, and everyone is invited. We are grateful it is unspoken, but I want to celebrate it.
>
> I have mentioned to you before that our whare is our marae [where] we allow for the blackout [dark rooms] to happen … because of the light sensitivity and because of the sensory issues … The silence can happen in our whare, the high-pitch squealing, we don't have to tone it down, it's our home.

Māmā Tuatahi had experienced negative judgements by others in the community, and she explained how she navigates those experiences:

> Why take them to a supermarket where people are going to judge, not only him but yourself? Why have someone frown down at you?
>
> I haven't [managed]. But of course, we do, we are mums, we have superpowers, like our beautiful children. Every day is a new day. At home … it's great because he is so predictable, and when he is not predictable, we all get along, we all pitch in.

In summary, Māmā Tuatahi found her experiences in the education system to be the most difficult to manage, with almost a complete lack of professionalism displayed by the majority of her son's educators towards herself and her son. Some aspects of the health system were welcomed by Māmā Tuatahi, but there were considerable barriers to accessing equitable health outcomes for her son, and she also felt discriminated against because she was a Māori māmā. For Māmā Tuatahi, home was the safest place for her whānau. It was a place to honour takiwātanga and for her son to live in a space where he was accepted and loved.

Māmā Tuarua

Māmā Tuarua had two sons aged 7 and 8 years old at the time of her kōrero in February 2020, both with a diagnosis of takiwātanga. She described parenting as an exciting experience in her life. Māmā Tuarua was having difficulties with settling her youngest son with a new classroom teacher, and she was considering moving back to her childhood town to be closer to her whānau for support.

Education

The experience at school for both her children had been mostly positive thus far. Her younger son was having considerable difficulties in adapting to the change of classroom teacher, and Māmā Tuarua was not afraid to speak up for herself and her son. She felt the teacher was using teaching methods that were too authoritative:

> And this is how she is trying to teach my son, forcing him … it's force, and I say no, you don't do that to my boy.
>
> Before this stuff came up, school was awesome, they loved going. They would run to the van, sometimes they would cry when they had to come home. They loved school. Not my baby so much. I have an appreciation of what [the school] goes through with my children on a daily [basis] … because they know what they are talking about ... but I don't actually think they do because until you live and breathe autism you don't know. There are natural ways [to teach] my son … he likes being outside … he likes going outside all of the time.

Māmā Tuarua is not afraid to speak up about how her son learns best and how she wants to be treated by the kaiako (teachers):

> But we get stereotyped, and this professional kōrero that comes at you, and *AT YOU*, they think they can speak at you … I go no, no, no, you don't talk to me like that … but I needed them to know that your approach with me is wrong, and you don't talk to me like that, you don't talk at me, you talk with me. And that is how you teach my son, with him, get down to his level, change your tone … If you are going to teach my son, you have to do it well.

Through her own research, Māmā Tuarua is not supportive of using medication as a tool for him to engage better in school.

> I have heard this often that about them trying to medicate children because they find that this is the easiest option … But I say to them that there is no scientific research to say that this is going to help my son, you are not going to use the easier option.

Lack of Home-School Communication. The conversation regarding medicating children was a shared experience for four other māmā in this research, with the pressure coming from the health system. Māmā Tuarua was the only māmā who discussed feeling direct pressure from the education system and teachers who promoted the use of medication to support changes in behaviour and promote learning.

> I am just battling at the moment … I get an insight to a lot more than they do [about my sons]. It is difficult telling them [the teachers] this. They are trying to build a case against my baby to medicate him.

One of the issues for this māmā was the lack of communication from the school about the pending transition for her son to another class, and a new teacher. One teacher discussed the issues she was having with the school during a home visit with Māmā Tuarua:

> Yes, they [the teachers] just get told a week or two out from [the transition] that my son was going to this class, and [the teachers] have to live with it. [They are told] if you can't live with it, you can find another job … and this is a teacher coming to my house and feeding me that information.

The new teacher is from overseas, and the māmā felt like this teacher was disrespectful towards her. She therefore advocated for herself and her sons to be treated with respect:

> And that was the way she was talking to me with snarky comments … [My thoughts were,] no you are not being rude to me. When I said to her, "Can I leave the room please, I need to go to the toilet to calm down, I feel I am getting heated." Now it is all please and thank you, in the way that she approaches me … and my son is coming home and he is way happier.

The teacher who conducted the home visit told this māmā she felt unsupported by her school:

> [The teacher] cry to me, it's like [the school] was not giving her enough support and was looking for my guidance to get that … My take is if you had a problem six months ago with my son, why wasn't I notified about it … and if I wasn't notified about it, I don't want to hear it, that's back then. We are going this way [forward]. And this is how I am approached. I arched my back up [got upset].

This māmā experienced a lack of cultural engagement during interactions with her sons' teachers:

> They want my help … in actual fact I went away from the meeting, I thought I could have dealt with that a bit better … They need my help for my boy. But it is going to take a little while to get over it … They need to change their approach. It is how you approach a Māori; it is not the same as you approach a Pākehā … In actual fact, Māori don't like to be told what to do. Unless you come to our level and you understand what is happening in our lives. [If not,] we arch our backs and we say hang on a minute.

Health

During her kōrero, Māmā Tuarua did not share any information – positive or negative – about her access to and experiences with the health system.

Home and the Community

Importance of a Supportive Community. Māmā Tuarua felt supported and accepted in the small community she resides in. She and her sons are well known in the area, and other children willingly play with her boys:

> I'm a solo mum, we live in a [lower socioeconomic area] … We often get judged for that, it was the only property to buy, at the time I bought my property. I love it [here] … We are a tight knit community … they look after me. They have an appreciation for my children with takiwātanga because they [other children in the area] play with them.

Being away from her whānau home presented issues around having enough support close by in order to feel less "vulnerable":

> I am living three hours away from my immediate whānau. Our family separated after 17 years of being together with their dad … living three hours away from my immediate whānau, so at the moment I am struggling … the whānau connection is pulling at the heart strings, I will probably look at moving home.
>
> I am sending my big boy to live with my mum because I feel I am vulnerable … and I am going to take him back for just a little time while I concentrate on my baby to get his anxiety under control … or so they say, just at school they have this problem.

A Judgemental Community. Stigma and judgement was felt by this māmā in relation to the expensive labelled clothing her sons wore. She felt that people thought she was engaging in illegal activity in order to afford these 'luxury' items:

> I am really fussy with what my children wear … we all wear labels [labelled clothes], some very highly labelled … [Therefore, people think] oh she has got to be selling drugs, you can't be on a benefit … The beauty of being able to pay your stuff off, you can pay for it over 10 payments … It means I can afford it.

At the time of writing, I learned that Māmā Tuarua had in fact returned to her whānau home to be close to her own māmā. Overall, Māmā Tuarua found parenting two boys with takiwātanga an exciting adventure: "Children on the spectrum take parenting to the next level but it is exciting, it is never a dull moment, but as long as we keep the routine the same, and everything the same, life is pretty awesome."

In summary, both sons of Māmā Tuarua had had positive experiences at school up until around the time of her kōrero. A change in teacher for the youngest son created issues resulting in a hui (meeting) between this māmā and the school that created some tensions between them. She did not make any comments regarding her experiences in the health system; however, she did highlight that her greatest support was experienced in the close-knit community in which she lived. There she felt her children were accepted and protected by those people who lived around her.

Māmā Tuatoru

Māmā Tuatoru has three young tamariki. Her youngest son is three years old and had been diagnosed with takiwātanga. Māmā Tuatoru and the children's pāpā (father) have separated. Although he lives in another city, he is very involved in the children's lives, especially the youngest tamariki with takiwātanga. Pāpā came to the interview location with Māmā Tuatoru to look after their boy with takiwātanga, who is always on the go, during the kōrero.

Education

Positive Experiences with a Specialist Character School. Māmā Tuatoru discussed her positive experiences with the education system and how well she was supported by the school staff and other members of the community associated with the school. All of her children attended the same specialist character school, which is a state school that is based on a particular philosophy, religion, or worldview. This provided a solid routine and opportunities for socialisation for her boy who has takiwātanga. The school is linked to her church and her Christian faith:

> I put in the extra effort to pay the extra money to get them through the private school, because it's a school of 140 kids … and the school is actually at my church. It provides consistency for [my son]. We go there to church every Sunday … I serve on the kids' church there, and this links to my Christian faith.
>
> They teach values of kindness, and celebrate differences … It's very caring … it provides consistency for [my son]. It's familiarity of the building. [My son] feels at home there. The way that I describe it is my turangawaewae [where I feel at home].

This māmā has financial support from another member of the church who sponsors the education of her three children: "I do have a sponsor [from the church] who helps me with the children [with school fees]."

Involvement with the church has helped Māmā Tuatoru see herself as a better parent by being more attentive and engaged in the ordinary daily routines with all of her children:

> [My son] started there at three months old, there were 15 free hours, and this is what helped with my Christian faith … my beliefs helped shape my beliefs especially around my children. We make the children's lunches. I have become a better parent by making their lunch, and being more involved … instead of turning up, dropping them off and leaving.

The takiwātanga journey began for this māmā when an early childhood teacher noticed her son's behaviours and suggested that her son might require a professional assessment:

> I didn't even know what takiwātanga was, I had no awareness at all … He doesn't look disabled. It was very intimidating to be approached by the daycare and them saying, ["We] don't want you to be sad but we think there is something that you need to be talking to your GP [General Practitioner] about." This is how it all started.

During her kōrero, Māmā Tuatoru did not indicate any negative experiences at school for her son or herself.

Health

Experiences in the health system for Māmā Tuatoru were a mixture of positives and negatives. She is a strong advocate for her son, and this resulted in a diagnosis for her son by the age of three.

Intuition of a Māmā. Right from his birth, Māmā Tuatoru intuitively knew that there was something different about her son:

> I said to them that there is something off, as a newborn he was not interested in food … the medical reason why he stayed in there so long [Special Care Baby Unit] … He was not feeding, he was not interested in [breast feeding], that was the real issue.

Dealing with Health Administrators. Māmā Tuatoru knew that building and maintaining relationships with staff working in health is important:

> When you have these interactions in this community and you face a professional that is predominantly white … and I know that, and that is why I try extra hard. I emailed the receptionist and she did not answer me quickly. I

> called up the Child Development Team [to arrange meeting] face to face … and I was quite short with her. I didn't know if she was going to be as helpful afterwards because I was a bitch on the phone … Those things do make a difference.

Her GP was most responsible for her positive experiences in the health system: "My GP, oh my, she was the game changer for me. Every time I need something, I go back to the GP… so I have got him (my son) another appointment with the child psychologists."

Māmā Tuatoru kept pressure on various parts of the health system, and this was key to getting a diagnosis of takiwātanga for her son. Her tenacity have also led to appropriate respite funding and the possibility of another diagnosis for her son related to behaviours associated with attention deficit hyperactivity disorder (ADHD).

> It is quite rare to get the diagnosis so young … because I really pushed for it. He has had his diagnosis for about a year now. I had to go and eliminate a lot of things [other health issues] for that diagnosis. He had glue ear, and I had to resolve that before we got the diagnosis, but you can tell he has really got it [takiwātanga]. Maybe because I am Māori, but I don't know, I had to fight really hard to get the diagnosis for my son at three.

Māmā Tuatoru had become very skilled in getting as much help for her son as possible from non-governmental organisations:

> And you are advocating for yourself with Support Net [Needs Assessment Service Co-ordination Association] … The response that you receive is that we [Support Net] are not going to pay someone $25 per hour to look after him. I asked what the minimum pay was and they said $15.50 [per hour] … for someone who can look after a 'high needs' boy … so, I am with [another fund holder] for respite.
>
> I am actually advocating now for ADHD, and so I have got him another appointment with the child psychologists, because [my son] was awake at 3 am this morning…and his likes are locks and escaping … He likes hoarding, he will hoard things, peeling kumaras [sweet potatoes] and fruits, he likes

> scavenging. I have a large property, so he will go out to the fruit trees, to the mandarins, or the lemons, he loves peeling them.

Whakawhanaungatanga and Whakapapa Create Security. Whakawhanaungatanga (making and maintaining relationships) and whakapapa (ancestral connections) were a source of strength for Māmā Tuatoru, providing a sense of identity, purpose, and belonging:

> From a positive point of view, my doctor has a Māori husband … and further to this we have got that relationship, we know each other's families. I think she is good at talking our language. She would say things like, "They [the boys] are at a good daycare, everything is working, so making drastic changes might make things worse."

Being a qualified professional did not automatically mean that this māmā was confident when dealing with the health system, and this was highlighted when she said that she felt overwhelmed by other professionals who worked with her son whose skills were beyond her expertise: "I am waiting for a funded car seat harness … The occupational therapist, she is really good. And the child psychologist is really good but I find it intimidating … well I find it intimidating."

Being Ignored by Health Professionals. Māmā Tuatoru discussed how she felt that her GP referral for a diagnosis was largely ignored at first:

> I felt like my GP got ignored [in her referral for specialist support] … This is not a feeling; this is a fact … I went back to my GP from about when my son was 1 year old … I was constantly going back to my GP.

Home and the Community

Māmā Tuatoru had close connections with members of her church, and although she and the father of her three children were separated, he remained close to her and the children, offering support and respite. Her son with takiwātanga enjoys constantly moving, touching, tasting and exploring every object in his environment. He has high energy levels and requires constant monitoring. When all New Zealanders were required to stay home for over a month in response to the COVID-19 pandemic in 2020, it was especially difficult for her son. Māmā Tuatoru has strived to find ways to keep her son engaged and settled:

> My strategy in coping with him is exhausting him through physical activities … COVID-19 changed a lot of things, he struggled through COVID, like really bad.
>
> My house is a fully fenced property, he likes to climb and escape, he is obsessed with escaping. And while he can probably climb over the fence, it gives me enough time to get to him and stop him.

This māmā and her son have experienced social support in a range of community spaces:

> I have been shopping with [my son] … Positive interactions I have had when shopping … have been with Māori or Pacific Island people. He just likes things he can't have, that is his obsession. He is obsessed with what he can't have. If he knows that is yours, he will want it. This Pākehā lady at [the local supermarket] … was looking at him so disgusted. I said he has autism. And she said, "I'm sorry. I didn't know." She must have been 60 plus … at least she said sorry.

Routines and Support from Personal Faith. Māmā Tuatoru found having routines for her son crucial, and feeling like she is a role model for her children supports her self-esteem:

> He has his routine, he goes to his daycare, Saturdays we are at the pools. On Sundays we are at church … that is his routine. … And you have a commitment as a parent, to walk with Christ. Through my journey … I started out and now I am serving at church and in the kids' church … and for my children to see me there in a leadership role is really healthy for them. My work as a mother at home is not valued. In church as a woman my role is valued. We have to make an extra effort to include him; this is what we did on the weekend [shows a video of her son peeling kumara at home]. Encouraging healthy eating and the end product. I try to do things with him as much as I can.

Stressful Factors for the Whānau. Māmā Tuatoru talked about the breakdown of her marriage with the father of her tamariki, which culminated in them separating. However, both

parents maintained a positive relationship with each other, and they focused on supporting one another with their tamariki, especially their son with takiwātanga:

> Takiwātanga, as anyone would know, takes a huge impact on marriage. [My husband] and I are married and we have split. We didn't know [our son] had takiwātanga when we split. But I can definitely tell you that through successive pregnancies and having a disabled child, it took its toll on our marriage.

Another stressful factor for Māmā Tuatoru is her son's compulsive eating disorder, or pica: "This is what I am seeing the dietician about. He eats anything, but he likes salt, sugar, he loves plants, he loves products like moisturiser, my deodorants and perfumes – pills and medication."

Her son also exhibits complex self-injurious behaviours that include head banging and lip biting:

> [My son] smashes his head. I have had two physical tantrums this week, which is unusual. One was smashing his head, and yesterday he bit down so hard his lip was bleeding. It's been difficult these last two days; I don't even know why. He is not sick or anything, it's been this weather I think, he is very sensitive. … [My son] struggles with sharing and taking turns. The smashing of the head is really hard, I stop him from doing that by constantly keeping him stimulated by activities, or day care, or water play. I don't have a bath so he sits in the shower with his bucket.

Spending extra time with her three-year-old makes it difficult for Māmā Tuatoru to give enough time to her other two older children: "It is really hard on the siblings … because he takes so much time being one on one. He has started hitting now, running up and jumping on [his siblings'] backs."

In summary, Māmā Tuatoru found a sense of safety in her religious faith, and her church community. The financial support from a church member for her children to attend a special character school added to her positivity towards the education system, alongside a good relationship with her former husband who is closely involved with all of their tamariki. She is a motivated advocate for her son, strongly

urging for health services to work together and provide the best possible care for her son.

Māmā Tuawhā

Māmā Tuawhā has three sons. The two older boys both have a diagnosis of takiwātanga and were aged 9 and 6 years, respectively, at the time of this research. Both sons require assistance with their toileting and the 6-year-old is always moving and needs constant stimulation. This takes the form of constantly walking around the school grounds and needing close monitoring by the staff at the school. The 9-year-old is more relaxed and likes to spend time sitting in the class reading area.

> I was married to their father … We have been divorced now for nearly 5 years. [In his whānau] there is foetal alcohol syndrome, so we were kind of looking (researching) that … then [our first son] came along … We kind of noticed things. I think we watched a documentary on takiwātanga. We took him to the doctors and he got his diagnosis. And my second son came along … he was kind of the same … but not.

Education

Positive aspects of her sons' schooling included interactions with staff members who made real connections with the boys and identified possible talents:

> The admin lady that is in there now used to be my son's teacher aide. She left her job and went into the office. She is very helpful. … The last [teacher aide] was real musical, and my second son was kind of getting into music, so they got him [teacher aide] to work with him.
>
> The new lady from the Ministry [of Education] was awesome. She thought about how [my son] was interested in art and how that can be used to be more involved with the other children.

Biased School Staff. However, Māmā Tuawhā felt discriminated against by some school staff because she was young and Māori:

> Yeah, not just being brown but being young … being a young brown mum. They expect that they will tell you what they are going to do with your child … and how it's going to be and that you will just listen to them.

> You are a young single brown mum and you don't know anything … I think that was a big thing for me, especially the school … There were teachers that were still there from when I was there, they know me and they just expect you to not question anything. Or not to go to them and say, "Actually, no, that is not working."

The way the school was funding the educational support worker (ESW)'s hours and other support for both her sons added to the feeling of discrimination for this māmā, as she struggled to understand how it all worked:

> The struggle with the whole teacher aide thing, ever since my kids started and I think it is the funding … I don't understand why that should be the issue with my sons being able to come to school every day like everyone else and learn and be safe. And the only reason they have is that [the school] don't have enough money[funding]. And I don't think that is good enough. That is probably my biggest issue, trying to negotiate with the school, and then try to negotiate with the Ministry to try and get what my sons deserve.

> Because [the younger boy] is so active, he would run away, and a lot of it had to do with funding … The school had to come up with a way to afford to keep him safe. That is pretty much it. And because the Ministry only funded for a certain number of hours … it did not even cover a full day of school. Somehow the school had to fund the teacher aide themselves, and I still don't even understand it … I don't think that they tell me 100% [everything].

Māmā Tuawhā felt that her own knowledge about her son's takiwātanga was not valued by the school:

> I will go to them and say what my sons need in order to come to school and be safe, and learn, and they're like, "Oh, we can't do that but we can do this." Or, "We can try and do that but we only have this to work with [funding]." And what can I do? … I cannot be here every day … even though I am, it's not just going to work.

Missing Out on Their Right to an Education. Māmā Tuawhā believed that the school's insufficient funding meant her sons did not get the education they

deserved. The shortfall in the funding meant that this māmā must be available to support both of her sons with nappy changing during school hours:

> It is stressful, and because they are my kids, if they need to be changed … I am not going to say no to my kids needing to be changed, and I think the school relies on that for my sons…so they never have to see that their system is not working.
>
> If the boys do not have a teacher aide, I will just keep them at home. Or if the boys cannot go to school before 9 a.m., so I drop them off at 9 a.m., and I go to work, and obviously I start at 9 a.m., but they know they do not have to find another way because I will just make it work. At the end of the day, I am IT … so, the school has never really had to work it out for themselves. It does get annoying and exhausting because I am constantly at the school.

Māmā Tuawhā knows that spending time outside in the natural environment (taiao) helps to engage her sons in their learning:

> In terms of education … I would probably hire a whānau member close to me to teach them. Alongside with my help … I think they respond to outdoor education more than indoor, so that's what we would do, outdoor, swimming, hikoi [walking trips], learning about nature, sports … Māori tikanga [customs] will be paramount, everything Māori … but not forgetting the world we live in. Just capitalising on those things that they like to do … and then try to introduce some sort of education, when they are at their best.

Volunteering of Her Own Time. Māmā Tuawhā provided unpaid support for both of her sons while at school. Having said that, as we saw above, she valued the educational support workers who interacted with them on a daily basis.

> They are both still completely in nappies. So, my oldest boy, his teacher aide finishes at 12.30 p.m., so between 12.30 and 3 p.m. I am on call to change nappies just in case there isn't another teacher aide available that will change them. The teacher aides themselves are awesome with my boys but it is the school system and the Ministry … their hands are tied. … There is one male teacher aide, and he is with my second son from 2 to 3 p.m. So, if [my son] needs to be changed at that time … I will have to come and do it.

> My second son will just run all day. He will do laps of the whole school. And that was part of them having three teacher aides as well … to give them a break … And that they had someone to take over lunch breaks.

Health

Māmā Tuawhā identified that the mobile immunisation clinic was one good aspect of the health system because it was easier to access than her doctor's surgery for her sons' vaccinations.

Focusing on Societal Expectations of Weight. Māmā Tuawhā described how appointments with health professionals focussed on medication and weight control for one of her sons. The suggestions that were made focussed on the biomedical model of illness and disease with little relevance to how takiwātanga shapes the lived experiences of this tamariki.

> I think I just got hoha [annoyed] with the health system … I thought I will come and see you if I need you … because you are not really helping me. Like, you will go into the GP and say my son is such and such and the GP will prescribe something. And I [say], "My son does not swallow things, so is there something else or is that all you can do?" It's like they don't fully understand that my son has takiwātanga, and that it is not going to work. This is your general response but it is not going to work for me. So [I say,] "Do you have anything else?" Nine times out of ten, they don't. They just say, "Well that's what we do so, sorry." So, I just don't even bother. And that is kind of how I got help with [my younger son with takiwātanga for his] sleeping … They were telling me to try this pill and try that pill, I just thought surely that can't be good for a three-year-old.

> And [my son] is quite big and they were trying to get me to give him some medication that could help him to lose weight … give him these pills that are used for [epileptic] seizures, but the side effect is weight loss. I was thinking, I'm not doing that. I didn't give them to him, because he does not have seizures. Why are you prescribing this, how can you even prescribe him something that it is not even used for?

Māmā Tuawhā was referred to various programmes and health appointments about her sons, which she attended. Her experiences of these highlighted a lack of knowledge about her, her tamariki, and takiwātanga.

> They referred me on to the 5 Plus a Day programme [healthy eating programme] … I am not stupid; I know that my son should eat healthy but do you understand that my son will not eat anything unless it is crunchy. He pretty much eats Doritos [corn chips], or Shapes [crackers] … dry toast or dry cereal. He does not like lollies, cakes, biscuits, won't touch fizzy drinks, he won't touch flavoured milk or juice, he will only have water and normal milk. [The programme] was not helpful at all. … I didn't think that anything that they referred me on with was helpful. Because it was general information for a general neurotypical person. I will give [my older son with takiwātanga] an apple and he will vomit … He will try to swallow it and then he will vomit. Do you understand that we are not lazy? … I don't just sit my kids in front of a table and feed them takeaways.

When Māmā Tuawhā was referred to another healthy eating programme, she found that the nutritionist taking the programme had no knowledge of takiwātanga and how it impacted how and what her sons eat:

> They put me on an 8-week programme to learn about healthy living. I come from a very healthy family … I like to go to the gym. My kids love bush walks, and I didn't complete the programme … I didn't like to be rude but I said to her [the nutritionist] this is not helpful for me and I do not have two hours a week to give to you to tell me things I already know … and are not really going to help me ... I don't need you to tell me that I should give my kids veggies. … I said, thanks but no thanks, and when I went back to the paediatrician … [I said,] "It didn't work so what else do you have?" … Oh, just the pills. … And the thing with the programme is that she isn't trained to deal with children with takiwātanga, she had no idea. She just assumed that she was coming to see a lady who needed to know about putting kids on a healthier diet. When I explained to her the situation, she had no idea how to help me.

A meeting with a nurse about medication revealed a similar lack of experience with takiwātanga:

> They even sent a health nurse to talk to me about how to medicate my kids and how to get [my oldest son with takiwātanga] to take his medication. Talking about things like hiding it in his food and just give it to him and he won't notice. Are you serious? … [My oldest son] will notice if I buy a different brand of anything. So that is not going to work, and they were talking about giving him a reward [when he takes his medication].
>
> When I tell people that [her younger son with takiwātanga] takes two pies to school … a packet of chips and two bottles of water, and that is it … I can offer him all of the food in the world and he won't eat it. They don't get it, they think [the boys] are just being fussy and they [the health professionals] don't get it … I think they think we have more control over it than we do.

Realising "It Is Not My Fault". Feeling inadequate and disempowered as a parent was a common theme in this research. However, by comparing her two older sons with takiwātanga to her youngest son, Māmā Tuawhā was reassured that neither her parenting style nor her knowledge of takiwātanga was inadequate:

> I am not going to be able to change what they eat … having a neurotypical son [the youngest of her three sons] helped me to realise that it is not my fault, or my parenting that is the issue, even if people could suggest that I could try this and try that, once I realised it is not me, it's not my parenting … I am not a lazy parent.

Home and the Community

Close Whānau Connections. Māmā Tuawhā discussed how her youngest son is closely connected to his older brothers with takiwātanga:

> It's been great especially for my youngest son, growing up with siblings that are on the spectrum … I can just see the difference in him as opposed to other 6-year-olds … he is very aware of [his older brothers'] safety.

> Because they can't talk … he will say things like, "My brothers can't talk but they know what you are saying," or he will say, "My brothers can't talk but I can talk for them because I know what they want." That's been good.

Māmā Tuawhā as a single parent is legally eligible to receive financial support as a beneficiary through New Zealand's Department of Work and Income. Despite the fact that she has two sons with takiwātanga, she often asked, "Why can't you get a job?":

> I will go down [to Work and Income] and take my boys with me. You kind of need to prove that my children need my full-time care. And not just sitting at home and enjoying my amazing benefit.

In summary, Māmā Tuawhā found the whakawhanaungatanga from school staff who know her two sons very reinforcing. Having two boys with takiwātanga polar-opposite personalities complicated the school's funding situation and has required her to volunteer her time to support her children to stay in school. Māmā Tuawhā has found the health system confrontational, with the health professionals she has dealt with having a poor understanding of takiwātanga. She feels blamed but resists the medicalised interventions she is offered because she deems them unsafe. She takes comfort in her youngest son's relationship with his older siblings, and this is a huge support for her.

Māmā Tuarima

Māmā Tuarima has lived in her hometown all of her life along with her whānau. Her values and beliefs align with a deep understanding of the Bible and her religious faith. She has strong networks of support from her whānau and her only tamariki, an 8-year-old son, has a diagnosis of takiwātanga.

Education

Māmā Tuarima sees education as vital in her son's life. Wellbeing and inclusion for her son are important to her. She describes her son experiencing acceptance and inclusion from "quirky" teachers:

> I want to know if my son's wellbeing is good at school. I think that education is … the key to embracing different ways of learning. His teachers … all of

> his teachers, you know what, he has had quirky teachers. And I feel like that is where he has been placed because they are all a little bit quirky. Quirky teachers have a love for quirky kids. I think it is about embracing our differences.

Tuakana-Teina as a Model of Support. The school supports whakawhanaungatanga (relationships) where tuakana (older tamariki) support teina (younger tamariki):

> [My son] has made friends, it is not a problem for him to go to school.
>
> They have got this beautiful thing too where they have the tuakana-teina, and you see it, if the younger ones are playing up, you see the older ones saying, "No, don't do that." All the kids at school know [my son]; they know that he is different. They say hi to him, wherever he goes.

Supportive Leadership. The principal of the school is "extra-supportive" of the children who attend her school and their parents:

> I think she has seen a need in our town too. Because there are a lot of children in [here] who are coming from whānau that struggle. She is extra-supportive, which is really good. They try their best with everyone.

Whakawhanaungatanga and Manaakitanga. For Māmā Tuarima, cultural appropriateness is an important aspect of her son's school.

> I think that they are trying to embrace and bring in those aspects of whanaungatanga, those aspects of manaakitanga. They are a school that is ahead, they are a school that is trying to change the system, that is trying to work with the cultural aspect, compared to a lot of other schools. That is inclusive. Māori culture is inclusive. We are an inclusive culture.
>
> Manaakitanga is one of our strengths. I do like his school considering the fact that working with the system that goes against our culture as a whole, they do really well. Even the ERO [Education Review Office] report, I wish they had some sort of education review that was viewed and based on the benefits of Indigenous people.

Flexible Lunchtime. Takiwātanga is associated with heightened sensory sensitivities such as finding noise and an unpredictable environment difficult to manage (Favre et al., 2015; Kanakri et al., 2017). Her son's teacher makes concessions for him by letting him have a flexible lunchtime so that he can eat before the normal break time in a quiet space:

> I am actually really blessed because [my son] has always eaten, but he won't eat at school because the lunch area is too noisy. His teacher is really good because she will try to get him to eat before the lunch break when it is quieter.

The costs related to having children attend school were mitigated by initiatives that save the parents money, and support students to attend. Although this relates to the whole school, the extra costs of raising a child with takiwātanga are well articulated in literature (Goodman, 2017; Mitra et al., 2017; Morris et al., 2022). These initiatives alleviated pressure from the costs of schooling for every parent whose child attends this school: "They have so many initiatives that are like the Breakfast Club [school-funded breakfast food] … There is no pressure to have to pay for anything [relating to school] for your children."

Learning Support. Access to MoE professionals providing specialist interventions was welcomed by Māmā Tuarima, particularly when the interventions support learning and socialisation for her son:

> He had a really good behaviour therapist; she worked alongside the RTLB [resource teacher: learning and behaviour], and they had these little social cue games … they still do it … [My son] takes it along with his classmates, and they learn social cues, but it is not just teaching [my son] … or singling him out, it is teaching the other children that sometimes people are different. So, the behavioural therapist … the RTLB and school have worked together and that has been a really good thing. My cousin has an autistic child and she is forced to sit in assembly – she hates the noise. My son does not have to … the school got noise cancelling headphones … giving him the option of being included.

However, these supports were not forthcoming until she paid for her son to be privately assessed for a diagnosis of takiwātanga:

> In order to get the best care for your children you have to have money … We decided to go private [the private health sector] with [my son] because the wait for him to see a paediatrician was up to 15 months. And he was suffering at school. So, we [paid]; it wasn't easy … $500 dollars, for a half hour appointment initially. [It is] shit, I can't say it any other way. In order to get the best care for your children you need money.

Health

Free or subsidised healthcare is available to New Zealand citizens through the national public health system. For those who have personal medical insurance or are prepared to pay for services, access can be gained through the private healthcare system. Having the option to pay for private medical services, although it came with a significant cost, ultimately meant that her son could access other funded services. The thirst for knowledge Māmā Tuarima has helps her to feel like she is doing the best for her son: "There has been nothing that he [the paediatrician] has told me that I don't already know or haven't researched myself. It is the quality of the care is what I am looking for."

> I feel grateful that I am privileged to know what this is about and that we have the means to reach out for that. It was only through my koro [grandfather] because he was very connected to [an iwi], so we were able to get funding for [my son]. But even with that, it has been a struggle.
>
> I feel for whānau who don't have that support. It is shit that you have to have money to get the best care, and support, to get anything really. It is one of those things that as a mother you try to all that you can do but when you are restricted, or the access is restricted, how is that an equal opportunity? The fact that we could go private. … We paid for the initial appointment and he [the paediatrician] said that's all you have to pay. [He said,] "I come down to [where she resides] once a month to see other children … you can just come there."

Medication. Medication has proven to be advantageous for her son. The benefits of the medication include improving his memory. This has helped him to retain learning in school and reduces the fatigue he experiences during the day:

> [My son] likes his medication, he says it helps him at school … to be not so tired and it helps him to remember. And I am like, OK. I listen to him. Even though it does dull him down, he is able to remember, and he is not so tired after school. I hated the fact of even having to try him on it, [but] my mum and dad said you will not know if it is going to work, unless you try. You can't not allow him that opportunity.

Māmā Tuarima is interested in alternative medication that could benefit her son. However, health professionals proposed Ritalin as the preferred medical intervention, which this māmā was not enthusiastic about:

> And [the child psychologist] looks at me, my parents put their heads down (*laughter*) … Surely there are other avenues to explore before going down that path …I hate Ritalin … it zaps out his creativity, his spark, and it is for him to conform to the education system. … Every appointment I have been into … they suggested for my son straight away to go on Ritalin … I said, "Hang on, shouldn't you be offering different therapies before immediately medicating my son … well, shouldn't you be?"

> I have asked if there are options for [my son] like CBD (Cannabidiol) oil. It is more natural than Ritalin. And there are long-term effects [of Ritalin], but it is hard to find a regulated CBD oil at the moment.

Racism. Māmā Tuarima discussed her understanding around the disparities in health that are linked to being Māori:

> I don't mean to be racist, but you see these success stories of takiwātanga … children, adults and how they are flourishing, and the best adults they can be, hands down they are Pākehā … because they have had the support from the get-go. The best paediatricians, the best behavioural therapists … It's the sad reality that we live in.

Māmā Tuarima has a strong cultural identity and could identify why she has had certain experiences within the health system:

> The system that we are under is colonised and it is made for the supremacy of Pākehā. Regardless of all of the initiatives that are put into place, it is not going to help our people because it is not designed for culture … But it is

> about knowing and understanding, and there is a shift now and people are becoming a lot more aware of those disparities. It's hard not to get angry. I think you can be productive with that anger.

Māmā Tuarima has studied at tertiary level and enjoys researching: "I think that has been one of the biggest strengths of myself is that I like to read. I go by Autism New Zealand or Google Scholar."

Home and the Community

Māmā Tuarima shared in her kōrero that her whānau were accepting and supportive of her. This made a great deal of difference to her life and to her son with takiwātanga. This included whānau attending medical appointments with her:

> [My son] has been the first moko [grandchild] on both sides. His father's and mine, my family have been really good, they have just embraced him for who he is. They have been to all of his appointments [with me].

Together with her son's kindergarten teacher, her koro was very instrumental in starting Māmā Tuarima on the path to getting a diagnosis:

> It was when [my son] was 3 or 4, and the Kindy [kindergarten] teacher said, I am not too sure because he is able to talk well, but he is flapping his arms – that he may be on the spectrum. I told my dad and straight away [immediately] he was doing research. It was my dad actually who gave me a book … My dad was reading up on all takiwātanga. He was the one that made me aware of what regression is and to be aware of all this.

Health and Mana Motuhake (Self-Determination). Māmā Tuarima questioned the biomedical model of health and how it does not align with the way that Māori māmā view what works for their children with takiwātanga:

> Like we are able to differentiate what works for us and what doesn't in the health system, and I do feel like Māori Indigenous mothers with autistic children, we are way going forward, because we are able to step away from the health model and question it. And look at our babies and say, "Well that doesn't work."

> I think that it is a benefit of social media too … I have connected with other mums, who have the same struggles … There needs to be more of a space created for us to understand that we have the answers within ourselves.

Working with a child with takiwātanga is best observed from the perspective that the māmā is the expert about their child and an expert in what takiwātanga means in that space. Māmā Tuarima felt this directly links to an Indigenous understanding:

> Every child is different, and you have to go forward with how they are. Get on their level and understand their world and work with them. To try and get them to be the best versions of themselves. They don't offer that in the health system at all. But I can tell you, hands down … any Indigenous mother, that is what we do. That is a cultural thing. That is who we are.

Sensory Aspects of Takiwātanga. Certain experiences in the community create tensions for Māmā Tuarima where her son struggles with environmental noise linked to auditory hypersensitivity:

> When we have whānau gatherings, [my son] hates being there at the table because everyone is talking. … Even at the marae in the wharekai [dining hall], it is too noisy, that is the only reason he won't eat. … I can't take him to a restaurant. MacDonald's … he just ends up flapping his arms.

Unpredictable Outbursts. Māmā Tuarima shared that her son has outbursts where he is unable to regulate himself due to being overwhelmed:

> He cannot process his emotions … I will be just like, "OK, go and brush your teeth," and next moment he threw the chair through the window and I was like, "Oh my God." I said, "What happened there?" and he is, like, "I did not want to brush my teeth … I do not like the feel of the toothbrush in my mouth." So, he has random little outbursts.

In summary, Māmā Tuarima had advocated strongly for her son based on sound evidence-based research about takiwātanga and her own cultural lens of social justice and Indigenous self-determination. Paying privately for health services enabled her to get an early diagnosis, and she received significant support and

understanding for her son from his school. She has strong and ongoing financial and emotional support from her whānau.

Māmā Tuaono

Māmā Tuaono was a mother to four children and her oldest whāngai (adopted) son has a diagnosis of takiwātanga. She reflected on where this journey has taken her whānau, including her husband with whom she had her three biological children.

Education

School a Trigger for Diagnosis. A change in behaviour in her whāngai son when he started attending school prompted Māmā Tuaono to investigate why it was happening, and this culminated in a diagnosis for him:

> And it was not until he started school that we thought something is going on here. He went from happy and content … into this angry and aggressive kid, so we went through the testing at 5 and got the diagnosis of takiwātanga.

Māmā Tuaono had created opportunities for learning for her whāngai son his whole life, and this has culminated in him requiring little support in school:

> He has never been in special needs education. It's interesting, when he was diagnosed, they said he was high needs. And he was discharged a year later, and so has never had a teacher aide. And now I think maybe I should have just let that happen.

Resistance from Kaiako. At the age of 10, her boy went from mainstream schooling to kura kaupapa Māori (full-immersion Māori-language school). This change highlighted difference in the understanding of takiwātanga between this māmā and the kaiako. This example shows that being a Māori kaiako does not guarantee a deep understanding of takiwātanga:

> When I said to her [the kaiako], "He has takiwātanga, that is why he does all of these things." And she looks at him, and she said, "He does not have takiwātanga." … I [said], "You don't experience his takiwātanga, but it's there. And you need to be mindful of it." And that became a new battle that I had never encountered before … yet when it came to his reports, [the kaiako]

> knew him so much more than the other teachers did. [She] just refused to see his takiwātanga.

Despite not requiring any formal learning support in the classroom, there have been other issues associated with her son that have translated into risks for him in the classroom environment:

> There were a few times when it became dangerous in the classroom because she [the kaiako] was giving him leadership roles, and I would say to her, he can do the leadership, but then he cannot switch it off. It is this fine balance. It became another battle.

Takiwātanga can be characterised by an inability to think in abstract terms or to find it difficult to understand complex social cues that can be covert or have dual meanings associated with the context and intonation of language or behaviour. This manifests in qualitative deficits in social interactions and is one of the core defining features of takiwātanga (Matson & Wilkins, 2007; Sousa, 2015). One such experience for Māmā Tuaono related to her son being bullied by other students:

> He was getting bullied a lot, but he could not see it, to him everyone is his friend. So, for him to understand some of the comments … he knew they were mean comments, but he did not understand where they were coming from or why.

Māmā Tuaono has experienced the education system from the perspective of an employee: "I did not realise how toxic our schools were until I started working for the Ministry [of Education]. And principals are horrible."

Health

From the moment her whāngai son was born, there was a sense of him being different:

> We knew there was something different with this one, even like the surgical team kind of just went, "Ahhhh," because he just looked at them, and when they lifted him up, he turned when he heard someone talking … We knew there was something different with this one.

A GP with an Open Mind. For Māmā Tuaono, having a GP who knew the medical history of her and her whānau was the most helpful aspect of the health system. Firstly, the

GP inspired confidence because of her close relationship with her whānau, and it allowed space for honest conversations about what was going on with her son. The process of whakawhanaungatanga that had established and grown this relationship meant the GP was able to quickly start to the assessment process when her whāngai son was older:

> We have a good family doctor who knows us really well … who put the referral in, and I was not sure what we were looking for, but she knew [our whānau]. When I explained what was happening to him in school, she said we will have to look at that to figure out what is going on … She gave that context that I was not thinking of at that time.
>
> The GP … she just gave me that reassurance. She pushed and we got seen really quickly. We had a cultural liaison who was not really useful, had a Māori name but that was about it.

Interestingly, Māmā Tuaono who was herself employed in the health system prior to this research being conducted, decided to change her career as a result of her professional expertise in takiwātanga.

> Seeing children with takiwātanga coming through the doors [in the health system] … so many and nobody knows how to work with them. That was my wakeup call … anytime anyone would see takiwātanga, they would come and get me. That's what triggered me to move into the community and work with whānau. So, I moved into education.

Home and the Community

Māmā Tuaono had experimented with lifestyle changes. This ranged from changing their diet to changing careers for both māmā and pāpā.

> We changed our diet. We were just trying to find ways to make it work. And our career changed into education because we had pretty crap experiences with him going through the MoE and MoH system … to try and figure out why it was so hard and what the solutions are.
>
> As soon as he got diagnosed, I dropped everything, changed the whole environment at home, and the way we did things. And once he knew he had all of my attention, things settled down for him.

Māori Ways of Knowing. Māmā Tuaono was raised on her local marae with her grandparents. This traditional form of living is based on tikanga [protocols and rules] and te ao Māori. Māmā Tuaono reflected on her own upbringing and how it might help her son and his diagnosis of takiwātanga:

> I was the eldest child; I grew up with grandmother and my grandfather … I grew up on the pa [Māori village] in those early years. And when I got that diagnosis [for my whāngai son], I thought about them and thought what would they have done … So that is the world that I created at home, the old world. One on one. A simple life … I did not ever focus on verbal, I knew growing up with my grandparents that we would have these rich conversations, sophisticated conversations with our eyes. So that is what I went back to … and it worked.
>
> [We] pretty much changed our whole lives around … We went full immersion in te reo Māori. For me it was trying to find the old ways to do this. Te reo Māori was the best thing … as he was speaking Māori, he settled right down.

The philosophy of the "old ways" is based on an Indigenous way of knowing where there is a person-centred approach to life. For Māmā Tuaono, the meaning of the "old ways" was:

> [Being] one on one [with my son]. Just pottering [doing this and that, with purpose but at a gentle pace]. Doing my thing but he was always there. And these are things that are new, knowing that this is what I have to do. I did not ever focus on verbal … And it decluttered everything … and wow, I knew it would work. But the problem I was going to have, and that I knew was coming … was how do I transition him, outside of this [our home] … Within a year, he was not high needs, but then at the same time it leads him into going under the radar. It [takiwātanga] is always there, it is just not high needs anymore. It got to a point where he could, and he was confident to engage in things, but at the same time he lost his ability to assess. He went from super-obsessed to being cautious to being just careless … you get through one mountain and then there is always just something new.

By being loud and boisterous, other members of the whānau have created a type of therapy where her son has developed a resilience to things that are normally confrontational for people with takiwātanga:

> I need chill and peace. And their dad and the other three [tamariki] … chaos … They are like walking tornadoes, you hear them pull up [in the car], even before they have got in the door. I know if I can barely manage that, how can [my son] manage that. But he is so easy going, when he is at home, he is just happy, even though it is better for him when it is quiet so he can think clearly … He will still go with all of the craziness and still laughs and has fun.

Living with Takiwātanga. Getting a diagnosis for Māmā Tuaono provided the foundations of understanding her son with takiwātanga.

> When we got the diagnosis, hubby didn't want him to go through that process – labelled and all of those things – he was terrified of what that would mean for him and his future. I went [ahead with the process] anyway … I needed to know how to work with it. And once we got the diagnosis, and we had a name, and started learning about it, he [her husband] thought, "Oh that is why he is so shy, that is why he won't do these things."
>
> My mum, she has had the closest relationship with him as a baby, so she was really angry that I went through the testing process. It still shocks me that she had that stance.

Another style of homegrown whānau therapy was continually exposing their son to social situations outside of the home, to increase his social skills and tolerance for everyday situations:

> We used to go to hui [meetings] and things, and if we were not the first ones there [my son] would not go in, things like that before he had started school. He was doing things like that, so when we go in for the diagnosis, [our attitude was] we are going, we are here. So, he was forced to do things. He was forced to interact, and then he had his little sister … who is the complete opposite to him come along, and her pulling him into situations. As a family, he has just been pulled along. Now people can't tell he has takiwātanga, they have not been able to tell for a long time, it's about him getting better at

> managing, coping and copying. … Everything his whole life has been roleplayed. So, going to the park when he was a little kid – "This is how you make a friend." … That has always been the number one, for him to think it through, or for him to act it through.

Māmā Tuaono had a strong sense of her own identity and the identity of her whāngai son, and she drew from te ao Māori to discover his purpose:

> I have prioritised te reo Māori, so it has been five years with a Māori speaking house … It has changed everything, having a Māori worldview has allowed me to see his purpose. Rather than the impact on us, he has a purpose and we have to make sure that he gets to explore that. To nurture him and his needs. If we had not made that shift … we would still be trying to make him fit into the world. He has got a whakapapa [a line of descent from his ancestors], he has a job to do. And that is the focus. It helps me to remove my own ego from the situation. The real battle was that. And so that has made me more recently look at myself, what are my triggers, and why do I think like that, to understand myself. And try to let go of those things. And make his environment better. Self-discovery to do it well now that I know what [being] well looks like.

With such a strong sense of self, Māmā Tuaono has moved away from the complex support systems to concentrate on her whānau and her own wellbeing:

> When he first got diagnosed, we were doing respite hours … the rule back then was you had to use your hours intermittently, the rules were so hard … I had to cluster the hours, and so I wanted it done and dusted in this two-week timeframe, they said no, but I went ahead anyway. And it worked. He bonded with the carer. And he had fun. And I was, "OK, this is what we need," [but] they booted us off and we stopped getting respite hours. And after that they wanted to investigate fraud and all of that … so, I thought that you are not really here to help then are you.
>
> He has matured, I don't even really care about the system or what is going on there anymore … Shifting focus helped to settle our household, I think. Our energy is going forward for one thing, the same thing, it is quite peaceful

now. We can enjoy life. Things have been good, especially in the last couple years, and doing my master's [degree] as well. Really refining what I am looking at and develop and to give back. It has taken a good 12 years, to get to that point.

Throughout her takiwātanga journey, Māmā Tuaono has developed an expertise that has not only seen her whāngai son thrive but also enabled her to arrive at a place where she feels more fulfilled than ever:

> I am happy to be there, where I am now. I can manage work; I can manage study and I can manage my family. It's taken time for that to happen. Just waiting for the next thing. Our relationship has survived which is a miracle. With my partner, when I think about the journey. Interestingly, by raising him, the whole family has become like him, we look like a whole family of autistic people. Osmosis or whatever it is, you are trying to be just in sync, because you have to, all six of us.

Plans for the Future. Māmā Tuaono was already anticipating the challenges around her son having relationships with girls and finding employment:

> [My son] is absolutely attractive. And this created a lot of attention for him. And he never liked it from a young age but he got used to it. Now that he is a man, he has girls looking at him, and kind of throwing themselves at him, and he is still like, "Uh, that's gross." And that is going to be the next thing.
>
> With [our son] we have had to really focus on teaching him to run his own business. I cannot trust that he will be able to find employment and hold that … [My son] really likes the idea to have his own little studio, sleepout, tiny house, whatever it is, just to be close and I am putting it out there. Because those sorts of things I worry about. I cannot turn that worry off no matter what. If I drop dead tomorrow, at least [my whānau] know my train of thought.

Whānau Resistance to Diagnosis. The whānau of Māmā Tuaono took time to truly understand and accept how takiwātanga influenced her whāngai son's decisions:

> [My mother] she refused to acknowledge it [takiwātanga]. One of the books that helped me a lot was [by autistic inventor] Temple Grandin; she was the

> best resource for me in the early years. My mum read the book and kind of went, "OK." And so that just opened her up a bit more. She became more accepting. And she had an experience with him a few years back, on the beach where it was really unsafe … So, when he was told to come in from the water, he thought, no, I know what I am doing, and just about drowned. Unfortunately, they had to be traumatised to really understand that.

In summary, Māmā Tuaono found that slowing down the pace of life, spending one on one time with her whāngai son, and "roleplay[ing]" life were ideal ways to socialise him and support his development. The powerful support network centred on her whāngai son helped him to do so well at school that the label of 'high needs' was no longer applicable to him. Māmā Tuaono altered the daily whānau diet to gluten-free and organically grown kai (food) and felt that this supported further positive changes for her son as well as the rest of the whānau. Furthermore, the entire whānau started speaking te reo Māori, and this had a calming effect in the home for everyone.

Māmā Tuawhitu

Māmā Tuawhitu was married with two children aged 5 and 3 when this research was conducted. Her 3-year-old son has a diagnosis of takiwātanga.

Education

At the time of her kōrero, Māmā Tuawhitu did not identify anything positive about her son's early childhood education (ECE) centre. She had experienced issues communicating with the ECE centre kaiako about her son and what works well with him. She was being ignored, so she organised from specialists from the MoE to validate her knowledge of takiwātanga:

> Things that you have to do differently for [my son] that you don't have to do differently for other kids, that is what they are having difficulty with. So, me saying this [to the ECE centre] it is not enough. I have to get the speech language therapist or the psychologist to say something, and it takes a long time before they say, "Oh, OK then." Because this kaiako has been a kaiako for 27 years … [She says,] "I know kids, I know what they need," but [my son] is a little bit different. It is still better than what I see in Primary School,

> including attitudes and teachers, and staff, it makes me really angry, mainstream, to be perfectly honest.

Sleep routines at the ECE centre were having an impact at home for this young tamariki with takiwātanga:

> At home he does not nap. He is up from 7 a.m. to 7.30 p.m. and he is busy [active] all day. But they [at the ECE centre] want him to sleep. My five-year-old still needs a nap. But [my younger son] doesn't and if he has a nap during the day, he will be up until 11 pm. So, it is difficult for us … He is happy, he is dancing and singing. He is happy to go into his room and he lies in bed and he jumps and he sings.

A Lack of Whakawhanaungatanga. Māmā Tuawhitu was a working teacher with a sound knowledge of the education system. She had not been impressed by the training she received when studying to become a kaiako:

> There is no diversity training at teachers' training college. There is hardly any relationship building, there is no whakawhanaungatanga. None. People who are mums and who go to training college have a lot more [understanding] … The teachers I have worked with who have no children, it's really bad … Principals are the worst. It was my principal [where I worked] that was really highly regarded, he was absolutely the worst person I ever encountered.

Māmā Tuawhitu described the staff where she worked as being discriminatory in their attitudes towards tamariki with high needs:

> Such a racist and ableist system … The school I have just finished up at, was the deciding factor for my kids never to attend mainstream. I have just switched to [work in] a new school, but at my previous school, I never disclosed [my son's] diagnosis. I never mentioned anything because of the awful attitude … They have quite a number of high needs kids … They talk [in a derogatory manner] in front of these children, and I am like, he can understand everything you are saying … and they are like no he won't understand because he is like a baby in a 10-year-old's body.

Health

Invested GPs (Doctors). Free medical visits were appreciated by Māmā Tuawhitu. Additionally, she was given an open invitation from her GP to visit whenever she felt the need to. This supported Māmā Tuawhitu to feel valued and believed:

> I am so grateful we live in a country where healthcare is subsidised … having a free GP for my kids, and when I am overwhelmed and I just turn up [at my GP]. She is fantastic and she [says] just come, doesn't matter what it is for … and I will turn up and say I am really overwhelmed … We will get something out of it. Even if it is just the conversation.
>
> She believes in me. [The GP says,] "You know when something is up, and I believe you" … every time. "If you need to come here every single day for a month, come." And there have been times when I have gone three times in one week.

Like other māmā in this research, Māmā Tuawhitu sensed something different about her son from an early age: "I have always said there is something up."

Barriers to Diagnosis. Getting a diagnosis for her son was not a simple exercise for this māmā. She had to develop phenomenal advocacy skills to get what she needed from the health system: "I got four rejections through GP referrals, saying no, he does not meet markers, he does not have enough markers, he is too young."

Being Open to Medication. Māmā Tuawhitu was open to considering medication for her son in the future:

> We have not been offered medication. He is only little and at this point, he is not displaying what society would consider as negative … at the moment he is just happy. I am open to medication though … I am completely open to it, if it is appropriate for him.

Being Persistent. Persistence has been the key for Māmā Tuawhitu in overcoming the resistance of the medical profession to diagnose a three-year-old with takiwātanga. Being an educational professional help this māmā to be a strong advocate with a "can do" attitude, which led to a positive outcome for her son:

> I would call and ask how we are going on the list [to be seen] … I'd ring at 4 o'clock at a certain clinic, I would ring the GP and ask about the referral. I would ring the speech language therapist … the psychologist. I would ring everybody; I would send emails. … I have had to be a really squeaky wheel with the Ministry of Health … But I went through [an agency] and they wrote a really comprehensive referral … They said you need to get an occupational therapist, a psychologist and … then you will see the paediatrician … So, I said, right, I am going to pay for some of these things. We got an occupational therapist who did a full report, and a speech language therapist to do a full report … We got the diagnosis this year, basically.
>
> It was only because I do not accept no. And I am adamant that early intervention is the key. Even though I do not have a lot of experience in teaching [2 years], I know that starting school at five with no extra needs is hard. I did not want that for my boy, so I am going to fund this, I am going to get help … I will ask everybody there is, everyone is going to say no but one day, somebody will say yes, and we eventually got there.

Māmā Tuawhitu persevered and persevered to make sure her son's case was always on the radar of the health services he needed:

> My husband would not have done quarter of the things I have done. [He says,] "You are going to be known as annoying" … and I say, "I don't care, this is my boy. I don't care." When we got on the list to see the paediatrician, I would ring every three weeks … to ask how are we going on the list … People … say, "Oh you are a bit much sometimes, but I would like to have you on my team if something was to go wrong."

Home and the Community

Māmā Tuawhitu had a strong support system that includes her husband and her own parents. She delights in her son's being a really easy-going, happy child:

> For me and my whānau, when I told them, they say, "Oh it's really good that you have a diagnosis so you can get support for him … My husband … he is awesome. He has always been like, "Oh, here is something new, let me learn." That is just his attitude to everything. My son is a really easy kid, so

> easy, as a baby he was just content, anywhere we took him, any new routine … He is just cruisy. He eats everything, he goes along with whatever, he is happy like all of the time, the happiest soul I have ever encountered in my life.
>
> Her son loves the outdoors and wide-open spaces:
>
> He will run in open spaces, he swims in open spaces, he has taught himself to swim, and he will just go and go and go. We went up North [towards the top of the North Island of New Zealand] recently and I found a playground and a massive open field that was fully fenced. I was, "Oh my gosh, this is the best." I got a coffee and just sat there. He just ran and ran. And climbed, and I was thinking, I don't even need to have to worry about him. It was the best. He just needs that freedom. We try to go out every weekend, and when we are at the beach … I am just going to let him go, and we went for 2 kilometres. Going along in the water splashing. Then I said, "We have to go back now," and it took a while, but when he realised, he could still run all the way back … We did it all the way back as well.

Knowing What Your Tamariki Is Communicating. Māmā Tuawhitu had such a deep knowledge of her son's takiwātanga that she was able to understand him in ways nobody else could:

> I understand a lot of his communications. Nobody else does. It's like he has his own language … I have to interpret for everyone else, but I would really like him to communicate with everyone else.
>
> When you look in a book, they will tell you all of the characteristics of autistic kids … He does not have the negative ones; he does not have meltdowns. I can see when he is overwhelmed, but it is very subtle … I notice lots of subtleties that others don't see in him.

What Matters the Most. Prioritising what was important and what was not has been one strategy for Māmā Tuawhitu as she reframes her son's behaviour and focuses on teachable moments through a strengths-based understanding:

> I have let go a lot … I am OK with having mess, him not eating all of the vegetables, or doing exactly what a three-year-old child is supposed to be

> doing … I look for opportunities and I look for positivity a lot more in everything … I see his strengths, and everyone else's strengths, I really like to celebrate the little things. I think I have let go of society's expectations.

Māmā Tuawhitu reframed the experience of creating a mess at home as part of her son learning from his environment: "He does make a mess, and my husband calls it trashing the house. I say it is just exploring. He is exploring everything, and if you don't give it to him … he will find a way to get it."

Whānau Attitudes. Māmā Tuawhitu felt her husband's whānau did not really try to understand her or her son with takiwātanga:

> I think that was the most difficult thing I have had so far. It's just his mother. My husband is Pākehā, and he grew up in a very conservative suburb with a conservative family … Before me he had not even dated anyone who was not white, so he had zero of anything about what was outside of his world … even just bringing my own perspective – I am Māori, Pākehā and African – is difficult … I feel like everything I do is kind of a challenge to them [his whānau]. … We went to a whānau birthday party, his mother came to me and said, "Oh, you brought [your son]." … She said most people would never bring an autistic kid out. It is really, really difficult. She has come from a place of not understanding and I don't believe she wants to understand … That is my biggest difficulty … is his family.
>
> I found their perspective on takiwātanga or disability to be really difficult … After we told them the diagnosis, I said I think he is autistic, they say, "Oh no, don't say that you are being mean to him." I say, "I'm not," actually this is not anything bad it is just about learning to understand him … This is hard on me; this is really emotionally difficult for me.
>
> I have been pushing for early intervention because I know that it is the best for him, but he is still exactly the same lovable boy that we have always had. Why is [my mother-in-law's] attitude kind of like he needs to be institutionalised?

In summary, Māmā Tuawhitu was a qualified and experienced teacher, which helped her focus sharply on the aspects of the education system that might be a barrier to her son's

development. This has included the openly biased and ableist attitudes of school staff in the ECE setting towards her son and in experiencing similar attitudes in the schools were she has taught. In the health system, Māmā Tuawhitu has been a strong and vocal advocate for her son, making sure the process of diagnosis was being followed up coordinated across specialists. She has an encouraging and empathetic whānau, including her own parents and husband, who have supported her on this journey.

Māmā Tuawaru

Māmā Tuawaru is a māmā of five children, and her youngest daughter, aged 8, has a diagnosis of takiwātanga. Moving from one town to another for work culminated in Māmā Tuawaru having to stay in emergency housing with her two youngest daughters for a time.

Education

Delay in Diagnosis. A delay in getting a diagnosis can lead to tamariki with takiwātanga missing out on early interventions, and this can impact on improving future outcomes (Eapen, 2016). Fortunately, there was a professional from the MoE who was supportive and proactive for this whānau, making the difference for Māmā Tuawaru and her daughter:

> There was a lady that came from the MoE, she was amazing but because so much time had passed. [My daughter] had missed out on speech language therapy that she was entitled to and all of these things … Because she slipped through the cracks, she missed out on things she was entitled to. The Ministry of Education got us Ongoing Resourcing Scheme funding. [My daughter] is now in a satellite class and she is doing really well.

Traits of Takiwātanga. Her daughter's ECE centre failed to communicate their concerns about her behaviour to Māmā Tuawaru because they didn't want to lose her business:

> The early childhood centre did not want to talk to me about the autistic traits [they could see in my daughter] because they had said this to another mum and she pulled the kid out the next day … I needed a reason because I was legit going nuts [with my daughter], not knowing what was up with her.

Sleep routines at ECE centre led to her daughter being awake most of the night:

> I went through a phase of not sleeping with [my daughter]. Eight months straight of her not going to bed before 3 a.m. and then getting up again at 7–8 a.m. I used to turn off the mains switch, she would get up and turn on all of the lights in the house, climb up and open all of the cupboards. I would get up and try to put her to sleep but she did not sleep. She would sleep at Kindy and come home with lots of energy.

Lacking Trust in Mainstream Education. Ultimately, the ECE centre could not manage her daughter's behaviour and this led to her being expelled. Māmā Tuawaru had had negative experiences with mainstream schooling with her other tamariki:

> [My daughter] ended up being kicked out of Kindy because she was too rough with the babies, and I was working full time at that time. I did not want her to go to any mainstream school … I know they can be arseholes and I am not there [at school] to protect my [daughter].

Health

Difficulties with toileting is a shared experience of the māmā across this research. There is funding available from the health system to supply toileting aids:

> We did get free nappies for a while. Because she would not go to the toilet … She refused for years to do 'number twos' in the toilet. And she would not do it in the nappy either … She would shut all the doors and find a place and just do it on the ground and not tell anyone … You open up the front door and it's right there. Thank God that phase it over, so she came out of nappies when we were in the hotel [emergency housing].

Being Blamed. Encountering unhelpful and judgemental medical professionals was a barrier for Māmā Tuawaru to engage with the health system. She was made to feel that she had let her daughter down, and she discussed how difficult it was for her to be heard in the health system:

> The doctor was absolutely no help. But I needed his referral to the hospital so she could get a diagnosis. When we did get a follow-up, the paediatrician

> went off [growled] at me and I felt so small … She [said] you know your child is going through this. It is up to you as a parent, you need to be doing this and that … It was hard for me to ask questions. I fully broke down in the hospital.

Diagnostic Issues. Her daughter was initially rejected for a diagnosis by one medical professional, but soon another paediatrician gave a full diagnosis, demonstrating that whānau are at the mercy of the medical professional who is making decisions about diagnosis:

> Even the paediatrician, when I first went into an appointment, she would not diagnose [my daughter], she said it was foetal alcohol syndrome. But it was an old Pākehā lady, and just the way she spoke to me straight away … She had another lady come in who was playing with [my daughter who said she] was displaying, instead of playing with the blocks … She was colour-coding everything. But it was up to the older lady to give a diagnosis, and she did not … The younger one … she knew straight away … that [my daughter] has autism, and then she goes, you have the diagnosis, she filled out the disability allowance for WINZ [Work and Income] … I didn't know anything about that … I was told to see the CDC [Child Development Centre]. He was useless.

Home and the Community

Previous experience of takiwātanga in the whānau helped Māmā Tuawaru to understand her daughter's behaviour: "My brother-in-law came down and he is the one with an autistic kid … He saw her running around in circles and it looked like she was chasing her own shadow … He says she might be autistic."

Support from the Community. Māmā Tuawaru recalled some supportive interactions with her local community, both in real life and online:

> I took her over to [a shopping centre] … She loves to go on buses … She had a full-on meltdown in the middle of the road. This older Pākehā lady came up and said I was doing a really good job. She has got really good out in public now. I totally remembered that lady because she was kind.

> With the group that I am part of [the Takiwātanga Facebook page], I was isolated, no one else I could talk to, until I was part of this group … I freaked out at how many stories [were like mine], it was like they were describing [my daughter].

The Stress of Emergency Housing. Being unable to find rental accommodation had resulted in this māmā and her tamariki having to stay in emergency housing in the past:

> We were in emergency housing at the time … [My daughter] absolutely hated being stuck in one room being so contained … I did get pulled up a few times because of [my daughter] and her meltdowns and banging on the walls, the rooms have thin walls. We did stick to ourselves inside the room unless I was out looking for a house … That was the other thing, getting rejected so many times … As soon as you say you are in emergency housing you get rejected.
>
> I get real bad anxiety attacks. I used to be a pretty social person, now I keep to myself. The panic attacks started since the emergency housing and with Work and Income.

Whānau Supports. Māmā Tuawaru is philosophical about why she has a daughter with takiwātanga: "I think having [my daughter with takiwātanga] was to humble me back down. I used to think that parenting was easy until [my daughter] came along."

The 10-year-old daughter of Māmā Tuawaru is truly supportive of her younger sister, demonstrating a sense of whakawhanaungatanga for her younger sibling.

> My 10-year-old daughter is a great older sister. She is a stroppy double-digit kid now, but she will let [her younger sister] ride on her back, like Bullseye on *Toy Story 3* … They will still act out favourite bits and the older one will sigh, but will still do it.

There were other examples of close relationships with whānau members who Māmā Tuawaru thinks have traits of takiwātanga as well:

> My oldest girl … is 16 years old, her and [my daughter with takiwātanga] have this freaky little bond that has happened in the last year or two … which makes me think that the [oldest daughter] might be a little bit autistic. She is] brainy … she dropped out of school because it was too boring for her. She is in a course; she does not have good social skills. She would rather stay at home and read a book.

The daughter with takiwātanga is very selective in terms of her diet and where her food is made:

> [Her] diet is restricted. I wish I could get more things into her; she will live off Nutella sandwiches, she will eat pizza when she feels like it, pancakes from McDonald's. She lives off five things, that's it. She won't eat meat unless its burgers, even then it's got to be things she likes. Pancakes are her favourite from McDonald's. I can make them at home but she won't eat them.

Connection to a World of Her Own. A discussion about her daughter and spirituality led to stories about her daughter connecting with others in spirit, whom only she could see: "She was not speaking at the time but would be cracking up laughing like someone was there. Sitting on a seat like someone is next to her, she would be talking to them."

Māmā Tuawaru felt that her daughter and takiwātanga has added meaning and purpose to her life. Part of that purpose for this māmā was to be very protective:

> I could not imagine my life if [my daughter] was not like the way she is. I could not imagine my life before this crazy … Like it is worse with my family who say she has a sickness or illness – I say no she is not sick, as much as she drives me nuts, I am really protective of her. Even my own kids, they are not allowed to pick on her, on each other is fine, but just not her. She has got so many hurdles, and in later life, you know, anything I can do to make her childhood good, as much as it drives us all nuts.

Safety Issues. Living in houses that were not suitable for a child who is determined to escape made things very difficult for Māmā Tuawaru:

> My baby, she is a runner … She has her own police file … She could escape from anything, even when she could hardly even walk … She is an escape

> artist. I would go to the toilet, and she would open up the window and be up the road. One [time] she ended up across the bridge, towards town [4 kilometres], in just a nappy. That was normal.

Her daughter could not only escape from home, she could also find her way into locked spaces:

> One centre had a six-foot fence, and they had no idea how she got in – she got into the centre that was all locked up. It was crazy. The distance she could travel in a short amount of time, and obstacles were nothing to her. My daughter has the 'wonder track', the one made for dementia patients … She will wear it when she wants to.
>
> The house that we are in now, we moved in July … before that we were in emergency housing. When she has a meltdown, she boots holes in the walls. I have learned how to do a good job [of fixing the holes] … In a former house, I am paying off $8,000 worth of damage [caused by my daughter].

Additional Expenses. This tamariki also obsesses over her favourite clothing, which deteriorates through continuous wearing. Electronic devices are another favoured item of this young tamariki, and phones are often broken or lost, requiring replacing:

> [My daughter] goes through clothes like nothing. She will have her favourites and she will wear them until they fall off her. I try to throw them out … They come back … I have had to replace two televisions, so many phones, all the devices – this is phone number five this year. I won't let her touch this one. [Work and Income] will go, "What have you spent your money on?" … Unless you have a kid with takiwātanga, you can't relate.

Staying Positive. Although Māmā Tuawaru is impacted by anxiety that is exacerbated by her daughter at times, she is able to remain positive to see how to problem-solve situations where takiwātanga collides with various aspects of ordinary life:

> I have so much anxiety going out in public with her because she would have her meltdowns anywhere and everywhere every single time. That's when I started having panic attacks, for a while I would only go to work and go

> home. The only place I would go with her was to the park. And I had to do that often – she likes open spaces and getting out. It has definitely been an adventure.

Māmā Tuawaru finds it difficult to imagine her daughter being looked after long term so that she can find full-time work:

> I have no one that I can depend on for [my daughter], otherwise I would go out and get a job tomorrow. It sucks on that level. I don't think that they get it. I might be able to get someone from [her current school] who wants to make extra hours, but that would not be an everyday thing so I could go out to work.

In summary, Māmā Tuawaru talked about living in emergency accommodation for a short time due to the housing shortage in Aotearoa. At the time of writing, I discovered she had moved to a permanent and fenced home which was ideal for her daughter, whom she described as an expert in absconding from their home as well as being able to force her way into locked spaces. A diagnosis of takiwātanga was hindered by barriers to accessing services and health professionals whose attitude towards this māmā created further barriers to her gaining support for her daughter. Despite this, Māmā Tuawaru remained positive and protective of her daughter, who was progressing well in the special education system.

Summary of the Findings

The māmā in this research identified the most helpful aspects of the education system as positive attitudes and behaviour among school staff. This included kaiako, teacher aides, principals, and MoE specialists who invested their time and expertise to support positive outcomes for the tamariki with takiwātanga. Staff members with talents in art and music also engaged with their tamariki. The māmā faced challenges associated with the unethical actions of kaiako either towards their tamariki or themselves. Their expertise in takiwātanga was disregarded, leading to a lack of trust in the education system being able to deliver the kind of learning and support their tamariki deserved. Funding associated with ESWs was highly complex and often inadequate for the needs of the tamariki while at school. The māmā felt judged by the school staff, and felt that being Māori wāhine placed them at a disadvantage and caused them to be discriminated against.

Experiences were similar for the māmā when engaging with the health system. Their journey towards a diagnosis of takiwātanga started with a GP. Having a GP who was proactive in supporting the māmā while closely monitoring and propelling the diagnostic process was pivotal for the māmā. Gaining a diagnosis provided access to educational services. Therefore, any delays in this process or a denial of a diagnosis created stress for the māmā, and directly impacted on access to these services. Paying privately for professional services linked to a diagnosis was one way for the māmā to circumnavigate these barriers, particularly in terms waitlisted health services. Experiencing pressure from medical professionals to medicate tamariki was common, and the programmes and advice that was offered to the māmā demonstrated a lack of understanding about takiwātanga. While the MoH does pay for respite care days, actually taking them when they were needed most proved difficult for the māmā. Finding suitably qualified people to care for their tamariki coupled with rigid rules about how to spend this funding added to the barriers to access for the māmā.

Active involvement of partners, other tamariki and whānau provided ongoing support for the māmā. Whānau members who took an active role in medical or educational meetings provided a sense of strength for the māmā. Social media platforms and personal research were other avenues open to the māmā to gain insights into the symptoms of their tamariki. Challenges and barriers for the māmā relating to home and the community were associated with not having enough support or understanding of partners and whānau. This was experienced as being distressful and hurtful, and negative judgement in the community of themselves and their tamariki led to them feeling excluded from ordinary spaces of daily life.

Overall, these findings reveal how Māori wāhine as māmā or primary caregivers create their own knowledge that supports a positive view of their tamariki. Over time, they develop tactics and skills of negotiation and activism that promote the rights of their tamariki. This analysis of the spaces these māmā navigate has been enabled through their pūrākau, which firmly placed their loved ones who have takiwātanga front and centre in their world.

The HP and PAR tools used in this research were appropriate because the māmā experienced their tamariki and takiwātanga through Western education and

health systems, and a predominantly Western community/social structure. In this study, these Western methodological tools ignited a whakaahua that transformed the Western-dominated spaces these māmā experience into spaces that strengthen mana wahine (the power of wāhine in society) and mātauranga wāhine (the knowledge of wāhine). The te ao Māori concepts of whakawhanaungatanga, manaakitanga, and tuakana-teina that are woven through their pūrākau provide another layer of protection and inspiration for the māmā in this research. These findings are discussed in relation to these concepts and the findings of the literature review in Chapter 5.

Chapter 5: Discussion

The preceding chapter has clearly demonstrated that all the māmā in this research promoted the potential of their tamariki (children) with takiwātanga (autism) and resisted notions of deficit from the education, health and community systems the interacted with. through their expert knowledge. The māmā utilised, engaged with, and propagated relationships that they recognised as being culturally enhancing for themselves and their tamariki. They were not afraid of Western education and health systems or Western-based community structures. They were wāhine toa (strong women), and they demonstrated mana wahine (female power/authority). The māmā harnessed the power their expertise in takiwātanga gave them and used it to obtain the best possible care for their tamariki.

At the same time, however, the māmā were aware of how they were stigmatised and judged by others. They channelled the support of whānau, partners and friends, and when they needed to resist, they used their metaphorical taiaha to defend their mōhio (expertise, wisdom, deep understanding) about their loved ones. As knowledge arrived in their mind and their hearts like the misty rainbow on the water, they saw the glow of atua (gods) illuminating the perfection of their tamariki from birth.

One way to interpret the experiences of the māmā in this research is to consider changing a term associated with the biomedical model of deficit – autism – to one that has emerged in Aotearoa in recent years – takiwātanga. As noted previously in this thesis, a medical diagnosis of takiwātanga links directly to support in school and the health system (Bevan-Brown, 2004; Priestley et al., 2022; Tupou et al., 2021). The wāhine were all keenly aware of this, but that was the extent of the meaning the Western word ‘autism’ had for them. They were not afraid of the word, and the māmā loved and protected their tamariki whilst embracing the useful parts of the Western system. As indicated in Chapter 1, I will now discuss the experiences of the māmā in this research in a space that privileges their understanding of takiwātanga, rather than autism, in dialogue with the findings of the literature review, particularly those associated with te ao Māori and other Indigenous understandings.

Reintroduction of the Taiaha Model

As noted in Chapter 3, the development of the methodology for this research mirrored the development of knowledge about takiwātanga for the māmā. The Taiaha model demonstrates how my methodology transforms (whakaahua) the Western deficit-based ideology of autism into the Indigenous strengths-based ideology of takiwātanga. From my perspective as researcher, the metaphorical taiaha represents the integration of theory – both Western and Indigenous – that guided me during the analysis process.

From the perspective of the māmā in this research, the taiaha metaphorically represents their actions in response to negative interactions with New Zealand's education and health systems, and their community. The mama wielded their taiaha in two main ways in the face of the Western deficit-based understanding of autism associated with the DSM-5-TR (American Psychiatric Association, 2022):

- *Te reo o ngā māmā (The mother's voice)*: They used the arero (tongue) of the taiaha to speak back to the education and health professionals who did not recognise the value of their lived experience and unique knowledge of their tamariki with takiwātanga.
- *Te tū toa (Standing tall)*: Their mōhio (deep understanding) of their tamariki with takiwātanga gave them the strength and resilience to parry the 'blows' of the education and health professionals whom they saw as unhelpful.

By responding in this way, the māmā were able to whakaahua (transform) the Western deficit-based management of autism into a strengths-based te ao Māori celebration of takiwātanga, in which tangata whaitakiwātanga are not only accepted but treasured, honoured, and considered perfect.

Each of the central contexts examined in this research – the education and health systems and the home and community – provided examples of the māmā speaking back to the system they found themselves in (te reo nga māmā) and their expert use of their metaphorical taiaha to demonstrate their capacity 'to go to war' in defence of their tamariki with takiwātanga (te tū toa).

Interpreting the pūrākau of the māmā through the metaphor of the taiaha lays the foundation for the following discussion of the three key concepts from te ao Māori that were interwoven within and between their kōrero: whakawhanaungatanga (relationship building),

manaakitanga (showing respect, generosity and care for others), and tuakana-teina (the relationship between an older [tuakana] person and a younger [teina] person).

Manaakitanga

Manaakitanga has been described as a space for crossing boundaries, involving ritual understandings that relate to generosity, respect and collaboration (Barlow, 1991; Wright & Heaton, 2021). Manaakitanga relates to building reciprocity and relationships, and at times a transactional process between borders and thresholds that move from tapu (sacredness) to noa (the ordinary). According to Wright and Heaton (1977), manaakitanga confers mana (respect/status) through the assumption that giving and accepting kindness imparts mana for both the manuhiri (guests) and the tangata whenua (hosts). Ritchie (1992) discusses manaakitanga as the obligation to care for and nurture others, especially in times of need.

In the context of this research, this means that people who come into contact with or work with tamariki with takiwātanga have the ethical responsibility to support them and enhance their mana. It is clear that some tamariki and rangatahi with takiwātanga will require support in the school environment, in the health system, and in the community (MoH & MoE, 2008; World Health Organization, 2019). Moreover, ethical responsibility involves professionals valuing others. According to te ao Māori, tamariki and rangatahi are considered taonga from birth, and as having literally the face of Atua (God) when they are born (Jenkins & Harte, 2011). Furthermore, their wairua (spirit) and tapu bestow mana. Mana is linked to Io Matua Kore (the Supreme Being), and forever embraces them inside mana tangata (whānau, hapū and iwi) and mana whenua (authority over land), and their turangawaewae (their whenua). These connections uphold the rights and protection of Māori tamariki and rangatahi, which inform what manaakitanga means for the māmā in this research.

It can be argued that provided a parent feels welcomed and part of their loved one's life across education, health, and the community, then spaces of respect and collaboration will flourish. This will benefit all parties, and can be seen in the kōrero of the māmā associated with manaakitanga, as they discussed how they felt welcomed and respected by others in the education and health systems or supported in the community by whānau, friends, neighbours, or even strangers.

Manaakitanga was demonstrated in ordinary ways through the mama being offered awhi (help) with paying school fees or their tamariki being made to feel at school. Knowing that they could visit their preferred general practitioner (GP) as often as needed was extremely comforting for some of the māmā.

Whakawhanaungatanga

In the pūrākau of the māmā, whakawhanaungatanga related to how they were being supported through their connections with others. It was important for the māmā to feel acknowledged and that their tamariki were valued by others. Therefore, this concept relates to all areas of the community including school, health authorities, and home that the māmā interacted with through the lens of takiwātanga. Whakawhanaungatanga provided a platform for building reciprocity in whānau relationships, so that when whānau members come into the space of tamariki who have takiwātanga, there is an accompanying responsibility to care and protect them as if they were your direct whānau.

Whakawhanaungatanga is a deceptively simple concept that is underpinned by a deeply profound meaning for Māori (Pere, 1991). This meaning is associated with connections Māori have through ancestral, spiritual and traditional philosophies that influence life, relationships between people, the world, and the universe. Ritchie (1992) describes whakawhanaungatanga as a cultural value linked to all things Māori and breaks down the three elements of the word's meaning: *whānau* (extended family); *ngā* (extends family beyond kin); and *tanga* (encompassing all relationships between kin).

According to Mead (2003), whakawhanaungatanga signifies an obligation to treat those people around us like whānau. Additionally, it relates to a sense of belonging to a social group or collective, and to relationships that are reciprocal and caring. Durie (1997) describes whānau as being intrinsically linked to oneself in the Māori mind. This positions tamariki as protected by those people around them as the living manifestation of their tipuna (ancestors). Whakawhanaungatanga can therefore be described as a concern for the spiritual and physical wellbeing of all concerned in everyday existence.

Tuakana-Teina

Tuakana-teina is associated with a philosophy that can be traced to traditional Māori society and is founded on the whakapapa and mana of people (Winitana, 2012). Oral history and cultural practices reveal that tuakana-teina interactions were related to order of birth. Additionally, a tuakana is defined as an older brother of a male, an older sister of a female, or a cousin of the same sex in an older branch of the whānau (Williams, 1985). A teina is a younger brother of a male, a younger sister of a female, or a cousin of the same sex in a younger branch of the whānau. According to Winitana (2012), senior and junior relationships between people and things are part of the natural structure that perpetuates through successive generations for a particular lineage. Traditionally, the social position and mana of a person correlated with their bloodlines (whakapapa). "Status was accorded to the tuakana before the teina, and it accounted for the structuring of reciprocal relationships between kin members of descent groups, tribal groups, and Māori and their environment" (Salmond, 1991, p. 348). According to Salmond (1991), mana was enhanced by relationships and a tuakana was expected to know the genealogical connections between whānau, hapū (sub-tribe) and iwi (tribe) and to share this knowledge with others (Dickson, 2010). Furthermore, skills in diplomacy and negotiation are expected of the tuakana alongside interests of the collective at heart; however, not all tuakana took on the role of peer leadership. Teina had less responsibilities and obligations, and therefore more freedom and at times, this meant that they outshone the tuakana. A strong element of this tuakana-teina relationship is to uphold the mana of all of those that are involved in the relationship, thereby reinforcing whakawhanaungatanga between them (Mead, 2003).

The concept of tuakana-teina featured in the kōrero of the māmā in relation to the relationships their tamariki with takiwātanga experienced, particularly in education. This concept was seen in older students including tamariki with takiwātanga in school activities and at times teaching them, as teina, how to behave appropriately in these spaces. Another example was the relationship between "quirky" teachers –the term used by Māmā Tuarima – and the tamariki with takiwātanga. Being accepted in the classroom by empathetic teachers as they passed down their knowledge to their students exemplifies tuakana-teina. Similarly, it can be argued that professional expertise being passed respectfully to the māmā is another form of tuakana-teina.

The following sections discuss the findings in relation to how each of these te ao Māori concepts operated in each of the main contexts in this research – the education and health systems and the home and community.

Education

The māmā in this research became activists for their tamariki with takiwātanga in education as they sought collaborative relationships that would protect the rights of their tamariki to a safe and inclusive educational experience. Each of the māmā indicated through their kōrero the understanding that gaining an education for their tamariki was very important. Attending school provided an opportunity for tamariki to learn new academic, communicative and social skills, supporting development in the main areas of need that are characterised by takiwātanga.

Common issues experienced by the māmā with the school system related to the complexity and intersectionality of takiwātanga. They often criticised the inflexibility of the school system with its class schedules and structured learning that collided with the characteristics of takiwātanga (Hodges et al., 2020). Seven out of 10 of the tamariki in this research required significant support in school, including needing an educational support worker (ESW) and an adapted curriculum. Challenges in this area were associated with a lack of funding or a lack of will from the principals or teachers to facilitate a safe learning space for the tamariki. There were also repeated failures to acknowledge parental expertise in takiwātanga (Kasari & Smith, 2013; Reeves et al., 2022).

A conflict of power was identified by most of the māmā, which often led to kaiako (teachers) being overtly unethical towards them and their tamariki. Most of the māmā felt their tamariki were specifically targeted by teachers who lacked knowledge or the will to learn, or to make adjustments to their expectations of their students (Milne, 2013). This was demonstrated by more than half the māmā reporting having their expertise in takiwātanga being ignored by teachers who forced their own opinions on the wāhine, without working collaboratively with them. These teachers demonstrated a lack of professionalism, and at times were openly hostile towards the māmā (Tso & Strnadová, 2017; Twemlow et al., 2006).

Tamariki with takiwātanga were openly mocked and disregarded by some teachers in the classroom environment (Milne, 2013). Māmā Tuawhitu identified the

school system as racist and ableist, and this has been identified in previous studies (Bishop, 2005; Bishop & Berryman, 2006; Meissel et al., 2017; Milne, 2013). This fostered mistrust between the māmā and the overall school system.

Funding for ESWs and teacher aide hours appeared to be inconsistent and confusing for more than half of the māmā, who personally made up for the shortfall in funding by volunteering their time or paying personally for services to support their tamariki at school, something noted by O'Neill (2016). Furthermore, accessing funding was directly linked to the health system, and māmā were forced to obtain a medical diagnosis as the only way to access funding for any school supports, including ESWs and teacher aides (Berg et al., 2018; McCarty et al., 2020; Obeid et al., 2021).

Manaakitanga and School

One of the most powerful ways for tamariki with takiwātanga to feel successful at school is for them to have an inclusive and supportive environment. Having the support of teachers and other school staff was highlighted as being crucial by the māmā in this research. Kaiako who did extra work to sit alongside tamariki with takiwātanga and aided their communication, socialisation and learning through personal investment was a powerful example of manaakitanga and of enhancing the mana of these tamariki. More than half of the māmā talked about teachers in ways that displayed a genuine and sincere regard and expressed how remarkable these kaiako were. In contrast, the māmā demonstrated their ability to push back against other kaiako who had no interest in supporting their tamariki or who purposefully targeted them by using their metaphorical taiaha to speak back to them or deflect their criticism.

Acts of authentic caring included tamariki being provided with noise cancelling headphones to attend school assemblies, which supported the tamariki being included in ordinary activities at school. Other kaiako allowed tamariki with takiwātanga to eat their lunch before the rest of the school at lunchtime in a quiet space, demonstrating their manaakitanga by supporting the physical health and wellbeing of the tamariki. As noted above, one māmā observed "quirky" teachers actively engaging with and including her tamariki, whom she described as also being quirky (Stevens, 2020; Pisano, 2017; Prior, 2017). Additionally, when a teacher

remarked to one māmā that their tamariki were loved and valued at school, this was very mana enhancing for her (Bishop & Berryman, 2009; Pillai, 2015)

Having their tamariki accepted and embraced by other students at school was an experience that the māmā valued in their kōrero. Fellow students including their tamariki in school games and actively developing friendships with them was a strong indicator of manaakitanga for the māmā. Making friends with your fellow students can be daunting for all tamariki, and those with takiwātanga are more likely to find it difficult to develop and maintain friendships. This is a common theme reflected in previous studies (Aukett et al., 1988; Bernadine et al., 2021; Cola et al., 2022; Sedgwick et al., 2016).

The characteristics of a school were an important factor for all of the māmā when choosing where their tamariki should attend. Schools whose philosophy embraced inclusion and kindness aligned well with the concept of manaakitanga and were highly appreciated by the māmā (Carrington et al., 2021, Francis et al., 2016, White et al., 2023). In addition, a smaller-sized school with a limited number of students was preferred by more than half of the māmā as they perceived that fewer students might mean quieter classrooms with a higher ratio of teachers and support staff to students, allowing more time and attention to be paid to their tamariki. These preferences have also been noted in previous research (Osborne & Reed, 2011; VanBergeijk et al., 2008).

There were tensions around ESW hours, in terms of how the school implemented the funding and how it was utilised for individual tamariki with takiwātanga, whose high, complex, and very individual needs were not always covered by sufficient funding (Dharan, 2020; Thabrew & Eggleston, 2018). Examples included tamariki who engaged in constant movement and stimulation and therefore needed monitoring for safety, requiring more than one ESW during the school day. The obstacle of employment contracts and the requirement of regular work breaks created a shortfall in funding or staffing.

Manaakitanga was demonstrated by māmā who shared their own resources with the school by volunteering their own time to support their tamariki, something also revealed in other studies (Benson, 2015; Benson et al., 2008; Shearn & Todd, 2000). Some māmā took part-time jobs to work in with school hours and be available to pick up their tamariki at short notice. A few māmā volunteered their time outside of work hours in support of extra-curricular events associated with the school on

weekends. This extra support allowed their tamariki to remain engaged in all learning activities in school, giving them academic, social and sporting experiences, and enhanced the mana of their tamariki.

Whakawhanaungatanga and School

As a central part of the community, a school is in a prime position to strengthen relationships between members of the community. Schools associated with this research had morning breakfast clubs for students providing a nutritious breakfast (Chote et al., 2022; McKelvie et al., 2023). Although this is a national strategy for low socio-economic schools in Aotearoa, it was recognised by the māmā in their kōrero as whakawhanaungatanga because it aligns with te ao Māori and tikanga (customs) linked to sharing of kai (food) as part of the rituals of whānau. Therefore, the breakfast clubs provided a sense of cultural safety for the māmā whilst supporting the tinana (physical health) of their tamariki. For Māori, any process that brings together a group of people who share kōrero and create and reaffirm connections reinforces the close bonds of whānau, hapū and iwi (Bishop, 2011).

Connecting with senior school staff who had Māori whakapapa (lineage) was clearly reinforcing and provided the māmā with a sense of confidence that their tamariki will be protected while attending school. In addition, whakawhanaungatanga and relationships were strongly linked to certain specialist team members from the MoE who worked collaboratively with the māmā while supporting their tamariki (Hasselbusch & Penman, 2008; Macfarlane & Macfarlane, 2013; Mutch & Collins, 2012). The socialisation and communication skills taught through specialist interventions were particularly appreciated by all of the māmā. An example of this is their tamariki being taught social games and skills to develop and widen their number of friendships in school (Boşnak & Turhan, 2020; Radley et al., 2020; Reed et al., 2011; Sansosti, 2010). This provided the possibility of developing relationships and opportunities to connect with others, both of which link closely to whakawhanaungatanga. Quick referral processes implemented by education specialists for equipment or outside services for the tamariki to support learning were highlighted by over half of the wāhine in this research as whakawhanaungatanga.

Other relationship connections were established by school staff members who were musical or artistic and who engaged with the tamariki with takiwātanga and

passed on their skills. This aligned with whakawhanaungatanga as a cultural passing down of knowledge through waiata (songs), pūrākau and artistic pursuits (Wirihana & Barnard, 2012), highlighting the use of art and music as a form of communication and pleasure for those people who have takiwātanga (Baron-Cohen et al., 2009; Fitzgerald, 2005; Ockelford, 2012; Roth, 2012).

Tuakana-Teina and School

The māmā highlighted examples of tuakana-teina demonstrated by other school students who were inclusive of their tamariki and other students who have takiwātanga. These students watched out for and included tamariki with takiwātanga in school activities. In addition, the tuakana-teina model meant that tamariki with takiwātanga were introduced to social boundaries and tikanga around education. Bossert (2013) sees this kind of social participation leading to positive interactions and acceptance between typically developing students and students with special education needs. When these tamariki are accepted by their peers and included in the tuakana-teina relationship, their sense of social responsibility is enhanced, as well as their mana.

Health

The māmā in this research had had both positive and negative experiences with the New Zealand healthcare system In order to gain a diagnosis of takiwātanga, the māmā were required to rely on medical professionals trained in the biomedical model. Therefore, these professionals were the gatekeepers for every kind of support for their tamariki in all areas of health, education, and the community. The biomedical model of illness and disease remains the standard for healthcare in Aotearoa and the world (Anderson-Chavarria, 2022; Stroebe, 2011). More than half of the māmā in this research discussed being repeatedly urged to medicate their tamariki by health professionals.

From a biomedical model perspective, medication is an empirically supported method of reducing maladaptive behaviours in tamariki who have takiwātanga. According to Handen et al. (2000), there is a wide range of pharmacologic interventions that support the reduction in the core and secondary features of takiwātanga. According to the UK National Collaborating Centre for Mental Health (2012), psychotropic medications including antipsychotics, antidepressants,

antiepileptic drugs and stimulant medication are a regular part of the medical regime for people with takiwātanga. Two drugs, risperidone and aripiprazole, have been approved by the US Food and Drug Administration for use associated with the management of behavioural disturbances and irritability for takiwātanga (European Medicines Agency, 2007; Marcus et al., 2009; McCracken et al., 2002; Owen et al., 2009; World Health Organization, 2013). The medication that had been prescribed for the tamariki of the mama in this research had side-effects that included disturbed sleep patterns, nausea, fatigue, and mood changes. As a result, all but one māmā disagreed with the use of all types of Western medication.

For Māmā Tuawhā, the persistent promotion of medication for her son was partly related to his weight – one of the side effects of the drug being suggested was weight loss. Psychosocial experiences of stigma regarding obesity in childhood are well documented in the literature and has been associated with negative characteristics. People who are obese are often dismissed as being lazy, dirty and stupid (Duncan, 2008). Interestingly, the proposed drug was an antiepileptic medication for those people who are impacted by epilepsy. Her son does not have epilepsy. A common side effect of some anti-epileptic drugs (AEDs) is weight loss, however there are important considerations when prescribing an AED purely for weight loss for children and adolescents, due to this being a period of rapid physical growth and maturation (Lagae et al., 2015; H. S. Lee et al., 2013).

Māmā Tuawhā was not impressed by the medical professional focusing only on her son's weight during health appointments. When describing her son's restricted diet routine due to his takiwātanga in her kōrero, she emphasised that she cannot easily change his diet to something deemed a weight loss diet. Furthermore, she had identified that her son likes to sit and read and is not very physically active – traditional ways to lose weight that are linked to exercise were not a viable option either. The added layer of complexity of takiwātanga left few options to decrease his weight. However, being offered an AED purely for weight was not acceptable for this māmā. Common side effects of AED medication include nausea, irritability, abdominal pain and dizziness (Y. W. Chen et al., 2017; Wagner et al., 2019). She used her metaphorical taiaha, in the context of te reo nga māmā, where she spoke back to the system and refused this medical advice.

More than half of the māmā in this research were concerned about their tamariki early in their developmental trajectory. Some of the tamariki in this research were so idiosyncratic

in terms of their behaviours that there was no doubt about their neurodiversity. However, the stress experienced by parents in this situation is often made worse when there is a delay in diagnosis, and this experience was highlighted in this research. According to Stone et al. (1999), takiwātanga can be reliably diagnosed by the age of two, and screening tests can highlight a risk for diagnosis by 12 months old (Corsello et al., 2013; Turner-Brown et al., 2013). Nearly half of the māmā were impacted by a delay in diagnosis for their tamariki, and two of them related this to being Māori, believing they were ignored and discounted by medical professionals because of their ethnicity. S. Magaña et al. (2012) found that disparities in follow-up care for Black and Hispanic children in the United States could be argued as attributable to race. Consistent delays in a formal diagnosis – in some instances by years – have been widely documented for people from different racial and ethnic minority groups in the United States (Bowden et al., 2020; Drysdale & van der Meer, 2020; Obeid et al., 2015; Ribeiro et al., 2017; Zuckerman et al., 2013).

Some māmā in this research were told their child was too young for a diagnosis, and that their children's behaviour was due to poor parenting, which was noted by Shepherd et al. (2021). This type of belittling of a parent's competence is evident in the stigmatising construction of 'the mad mother of a disabled child' widely seen in Western health systems (Douglas et al., 2021; Robertson, 2014; Warden, 2020). Other issues for the māmā in this research relate to long waitlists for an assessment with a health professional adding to the difficulty in gaining a timely diagnosis, and this is also reflected in the literature (Drysdale & van der Meer, 2020; Eggleston et al., 2019; McAnelly & Gaffney, 2017; Thabrew & Eggleston, 2018). Two māmā found the waitlist for services too long, and this meant long delays in getting support for their tamariki, so they decided to pay for the diagnosis personally through the private healthcare system (Dharan, 2020; Taylor et al., 2021; van der Meer & Evans 2021; Wallace-Watkin et al., 2021). Paying privately meant that their tamariki could access funded services earlier from the MoE, MoH and MSD. This brings into focus issues relating to equity and the ability for whānau to be able to receive vital support for their tamariki.

Half of the māmā were confronted with difficulties relating to finding someone suitable to care for the tamariki in their absence, while some were challenged about how they wanted to use the allocated respite funding. The māmā all indicated that they preferred to have whānau as respite care givers, and this relates to whakawhanaungatanga and the sense

of security this Māori concept provides. However, the rules about spending respite funding are highly restrictive (Whaikaha – Ministry of Disabled People and MoE, 2022).

Over half of the wāhine in this research identified the administrators/receptionists at clinics and health organisations as having considerable power in relation to obtaining timely health services (D. Magaña, 2020; Stevens et al., 2020). The māmā either befriended them or pushed back at them in order to gain access to appointments or to find out how their referrals or specialist appointments were tracking. All of the māmā approached professionals and staff in the health system using similar Māori concepts they used in the education system, linking to manaakitanga and whakawhanaungatanga.

Manaakitanga and Health Practitioners

A significant form of assistance in the health system was having a supportive general practitioner (GP). A GP is a community-based doctor who is registered with the Medical Council of New Zealand and making referrals to specialists is one of their primary roles. Similar to having a supportive teacher in school, having a GP who supported them unconditionally was described as making all of the difference for the māmā and their tamariki who have takiwātanga. Words that the māmā used when talking about their experiences with their GP included "game changer" and "awesome". This sense of changing the game relates to enhancing the mana and supporting the wellbeing of the wāhine and their tamariki. In this situation, manaakitanga relates to the GP being able to cross the borders and thresholds that frame the health system, and ultimately the diagnostic process. Furthermore, being listened to with acceptance and without judgement further enhanced the mana of the wāhine (Doherty et al., 2020; Heron et al., 2020).

Whakawhanaungatanga and Health Practitioners

The GP of one māmā was married to a member of her whānau, which greatly helped with whakawhanaungatanga. Having a proactive GP was crucial in getting a swift diagnosis and therefore access to support services. Very close relationships were built between the māmā and those GPs who pursued a diagnosis for their tamariki and treated the māmā with genuine sensitivity and interest outside of their role as a practitioner.

Being enrolled with your GP long term and bearing multiple children during that time builds significant bonds and investment by both the GP and the māmā. Being told that "I know you, I know your whānau" by a GP indicates a deeper relationship than that of a client/practitioner in ordinary circumstances. Māmā in this research stated they would travel to see their GP, even if it meant several hours' drive. Two of the māmā discovered they had the same GP and discussed her characteristics and importance to their whānau. This included seeing the māmā as often as two to three times in one week just to talk things through. The simple act of a GP actively listening was highlighted across the research by all but one of the māmā as very important. (The other māmā did not make any comment regarding access to and experiences of health services in this research.)

Health professionals or staff working in health services who refused to engage in the cultural understanding of whakawhanaungatanga were circumnavigated in pursuit of other professionals who were happy to form reciprocal relationships with the māmā. This advocacy was not always overt, however. Half of the māmā protested passively by simply thanking unhelpful health professionals for their advice but not following it at all. This demonstrated that the māmā knew what was best for their tamariki, and they were prepared to ignore what were considered normal interventions for takiwātanga. They relied instead on their own research about takiwātanga, and their cultural values and beliefs.

Tuakana-Teina and Health Practitioners

Building whakawhanaungatanga through strong relationships extended to the specialist health practitioners such as psychologists and occupational therapists who provided services and facilitated other specialist support in the education and health systems. These experts acted as tuakana for the māmā, mentoring them on their takiwātanga journey. All of the māmā recognised the expertise in these specialists who concentrated on specific areas of development and were able to provide more in-depth specialist knowledge for the māmā and their loved ones. This was particularly welcomed in relation to included language acquisition, socialisation skills and cognitive development. Some māmā discussed paying privately for specialist appointments to speed up diagnostic and treatment processes. The advantages of early intervention for tāngata whaitakiwātanga are described in the literature as one of the

most effective ways to promote development in the early years of a child's life (Fuller & Kaiser, 2020; Pickles et al., 2016; Waddington et al., 2020). With increased brain plasticity at this age, there is the possibility of sustained long-term brain and behaviour changes from early intervention (Webb et al., 2014). This also applies to social and developmental interventions, which should start as early as possible to provide the best chance of positive outcomes for the child with takiwātanga.

Home and the Community

The positive outcomes of early intervention filter down to whānau and the wider community. Additionally, early support can have long-term education and health benefits, including increased independence and possibly lowering the need for funded services during the lifetime of the tamariki. Further types of support in the health system highlighted in this research included access to a mobile vaccination clinic, meaning one less trip to the doctor – something that created anxiety for the tamariki of one māmā (Doherty et al., 2020).

The lived experience of home and the community for the māmā was influenced by the sensitivities of their child(ren) with takiwātanga in these shared spaces. Community life involves personal maintenance and development, shopping, the skills to use private and public transport, and managing finances (Beakley et al., 2003; Cascio et al., 2020; Y. W. Chen et al., 2017). Additionally, community life is associated with the ability to use smartphones and access sports clubs and other community facilities providing vocational opportunities. The characteristics of takiwātanga can make engaging in the community difficult (Tayyare et al., 2013), and the māmā experienced difficulties in trying to socialise their tamariki in the community. All of the māmā felt judged in communal areas when the characteristics of takiwātanga violated social rules and expectations in those spaces. Tamariki having "meltdowns" while out in the community was a frequently mentioned, indicating an inability to self-regulate, which is associated with takiwātanga (Dijkhuis et al., 2017; Dudek, 2022; Gomez & Baird, 2005). Some māmā observed their tamariki being judged by their appearance. For example, Māmā Tuarua liked to dress her tamariki in expensive labelled clothing, but the looks she received from some in the community implied that, as Māori woman living in a low socioeconomic area, she must be involved in criminal activities to be able to afford such luxuries. Such racist assumptions and negative

judgements led to the māmā feeling stigmatised and excluded (Bevan-Brown, 2013; Searing et al., 2015; Weastell, 2017).

There was a distinct lack of whānau support for more than half of the māmā in this research. Often māmā lived in a different area of Aotearoa, sometimes three to four hours' drive away from close relatives further adding to the sense of isolation and lack of support networks. For others, whānau showed little interest or resistance to understanding takiwātanga which was the most distressing for the māmā who experienced this. Māmā felt hurt when whānau talked about tamariki with takiwātanga as having a type of sickness or illness. A longitudinal study conducted in Aotearoa by Gray (2002) identified a lack of understanding and support from grandparents of tamariki who have takiwātanga. This was the case for Māmā Tuawhitu as her husband's parents were not supportive of her or their son with takiwātanga.

Manaakitanga and Home Life

Some māmā had supportive whānau, and they emphasised the importance of this (Goedeke et al., 2019; Searing et al., 2015). Support included physical support with caregiving, financial support with the extra costs associated with takiwātanga, and emotional support, helping the māmā to manage the ongoing high and complex needs of their loved ones on an ongoing basis. This assistance stretched well beyond the years when tamariki are expected to be more independent. In one instance, a koro (grandfather) researched takiwātanga from the moment the whānau questioned whether his grandson might have the condition. He purchased books for his daughter to start reading about takiwātanga and accessed iwi funding for her pursuit of a formal diagnosis.

Another māmā was supported by her partner even though they had been separated before the diagnosis of their son was confirmed. This pāpā visited and stayed regularly with the māmā to spend time with his tamariki and maintained a close and positive relationship with his ex-wife. Their son with takiwātanga loved physical rough and tumble play with his pāpā when he visited. A stepfather made the difference in the life of another māmā and her tamariki. He created a strong foundation from which this māmā drew strength and security to manage the stressors of her life associated with takiwātanga.

Having a significant other who is invested in you and your whānau was hugely supportive and lowered the risk of social isolation from having a child with complex needs (H. R. Hall & Graff, 2010; Samsell et al., 2022). In lieu of this, the next best type of support was wider whānau, friends and the community. Perceived social support in the community was also uplifting for the māmā. Māori and Pasifika people were found to be more supportive in the community in places like the supermarket. When things were going awry with their tamariki, some māmā were asked if they needed help when this happened.

While parenting alone was identified as challenging due to the increased workload, some māmā identified living away from their own whānau as significantly more difficult emotionally than being separated from their partner. Coping is the ability to lessen potential stressors in life and has received significant attention in the literature (Davis & Kiang, 2020; Lai et al., 2015; McCubbin, 1979). Two prominent models of managing stress are instrumental strategies and palliative strategies (Greenglass & Fiksenbaum, 2009; Gupta & Kumar, 2020). Instrumental strategies are associated with empowering parents to implement change in the person or the environment. Palliative strategies are linked to building resilience to tolerate stress through internal mechanisms like self-care and self-help understandings. Identified coping strategies for parents with tamariki with takiwātanga include support from a spouse, the acceptance of the child, social networks, formal services, training programmes and personal research (Greenglass et al., 2009). It could be argued that the māmā in this research employed instrumental strategies to implement change through personal and professional development demonstrated by becoming experts in takiwātanga. Palliative strategies used by the māmā included advocating for their loved ones, with positive outcomes reinforcing the emotional health of the māmā as a form of self-care.

Having structures and routines is extremely important for things to work smoothly in a busy household, and some māmā reframed their understanding of home by adapting their whare (house) to meet the sensory needs of their tamariki. This included the use of blackout curtains for light sensitivities, making clothing optional if tamariki disliked the feeling of clothing against their skin, and allowing the use of an outdoor swing well into the night to soothe tamariki with the motion of the swing.

While māmā adapted their whare to accommodate the needs of their tamariki, they also became adept at using social media, Facebook in particular. Half of the māmā used Facebook to gain a better understanding of takiwātanga and to connect to others with similar experiences. There are spaces on these social media pages to reach out for advice about the lifespan experience of takiwātanga from both a Western and te ao Māori understanding. Whakawhanaungatanga and manaakitanga were easily identifiable and demonstrated by the words of encouragement the māmā received from other wāhine and tāne (men) in these closed discussions. Gaining membership of Facebook groups is a rigorous process and privacy is well-protected.

Whakawhanaungatanga and Living in the Community

Acceptance of tamariki with takiwātanga in the community was extremely motivating for the māmā in this research. For Māmā Tuarua, her "tight knit" community allowed for the local tamariki to play with one another and include her two tamariki with takiwātanga. The concept of whakawhanaungatanga aligns with this sense of inclusion and caring, making the community feel like extended whānau.

One way to redefine your lived experience is to reframe the language and ideas that define your life. Māmā Tuatahi described herself and her tamariki with takiwātanga as having "superpowers". When they went out into the community, their takiwātanga "glitter" was unavoidable and stuck to anyone who the whānau brushed up against. In the literature, this is understood as self-distancing, a tactic used to manage during difficult times when facing chronic health conditions (White & Carlson, 2017). Furthermore, the strongest self-distancing effect was observed when children took the role of a famous fictional superhero. The metaphor of takiwātanga as a glittery gift used by Māmā Tuatahi was very apt – anyone who has had glitter on them will acknowledge how difficult it is to remove.

This is a powerful example of a māmā reframing the experiences of her whānau and community members in public spaces. All of the māmā reframed the negative experiences of their tamariki in the community as opportunities for others to learn about and experience takiwātanga, so that they too can see tāngata whaitakiwātanga as taonga (treasures) – as gifts that they were bestowed by atua.

Seven māmā altered their employment following the diagnosis of their loved one with takiwātanga (Cidav et al., 2012). Some began to work part-time or worked

from home to better support their whānau. Gaining employment with the MoE provided a space for one whānau, where both parents were "on the inside" of the education system and learned first-hand how best to utilise it in relation to their tamariki with takiwātanga. Working part-time or working from home supported more opportunities to spend time teaching tamariki. Whakawhanaungatanga was demonstrated by supportive employers who allowed flexible work hours, helping some māmā to support their tamariki during school hours. Developing the skills to balance work, daily life at home, and tamariki with takiwātanga amounts to double the average workload for these māmā (Baker, 2010; Home, 2004).

The māmā in this research placed emphasis on feeling blessed and how their lives had been enriched by being a māmā of a tamariki with takiwātanga. They saw their tamariki through a strengths-based understanding and discussed how they felt they had a purpose in the world. In research by Cost et al. (2021), Canadian parents endorsed positive traits and described the 'best things' about their children who were autistic, including love, kindness, happiness, and sense of humour. Their responses emphasised strengths and resilience, reflecting a paradigm shift whereby autism is viewed through the lens of neurodiversity. This creates space to identify positive attributes and strengths associated with autism and offers a more holistic perspective of this lived experience (Kapp et al., 2013; Lam et al., 2020; McCrimmon & Montgomery, 2014; Nicholas et al., 2019; Riwai-Couch, 2019; Tesfay et al., 2019). This aligns with the positive psychology movement, which employs creative methodologies to capture the vibrancy of individuals, whānau and communities (Seligman & Csikszentmihalyi, 2000).

It is important to acknowledge the living arrangements of Māmā Tuawaru, who during the COVID-19 pandemic was living in emergency housing, and how this experience collided with the characteristics of takiwātanga. This māmā and her daughter with takiwātanga stayed in a one-bedroom motel room and being confined in such a small space meant the māmā had to monitor her daughter –who was always on the move – continually to keep the noise down. Other people staying in the motel were affiliated with a "rough crowd" and keeping quiet and to themselves was linked to staying safe during this time for this whānau. The basic necessity of having a stable home was critical for the wellbeing of this whānau at a time when emergency housing has become 'the new normal' for Aotearoa, where the availability of affordable rental

accommodation has been severely limited by the housing crisis (Ministry of Housing and Urban Development, 2022).

The COVID-19 pandemic further exacerbated the need for emergency housing as people lost their jobs due to nationwide lockdown measures beginning in March 2020 (Le Dé et al., 2023). The conditions this māmā and her daughter were forced to live in demonstrate the failure of the government to provide adequate living conditions for vulnerable people. The perpetuation of this vulnerability is particularly stressful for tamariki who have takiwātanga. Strategies this māmā employed to support her daughter included going out often to parks and to ride on buses which was one of her favoured activities.

A fenced home is advantageous for any whānau with children to help keep them within the property and safe. Fencing is a necessity for those tamariki with takiwātanga who tend to wander (Guan & Li, 2017; C. E. Rice et al., 2016) and becomes the first line of safety for whānau. Fenced properties are usually more expensive to rent, however. Such housing dilemmas were part of the day-to-day life of some māmā in this study.

While out in the community, in order to reduce the impact of judgemental and discriminatory attitudes, and the māmā reframed their experiences in several ways. One way involved changing the language that they used to describe their tamariki who have takiwātanga. They also took it upon themselves to learn all they could about takiwātanga, and to advocate for and support their tamariki. Their mere presence created a space for activism at any opportunity and in any moment (Boshoff, 2016; Bumiller, 2008). Māmā make powerful activists and advocates, and although some of the māmā in this research were overt and voiced their opinion readily and loudly, others quietly and passively resisted by saying nothing or attending various programmes that were promoted to them despite knowing it might not be useful for them. Overt or not, these actions supported the māmā in making their views known.

Tuakana-Teina and the "Old Ways"

Māmā Tuaono used what she described as the "old ways" in raising her son with takiwātanga. These old ways related to the Indigenous knowledge she had gained while being raised by her grandparents, which was partly imparted through the tuakana-teina process of peer learning. After realising that the whānau environment

was not set up for her son with takiwātanga, Māmā Tuaono decided the whole whānau needed to speak exclusively in te reo Māori while at home, including her son who has takiwātanga. The use of te reo Māori offers a deep sense of cultural and emotional security, according to Te Maihāroa (2011). Furthermore, benefits of speaking te reo Māori relate to gaining an integrated sense of personal identity through the amelioration of cultural and familial relationships (whakawhanaungatanga).

Māmā Tuaono also slowed the pace of her life, spending time one on one with her son and supporting his development by quietly showing and doing things with him at her side at all times. She changed the whānau diet completely, replacing sugary and processed foods with whole and natural foods. This manaakitanga displays her deep understanding of her son, as she put in place a transformative intervention to give her son the optimal learning environment. Additionally, she had implemented roleplaying as a method to teach her son how to act socially (Leaf et al., 2016; Patel et al., 2022). Roleplaying how to think through social situations and how to act in socially appropriate ways supported the development of her son's social skills. Her deep understanding of te ao Māori has created a wonderful environment for her son who has takiwātanga to flourish by connecting to being Māori through language and identity.

Summary

The eight māmā in this research strongly advocated for the rights of their tamariki with takiwātanga, and this can be seen in their kōrero across their interactions with New Zealand's education and health systems, and in home and the community. Information and advice from any person, whether professional, whānau or friend, was ignored if it did not align with their own knowledge and experience of takiwātanga. The māmā pushed back against anything that negated the value of their tamariki or their lived experience. Having said that, they all utilised knowledge from both Western and Indigenous spaces that worked for their tamariki. As I have noted previously, the wāhine were not afraid of the Western term associated with takiwātanga as a negative label. They used the power of that label as a way to access resources and services for their tamariki. Having supportive professionals, whānau, partners and friends was the most uplifting factor in the lives of these māmā.

Moea tō poi, moea tō taiaha.

Sleep with your poi; sleep with your taiaha.

This whakataukī (proverb) can be interpreted as you need to be prepared for the unexpected. A poi is a light ball on a string of varying length which is swung or twirled rhythmically to waiata (singing). Traditionally made raupō (bullrush) leaves, poi were used during waiata and kapa haka (dancing and chanting) performances by wāhine. Their actions supported the flexibility of their hands, and poi were also used by tāne (men) to improve coordination, conditioning and stamina required for warfare.

The māmā in this research had been and were still on a journey none of them could have predicted, but this is not to say that their journeys were not joyful or unwelcomed. However, it has meant that these wāhine have had to prepare themselves and for the unpredictable nature of takiwātanga when interacting with the education and health systems and at home and in their community. They have had to remain nimble and flexible, keeping their poi swinging in time whilst navigating these systems to support their tamariki and rangatahi where at times they would have needed their metaphorical taiaha to defend their position and hold the whenua (land) where they had planted their waewae (feet).

Sleeping with your poi *and* your taiaha as the whakataukī advises captures the lived experience of these māmā who have encountered openly hostile and structurally racist aspects of the New Zealand's health and education systems on their takiwātanga journeys. In addition, They had all been the victims of sexism whereby their strengths and knowledge of takiwātanga were either dismissed or ignored.

It is widely accepted by Māori scholars that colonisation has created and continues to re-create experiences of racism and disparities for Māori across all sectors of society in contemporary times (Pihama, 2019; L. T. Smith, 2021). The decolonising methodologies powerfully articulated by Linda Tuhiwai Smith (2021) aim to reveal just how entrenched colonialism continues to be in Aotearoa. In bravely challenging this ongoing colonialism and its impact on their lived experience, the māmā in this research champion the te ao Māori concepts of manaakitanga, whakawhanaungatanga and tuakana-teina in relation to their tamariki who have takiwātanga. This approach is diametrically opposed to that of the objective and distanced practitioner, whether from the education or health system, who is expected to stay detached and 'practise' on their 'clients'.

The māmā in the research knew how structural racism and sexism underpinned their lived experiences, and this was articulated in their kōrero through references to being "young," "brown" and "a single mother", and in the negative comments they'd received

about how they dressed and where they lived. They knew these factors worked together to stigmatise them as ‘bad māmā’ who either asked for too much or did not do enough for their tamariki. Everyone, they had found, had an opinion: education and health professionals and their own whānau had an opinion about takiwātanga. The relatively few who listened to and endorsed the expertise of the māmā were cherished. With those who did not listen, they either pushed back or ignored what they considered as unhealthy or prejudicial advice.

With their deep awareness of this structural discrimination, the wāhine were able to manage their everyday lives through their own ways of knowing, and from this standpoint the māmā were clearly experts in both their tamariki with takiwātanga and takiwātanga itself (Pihama, 2020). This was demonstrated by the wāhine not being submissive to overt discrimination. They resisted the deficit nature of the dominant Western biomedical model that positions their tamariki as negative, negated, and othered from normal. The māmā also engaged in connecting strategies that included being a kaiako for their tamariki and ensuring they were included in tuakana-teina relationships, and in connecting with professionals who projected the te ao Māori concepts of whakawhanaungatanga and manaakitanga.

Te Mana Wahine: Winning the ‘War’

The following discussion honours the knowledge created by the māmā on their takiwātanga journeys from the perspective of Mana Wahine theory (Pihama, 2001). Each of the central contexts examined in this research – the education and health systems and the home and community – provided examples of the māmā speaking back to the system they found themselves in (te reo nga māmā) and demonstrating the diligent use of their metaphorical taiaha to demonstrate their capacity for metaphorical war in defence of their tamariki with takiwātanga (te tū toa).

Te Mana Wahine and Expertise in Education

All of the māmā in this research were passionate advocates for their tamariki and rangatahi who had takiwātanga and occupied a unique position in the social and political space of contemporary Aotearoa (Brock, 2014; Hyland, 2020; Pihama, 2020). Their practice of mana wahine was evident in all areas of education from early childhood through to secondary school. Kaiako were questioned or informed by the māmā about the best practice for their tamariki and rangatahi with takiwātanga. Kōrero between the māmā and kaiako was overt and to the point from their position on takiwātanga and as experts in their own whānau about this unique lived experience. This expertise was characterised by knowing their

tamariki and knowing exactly how takiwātanga uniquely affects their tamariki and their whānau.

Since the foundation of New Zealand, education has been a tool to assimilate Māori into a Western paradigm of thought and knowledge (L. T. Smith, 2021). Claiming back their own expert knowledge of how their tamariki and rangatahi learn best was one tool or metaphorical taiaha that the wāhine used to defend, maintain, or take back power while interacting with the education system. At times, this looked like challenging the kaiako or the MoE assessment processes for school support; at other times it looked like actively 'recruiting' the best front-line 'troops' or education specialists from within the system itself. The māmā described utilising the best that a Western education system could offer, rejecting what they were not prepared to accept while maintaining their own mōhio (deep understanding) of takiwātanga. These experiences highlight the failure of the education system in Aotearoa to be attuned to the needs of Māori, especially Māori tamariki with takiwātanga and their whānau (Egan, 2022; G. H. Smith, 2000).

Bogotch and Waite (2017) discuss the need for educational leadership when the unpredictability of current global affairs means we require a different set of processes for decision making that engages with uncertainty and ignores the need to find perfect solutions. *Transformative leadership* demands that we examine how our own and others' world beliefs impact on the experience of Māori students and their whānau while critically assessing and challenging the educational status quo that continues to subjugate minority groups (Gooden, 2002).

Egan (2022) argues that in order to transform the education system in Aotearoa we must first embrace our unique roles through the lens of equity and endorse our shared humanity. This was observed in the research when the māmā actively connected with educational professionals who showed and shared their humanity and purposefully avoided the ones who did not. A connection to an invested teacher or principal made a clear and very positive difference to the experiences for māmā, and this type of relationship replicates a traditional Māori way of knowing and living associated with the accountability of treating whānau in need as a taonga and part of the fabric of belonging for a collectivist understanding of iwi, hapū and whānau.

Māmā being teachers for the tamariki is not a new concept. However, taking into consideration the diversity and complexity of learning associated with takiwātanga, this

makes the activity of teaching more multifaceted as the māmā integrate the expertise they have developed caring for their loved one with takiwātanga. In terms of teaching and supporting the learning of their tamariki, the māmā in this research had a deep, innate and instinctive understanding of how their children learned and how to teach them new skills. This ranged from slowing down learning activities and taking time to interact with their loved ones who have takiwātanga one on one. Another form of expertise was associated with te ao Māori, which included only speaking te reo Māori within their whare. Making this decision to kōrero te reo Māori directly connected with Māori identity, tikanga and Māori spirituality. A study by Tupou et al. (2023) found that parents of tamariki with takiwātanga had multiple strategies that were useful for cultural development, including the expressive nature of te reo Māori. The benefits of learning or hearing te reo Māori was highlighted by the māmā and was linked to when whānau attended hui (meetings) on the marae. Traditional ceremonies on the marae are spaces where te reo Māori links to tikanga and protocols of engagement that are unique to being Māori. Attending hui presents an opportunity for tamariki and rangatahi with takiwātanga to develop their knowledge of not only te reo Māori but also to self-regulate in crowded and often noisy situations.

Te Mana Wahine and Expertise in Health

The most common Western definition of autism is that given in the DSM-5-TR (American Psychiatric Association, 2022), where its characteristics are identified as restrictive, repetitive patterns of behaviour, deficits in social communication and interactions, and severe maladaptive behavioural disturbances that can include aggression and self-injury (Attwood, 2003; Samson; 2015; Sannar et al., 2018). However, through the lens of Mana Wahine theory, there is nothing that is disordered or in need of changing about these tamariki, who have been given celestial acknowledgement of their uniqueness (Jenkins, 2011). Part of the resistance demonstrated by the māmā in this research to the health system included similar strategies that were utilised in the education system. Advocacy was a commonly used tactic by the māmā, and it was instigated through questioning the wisdom of doctors, paediatricians and other medical professionals.

The need to have a diagnosis of takiwātanga in order to access funding for support in education and the wider community made the health system extremely important to the māmā in this research. Obtaining a diagnosis of takiwātanga has been highlighted in other research as stressful and difficult for whānau (Crane et al., 2016; Eggleston et al., 2019; Moh &

Magiati, 2012). Additionally, challenges associated with the patient–health provider relationship include obstacles in communication, perceived limited knowledge of takiwātanga by health providers, and failing to recognise the expertise and role of whānau (Stace, 2011; S. A. Wilson & Peterson, 2018). These factors potentially delay a formal diagnosis. The importance of having a strong relationship with a GP was highlighted in the research and whakawhanaungatanga with health professionals who supported the māmā by listening to them and treating their concerns with authentic interest helped to facilitate a timely diagnosis and access to health services.

From another perspective, ignoring medical advice pertaining to medications demonstrated the tenacity of the māmā in this research to push or speak back to health professionals if they did not agree with them. This related to the promotion of medication that all but one of the māmā deemed inappropriate. A report by the Royal College of Psychiatrists (2021) asserts that people with an intellectual disability use more medication than others in the general population, aligning with a higher prevalence of physical and mental health disorders in this group. The report calls for judicious prescribing of medication after the overuse of potent psychotropic medication was highlighted in the Serious Case Review into Winterbourne View Hospital in England in 2012. This report recommended avoiding unnecessary and inappropriate use of medication for people with intellectual disabilities, takiwātanga or both. A study in Aotearoa by Ooi (2023) finds the reason for overtreatment by GPs relates to inter-related factors including the influence from pharmaceutical companies, how doctors are trained and remunerated, and whether they practise defensively to avoid patient complaints. Both pieces of literature support the prescription of medication provided there is clear clinical indications for its need.

Te Mana Wahine and Expertise in the Home and Community

According to Derby (2013), pre-colonisation traditional life for Māori consisted of collective experience of living in a village, with members of their whānau, hapū and iwi. Roles and responsibilities for the iwi were shared by everyone, which included the care of tamariki who were considered as belonging to the wider community in addition to their parents (Higgins & Meredith, 2011). Furthermore, direct whānau members such as kuia (elderly female relatives) and koroua (elderly male relatives) offered substantial parenting support, and historically their role was linked to leadership of the whānau; overseeing the use and control of whānau property; supporting their adult tamariki, and educating their

mokopuna. Kuia and koroua would care for children while their parents were away working or away during warfare. Whānau that were willing to help the māmā in this research were identified as a strong protective factor for their physical health and psychological wellbeing. Having practical support with caregiving or household duties, and the availability of emotional support for the māmā who needed someone to share their experiences with, were highly reinforcing and supported their resilience and perception of their quality of life (Emily & Grace, 2015).

Adjusting the living environment to best suit tamariki with takiwātanga was another strategy used to improve the wellbeing of the whole whānau. This might involve altering the lighting and blocking sunlight to soothe tamariki and rangatahi who are light sensitive. Taking a positive attitude regarding the behaviour of their tamariki by reframing everyday experiences of takiwātanga helped the māmā to highlight the strengths of their children and facilitated better daily functioning of the whare. According to Llias et al. (2019), parents do adjust to a new journey of parenting after receiving a diagnosis of takiwātanga. The māmā used their expert knowledge of takiwātanga to manage daily life at home and in the community by reframing and re-storying their experiences.

Prioritising their child(ren) with takiwātanga as taonga to be celebrated helped the mama demonstrate to others that the ways their tamariki see, feel and respond to the world should be honoured and valued. Self-efficacy is an important factor for parents in this situation to remain positive and to have hope for the future of their children. However, before the present study, there has been little research that links self-efficacy and parenting competence to the lived experience of takiwātanga (Kuhn & Carter, 2006). Benson (2010) found that the use of a range of adaptive strategies supported better outcomes, particularly when social support was available for parents managing takiwātanga.

PhD Summary Feedback

It is with immense pleasure that I present brief feedback from all eight māmā after providing them with a copy of a summary of the PhD. I asked for an update on their whānau and if they wanted to provide any feedback about the summary. All the māmā talked about the physical and emotional growth of their tamariki, now ranging in age from 8-20 years old. One older tamariki had moved into permanent employment. For other māmā their tamariki were adolescents or nearing adolescence and they were doing well at school and enjoying friendships with other students. One adolescent was transitioning to high school, and he

participated in making incredible art as part of his school day. His brother was dealing with a back injury and was not attending school at the time of contact. This māmā commented that she and her whānau were navigating their way through life and that they were all doing well. One māmā had welcomed a new moko (grandchild) into her whānau. One māmā has recently had another baby. One māmā was off grid in Australia and talked about her son who had graduated from high school staying connected with one close friend from school. Another māmā was enjoying her new career and her sons were doing well in school. She had moved back "home" close to whānau. One māmā sent me photographs and a video of her boy enjoying himself at a water park. I met him in 2020, and he had grown tall with flowing curly hair. Although he was still non-verbal, his communication skills had developed through sign language and noises as described by his māmā.

Feedback about the summary of this research included comments like *"I can see myself in the summary."* One comment stated, *"I absolutely loved reading the summary"* and that "*you have captured everything perfectly."* Another comment shared included *such beautiful words and while reading the summary I cried more than once*." *"I absolutely enjoyed your writing; it was informative and insightful; share it to any/all."* Another māmā commented that whānau were the key element for the wellbeing, safety, and development of tamariki with takiwātanga. Barriers and push backs were still experienced and articulated by one māmā who stated that she *"continued to fight for her tamariki through education and doing her best to ensure they were happy, safe and thriving given their diagnosis."*

Chapter 6: Conclusion

E tipu e rea mo ngā rā o tō ao
Ko tō ringa ki ngā rākau ā te Pākehā Hei ara mō tō tinana
Ko tō ngākau ki ngā tāonga a ō tīpuna Māori
Hei tikitiki mō tō māhuna
Ko tō wairua ki tō Atua, Nānā nei ngā mea katoa

Grow up and thrive for the days destined to you.
Your hands to the tools of the Pākehā to provide physical sustenance,
Your heart to the treasures of your Māori ancestors as a diadem for your brow,
Your soul to your God, to whom all things belong.

—Tā (Sir) Āpirana Ngata

I offer this whakataukī (proverb), composed by one of Aotearoa New Zealand's best-known figures, the Ngāti Porou leader and politician Tā Āpirana Ngata, at the start of this final chapter because it captures a central finding of this research: While the māmā in this research pushed back against anything that negated the value of their tamariki or their lived experience as Māori, they nevertheless utilised knowledge – what Tā Āpirana Ngata calls "the tools of the Pākehā" – from the Western understanding of autism that improved the wellbeing of their tamariki with takiwātanga.

This thesis has sought to answer the following research question:

What are the experiences of Māori māmā with education, health, home and the community in raising a loved one with takiwātanga (autism)?

As the findings of this study have made abundantly clear, the māmā had expert knowledge about their tamariki with takiwātanga and knew which strategies worked best for them in the home and the community. The māmā utilised support from their whānau, extended whānau, and the wider communities where they lived. They enhanced the mana of their tamariki by acting as advocates and activists for them.

The māmā who participated in this research strategically used the best parts New Zealand's education and health systems and its Western community structures to support positive outcomes for their tamariki with takiwātanga. The knowledge of takiwātanga that the

mama demonstrated came from a strengths-based te ao Māori perspective, and their knowledge of autism came from their interactions with a Western deficit-based perspective.

When their experience and knowledge of takiwātanga was challenged by education and health professionals they encountered in these systems, the māmā picked up their metaphorical taiaha to deflect advice that was not congruent with their knowledge, values and beliefs. The māmā pushed back against these experiences and, where necessary, forcefully defended the te ao Māori concepts that improved the wellbeing of their loved one(s) with takiwātanga.

The māmā became expert navigators of the services available for disability in Aotearoa and developed phenomenal skills to promote the best outcomes for their tamariki. They protested loudly or quietly against what they perceived as biases and racism directed towards them or their tamariki. At the same time, they emulated supportive speech language therapists, occupational therapists and educational psychologists who helped them develop best practice principles that worked for their individual tamariki.

The resistance of the māmā against the Western deficit-based model of autism increased their resilience and self-esteem and helped them to see and value the strengths of their tamariki with takiwātanga, who were treasured as a unique part of the whānau, hapu and iwi.

Implications for Policy around Takiwātanga

It is important to consider the implications of the findings of this research and how they might improve the lived experience of the māmā who generously gave their time and energy to participate in this study – and of course their whānau, extended whānau, hapū and iwi. This section therefore identifies ways the findings can inform policy and practice associated with takiwātanga (autism) in New Zealand's education and health systems, and in the home and community.

The New Zealand Disability Strategy 2016–2026 ('Disability Strategy') published by the MSD (2016) and the third edition of the Aotearoa New Zealand Autism Guideline: He Waka Huia Takiwātanga Rau ('Guideline') published by Whaikaha – Ministry of Disabled People and MoE in 2022 outline very clearly the philosophical, theoretical and practice expectations of our educational, health, community or societal sectors as they relate to the

human rights of those people who have the lived experience of takiwātanga. The findings of this research have implications for both of these documents.

The Disability Strategy promotes a vision of disabled people in Aotearoa having equal opportunities to achieve their dreams and aspirations, and argues that it is the responsibility of everyone in Aotearoa to work together to achieve this. Further, to become a truly non-disabling society, barriers in society that disable people with impairments are to be removed. The foundations of the Disability Strategy include the Convention on the Rights of Persons with Disabilities (UN, 2006); te Tiriti o Waitangi | Treaty of Waitangi; the promotion of disabled people being involved in decision-making that impacts them; and a whole-of-life, long-term approach to social investment and mainstream supports (Office for Disabilities Issues, 2017b). Since 2016, the Disability Strategy has had four separate public consultation processes. and its Disability Action Plan has been steadily updated. Outcomes 1, 3 and 6 of the Disability Strategy will now be briefly discussed in terms of the findings of this research.

Outcome 1, Education, relates to learning pathways for tāngata whaikaha (people with disabilities) supporting the facilitation and development of educational and social skills inside and outside of their formal schooling system. This includes building friendships and social skills, resilience, and confidence for tāngata whaikaha. Furthermore, it is expected that all schools and education services will welcome students who identify as disabled and value their contribution to the learning environment.

Tāngata whaikaha have access to policy and have an active and authentic role in the development and implementation of legislation that impacts their lives including education. Additionally, the decision-making process regarding education and disability is underpinned by robust research and evidence-based practice. An important aspect here is that the Disability Strategy states that the expertise of whānau will be honoured without question. When the māmā in this research had relationships within the education system that included principals, kaiako, staff and other students that emulated manaakitanga, whakawhanaungatanga and tuakana-teina, their tamariki enjoyed increased opportunities to develop their learning across all areas of education and a greater chance of meeting the aspirations of the Disability Strategy.

Outcome 3, Health and Wellbeing, links to the timely and appropriate support for client health needs associated with client choice, accessibility to early diagnosis, and, therefore, early intervention. All health information has to be clear and in accessible formats

so that informed decisions can be supported with the understanding that tāngata whaikaha are the experts in their lives. Health is also constructed as tāngata whaikaha having access to sports and recreational and art activities to facilitate a sense of belonging in the community.

The findings of this research identified clear breaches of this outcome, particularly regarding timely and appropriate support for an early diagnosis. Another breach included a lack of respect being afforded to the māmā by health professionals. This was experienced as racist and sexist discrimination regarding them being Māori, wāhine and having a tamariki or rangatahi with high needs. Everyday stratagems demonstrated by the māmā in their interactions with the health system were similar to those utilised in education, including seeking to engage with professionals through the concepts of manaakitanga and whakawhanaungatanga. The māmā used their metaphorical taiaha to speak back to any health professional whose intentions were not transparent, ethical or authentic.

At other times, the māmā simply circumnavigated these health professionals who demonstrated a lack of knowledge or empathy about takiwātanga. Changing your doctor or health professional is much easier than changing a kaiako in a school class. However, those health professionals that invested their time and used their influence to expedite the processes of diagnosis or other health services were embraced and revered as "game changers" by the māmā. Their attitude was one of genuine manaakitanga, and long-term relationships with GPs became like whānau relationships built on whakawhanaungatanga.

Outcome 6, Attitudes, proposes that disability should be understood and accepted as a part of the diversity of the human experience and that people with disabilities should be treated with dignity and respect by people around them and society more broadly. This outcome calls for disabled people to be represented in initiatives to change attitudes and behaviours, which will also ensure that disabled people are seen as part of other communities or groups. Further, there is a specific focus on the onus on all frontline service providers and professionals to be respectful and to protect the dignity of disabled people. Some of the māmā in this research had excellent community networks that supported a positive lived experience for themselves and their tamariki or rangatahi. It is important to highlight, however, that the māmā also distanced themselves from community members when they were not on board with their values and beliefs regarding their tamariki and rangatahi. The contexts of te ao Māori, te reo Māori and te Tiriti o Waitangi are included in the Disability Strategy, but extending the discussion be exploring key concepts such as the ones revealed by this research

– manaakitanga, whakawhanaungatanga and tuakana-teina – would facilitate education and health providers gaining a better understanding of takiwātanga.

Another influential document I would like to discuss in light of this research is the third edition of the Aotearoa New Zealand Autism Guideline: He Waka Huia Takiwātanga Rau (2022). The original guidelines were published in 2008 as a living document to guide best practice, and the third edition is the latest instalment. Additions include using te reo Māori, with the term *takiwātanga* featuring in the document for the first time, and incorporating the Māori health model Te Whare Tapa Whā (Durie, 1984) to acknowledge te ao Māori.

Part 7 of the Guideline describes the Māori perspective of takiwātanga and includes a summary of recommendations relating to best practice understandings of working with tamariki who have takiwātanga (see Chapter 2). 'Whanaungatanga' features only twice in the Guideline and is translated as 'kinship and relationships'. Manaakitanga, meanwhile, does not feature once, and 'te ao Māori' is mentioned just three times. None of the te ao Māori concepts are explained in any great depth. Māori reading the Guideline would feel more included if they could see themselves reflected in expanded discussions of the meanings of a greater range of te ao Māori concepts – particularly those interwoven through the pūrākau of the mama in this research: manaakitanga, whakawhanaungatanga and tuakana-teina.

It is important to remember that both of the documents discussed here are aspirational – they have no regulatory power, and practitioners are free to ignore their recommendations if they so wish. Changing attitudes in a system that is dominated by Western values and that has for decades ignored a Māori way of knowing is challenging to say the least. While including Māori concepts in policy statements is noteworthy and essential, the concepts of te ao Māori reach back into the ancient knowledge of Māori ancestors, and their meaning and value cannot be expressed in one or two brief mentions. Including thorough descriptions of what these concepts mean in terms of practice is important.

Politicians both local and national need to participate in a transformative and decolonising process that promotes the strengths of tāngata whaikaha, including tāngata whaitakiwātanga. This understanding needs to filter down to the front lines of practice from all agencies in education, health, and the community. Guidelines for ethical and practice standards relating to education and health should include mechanisms to assess the competence of professionals in relation to te ao Māori and te reo Māori.

The practice-based sector of tertiary education is another space that could benefit from the findings of this research. Educating our future education and health professionals needs to include greater emphasis on te ao Māori and the most relevant concepts in the lived experience of Māori.

Māori whānau living with takiwātanga have the right to expect culturally appropriate and mana enhancing services that include manaakitanga, whakawhanaungatanga and tuakana-teina. Moreover, Māori whānau are experts in their own lives and the lives of their tamariki who have takiwātanga. Finally, Māori whānau also have the right to make a formal complaint when they feel their rights and the rights of their tamariki with takiwātanga are not being respected.

Limitations

No research is without limitations, and the most obvious limitation of this study is its small sample size, which means the findings cannot be generalized across all Māori whānau with the lived experience of takiwātanga in Aotearoa. Nevertheless, I believe my interpretation of the pūrākau of the māmā faithfully represents their lived experience, and the fact that their pūrākau showed so many similarities suggests that their journeys with their tamariki with takiwātanga are at least partially representative of those taken by other Māori whānau in Aotearoa.

As a Māori māmā of a young woman who has a formal diagnosis of takiwātanga, my own negative experiences of education, health and other social experiences that have impacted my daughter and the life of our whānau had the potential to introduce bias into my interpretation of the pūrākau of the wāhine in this research. As Chapter 3 made clear, however, it is impossible for a researcher to be completely unbiased regarding their research.

I personally view my personal biases as an advantage to Kaupapa Māori research. Having two māmā and myself in the focus groups allowed for emotions to be expressed in a safe space because every one of us had the lived experience of takiwātanga and could be supportive on all levels of the discussion.

Recommendations

Māori academics have for decades called for a change in the balance of power between Western research methodologies and Indigenous ways of knowing and being (Durie, 1994; Pihama, 2001; L. T. Smith, 2021). Furthermore, te Tiriti o Waitangi guarantees the

rights of Māori, which includes those relating to education, health, and the social development of communities in which they live. Decolonising methodologies based on Kaupapa Māori theory have proven to be effective in highlighting and addressing the power imbalance between Pākehā and Māori. Despite these gains, whaikaha Māori (Māori with a disability) continue to be marginalised, and this is particularly evident in relation to takiwātanga.

The finding that education and health professionals need to support Māori whānau in a manner that is culturally appropriate is not new, and this basic right guaranteed under te Tiriti o Waitangi is not absent from government policy. In point of fact, there are copious policies that state that health and education workers must follow tikanga with Māori clients. Why, then, was this not the experience of the eight māmā who have tamariki with takiwātanga question of why is it not being done across the education and health sectors in Aotearoa? Under current legislation, it comes down to the personal choice of education and health professionals whether to recognise and endorse te ao Māori understandings of tamariki with takiwātanga. When such recognition and endorsement is lacking – as experienced on more than one occasion by all eight māmā in this research, this perpetuates the cumulative experience of discrimination for whānau living with takiwātanga.

There are four recommendations that flow from this research:

1. Cultural competence for registered professionals in education and health should include formal assessments of their competence in te ao Māori concepts of manaakitanga, whakawhanaungatanga, and tuakana-teina in relation to takiwātanga. This would require them to participate in case studies working with Māori in a manner that demonstrates their understanding of takiwātanga as a strengths-based condition rather than a deficit-based one.

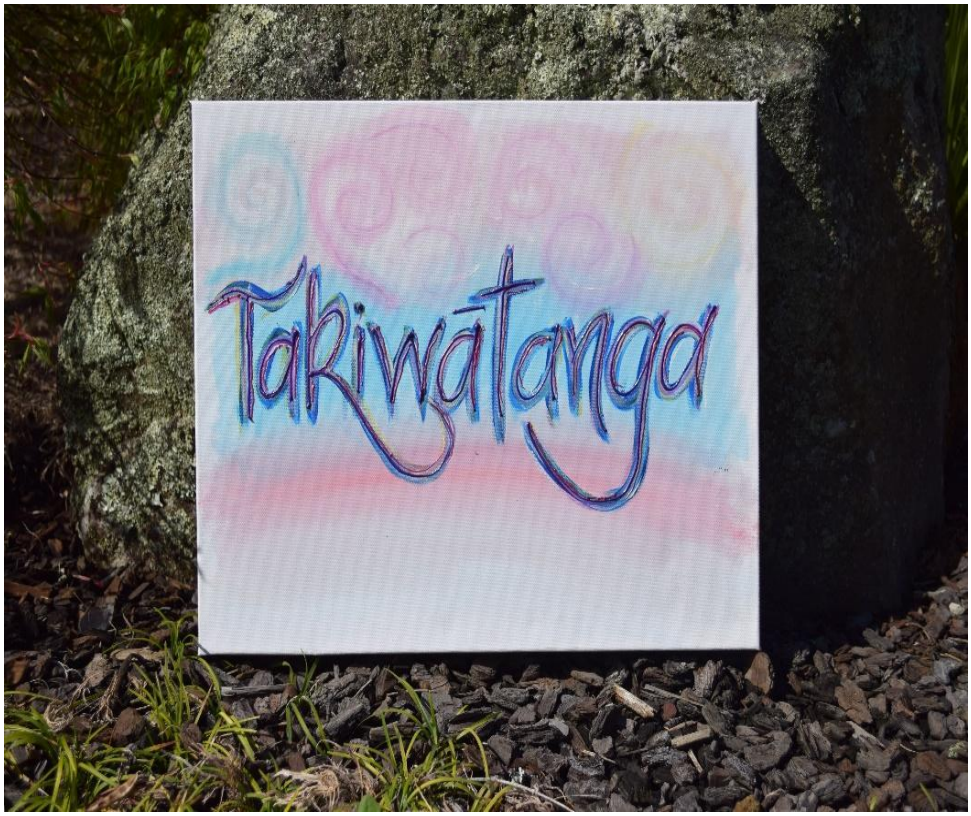
2. Professionals need to acknowledge that māmā, pāpā, whānau, and significant others with aroha (love) for those with the lived experience of takiwātanga are experts in terms of their knowledge of tāngata whaitakiwātanga (people with autism), and uphold and honour their expertise.

3. Professionals need to understand that tāngata whaitakiwātanga are considered perfect from birth in te ao Māori, bestowed with gifts from Atua (God) and therefore taonga (to be treasured).

4. Tertiary education is the ideal space where aspiring education and health graduates can gain more than a surface-level understanding of te ao Māori that will support their practice journey towards mōhio – truly knowing – the lived experience of māmā, pāpā and whānau with takiwātanga.

Figure 2

Te Mana Wahine o Māmā Tuawaru (The Female Power of Māmā Tuawaru): Takiwātanga (2021).



Note. Māmā Tuawaru stated she did not always closely affiliate herself to te ao Māori, but she felt that 'takiwātanga' was a beautiful Māori kupu (word) for autism.

References

Agmon, M., Sa'ar, A., & Araten-Bergman, T. (2016). The person in the disabled body: A perspective on culture and personhood from the margins. *International Journal for Equity in Health*, *15*(1), 1–11. https://doi.org/10.1186/s12939-016-0437-2

Ahmad, S., Wasim, S., Irfan, S., Gogoi, S., Srivastava, A., & Farheen, Z. (2019). Qualitative v/s. quantitative research: A summarized review. *Journal of Evidence Based Medicine and Healthcare*, *6*(43), 2828–2832. https://doi.org/10.18410/jebmh/2019/587

Aksoy, S., & Elmali, A. (2002). The core concepts of the four principles of bioethics as found in Islamic tradition. *Medicine and Law*, *21*(2), 211–224.

Alenazi, D. S., Hammad, S. M., & Mohamed, A. E. (2020). Effect of autism on parental quality of life in Arar city, Saudi Arabia. *Journal of Family & Community Medicine, 27*(1), 15–22. https://doi.org/10.4103/jfcm.JFCM_157_19

Alsa, A., Sovitriana, R., Kasari, A., & Endri, E. (2021). Psychological well-being of mothers with children. *Journal of Educational and Social Research*, *11*(6), 247–254. https://doi.org/10.36941/jesr-2021-0144

Altogether Autism. (2022). *Autism prevalence in New Zealand.* https://www.altogetherautism.org.nz/autism-prevalence-in-new-zealand/

Altogether Autism. (2020). *A time and space for takiwātanga.* https://www.altogetherautism.org.nz/a-time-and-space-for-takiwatanga/

American Psychiatric Association. (2022). *Diagnosis and statistical manual of mental disorders* (5th ed., text rev.). http://doi.org/10.1176/appi.books.9780890425787

Anderson-Chavarria, M. (2022). The autism predicament: Models of autism and their impact on autistic identity. *Disability & Society*, *37*(8), 1321–1341. https://doi.org/10.1080/09687599.2021.1877117

Anthony, B. J., Robertson, H. A., Verbalis, A., Myrick, Y., Troxel, M., Seese, S., & Anthony, L. G. (2020). Increasing autism acceptance: The impact of the Sesame Street "See Amazing in All Children" initiative. *Autism*, *24*(1), 95–108. https://doi.org/10.1177/1362361319847927

Ariotti, L. J. (1997). *The newly planted tree: An exploration of Anangu perceptions of disability* [Unpublished doctoral thesis]. Flinders University of South Australia.

Arvin, M., Tuck, E., & Morrill, A. (2013). Decolonizing feminism: Challenging connections between settler colonialism and heteropatriarchy. *Feminist Formations*, *25*(1), 8–34. https://doi.org/10.1353/ff.2013.0006

Asbury, K., & Toseeb, U. (2023). A longitudinal study of the mental health of autistic children and adolescents and their parents during COVID-19: Part 2, qualitative findings. *Autism*, *27*(1), 188–199. https://doi.org/10.1177/13623613221086997

Asperger, H. (1944). Die "Autistischen Psychopathen" im Kindesalter. *Archiv für psychiatrie und Nervenkrankheiten*, *117*(1), 76–136. https://doi.org/10.1007/BF01837709

Atatoa-Carr, P., Hudson, M., Kingi, T., & Moore, A. (2012). *Āhuatanga ū ki te tika me te Pono mō te Rangahau Māori. Māori Research Ethics. An overview.* National Ethics Advisory Committee.

Attwood, T. (2003). Understanding and managing circumscribed interests. In M. Prior (Ed.), *Learning and behavior problems in Asperger syndrome* (pp. 126–147). Guildford Press.

Aukett, R., Ritchie, J., & Mill, K. (1988). Gender differences in friendship patterns. *Sex Roles*, *19*(1), 57–66. https://doi.org/10.1007/BF00292464

Bailey Jr., D. B., Golden, R. N., Roberts, J., & Ford, A. (2007). Maternal depression and developmental disability: Research critique. *Mental Retardation and Developmental Disabilities Research Reviews*, *13*(4), 321–329. https://doi.org/10.1002/mrdd.20172

Baker, D. L., & Drapela, L. A. (2010). Mostly the mother: Concentration of adverse employment effects on mothers of children with autism. *Social Science Journal, 47*(3), 578–592. https://doi.org/10.1016/j.soscij.2010.01.013

Barlow, C. (1991). *Tikanga whakaaro: Key concepts in Māori culture*. Oxford University Press.

Barnes, C. & Mercer, G. (2003) *Disability.* Polity Press.

Baron-Cohen, S. (2009). Autism: The empathizing–systemizing (E-S) theory. *Annals of the New York Academy of Sciences*, *1156*(1), 68–80. https://doi.org/10.1111/j.1749-6632.2009.04467.x

Barone, T., & Eisner, E. W. (2011). *Arts-based research*. SAGE. https://doi.org/10.4135/9781452230627

Beakley, B. A., Yoder, S. L., & West, L. L. (2003). *Community-based instruction: A guidebook for teachers*. Council for Exceptional Children.

Benjak, T., Vuletić Mavrinac, G., & Pavić Šimetin, I. (2009). Comparative study on self-perceived health of parents of children with autism spectrum disorders and parents of nondisabled children in Croatia. *Croatian Medical Journal*, *50*(4), 403–409. https://doi.org/10.3325/cmj.2009.50.403

Benson, P. R. (2010). Coping, distress, and well-being in mothers of children with autism. *Research in Autism Spectrum Disorders*, *4*(2), 217–228. https://doi.org/10.1016/j.rasd.2009.09.008

Benson, P. R. (2015). Longitudinal effects of educational involvement on parent and family functioning among mothers of children with ASD. *Research in Autism Spectrum Disorders*, *11*, 42–55. https://doi.org/10.1016/j.rasd.2014.11.011

Benson, P., Karlof, K. L., & Siperstein, G. N. (2008). Maternal involvement in the education of young children with autism spectrum disorders. *Autism, 12*(1), 47–63. https://doi.org/10.1177/1362361307085269

Berg, K. L., Acharya, K., Shiu, C. S., & Msall, M. E. (2018). Delayed diagnosis and treatment among children with autism who experience adversity. *Journal of Autism and Developmental Disorders, 48,* 45–54. https://doi.org/10.1007/s10803-017-3294-y

Bernard, L. C., & Krupat, E. (1994). *Health psychology: Biopsychosocial factors in health and illness*. Harcourt Brace College Publishers.

Berryman, M., & Woller, P. (2013). Learning about inclusion by listening to Māori. *International Journal of Inclusive Education, 17*(18), 827–838. https://doi.org/10.1080/13603116.2011.602533

Best, E. (1924). *Māori religion and mythology, part one.* Dominion Museum Bulletin No. 10. Government Printer.

Bevan-Brown, J. (2004). *Māori perspectives of autistic spectrum disorder*. Ministry of Education.

Bevan-Brown, J. (2010). Messages from parents of children with autism spectrum disorder (ASD). *Kairaranga*, *11*(2), 16–22. https://doi.org/10.54322/kairaranga.v11i2.234

Bevan-Brown, J. (2013). Including people with disabilities: An Indigenous perspective. *International Journal of Inclusive Education*, *17*(6), 571–583. https://doi.org/10.1080/13603116.2012.694483

Bevan-Brown, J., Berryman, M., Hickey, H., Macfarlane, S., Smiler, K., & Walker, T. (2016). *Working with Māori children with special education needs.* NZCER Press.

Bezyak, J. L., Sabella, S., Hammel, J., McDonald, K., Jones, R. A., & Barton, D. (2020). Community participation and public transportation barriers experienced by people

with disabilities. *Disability and Rehabilitation*, *42*(23), 3275–3283. https://doi.org/10.1080/09638288.2019.1590469

Bingham, C., Clarke, L., Michelsens, E., & Van De Meer, M. (2013). Towards a social model approach? British and Dutch disability policies in the health sector compared. *Personnel Review*, *42*, 613–637. https://doi.org/10.1108/PR-08-2011-0120

Bishop, R. (1996). *Whakawhanaungatanga: Collaborative research stories.* Dunmore Press.

Bishop, R. (1999). Kaupapa Māori research: An indigenous approach to creating knowledge. In N. Robertson (Ed.), *Māori and psychology: Research and practice. Proceedings of a symposium sponsored by the Māori & Psychology Research Unit, Department of Psychology, Hamilton, Thursday 26th August 1999* (pp. 1–6). University of Waikato.

Bishop, R. (2005). Freeing ourselves from neo colonial domination in research: A kaupapa Māori approach to creating knowledge. In N. K. Denzin & Y. S. Lincoln (Eds.), *The SAGE handbook of qualitative research* (3rd ed., pp. 109–164). SAGE.

Bishop, R., & Berryman, M. (2006). *Culture speaks*. Huia.

Bishop, R., & Berryman, M. (2009). The Te Kotahitanga effective teaching profile. *Set: Research Information for Teachers*, *2*(2), 27–33. https://doi.org/10.18296/set.0461

Bishop, R., Berryman, M., Tiakiwai, S., & Richardson, C. (2003). *Te Kotahitanga: The experiences of year 9 and 10 Māori students in mainstream classrooms*. Māori Education Research Institute.

Bishop-Fitzpatrick, L., Dababnah, S., Baker-Ericzén, M. J., Smith, M. J., & Magaña, S. M. (2019). Autism spectrum disorder and the science of social work: A grand challenge for social work research. *Social Work in Mental Health*, *17*(1), 73–92. https://doi.org/10.1080/15332985.2018.1509411

Blomdahl, C., Wijk, H., Guregard, S., & Rusner, M. (2018). Meeting oneself in inner dialogue: A manual-based phenomenological art therapy as experienced by patients

diagnosed with moderate to severe depression. *The Arts in Psychotherapy, 59*, 17–24. https://doi.org/10.1016/j.aip.2017.08.006

Blustein, J. (2012). Philosophical and ethical issues in disability. *Journal of Moral Philosophy*, *9*(4), 573–587. https://doi.org/10.1163/17455243-00904002

Bogotch, I., & Waite, D. (2017). Working within radical pluralism. In I. Bogotch & D. Waite (Eds.), *The Wiley international handbook of educational leadership* (pp. 1–14). John Wiley & Sons. https://doi.org/10.1002/9781118956717.ch0

Boshoff, K., Gibbs, D., Phillips, R. L., Wiles, L., & Porter, L. (2016). Parents' voices: 'Why and how we advocate'. A meta-synthesis of parents' experiences of advocating for their child with autism spectrum disorder. *Child: Care, Health and Development, 42*(6), 784–797. https://doi.org/10.1111/cch.12383

Bossert, W. H. (2013). The use of technology to improve two key classroom relationships. In *Technology in Education* (pp. 275-284). Routledge.

Bowden, N., Thabrew, H., Kokaua, J., & Braund, R. (2020). National prescribing rates and polypharmacy for children and young people in New Zealand with and without autism spectrum disorder. *Research in Autism Spectrum Disorders*, *78*, Article 101642. https://doi.org/10.1016/j.rasd.2020.101642

Bowden, N., Thabrew, H., Kokaua, J., Audas, R., Milne, B., Smiler, K., Stace, H., Taylor, B., & Gibb, S. (2020). Autism spectrum disorder/Takiwātanga: An integrated data infrastructure-based approach to autism spectrum disorder research in New Zealand. *Autism*, *24*(8), 2213–2227. https://doi.org/10.1177/1362361320939329

Bradbury-Jones, C., Breckenridge, J., Clark, M. T., Herber, O. R., Wagstaff, C., & Taylor, J. (2017). The state of qualitative research in health and social science literature: A focused mapping review and synthesis. *International Journal of Social Research Methodology*, *20*(6), 627–645. https://doi.org/10.1080/13645579.2016.1270583

Brandon, T., & Pritchard, G. (2011). “Being fat”: A conceptual analysis using three models of disability. *Disability & Society*, *26*(1), 79–92. https://doi.org/10.1080/09687599.2011.529669

Braun, V., & Clarke, V. (2013). *Successful qualitative research: A practical guide for beginners*. SAGE.

Braun, V., Clarke, V., & Weate, P. (2016). Using thematic analysis in sport and exercise research. In B. Smith & A. C. Sparkes (Eds.), *Routledge handbook of qualitative research in sport and exercise* (pp. 213–227). Routledge. https://doi.org/10.4324/9781315762012-26

Brekke, J. S. (2012). Shaping a science of social work. *Research on Social Work Practice*, *22*(5), 455–464. https://doi.org/10.1177/1049731512441263

Brittain, I. (2004). Perceptions of disability and their impact upon involvement in sport for people with disabilities at all levels. *Journal of Sport & Social Issues*, *28*(4), 429–452. https://doi.org/10.1177/0193723504268729

Brock, S. (2014). The impact of “good mothering” ideology on identity perception for mothers of children with disabilities. *Hecate*, *40*(1), 20–35.

Cajete, G. (2000). *Native science: Nature laws of interdependence*. Clear Light Publishers.

Carter, S. M., & Little, M. (2007). Justifying knowledge, justifying method, taking action: Epistemologies, methodologies, and methods in qualitative research. *Qualitative Health Research*, *17*(10), 1316–1328. https://doi.org/10.1177/1049732307306927

Carver, C. S., & Connor-Smith, J. (2010). Personality and coping. *Annual Review of Psychology*, *61*, 679–704. https://doi.org/10.1146/annurev.psych.093008.100352

Centers for Disease Control and Prevention. (2014, March 28). Prevalence of autism spectrum disorders among children aged 8 years: Autism and developmental

disabilities monitoring network, 11 sites, United States, 2010. *Morbidity and Mortality Weekly Report*, *63*(2): 1–22). http://www.cdc.gov/mmwr/pdf/ss/ss6302.pdf

Chase, S. E. (2007). Multiple lenses, approaches, voices. *Collecting and Interpreting Qualitative Materials*, *57*(3), 651–679.

Chen, C. Y., Liu, C. Y., Su, W. C., Huang, S. L., & Lin, K. M. (2008). Urbanicity-related variation in help-seeking and services utilization among preschool-age children with autism in Taiwan. *Journal of Autism and Developmental Disorders*, *38*(3), 489–497. https://doi.org/10.1007/s10803-007-0416-y

Chen, Y. W., Bundy, A. C., Cordier, R., Chien, Y. L., & Einfeld, S. L. (2017). A cross-cultural exploration of the everyday social participation of individuals with autism spectrum disorders in Australia and Taiwan: An experience sampling study. *Autism*, *21*(2), 231–241. https://doi.org/10.1177/1362361316636756

Cherrington, L. (2003). The use of Māori mythology in clinical settings: Training issues and needs. In L. W. Nikora, M. Levy, B. Masters-Awatere, W. Waitoki, N. Te Awekotuku, & R. J. M. Etheredge (Eds). (2003). *The proceedings of the National Māori Graduates of Psychology Symposium 2002: Making a difference Māori & Psychology Research Unit at the University of Waikato, Hamilton, 29–30 November 2002* (pp. 117–120). Waikato University.

Chote, B., Rees, D., Swinburn, B., McKelvie-Sebileau, P., Glassey, R., & Tipene-Leach, D. (2022). Systems mapping of the New Zealand free and healthy school lunch programme: Perspectives from lunch providers. *Nutrients, 14*(20), 4336. https://doi.org/10.3390/nu14204336

Cidav, Z., Marcus, S. C., & Mandell, D., S. (2012). Implications of childhood autism for parental employment and earnings. *Pediatrics*, *129*(4), 617–623. https://doi.org/10.1542/peds.2011-2700

Cola, M., Yankowitz, L. D., Tena, K., Russell, A., Bateman, L., Knox, A., Plate, S., Cubit, L. S., Zampella, C. J., Pandey, J., Schultz, R. T., & Parish-Morris, J. (2022). Friend matters: Sex differences in social language during autism diagnostic interviews. *Molecular Autism*, *13*(1), 1–16. https://doi.org/10.1186/s13229-021-00483-1

Colavita, A. A., Luthra, N., & Perry, A. (2014). Strengths and challenges of children with a developmental disability: A qualitative analysis of parent perceptions. *Journal on Developmental Disabilities*, *20*(3), 80–87.

Coleman, P. (2011). Special Education 2000 policy: Our leaky home? *Kairaranga*, *12*(1), 10–22. https://doi.org/10.54322/kairaranga.v12i1.150

Cornish, F., Breton, N., Moreno-Tabarez, U., Delgado, J., Rua, M., de-Graft Aikins, A., & Hodgetts, D. (2023). Participatory action research. *Nature Reviews Methods Primers 3*, Article 34. https://doi.org/10.1038/s43586-023-00214-1

Corsello, C. M., Akshoomoff, N., & Stahmer, A. C. (2013). Diagnosis of autism spectrum disorders in 2-year-olds: A study of community practice. *Journal of Child Psychology and Psychiatry*, *54*(2), 178–185. https://doi.org/10.1111/j.1469-7610.2012.02607.x

Cost, K. T., Zaidman-Zait, A., Mirenda, P., Duku, E., Zwaigenbaum, L., Smith, I. M., Ungar, W. J., Kerns, C., Bennett, T., Szatmari, P., Georgiades, S., Waddell, C., Elsabbagh, M., & Vaillancourt, T. (2021). "Best things": Parents describe their children with autism spectrum disorder over time. *Journal of Autism and Developmental Disorders*, *51*(12), 4560–4574. https://doi.org/10.1007/s10803-021-04890-4

Crane, L., Chester, J. W., Goddard, L., Henry, L. A., & Hill, E. (2016). Experiences of autism diagnosis: A survey of over 1000 parents in the United Kingdom. *Autism*, *20*(2), 153–162. https://doi.org/10.1177/1362361315573636

Crawford, A. (2018). *Social cognition, executive functioning and IQ. What are the important influences on adaptive functioning in children with fetal alcohol spectrum disorder?* University of Auckland.

Cridland, E. K., Jones, S. C., Magee, C. A., & Caputi, P. (2014). Family-focused autism spectrum disorder research: A review of the utility of family systems approaches. *Autism*, *18*(3), 213–222. https://doi.org/10.1177/1362361312472261

Crotty, M. (1998). *The foundations of social research: Meaning and perspectives in the research processes.* Allen & Unwin.

Dalley, G. (1996). Ideologies of caring. *Rethinking community and collectivism*. Bloomsbury Publishing. https://doi.org/10.1007/978-1-349-24733-2

Davis III, R. F., & Kiang, L. (2020). Parental stress and religious coping by mothers of children with autism. *Psychology of Religion and Spirituality*, *12*(2), 137. https://doi.org/10.1037/rel0000183

Dawson, G., Toth, K., Abbott, R., Osterling, J., Munson, J., Estes, A., & Liaw, J. (2004). Early social attention impairments in autism: Social orienting, joint attention and attention to distress. *Developmental Psychology*, *40*(2), 271–284. https://doi.org/10.1037/0012-1649.40.2.271

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

Delvin, R., & Pothier, D. (Eds.). (2006). *Critical disability theory: Essays in philosophy, politics, and law.* UBC Press. https://doi.org/10.59962/9780774851695

Department of Education (NZ). (1988). *Tomorrow's Schools. The reform of education administration in New Zealand.*

Department of Education and Science (UK). (1978). *Special educational needs: The Warnock report*. HMSO.

Derby, M. (2013). Daily life in Māori communities – te noho a te hapori. In *Te ara: The encyclopaedia of New Zealand*. https://teara.govt.nz/en/daily-life-in-māori-communities-te-noho-a-te-hapori/print

Dewis, P., & Kay, J. (2018). Data analysis. In C. Carter (Ed.), *Successful dissertations: The complete guide for education, childhood and early childhood studies students* (2nd ed., pp. 195– 226). Bloomsbury Academic.

Dharan, V. (2020). It is not THEM and US: Working together for sustainable outcomes for children with autism. *Kairaranga, 21*(1), 17–28. https://doi.org/10.54322/kairaranga.v21i1.319

Dickson, M. (2010). Te Piringa. *Waikato Law Review: Taumauri, 18*, 66–71.

Dijkhuis, R. R., Ziermans, T. B., Van Rijn, S., Staal, W. G., & Swaab, H. (2017). Self-regulation and quality of life in high-functioning young adults with autism. *Autism, 21*(7), 896–906. https://doi.org/10.1177/1362361316655525

Doherty, A. J., Atherton, H., Boland, P., Hastings, R., Hives, L., Hood, K., James-Jenkinson, L., Leavey, R., Randell, E., Reed, J., Taggart, L., Wilson, N., & Chauhan, U. (2020). Barriers and facilitators to primary health care for people with intellectual disabilities and/or autism: An integrative review. *BJGP Open, 4*(3). https://doi.org/10.3399/bjgpopen20X101030

Dolnick, E. (1998). *Madness on the couch: Blaming the victim in the heyday of psychoanalysis*. Simon & Schuster.

Donaldson, A. M., Hays, T., & Romani, P. (2019). Autism spectrum disorder: Effects on child and family functioning. *Journal of Student Research, 8*(1). https://doi.org/10.47611/jsr.v8i1.591

Douglas, P., Rice, C., & Siddiqui, A. (2020). Living dis/artfully with and in illness. *Journal of Medical Humanities, 41*(3), 395–410. https://doi.org/10.1007/s10912-019-09606-5

Douglas, P., Runswick-Cole, K., Ryan, S., & Fogg, O. (2021). Mad mothering: Learning from the intersections of madness, mothering and disability. *Journal of Literary & Cultural Disability Studies 15*(1). https://doi.org/10.3828/jlcds.2021.3

Dreyfus, H. L. (1990). *Being-in-the-world: A commentary on Heidegger's "Being in Time" Division 1*. MIT Press.

Drysdale, H., & van der Meer, L. (2020). Rates of autism spectrum disorder diagnoses for children and adolescents in the Hutt Valley Region of New Zealand between 2012 and 2016. *Research in Autism Spectrum Disorders*, *73*, Article 101547. https://doi.org/10.1016/j.rasd.2020.101547

Dudek, P. (2022). *Visual supports for behavior in students with autism* [Field report, University of Wisconsin Oshkosh]. MINDS@UW. http://digital.library.wisc.edu/1793/83290

Dudley, C., & Emery, J. C. (2014, January). The value of caregiver time: Costs of support and care for individuals living with autism spectrum disorder. *SPP Research Papers*, *7*, no. 1. https://doi.org/10.2139/ssrn.2379633

Duncan, E. (2008). *Obesity and its determinants in girls from five ethnic groups* [Doctoral thesis, Auckland University of Technology]. Tuwhera. https://hdl.handle.net/10292/463

Durate, C. S., Bordin, I. A., Yazigi, L., & Mooney, J. (2005). Factors associated with stress in mothers of children with autism. *Autism*, *9*(4), 416–427. https://doi.org/10.1177/1362361305056081

Durie, M. (1977). Māori attitudes to sickness, doctors, hospitals. *New Zealand Medical Journal*, *86*(600), 483–485.

Durie, M. H. (1984). " Te taha hinengaro": An integrated approach to mental health. *Community Mental Health in New Zealand*.

Durie, M. (1994). *Whaiora: Māori health development*. Oxford University Press.

Durie, M. (1998). *Whaiora: Māori health development* (2nd ed.). Oxford University Press.

Dwyer, S. C., & Buckle, J. L. (2009). The space between: On being an insider-outsider in qualitative research. *International Journal of Qualitative Methods*, *8*(1), 54–63. https://doi.org/10.1177/160940690900800105

Education Act (NZ). (1989). https://www.legislation.govt.nz/act/public/1989/0080/latest/DLM175959.html

Education and Training Act (NZ). (2020). https://www.legislation.govt.nz/act/public/2020/0038/latest/LMS170676.html.

Education Review Office. (2015). *Inclusive practices for students with special needs in schools*. https://ero.govt.nz/sites/default/files/2021-05/Inclusive-practices-for-students-with- special-needs-in-schools.pdf

Egan, M. (2022). *Equity, inclusivity and shared humanity: Addressing intergenerational failure. of schooling for Māori* [Doctoral thesis, University of Waikato]. Research Commons. https://hdl.handle.net/10289/15290

Eggleston, M. J., Thabrew, H., Frampton, C. M., Eggleston, K. H., & Hennig, S. C. (2019). Obtaining an autism spectrum disorder diagnosis and supports: New Zealand parents' experiences. *Research in Autism Spectrum Disorders*, *62*, 18–25. https://doi.org/10.1016/j.rasd.2019.02.004

Elder, H. (2017). Te Waka Kuaka and Te Waka Oranga: Working with whānau to improve outcomes. *Australian and New Zealand Journal of Family Therapy 38*, 27–42. https://doi.org/10.1002/anzf.1206

Emerson, L.M., Monk, R., van der Meer, L., & McLay, L. (2022). *Autistic co-led autism research priorities for Aotearoa New Zealand: A partnership with Autistic people,*

families and whānau, service and support providers, and researchers. Te Whare Wānanga o Waitaha | University of Canterbury.

Emily, G., & Grace, I. (2015). Family quality of life and ASD: The role of child adaptive functioning and behavior problems. *Autism Research*, *8*(2), 199–213. https://doi.org/10.1002/aur.1442

Engel, G. L. (1977). The need for a new medical model: A challenge for biomedicine. *Science*, *196*(4286), 129–136. https://doi.org/10.1126/science.847460

Ennis-Cole, D., Durodoye, B. A., & Harris, H. L. (2013). The impact of culture on autism diagnosis and treatment: Considerations for counsellors and other professionals. *The Family Journal*, *21*(3), 279–287. https://doi.org/10.1177/1066480713476834

Estes, A., Munson, J., Dawson, G., Koehler, E., Zhou, X., & Abbott, R. (2009). Parenting stress and psychological functioning among mothers of preschool children with autism and developmental delay. *Autism*, *13*(4), 375–387. https://doi.org/10.1177/1362361309105658

European Medicines Agency. (2007). *Assessment of the pediatric needs psychiatry.*

Falk, N., H., Norris, K., & Quinn, M. G. (2014). The factors predicting stress, anxiety and depression in parents of children with autism. *Journal of Autism and Developmental Disorders*, *44*(12), 3185–3203. https://doi.org/10.3389/fnins.2015.00127

Favre, M. R., La Mendola, D., Meystre, J., Christodoulou, D., Cochrane, M. J., Markram, H., & Markram, K. (2015). Predictable enriched environment prevents development of hyper-emotionality in the VPA rat model of autism. *Frontiers in Neuroscience*, *9*, Article 127. https://doi.org/10.3389/fnins.2015.00127

Featherstone, H. (1985). *Difference in the family*. Penguin Books.

Feinstein, A. (2011). *A history of autism: Conversations with the pioneers*. John Wiley & Sons. *Research in Psychology*, 11(2), 121–141. https://doi.org/10.1080/14780887.2013.807899

Fine, M. (2019). Critical disability studies: Looking back and forward. *Journal of Social Issues, 75*(3), 972–984. https://doi.org/10.1111/josi.12344

First, M. B., Youisf, L. H., Clarke, D. E., Wang, P. S., Gogtay, N., & Apllebaum, P. S. (2022). DSM-5-TR: overview of what's new and what's changed. *World Psychiatry 21*(2), 218–219. https://doi/10.1002/wps.20989

Fitzgerald, M. (2005) *The genesis of artistic creativity: Asperger's syndrome and the arts*. Jessica Kingsley Publishers.

Forhan, M. (2009). An analysis of disability models and the application of the ICF to obesity. *Disability and Rehabilitation, 31*(16), 1382–1388. https://doi.org/10.1080/09638280802572981

Francis, G. L., Blue-Banning, M., Turnbull, A. P., Hill, C., Haines, S. J., & Gross, J. M. (2016). Culture in inclusive schools: Parental perspectives on trusting family-professional partnerships. *Education and Training in Autism and Developmental Disabilities, 51*(6), 281–293.

Fuller, E. A., & Kaiser, A. P. (2020). The effects of early intervention on social communication outcomes for children with autism spectrum disorder: A meta-analysis. *Journal of Autism and Developmental Disorders, 50*, 1683–1700. https://doi.org/10.1007/s10803-019-03927-z

Gair, S. (2012). Feeling their stories: Contemplating empathy, insider/outsider positionings, and enriching qualitative research. *Qualitative Health Research*, *22*(1), 134–143. https://doi.org/10.1177/1049732311420580

Garland-Thomson, R. (2005). Feminist disability studies. *Signs: Journal of Women in Culture and Society*, *30*(2), 1557–1587. https://doi.org/10.1086/423352

Gerstein, E. D., Crnic, K., Blacher, J., & Baker, B. (2009). Resilience and the course of daily parenting stress in families of young children with intellectual disabilities. *Journal of Intellectual Disability Research*, *53*(12), 981–997. https://doi.org/10.1111/j.1365-2788.2009.01220.x

Gething., L. (1994). *Across the divide: Distance, diversity and disability – Aboriginality and disability*. Community Disability and Ageing Program, University of Sydney.

Gibson, P. (2010, March 10). *The current state of education for disabled students*. Human Rights Commission. https://web.archive.org/web/20110303074136/http://www.hrc.co.nz/newsletters/manahau/2010/03/the-current-state-of-education-for-disabled-students/

Gibson, P. (2012, June 21). *Manahau, mana haua, and Matariki.* https://web.archive.org/web/20121203014159/http://www.hrc.co.nz/newsletters/manahau/2012/06/manahau-mana-haua-and-matariki/

Goedeke, S., Shepherd, D., Landon, J., & Taylor, S. (2019). How perceived support relates to child autism symptoms and care-related stress in parents caring for a child with autism. *Research in Autism Spectrum Disorders*, *60*, 36–47. https://doi.org/10.1016/j.rasd.2019.01.005

Gold, J., L. (2016). *Parent experiences and coping processes when raising children with Asperger syndrome: Challenges, turning points and building resilience* [Doctoral thesis, Victoria University of Wellington]. Open Access. https://doi.org/10.26686/wgtn.17014001

Gomez, C. R., & Baird, S. (2005). Identifying early indicators for autism in self-regulation difficulties. *Focus on Autism and Other Developmental Disabilities*, *20*(2), 106–116. https://doi.org/10.1177/10883576050200020101

Gomm, R. (2009). *Key concepts in social research methods*. Bloomsbury. https://doi.org/10.1007/978-1-137-06876-7

Good, G. A., Hollis-English, A., Attwell, A., Dickson, A., Gibbs, A., Gordon, J., & Taylor, J. M. T. (2017). Social-model mothers: Disability, advocacy, and activism. *Counter Futures*, *4*, 107–135. https://doi.org/10.26686/cf.v4i0.6407

Gooden, M. (2002). Stewardship and critical leadership: Sufficient for leadership in urban schools? *Education and Urban Society*, *35*(1), 133–143. https://doi.org/10.1177/001312402237218

Goodley, D. (2001). Learning difficulties, the social model of disability and impairment: Challenging epistemologies. *Disability & Society*, *16*(2), 207–231. https://doi.org/10.1080/09687590120035816

Goodley, D. (2013). Dis/entangling critical disability studies. *Disability & Society*, *28*(5), 631–644. https://doi.org/10.1080/09687599.2012.717884

Goodman, N., O'Day, B., & Morris, M. (2017). *Financial capability of adults with disabilities: Findings from the National Financial Capability Study*. National Disability Institute. https://www.nationaldisabilityinstitute.org/wp-content/uploads/2019/01/ndi-finra-report-2017.pdf

Government Inquiry into Mental Health and Addiction. (2018). *He ara oranga: Report of the government inquiry into mental health and addictions.* https://www.mentalhealth.inquiry.govt.nz/assets/Summary-reports/He-Ara-Oranga.pdf

Gray, D. E. (2002). Ten years on: A longitudinal study of families of children with autism. *Journal of Intellectual & Developmental Disability*, *27*(3), 215–222. https://doi.org/10.1080/1366825021000008639

Grey, G. (1922). *Polynesian mythology and ancient traditional history of the New Zealanders*. George Routledge and Sons.

Guan, J., & Li, G. (2017). Characteristics of unintentional drowning deaths in children with autism spectrum disorder. *Injury Epidemiology*, *4*, 1–4. https://doi.org/10.1186/s40621-017-0129-4

Guest, G., MacQueen, K., & Narney, E. (2012). *Applied thematic analysis*. SAGE. https://doi.org/10.4135/9781483384436.n4

Gupta, S., & Kumar, A. (2020). The mediating role of positive perceptions on coping strategies and psychological well-being among mothers of children with intellectual disabilities. *Advances in Mental Health and Intellectual Disabilities*, *14*(6), 263–272. https://doi.org/10.1108/AMHID-02-2020-0004

Haegele, J. A., & Hodge, S. (2016). Disability discourse: Overview and critiques of the medical and social models. *Quest*, *68*(2), 193–206. https://doi.org/10.1080/00336297.2016.1143849

Hall, H. R., & Graff, J. C. (2010). Parenting challenges in families of children with autism: A pilot study. *Issues in Comprehensive Pediatric Nursing*, *33*(4), 187–204. https://doi.org/10.3109/01460862.2010.528644

Hall, M. C. (2019, September). Critical disability theory. In *Stanford encyclopedia of philosophy*. https://plato.stanford.edu/entries/disability-critical/

Hammersley, M. (2008). *Questioning qualitative inquiry: Critical essays*. SAGE. https://doi.org/10.4135/9780857024565

Handen, B. L., Johnson, C. R., & Lubetsky, M. (2000). Efficacy of methylphenidate among children with autism and symptoms of attention-deficit hyperactivity disorder. *Journal of Autism and Developmental Disorders, 30*(3), 245–255. https://doi.org/10.1023/A:1005548619694

Harder, J. A., Keller, V. N., & Chopik, W. J. (2019). Demographic, experiential, and temporal variation in ableism. *Journal of Social Issues, 75*(3), 683–706. https://doi.org/10.1111/josi.12341

Hasselbusch, A., & Penman, M. (2008). Working together: An occupational therapy perspective on collaborative consultation. *Kairaranga, 9*(1), 24–31. https://doi.org/10.54322/kairaranga.v9i1.109

Hastie, J. L., & Stephens, C. (2019). Vicarious futurity: Parents' perspectives on locating strengths in adolescents with autism. *Aotearoa New Zealand Social Work, 31*(1), 89–100. https://doi.org/10.11157/anzswj-vol31iss1id505

Hayfield, N., & Huxley, C. (2015). Insider and outsider perspectives: Reflections on researcher identities in research with lesbian and bisexual women. *Qualitative Research in Psychology, 12*(2), 91–106. https://doi.org/10.1080/14780887.2014.918224

HealthCare New Zealand. (n.d.). *Explore specialist advice.* https://www.healthcarenz.co.nz/service/explore-specialist-advice/behaviour-support-services/

Heidegger, M. (1962). *Being and time* (J. Macquarrie & E. Robinson, Trans). Harper & Row.

Heidegger, M. (1977). *The question concerning technology, and other essays*. Harper & Row.

Heidegger, M. (1982 [1975]). *Basic problems of phenomenology* (A. Hofstadter, Trans.). Indiana University Press.

Henare, M. (1988). Ngā tikanga me Nga ritenga o te ao Mäori: Standards and foundations of Māori society. In *Report of the Royal Commission on Social Policy* (Vol. 3, Pt. I, pp. 5–41). Government Printer.

Heron, L. M., Agarwal, R., Greenup, J., Maddux, M., Attong, N., & Burke, S. L. (2020). Disparities in healthcare transition support received by adolescents with special healthcare needs. *Journal of Applied Research in Intellectual Disabilities, 33*(2), 180–192. https://doi.org/10.1111/jar.12658

Heshusius, L. (1994). Freeing ourselves from objectivity: Managing subjectivity or turning toward a participatory mode of consciousness? *Educational Researcher, 23*(3),15–22. https://doi.org/10.3102/0013189X023003015

Heshusius, L. (1996). Modes of consciousness and the self in learning disabilities research: Considering past and future. *Cognitive Approaches to Learning Disabilities*, *3*, 651–671.

Heshusius, L. (2002). More than the merely rational. Imagining inquiry for ability diversity. An essay response to Jim Paul. *Disability, Culture and Education, 1*(2), 95–118.

Heywood, J. (2010). Childhood disability: Ordinary lives for extraordinary families. *Community Practitioner*, *83*(4), 19–22.

Hickey, H., & Wilson, D. (2017). Whānau hauā: Reframing disability from an Indigenous perspective. *MAI Journal*, *6*(1), 82–94. https://doi.org/10.20507/MAIJournal.2017.6.1.7

Hide, R. (2010, October 21). *Success for all: Every school, every child* [Press release]. Beehive.govt.nz. https://www.beehive.govt.nz/release/success-all-every-school-every-child

Higgins, R., & Meredith, P. (2011). Ngā tamariki – Māori childhoods. In *Te ara: The encyclopaedia of New Zealand* https://teara.govt.nz/en/nga-tamariki-maori-childhoods/print

Higgins, R., & Meredith, P. (2013). Kaumātua–Māori elders. In *Te ara: The encyclopaedia of New Zealand*. https://teara.govt.nz/en/kaumatua-maori-elders/print

Hill, E. L., Jones, A. P., Lang, J., Yarker, J., & Patterson, A. (2015). Employment experiences of parents of children with ASD or ADHD: An exploratory study. *International Journal of Developmental Disabilities*, *61*(3), 166–176. https://doi.org/10.1179/2047387714Y.0000000037

Home, A. (2004). The work that never ends: Employed mothers of children with disabilities. *Journal of the Motherhood Initiative for Research and Community Involvement*, *6*(2). https://jarm.journals.yorku.ca/index.php/jarm/article/view/4920/4114

Hornby, G. (2014). Special education today in New Zealand. In A. F. Rotatori, J. P. Bakken, S. Burkhardt, F. E. Obiakor, & U. Sharma (Eds.), *Special education international perspectives: Practices across the globe* (pp. 643–660). Emerald Group. https://doi.org/10.1108/S0270-401320140000028007

Hudson, M. (2004). *He matatika Māori: Māori and ethical review of health research* [Master's thesis, Auckland University of Technology]. Tuwhera. https://hdl.handle.net/10292/151

Hudson, M. L., & Russell, K. (2009). The Treaty of Waitangi and research ethics in Aotearoa. *Bioethical Inquiry*, *6*(1), 61–68. https://doi.org/10.1007/s11673-008-9127-0

Hughes, D., & DuMont, K. (1993). Using focus groups to facilitate culturally anchored research. *American Journal of Community Psychology*, *21*(6), 775–806. https://doi.org/10.1007/BF00942247

Humpage, L. (2007). Models of disability, work and welfare in Australia. *Social Policy & Administration, 41*(3), 215–231. https://doi.org/10.1111/j.1467-9515.2007.00549.x

Indjov, D. (2007). The disability movement. *Amputee Sports for Victims of Terrorism, 31*(1), 78–82.

Ingham, T. R., Jones, B., Perry, M., King, P. T., Baker, G., Hickey, H., ... & Nikora, L. W. (2022). The multidimensional impacts of inequities for tāngata whaikaha Māori (Indigenous Māori with lived experience of disability) in Aotearoa, New Zealand. *International Journal of Environmental Research and Public Health, 19*(20), Article 13558. https://doi.org/10.3390/ijerph192013558

Irwin, K. (1992). Towards theories of Māori feminism. In Du Plessis (Ed.), *Feminist voices: Women's studies texts for Aotearoa/New Zealand* (pp. 1–22). Oxford University Press.

Jack, J. (2014). *Autism and gender: From refrigerator mothers to computer geeks.* University of Illinois Press. https://doi.org/10.5406/illinois/9780252038372.001.0001

Jenkins, K., & Harte, H. M. (2011). *Traditional Māori parenting. An historical review of literature of traditional Māori child rearing practices in pre-European times.* Te Kahui Mana Ririki.

Joffe, H. (2012). Thematic analysis. In D. Harper & A. Thompson (Eds.), *Qualitative methods in mental health and psychotherapy* (pp. 210–223). Wiley. https://doi.org/10.1002/9781119973249.ch15

Johnson, C. P., Myers, S. M., & The Council on Children with Disabilities. (2007). Identification and evaluation of children with autism spectrum disorders. *Paediatrics 120*(5), 1183–1215. https://doi.org/10.1542/peds.2007-2361

Johnson, K., & Walmsley J. (2003). *Inclusive research with people with learning disabilities: Past, present and futures.* Jessica Kingsley Publishers.

Jones, K. (2010, October 13). *Performative social science: What it is, what it isn't* [Seminar]. Bournemouth University, United Kingdom.

Kahn-John (Diné), M., & Koithan, M. (2015). Living in health, harmony, and beauty: The Diné (Navajo) Hózhó wellness philosophy. *Global Advances in Health and Medicine, 4*(3), 24–30. http://doi.org/10.7453/gahmj.2015.044

Kanakri, S. M., Shepley, M., Varni, J. W., & Tassinary, L. G. (2017). Noise and autism spectrum disorder in children: An exploratory survey. *Research in Developmental Disabilities*, *63*, 85–94. https://doi.org/10.1016/j.ridd.2017.02.004

Kanner, L. (1943). Autistic disturbances of affective contact. *Nervous Child, 2*(3), 217–250.

Kapp, S., Gillespie-Lynch, K., Sherman, L., & Hutman, T. (2013). Deficit, difference, or both? autism and neurodiversity. *Developmental Psychology*, *49*(1), 59–71. https://doi.org/10.1037/a0028353

Kasari, C., & Smith, T. (2013). Interventions in schools for children with autism spectrum disorder: Methods and recommendations. *Autism, 17*(3), 254–267. https://doi.org/10.1177/1362361312470496

Keane, B. (2012). Riri – traditional Māori warfare – Rākau Māori – Māori weapons and their uses. In *Te ara: The encyclopaedia of New Zealand.* https://teara.govt.nz/en/riri-traditional-Māori-warfare/page-3

Kearney, A., & Kane, R. (2006). Inclusive education policy in New Zealand: Reality or ruse? *International Journal of Inclusive Education, 10*(2–3), 201–219. https://doi.org/10.1080/13603110500256145

Kelly, C. (2013). Building bridges with accessible care: Disability studies, feminist care scholarship, and beyond. *Hypatia*, *28*(4), 784–800. https://doi.org/10.1111/j.1527-2001.2012.01310.x

Kemmis, S., Smith T. J. (Eds.). (2008). *Enabling praxis: Challenges for education*. Brill. https://doi.org/10.1163/9789087903275

Kenny, L., Hattersley, C., Molins, B., Buckley, C., Povey, C., & Pellicano, E. (2016). Which terms should be used to describe autism? Perspectives from the UK autism community. *Autism, 20*(4), 442–462. https://doi.org/10.1177/1362361315588200

Kerr, S. (2012). Kaupapa Māori theory-based evaluation. *Evaluation Journal of Australasia*, *12*(1), 6–18. https://doi.org/10.1177/1035719X1201200102

Khan, S. A., & VanWynsberghe, R. (2020, April). A synthesis of the research on community service learning in preservice science teacher education. *Frontiers in Education, 5*, Article 45. https://doi.org/10.3389/feduc.2020.00045

Kingston, A., K. (2007). *Mothering special needs: A different maternal journey*. Jessica Kingsley Publishers.

Kuhn, J. C., & Carter, A. S. (2006). Among the cognitions of maternal self-efficacy and dec parenting. *American Journal of Orthopsychiatry*, *76*(4), 564–575. https://doi.org/10.1037/0002-9432.76.4.564

Labaree, R. V. (2002). The risk of 'going observationalist': Negotiating the hidden dilemmas of being an insider participant observer. *Qualitative Research, 2*(1), 97–122. https://doi.org/10.1177/1468794102002001641

Lagae, L., Meshram, C., Giorgi, L., & Patten, A. (2015). Effects of adjunctive zonisamide treatment on weight and body mass index in children with partial epilepsy. *Acta Neurologica Scandinavica*, *131*(5), 341–346. https://doi.org/10.1111/ane.12373

Lai, W. W., Goh, T. J., Oei, T. P. S., & Sung, M. (2015). Coping and well-being in parents of children with autism spectrum disorders (ASD). *Journal of and Developmental Disorders, 45*(8), 2582-2593. https://doi.org/10.1007/s10803-015-2430-9

Lam, G. Y. H., Holden, E., Fitzpatrick, M., Mendez, L., & Berkman, K. (2020). “Different but connected”: Participatory action research using Photovoice to explore well-being in autistic young adults. *Autism, 24*(5), 1246–1259. https://doi.org/10.1177/1362361319898961

Landon, J., Shepherd, D., & Goedeke, S. (2018). Predictors of satisfaction with life in parents of children with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 48,* 1640–1650. https://doi.org/10.1007/s10803-017-3423-7

LaSala, M. C. (2003). When interviewing “family”: Maximizing the insider advantage in the qualitative study of lesbians and gay men. *Journal of Gay & Lesbian Social Services, 15*(1–2), 15–30. https://doi.org/10.1300/J041v15n01_02

Leaf, J. B., Taubman, M., Milne, C., Dale, S., Leaf, J., Townley-Cochran, D., Tsuji, K., Kassardjian, A., Alcalay, A., Leaf, R., & McEachin, J. (2016). Teaching social communication skills using a cool versus not cool procedure plus role-playing and a social skills taxonomy. *Education and Treatment of Children, 39*(1), 44–63. https://doi.org/10.1353/etc.2016.0006

Le Dé, L., Fraser, A., & St Martin, M. (2023). Homelessness and COVID-19 in New Zealand: Challenges, emergency responses, and implications for disaster risk reduction. *Habitat International, 139,* Article 102885. https://doi.org/10.1016/j.habitatint.2023.102885

Lee, G. K. (2009). Parents of children with high functioning autism: How well do they cope and adjust? *Journal of Developmental and Physical Disabilities, 21*(2), 93–114. https://doi.org/10.1007/s10882-008-9128-2

Lee, H. S., Wang, S. Y., Salter, D. M., Wang, C. C., Chen, S. J., & Fan, H. C. (2013). The impact of the use of antiepileptic drugs on the growth of children. *BMC Pediatrics, 13*(1), 1–7. https://doi.org/10.1186/1471-2431-13-211

Lee, J. (2009). Decolonising Māori Narratives: Pūrākau as method. *MAI Review*, no. 3, 1–12.

Lee, J. (2019). *Single-mother led families with disabled children in Aotearoa New Zealand* [Master's thesis, Massey University]. Massey Research Online. http://hdl.handle.net/10179/15481

Lewiecki-Wilson, C., & Cellio-Miller, J. (2011). *Disability and mothering: Liminal spaces of embodied knowledge.* Syracuse University Press.

Llias, K., Cornish, K., Park, M. S. A., Toran, H., & Golden, K. J. (2019). Risk and resilience among mothers and fathers of primary school age children with ASD in Malaysia: A qualitative constructive grounded theory approach. *Frontiers in Psychology*, *9*, Article 2275. https://doi.org/10.3389/fpsyg.2018.02275

Lorenzetti, L., & Dhungel, R. (2020). Community-led transformative research tools and applications: From Canada to Nepal. *Canadian Journal of Action Research, 20*(3), 36–54. https://doi.org/10.33524/cjar.v20i3.497

Lundy, L., Kilkelly, U., Byrne, B., & Kang, J. (2012). *The UN Convention on the Rights of the Child: A study of legal implementation in 12 countries*. Centre for Children's Rights, Queens University, Belfast. https://downloads.unicef.org.uk/wp-content/uploads/2012/11/UNICEFUK_2012CRCimplementationreport-FINAL-PDF-version.pdf?_ga=2.143449526.2074372114.1564059496-355458155.1563455639

Lyons, A. C., & Chamberlain, K. (2008). *Health psychology: A critical introduction.* Cambridge University Press.

MacDonald, C. D. (2012). Understanding participatory action research: A qualitative research methodology option. *Canadian Journal of Action Research, 13*(2), 34–50. https://doi.org/10.33524/cjar.v13i2.37

Macfarlane, S., & Macfarlane, A. (2013). Culturally responsive evidence-based special education practice: Whaia ki te ara tika. *Waikato Journal of Education*, *18*(2). https://doi.org/10.15663/wje.v18i2.162

Macfarlane, S., Macfarlane, A., & Gillion, G. (2015). Sharing the food baskets of knowledge: Creating space for a blending of streams. In A. Macfarlane, S. Macfarlane, & M. Webber (Eds.), *Sociocultural realities: Exploring new horizons* (pp. 52–67). Canterbury University Press.

Magaña, D. (2020). Local voices on health care communication issues and insights on Latino cultural constructs. *Hispanic Journal of Behavioral Sciences*, *42*(3), 300–323. https://doi.org/10.1177/0739986320927387

Magaña, S., Parish, S. L., Rose, R. A., Timberlake, M., & Swaine, J. G. (2012). Racial and ethnic disparities in quality of health care among children with autism and other developmental disabilities. *Intellectual and Developmental Disabilities*, *50*(4), 287–299. https://doi.org/10.1352/1934-9556-50.4.287

Mandell, D. S., Ittenbach, R. F., Levy, S. E., & Pinto-Martin, J. A. (2007). Disparities in diagnoses received prior to a diagnosis of autism spectrum disorder. *Journal of Autism and Developmental Disorders*, *37*(9), 1795–1802. https://doi.org/10.1007/s10803-006-0314-8

Mandell, D. S., Wiggins, L. D., Carpenter, L. A., Daniels, J., DiGuiseppi, C., Durkin, M. S., ... & Kirby, R. S. (2009). Racial/ethnic disparities in the identification of children with autism spectrum disorders. *American Journal of Public Health*, *99*(3), 493–498. https://doi.org/10.2105/AJPH.2007.131243

Marcus, R. N., Owen, R., Kamen, L., Manos, G., McQuade, R. D., Carson, W. H., & Aman, M. G. (2009). A placebo-controlled, fixed-dose study of aripiprazole in children and adolescents with irritability associated with autistic disorder. *Journal of the American*

Academy of Child & Adolescent Psychiatry, *48*(11), 1110–1119. https://doi.org/10.1097/CHI.0b013e3181b76658

Marsden, M. (1988). *The natural world and natural resources: Māori value systems and perspectives* (Resource Management Law Reform Working Paper No. 29, Part A). Ministry for the Environment.

Matson, J. L., & Wilkins, J. (2007). A critical review of assessment targets and methods for social skills excessed and deficits for children with autism spectrum disorders. *Research in Autism Spectrum Disorders*, *1*(1), 28–37. https://doi.org/10.1016/j.rasd.2006.07.003

Matta, C. (2022). Philosophical paradigms in qualitative research methods education: What is their pedagogical role? *Scandinavian Journal of Educational Research*, *66*(6), 1049–1062. https://doi.org/10.1080/00313831.2021.1958372

Mazurek, M. O., Handen, B. L., Wodka, E. L., Nowinski, L., Butter, E., & Engelhardt, C. R. (2014). Age at first autism spectrum disorder diagnosis: The role of birth cohort, demographic factors, and clinical features. *Journal of Developmental & Behavioral Pediatrics*, *35*(9), 561–569. https://doi.org/10.1097/DBP.0000000000000097

McAnelly, K., & Gaffney, M. (2017). He waka eke noa: A case study of active participation for a disabled child in an inclusive early childhood community of practice. *Early Childhood Folio*, *21*(1), 16–21. https://doi.org/10.18296/ecf.0031

McBride, P. A., Anderson, G. M., & Shapiro, T. (1996). Autism research: Bringing together approaches to pull apart the disorder. *Archives of General Psychiatry*, *53*(11), 980–983. https://doi.org/10.1001/archpsyc.1996.01830110011002

McCarty, P., & Frye, R. E. (2020, October). Early detection and diagnosis of autism spectrum disorder: Why is it so difficult? In *Seminars in Pediatric Neurology*, 35, Article 100831. https://doi.org/10.1016/j.spen.2020.100831

McCracken, J. T., McGough, J., Shah, B., Cronin, P., Hong, D., Aman, M. G., ... & McMahon, D. (2002). Risperidone in children with autism and serious behavioral problems. *New England Journal of Medicine*, *347*(5), 314–321. https://doi.org/10.1056/NEJMoa013171

McCrimmon, A. W., & Montgomery, J. M. (2014). Resilience-based perspectives for autism spectrum disorder. In S. Prince-Embury & D. H. Saklofske (Eds.), *Resilience interventions for youth in diverse populations* (pp. 375–396). Springer. https://doi.org/10.1007/978-1-4939-0542-3_17

McCubbin, H. I. (1979). Integrating coping behaviour in family stress theory. *Journal of Marriage and the Family*, *41*, 237–244. https://doi.org/10.2307/351693

McIntyre, A. (2002). Women researching their lives: Exploring violence and identity in Belfast, the North of Ireland. *Qualitative Research*, *2*, 387–409. https://doi.org/10.1177/146879410200200306

McKelvie-Sebileau, P., Swinburn, B., Glassey, R., Leach, D. T., & Gerritsen, S. (2023). Health, wellbeing and nutritional impacts for students and families after two years of government-funded school lunches in low advantage schools in Aotearoa New Zealand *Health Promotion International*, *38*(4), Article daad093. https://doi.org/10.1093/heapro/daad093

Mead, H. M. (2003). *Tikanga Māori: Living by Māori values*. Huia.

Meekosha, H., & Shuttleworth, R. (2009). What's so 'critical' about critical disability studies? *Australian Journal of Human Rights*, *15*(1), 47–75. https://doi.org/10.1080/1323238X.2009.11910861

Meissel, K., Meyer, F., Yao, E. S., & Rubie-Davies, C. M. (2017). Subjectivity of teacher judgments: Exploring student characteristics that influence teacher judgments of

student ability. *Teaching and Teacher Education, 65*, 48–60. https://doi.org/10.1016/j.tate.2017.02.021

Mertens, D. M. (2009). *Transformative research and evaluation*. Guilford Press.

Mertens, D. M. (2017). Transformative research: Personal and societal. *International Journal for Transformative Research*, *4*(1), 18–24. https://doi.org/10.1515/ijtr-2017-0001

Meyer, M. A. (2008). Indigenous and authentic: Hawaiian epistemology and the triangulation of meaning. In N. K. Denzin, Y. S. Lincoln, & L. T. Smith (Eds), *Handbook of critical and Indigenous methodologies* (pp. 217–232). SAGE. https://doi.org/10.4135/9781483385686.n11

Miller, J., & Glassner, B. (2016). The 'inside' and the 'outside': Finding realities in interviews. In D. Silverman (Ed.), *Qualitative data analysis* (pp. 131–148). SAGE.

Million, D. (2009). Felt theory: An Indigenous feminist approach to affect and history. *Wicazo Sa Review*, *24*(2), 53–76. ttps://doi.org/10.1353/wic.0.0043

Milne, A. (2013). *Colouring in the white spaces: Reclaiming cultural identity in whitestream schools* [Doctoral thesis, University of Waikato]. Research Commons. https://hdl.handle.net/10289/7868

Minh, H. V., Giang, K. B., Liem, N. T., Palmer, M., Thao, N. P., & Duong, L. B. (2015). Estimating the extra cost of living with disability in Vietnam. *Global Public Health*, *10*(Suppl. 1), S70–S79. https://doi.org/10.1080/17441692.2014.971332

Ministerial Advisory Committee. (1986). *Puao-te-ata-tu; Day break: The report of the Ministerial Advisory Committee on a Māori perspective of the Department of Social Welfare.* https://ndhadeliver.natlib.govt.nz/delivery/DeliveryManagerServlet?dps_pid=IE35576520

Ministry of Education. (2010b). *Success for all – every school, every child*. Accessed August 22, 2013. https://www.education.govt.nz/assets/Documents/School/Inclusive-education/SuccessForAllEnglish.pdf

Ministry of Education. (2012). *The New Zealand Curriculum update,* no. 16. https://nzcurriculum.tki.org.nz/Curriculum-resources/NZC-Updates/Issue-16-January-2012

Ministry of Education. (2013). *Ka hikitia: Accelerating success 2013–2017: The Māori education strategy*. http://www.education.govt.nz/quick-links/maori/

Ministry of Education. (2015). *Special Education Update: summary of engagement.* https://assets.education.govt.nz/public/Documents/Ministry/Initiatives/special-education-update/Special-Education-Update-summary-of-engagement-findings-Nov-2015.pdf

Ministry of Education. (2018). *Our schooling future stronger together: Whiria ngā kura tūātinitini. Report by the Tomorrow's Schools Independent Taskforce.*

Ministry of Education. (2019). *Learning support action plan 2015–2025.* https://planipolis.iiep.unesco.org/sites/default/files/ressources/new_zealand_learning-support-action-plan-2019-to-2025.pdf

Ministry of Education. (2021). *Resource teachers: Learning and behaviour service.* https://www.education.govt.nz/school/student-support/special-education/resource-teachers-learning-and-behaviour-service

Ministry of Education (2022). *Education in New Zealand.* https://www.education.govt.nz/our-work/our-role-and-our-people/education-in-nz/

Ministry of Education. (2023). *Ka hikitia – Ka hāpaitia: The Māori education strategy.* https://www.education.govt.nz/our-work/overall-strategies-and-policies/ka-hikitia-ka-hapaitia/

Ministry of Health. (2018). *Whāia Te Ao Mārama 2018 to 2022: The Māori Disability Action Plan*. https://www.health.govt.nz/publications/whaia-te-ao-marama-2018-to-2022-the-maori-disability-action-plan

Ministry of Health. (2019). *Health status indicators: Disability.* https://web.archive.org/web/20190131072527/https://www.health.govt.nz/our-work/populations/maori-health/tatau-kahukura-maori-health-statistics/nga-mana-hauora-tutohu-health-status-indicators/disability

Ministry of Health. (2020). *Annual report for the year ended 30 June 2020.*

Ministry of Health. (2023). *New Zealand Health Strategy*. https://www.health.govt.nz/publication/new-zealand-health-strategy

Ministry of Housing and Urban Development. (2022). *Assessment of the housing system with insights from the Hamilton-Waikato area.* The Treasury.

Ministry of Social Development. (n.d.-a). *Child Disability Allowance.* https://www.workandincome.govt.nz/products/a-z-benefits/child-disability-allowance.html

Ministry of Social Development. (n.d.-b). *Disability Allowance.* https://www.workandincome.govt.nz/products/a-z-benefits/disability-allowance.html

Ministry of Social Development. (n.d.-c). *Supported Living Payment.* https://www.workandincome.govt.nz/products/a-z-benefits/supported-living-payment.html

Ministry of Social Development. (2016). *New Zealand Disability Strategy (2016–2026).*

Ministry of Social Development. (2021). *New ministry for disabled people*. https://www.msd.govt.nz/about-msd-and-our-work/work-programmes/disability-system-transformation/ministry-for-disabled-peopleestablishment-unit/index.html

Minto, J. (2010, August 20). Credit to Roy for special education insight. https://www.stuff.co.nz/business/blogs/frontline/4044524/Credit-To-Roy

Mitchell, D. R., & Singh, N. N. (Eds.). (1987). *Exceptional children in New Zealand*. Dunmore Press.

Mitra, S., Palmer, M., Kim, H., Mont, D., & Groce, N. (2017). Extra costs of living with a disability: A review and agenda for research. *Disability and Health Journal*, *10*(4), 475–484. https://doi.org/10.1016/j.dhjo.2017.04.007

Moh, T. A., & Magiati, I. (2012). Factors associated with parental stress and satisfaction during the process of diagnosis of children with autism spectrum disorders. *Research in Autism Spectrum Disorders*, *6*(1), 293–303. https://doi.org/10.1016/j.rasd.2011.05.011

Montes, G., & Halterman, J. S. (2007). Psychological functioning and coping among mothers of children with autism: A population-based study. *Pediatrics*, *119*(5), 1040–1046. https://doi.org/10.1542/peds.2006-2819

Morgan, P. L. (2009). *Parenting an adult with disabilities or special needs: Everything you need to know to plan for and protect your child's future*. Amacom.

Morris, Z. A., McGarity, S. V., Goodman, N., & Zaidi, A. (2022). The extra costs associated with living with a disability in the United States. *Journal of Disability Policy Studies*, *33*(3), 158–167. https://doi.org/10.1177/10442073211043521

Morris, Z. A., & Zaidi, A. (2020). Estimating the extra costs of disability in European countries: Implications for poverty measurement and disability-related decommodification. *Journal of European Social Policy*, *30*(3), 339–354. https://doi.org/10.1177/0958928719891317

Mostern, K. (1996). Three theories of the race of W. E. B. Du Bois. *Cultural Critique*, *34*, 27– 63. https://doi.org/10.2307/1354611

Mueller, C. O., Forber-Pratt, A. J., & Sriken, J. (2019). Disability: Missing from the conversation of violence. *Journal of Social Issues, 75*(3), 707–725. https://doi.org/10.1111/josi.12339

Mutch, C., & Collins, S. (2012). Partners in learning: Schools' engagement with parents, families, and communities in New Zealand. *School Community Journal, 22*(1), 167–187.

National Collaborating Centre for Mental Health. (2012). *Autism recognition, referral, diagnosis and management of adults on the autism spectrum*. British Psychological Society and Royal College of Psychiatrists.

Nelson, G., Ochocka, J., Griffin, K., & Lord, J. (1998). 'Nothing about me, without me': Participatory action research with self/help organisations for psychiatric consumer/survivors. *American Journal of Community Psychology*, *26*(6), 881–912. https://doi.org/10.1023/A:1022298129812

Nelson G., & Prilleltensky, I. (2010). *Community psychology: In pursuit of liberation and well- being*. Palgrave Macmillan.

Nespor J., & Hicks, D. (2010). Wizards and witches: Parent advocates and contention in special education in the USA. *Journal of Education Policy 25*(3), 309–334. https://doi.org/10.1080/02680931003671954

New Zealand Bill of Rights Act. (1990). https://www.legislation.govt.nz/act/public/1990/0109/latest/DLM224792.html

New Zealand Guidelines Group. (2010) *What does ASD look like? A resource to help identify autism spectrum disorder*. https://www.kidshealth.org.nz/sites/kidshealth/files/100527_1_What_does_ASD_look_like_FINAL.pdf

Nicholas, D., Orjasaeter, J., & Zwaigenbaum, L. (2019). Considering methodological accommodation to the diversity of ASD: A realist synthesis review of data collection methods for examining first-person experiences. *Review Journal of Autism and Developmental Disorders*, *6*(2), 216–232. https://doi.org/10.1007/s40489-019-00164-z

Oades, L. M. (2021). Mamae nui me te takiwātanga: Surplus suffering and autism spectrum disorder in school social work practice. *Aotearoa New Zealand Social Work*, *33*(1), 55–66. https://doi.org/10.11157/anzswj-vol33iss1id823

Obeid, R., Bisson, J. B., Cosenza, A., Harrison, A. J., James, F., Saade, S., & Gillespie-Lynch, K. (2021). Do implicit and explicit racial biases influence autism identification and stigma? An implicit association test study. *Journal of Autism and Developmental Disorders*, *51*, 106–128. https://doi.org/10.1007/s10803-020-04507-2

Obeid, R., Daou, N., DeNigris, D., Shane-Simpson, C., Brooks, P. J., & Gillespie-Lynch, K. (2015). A cross-cultural comparison of knowledge and stigma associated with autism spectrum disorder among college students in Lebanon and the United States. *Journal of Autism and Developmental Disorders*, *45*(11), 3520–3536. https://doi.org/10.1007/s10803-015-2499-1

Ochocka, J., Janzen, R., & Nelson, G. (2002). Sharing power and knowledge: Professional and mental health consumer/survivor researchers working together in a participatory action research project. *Psychiatric Rehabilitation Journal*, *25*(4), 379–387. https://doi.org/10.1037/h0094999

Ockelford, A. (2012). Songs without words: Exploring how music can serve as a proxy language in social interaction. In R. MacDonald (ed.), *Music, health, and wellbeing* (pp. 289–323). Oxford University Press. https://doi.org/10.1093/acprof:oso/9780199586974.003.0021

Office for Disability Issues. (2017a). *Towards a non-disabling New Zealand.* https://www.whaikaha.govt.nz/assets/About-us/Corporate-Publications/Annual-Reports/2017-Annual-Progress-Report-on-implementation-of-NZDS.pdf

Office for Disability Issues. (2017b). *Principle approaches*. https://www.odi.govt.nz/nz-disability-strategy/about-the-strategy/new-zealand-disability-strategy-2016-2026/read-the-new-disability-strategy/new-zealand-disability-strategy-read-online/principles-and-approaches/#oneprinciples

Office of the Children's Commissioner and Oranga Tamariki–Ministry for Children. (2018). *What makes a good life? Children and young people's views on wellbeing*. https://www.orangatamariki.govt.nz/assets/Uploads/About-us/Research/Latest-research/What-makes-a-good-life/What-makes-a-good-life-report-2019.pdf

Oliver, K. L., & Kirk, D. (2015). *Girls, gender and physical education: An activist approach*. Routledge. https://doi.org/10.4324/9781315796239

Olson, L., Chen, B., Ibarra, C., Wang, T., Mash, L., Linke, A., Kinnear, M., & Fishman, I. (2021). Externalizing behaviors are associated with increased parenting stress in caregivers of young children with autism. *Journal of Autism and Developmental Disorders, 52,* 975–986. https://doi.org/10.1007/s10803-021-04995-w

O'Neill, J. (2016). Targeted social investment as an equity strategy. *New Zealand Educational Studies, 51*(2), 269–274. https://doi.org/10.1007/s40841-016-0064-x

Ooi, A., Banno, B., McFee, K., Elbe, D., & Friedlander, R. (2023). Evaluating and managing irritability and aggression in children and adolescents with autism spectrum disorder: An algorithm. *British Columbia Medical Journal*, *65*(8). https://bcm.org/sites/ default/files/BCMJ_Vol65_No8_austism-algorithm.pdf

Ooi, K., Ong, Y. S., Jacob, S. A., & Khan, T. M. (2020). A meta-synthesis on parenting a child with autism. *Neuropsychiatric Disease and Treatment*, *12*, 745–762. https://doi.org/10.2147/NDT.S100634

Owen, R., Sikich, L., Marcus, R. N., Corey-Lisle, P., Manos, G., McQuade, R. D., Carson, W. H., & Findling, R. L. (2009). Aripiprazole in the treatment of irritability in children and adolescents with autistic disorder. *Pediatrics*, *124*(6), 1533–1540. https://doi.org/10.1542/peds.2008-3782

Palmer, M., & Harley, D. (2012). Models and measurement in disability: An international review. *Health Policy and Planning*, *27*(5), 357–364. https://doi.org/10.1093/heapol/czr047

Palmer, R. (2024, August 15). *Disability services to shift from Whaikaha to MSD after budget*. RNZ. https://www.rnz.co.nz/news/political/525212/watch-disability-services-to-shift-from-whaikaha-to-msd-after-budget

Patel, D. B., Ogletree, X., & Pei, Y. (2022, March 12–14). Learning communication with autistic people with a mobile serious role-playing game. In P. Kommers, I. Arnedillo Sánchez, & P. Isaías (Eds.), *Proceedings of the International Conferences on E-Society 2022 and Mobile Learning 2022* (pp. 195–202). IADIS Press.

Pellicano, E., Dinsmore, A., & Charman, T. (2014). What should autism research focus upon? Community views and priorities from the United Kingdom. *Autism*, *18*(7), 756–770. https://doi.org/10.1177/1362361314529627

Pere, R. R. (1991). Te Wheke: Whaia te mātauranga me te aroha. In S. Middleton (Ed.), *Women and education in Aotearoa* (pp. 6–19). Allen & Unwin/Port Nicholson Press.

Pickles, A., Le Couteur, A., Leadbitter, K., Salomone, E., Cole-Fletcher, R., Tobin, H., … Green, J. (2016). Parent-mediated social communication therapy for young children

with autism (PACT): Long-term follow-up of a randomized trial. *The Lancet*, *388*, 2501–2509. https://doi.org/10.1016/S0140-6736(16)31229-6

Pihama, L. (2001). *Tihei mauri ora: Honouring our voices. Mana wahine as a Kaupapa Māori theoretical framework* [PhD thesis, University of Auckland]. ResearchSpace.

Pihama, L. (2019). Colonisation, neoliberalism and Māori education: Herbison invited lecture, NZARE Annual Conference 2017. *New Zealand Journal of Educational Studies*, *54*, 5–19. https://doi.org/10.1007/s40841-019-00130-7

Pihama, L. (2020). Mana wahine: Decolonising gender in Aotearoa. *Australian Feminist Studies*, *35*(106), 351–365. https://doi.org/10.1080/08164649.2020.1902270

Pihama, L., Cram, F., & Walker S. (2002). Creating methodological space: A literature review of Kaupapa Māori. *Canadian Journal of Native Education 26*(1), 30–43.

Pillai, G. P. (2015). Te Kotahitanga: The effective teaching profile and its impact on Māori student achievement. *Kairaranga, 16*(1), 52–57. https://doi.org/10.54322/kairaranga.v16i1.195

Pini, B. (2002) Focus groups, feminist research and farm women: Opportunities for empowerment in rural social research. *Journal of Rural Studies 18*(3), 339–351. https://doi.org/10.1016/S0743-0167(02)00007-4

Plumb, J. C. (2011). *The impact of social support and family resilience on parental stress in families with a child diagnosed with an autism spectrum disorder* [Doctoral dissertation, University of Pennsylvania]. Scholarly Commons. https://repository.upenn.edu/handle/20.500.14332/32838

Priestley, R., Yeung, P., & Cooper, L. (2022). Qualitative research: The impact of individualised funding on the wellbeing of mothers raising an autistic child in Aotearoa New Zealand. *Aotearoa New Zealand Social Work*, *34*(3), 116–129. https://doi.org/10.11157/anzswj-vol34iss3id980

Pruitt, M. M., Rhoden, M., & Ekas, N. V. (2018). Relationship between the broad autism phenotype, social relationships and mental health for mothers of children with autism spectrum disorder. *Autism*, *22*(2), 171–180. https://doi.org/10.1177/1362361316669621

Radley, K. C., Dart, E. H., Brennan, K. J., Helbig, K. A., Lehman, E. L., Silberman, M., & Mendanhall, K. (2020). Social skills teaching for individuals with autism spectrum disorder: A systematic review. *Advances in Neurodevelopmental Disorders*, *4*, 215–226. https://doi.org/10.1007/s41252-020-00170-x

Reed, F. D. D., Hyman, S. R., & Hirst, J. M. (2011). Applications of technology to teach social skills to children with autism. *Research in Autism Spectrum Disorders*, *5*(3), 1003–1010. https://doi.org/10.1016/j.rasd.2011.01.022

Reeves, P., Ng, S. L., Harris, M., & Phelan, S. K. (2022). The exclusionary effects of inclusion today:(re) production of disability in inclusive education settings. *Disability & Society*, *37*(4), 612–637. https://doi.org/10.1080/09687599.2020.1828042

Reicher, S. (2000). Against methodolatry: Some comments on Elliot, Fischer and Rennie. *British Journal of Clinical Psychology*, *39*(1), 1–6. https://doi.org/10.1348/014466500163031

Reid, J. (1985). 'Going up or going down': The status of old people in an Australian Aboriginal society. *Ageing and Society*, *5*(1), 69–95. https://doi.org/10.1017/S0144686X00011296

Reid, P., Cormack, D., & Paine, S. J. (2019). Colonial histories, racism and health: The experience of Māori and Indigenous peoples. *Public Health*, *172*, 119–124. https://doi.org/10.1016/j.puhe.2019.03.027

Reinharz, S. (1992) *Feminist methods in social research*. Oxford University Press.

Ribeiro, S. H., Paula, C. S. D., Bordini, D., Mari, J. J., & Caetano, S. C. (2017). Barriers to early identification of autism in Brazil. *Brazilian Journal of Psychiatry, 39*, 352–354. https://doi.org/10.1590/1516-4446-2016-2141

Rice, B., Oakes, J. E., & Riewe, R. R. (Eds.). (2005). *Seeing the world with Aboriginal eyes: A four directional perspective on human and non-human values, cultures and relationships on Turtle Island*. Aboriginal Issues Press.

Rice, C. E., Zablotsky, B., Avila, R. M., Colpe, L. J., Schieve, L. A., Pringle, B., & Blumberg, S. J. (2016). Reported wandering behavior among children with autism spectrum disorder and/or intellectual disability. *Journal of Pediatrics, 174*, 232–239. https://doi.org/10.1016/j.jpeds.2016.03.047

Rimland, B. (1964). *Infantile autism: The syndrome and its implications for a neural theory of behavior*. Appleton-Century-Crofts.

Ristock, J., L., & Pennell, J. (1996). *Community research as empowerment: Feminist links, postmodern interruptions.* Oxford University Press.

Ritchie, J. E. (1992). *Becoming bicultural*. Huia.

Rivard, M., Terroux, A., Parent-Boursier, C., & Mercier, C. (2014). Determinants of stress in parents of children with autism spectrum disorders. *Journal of Autism and Development Disabilities, 44*(7), 1609–1620. https://doi.org/10.1007/s10803-013-2028-z

Riwai-Couch, M. (2021). *Poipoia ngā ākonga kanorau ā-roro: A literature review prepared for the Ministry of Education*. https://inclusive.tki.org.nz/assets/inclusive-education/resources/files/Akonga-Kanorau-a-roro-Final-Draft-of-Literature-Review-MRC-1.pdf

Robertson, R. (2014). "Misfitting" mothers: Feminism, disability and mothering. *Hecate, 40*(1), 7–19.

Robson, B., & Harris R. (2007). *Hauora: Māori Standards of Health IV. A study of the years 2000–2005.* Te Rōpū Rangahau Hauora a Eru Pōmare.

Rosenberg, R. E., Landa, R., Law, J. K., Stuart, E. A., & Law, P. A. (2011). Factors affecting age at initial autism spectrum disorder diagnosis in a national survey. *Autism Research and Treatment,* Article 874619. https://doi.org/10.1155/2011/874619

Roth, L. (2012) Autism, creativity and aesthetics. *Qualitative Research in Psychology*, *17*(4), 498–508. https://doi.org/10.1080/14780887.2018.1442763

Roush, S. E., & Sharby, N. (2011). Disability reconsidered: The paradox of physical therapy. *Physical Therapy*, *91*(12), 1715–1727. https://doi.org/10.2522/ptj.20100389

Royal, T. A. C. (Ed.). (2003). *The woven universe*: *Selected writings of Rev. Māori Marsden.* Estate of Rev. Māori Marsden.

Royal College of Psychiatrists. (2021, August). *Position Statement PS05/21*: *Stopping the overprescribing of people with intellectual disability, autism or both (STOMP) and supporting treatment and appropriate medication in paediatrics (STAMP)*. https://www.rcpsych.ac.uk/docs/default-source/improving-care/better-mh-policy/position-statements/position-statement-ps0521-stomp-stamp.pdf?sfvrsn=684d09b3_6

Rua, M., Hodgetts, D., & Stolte, O. E. E. (2017). Māori men: An Indigenous psychological perspective on the interconnected self. *New Zealand Journal of Psychology*, *46*(23), 55–63.

Ruangjiratain, S., & Kendall, J. (1998). Understanding women's risk of HIV infection in Thailand through critical hermeneutics. *Advances in Nursing Science*, *21*(2), 42–51. https://doi.org/10.1097/00012272-199812000-00005

Ryan, A., & Walsh, T. (Eds.). (2018). *Reflexivity and Critical Pedagogy* (pp. 1–14). Brill. https://doi.org/10.1163/9789004384507_001

Ryan, S., & Cole, K. R. (2009). From advocate to activist? Mapping the experiences of mothers of children on the autism spectrum. *Journal of Applied Research in Intellectual Disabilities, 22*(1), 43–53. https://doi.org/10.1111/j.1468-3148.2008.00438.x

Salkas, K., Magaña, S., Marques, I., & Mirza, M. (2016). Spirituality in Latino families of children with autism spectrum disorder. *Journal of Family Social Work, 19*, 38–55. https://doi.org/10.1080/10522158.2015.1114060

Salmond, A. (1991). *Two worlds.* Viking Penguin.

Samsell, B., Lothhan, K., Samsell E. E., & Ideishi R. I. (2022). Parents' experiences of caring for a child with autism spectrum disorder in the United States: A systematic review and metasynthesis of qualitative evidence. *Family Systems & Health*, *40*(1), 93–104. https://doi.org/10.1037/fsh0000654

Samson, A. C., Hardan, A. Y., Lee, I. A., Phillips, J. M., & Gross, J. J. (2015). Maladaptive behavior in autism spectrum disorder: The role of emotion experience and emotion regulation. *Journal of Autism and Developmental Disorders, 45*, 3424–3432. https://doi.org/10.1007/s10803-015-2388-7

Sangster, J. (1994). Telling our stories: Feminist debates and the use of oral history. *Women's History Review, 3*(1), 5–28. https://doi.org/10.1080/09612029400200046

Sannar, E. M., Palka, T., Beresford, C., Peura, C., Kaplan, D., Verdi, M., Siegel, M., Kaplan, S., & Grados, M. (2018). Sleep problems and their relationship to maladaptive behavior severity in psychiatrically hospitalized children with autism spectrum disorder (ASD). *Journal of Autism and Developmental Disorders, 48*, 3720–3726. https://doi.org/10.1007/s10803-017-3362-3

Sanson, D. (2017). Cosmopolitanism, neo-shamans and contemporary Māori healers in New Zealand. In K. Rountree (Ed.)., *Cosmopolitanism, nationalism, and modern paganism* (pp. 221–243). Palgrave Macmillan. https://doi.org/10.1057/978-1-137-56200-5_11

Sansosti, F. J. (2010). Teaching social skills to children with autism spectrum disorders using tiers of support: A guide for school-based professionals. *Psychology in the Schools, 47*(3), 257–281. https://doi.org/10.1002/pits.20469

Schwandt, T. A. (2012). Valuing methodological diversity. *Qualitative Social Work, 11*(2), 125– 129. https://doi.org/10.1177/1473325011433928a

Searing, B. M. J., Graham, F., & Grainger, R. (2015). Support needs of families living with children with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 45*, 3693–3702. https://doi.org/10.1007/s10803-015-2516-4

Sefotho, M. M., & Leshota, P. L. (2020). Being differently abled: Disability through the lens of hierarchy of binaries and Bitso-lebe-ke Seromo. *African Journal of Disability, 9*(1), 1–7. https://doi.org/10.4102/ajod.v9i0.643

Seligman, M., & Csikszentmihalyi, M. (2000). Positive psychology: An introduction. *American Psychologist, 55*(1), 5–14. https://doi.org/10.1037//0003-066X.55.1.5

Selvaraj, J. (2015). Inclusive education in New Zealand: Policies, politics and contradictions. *International Journal of Inclusive Education, 19*(1), 86–101. https://doi.org/10.1080/13603116.2014.907584

Shakespeare, T. (2006). The social model of disability. *The Disability Studies Reader*, *2*, 197–204.

Shakespeare, T. (2013). *Disability rights and wrongs revisited*. Routledge. https://doi.org/10.4324/9781315887456

Shakespeare, T., & Watson, N. (2001). The social model of disability: An outdated ideology? In S. N. Barnartt & B. M. Altman (Eds.), *Exploring theories and expanding*

methodologies: Where we are and where we need to go (Vol. 2, pp. 9–28). Emerald Group. https://doi.org/10.1016/S1479-3547(01)80018-X

Sharples, P. (1988). *Kura kaupapa Māori: Recommendations for policy*. Te Kura o Hoani Waititi Marae.

Sharples, P. (2015). *Wāhine toa.* Te Rūnanga o Ngāi Tahu. https://ngaitahu.iwi.nz/opportunities-and-resources/publications/te-karaka/wahine-toa/

Shearn, J., & Todd, S. (2000). Maternal employment and family responsibilities: The perspectives of mothers of children with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, *13*(3), 109–131. https://doi.org/10.1046/j.1468-3148.2000.00021.x

Shepherd, D., Landon, J., & Goedeke, S. (2018). Symptom severity, caregiver stress and intervention helpfulness assessed using ratings from parents caring for a child with autism. *Autism*, *22*(5), 585–596. https://doi.org/10.1177/1362361316688869

Shepherd, D., Landon, J., Goedeke, S., & Meads, J. (2021). Stress and distress in New Zealand parents caring for a child with autism spectrum disorder. *Research in Developmental Disabilities*, *111*, Article 103875. https://doi.org/10.1016/j.ridd.2021.103875

Shildrick, M. (2009). *Dangerous discourses of disability, subjectivity and sexuality*. Springer. https://doi.org/10.1057/9780230244641

Sikora, D., Moran, E., Orlich, F., Hall, T. A., Kovacs, E. A., Delahaye, J., Clemons, T. E., & Kuhlthau, K. (2013). The relationship between family functioning and behavior problems in children with autism spectrum disorders. *Research in Autism Spectrum Disorders*, *7*(2), 307–315. https://doi.org/10.1016/j.rasd.2012.09.006

Silverman, C. (2012). *Understanding autism*. Princeton University Press.

Simmonds, N. B. (2014). *Tū te turuturu nō Hine-te-iwaiwa: Mana wāhine geographies of birth in Aotearoa New Zealand* [PhD thesis, University of Waikato]. Research Commons. https://hdl.handle.net/10289/8821

Simon, J. (1998). *Schooling for Māori: The control of access to knowledge* [Conference presentation]. Joint AARE/NZARE Conference, Geelong, Australia. http://www.aare.edu.au/data/publications/1992/simoj92382.pdf

Skarstad, K. (2018). Human rights through the lens of disability. *Netherlands Quarterly of Human Rights, 36*(1), 24–42. https://doi.org/10.1177/0924051917753251

Smith, G. H. (1992). *Tane-nui-a-rangi's legacy: propping up the sky. Kaupapa Māori as resistance and intervention.* A paper presented at the New Zealand Association for Research in Education/Australia Association for Research in Education joint conference, Deakin University.

Smith, G. H. (2000). Māori education: Revolution and transformative action. *Canadian Journal of Native Education, 24*(1), 57–72.

Smith, G. H. (2012). Interview: Kaupapa Māori: The dangers of domestication. *New Zealand Journal of Educational Studies*, *47*(2), 10–20.

Smith, L. T. (2021). *Decolonizing methodologies: Research and indigenous peoples* (3rd ed.). Bloomsbury.

Smith, L. T., Maxwell, T. K., Puke, H., & Temara, P. (2016). Indigenous knowledge, methodology and mayhem: What is the role of methodology in producing Indigenous insights? A discussion from mātauranga Māori. *Knowledge Cultures, 4*(3), 131–156.

Smithson, J. (2000). Using and analysing focus groups: Limitations and possibilities. *International Journal of Social Research Methodology, 3*(2), 103–119. https://doi.org/10.1080/136455700405172

Smythe, L., & Giddings, L. S. (2007). From experience to definition: Addressing the question 'What is qualitative research?' *Nursing Praxis in New Zealand*, *23*(1), 37–57.

Sosnowy, C., Silverman, C., Shattuck, P., & Garfield T. (2018). Setbacks and successes: How young adults on the autism spectrum seek friendship. *Autism in Adulthood: Knowledge, Practice and Policy*, *1*(1), 1–8. https://doi.org/10.1089/aut.2018.0009

Sousa, C. G. (2015). *Development of a computerized task to examine differential acquisition of operant responding in autism. Using social and non-social discriminative stimuli* [Master's thesis, University of Manitoba]. MSpace. http://hdl.handle.net/1993/30732

Special Education 2000. (1997). Beehive.govt.nz. https://www.beehive.govt.nz/feature/special-education-2000

Spezio, M. L., Adolphs R., Hurley, R. S., & Piven, J. (2007). Abnormal use of facial information in high-functioning autism. *Journal of Autism and Developmental Disorders*, *37*(5), 929–939. https://doi.org/10.1007/s10803-006-0232-9

Stace, H. (2010). Social justice, the social model and disability policy in Aotearoa New Zealand. *Social Work Now*, *4*, 19–24.

Stace, H. (2011). *Moving beyond love and luck: Building right relationships and respecting lived experience in New Zealand autism policy* [Doctoral thesis, Victoria University Wellington]. Open Access. https://doi.org/10.26686/wgtn.16992841.v1

Stevens, M., Martineau, S., Manthorpe, J., Steils, N., & Bramley, S. (2020). *The availability of section 12 doctors for Mental Health Act assessments: A scoping review of the literature*. https://kclpure.kcl.ac.uk/portal/en/publications/the-availability-of-section-12-doctors-for-mental-health-act-assessments--a-scoping-review-of-the-literature(03c99f34-1fd1-43a2-8aa4-e6b3cd5100db).html

Stone, W. L., Lee, E., Ashford, L., Brissie, J., Hepburn, S. L., Hepburn, S. L., Coonrod, E. E., & Weiss, B. H. (1999). Can autism be diagnosed accurately in children under 3 years*?*

Journal of Child Psychology and Psychiatry, and Allied Disciplines, *40*(2), 219–226. https://doi.org/10.1111/1469-7610.00435

Stroebe, W. (2011). *Social psychology and health*. McGraw-Hill Education.

Taylor, L. J., Eggleston, M. J., Thabrew, H., van der Meer, L., Waddington, H., Whitehouse, A. J., & Evans, K. (2021). An investigation of adherence to best practice guidelines for autism diagnosis in New Zealand. *Autism*, *25*(7), 2087–2100. https://doi.org/10.1177/13623613211015757

Tayyare, B. Ç., Akçin, N., Fakultesi, A. E., Bolumu, O. E., & Goztepe, K. (2013). The difficulties encountered by the mothers having children with mental disabilities or autism in participating to community life. *International Journal of Special Education*, *28*(2), 123–135.

Te Awekotuku, N. (2003). *Ruahine*: *Mythic women*. Huia.

Te Whatu Ora. (2022). *Engaging with people with autism spectrum disorder*. https://web.archive.org/web/20230320155237/https://www.tewhatuora.govt.nz/whats-happening/work-underway/making-services-better-for-users/community-engagement-with-people-with-disabilities/engaging-with-people-with-particular-impairments/engaging-with-people-with-autism-spectrum-disorder/

Thabrew, H., & Eggleston, M. (2018). Spectrum of care: Current management of childhood autism spectrum disorder (ASD) in New Zealand. *Australasian Psychiatry*, *26*(3), 294–298. https://doi.org/10.1177/1039856217716290

Tibble, M. (2005). *Review of existing research on the extra costs of disability*. Corporate Document Services.

Tipene, R. (2017). *Māori public health practitioners' views of Māori leadership in the New Zealand public health context: A critical hermeneutic study* [Master's thesis, Auckland University of Technology]. Tuwhera. https://hdl.handle.net/10292/10460

Tolich, M., & Davidson, C. (2011). *An introduction to research methods: Getting started.* Pearson.

Traustadottir, R. (1991). Mothers who care: Gender, disability, and family life. *Journal of Family Issues*, *12*(2), 211–228. https://doi.org/10.1177/019251391012002005

Traustadottir, R. (1999). Gender, disability, and community life: Towards a feminist analysis. In H. Bersani (Ed.), *Responding to the challenge: Current trends and international issues in developmental disabilities*. Brookline Books.

Traustadottir, R. (2001). Research with others: Reflections on representation, difference and othering. *Scandinavian Journal on Disability Research*, *3*(2), 9–28. https://doi.org/10.1080/15017410109510773

Traustadottir, R. (2006). Disability and gender: Introduction to the special issue. *Scandinavian Journal of Disability Research*, *8*(2–3), 81–84. https://doi.org/10.1080/15017410600831341

Treffert, D. A. (2009). The savant syndrome: An extraordinary condition. A synopsis: Past, present and future. *Philosophical Transactions of the Royal Society*, *364*(1522), 1351– 1357. https://doi.org/10.1098/rstb.2008.0326

Tso, M., & Strnadová, I. (2017). Students with autism transitioning from primary to secondary schools: Parents' perspectives and experiences. *International Journal of Inclusive Education*, *21*(4), 389–403. https://doi.org/10.1080/13603116.2016.1197324

Tupou, J., Ataera, C. R., Waddinton, H. (2021). Experiences of whānau Māori caring for a young child on the autism spectrum. *AlterNative: An International Journal of Indigenous Peoples*, *19*(2), 437–446. https://doi.org/10.1177/13623613231181622

Tupou, J., Ataera, C., Wallace-Watkin, C., & Waddington, H. (2023). Supporting tamariki takiwātanga Māori (autistic Māori children): Exploring the experience of early

childhood educators. *Autism*, *28*(3), 705–707. https://doi.org/10.1177/13623613231181622

Turner-Brown, L., Baranek, G. T., Reznick, J. S., Watson, L. R., & Crais, E. R. (2013). The first-year inventory: A longitudinal follow-up of 12-month-old to 3-year-old children. *Autism*, *17*(5), 527–540. https://doi.org/10.1177/1362361312439633

Twemlow, S. W., Fonagy, P., Sacco, F. C., & Brethour Jr., J. R. (2006). Teachers who bully students: A hidden trauma. *International Journal of Social Psychiatry*, *52*(3), 187–198.

United Nations. (1989). *United Nations Convention on the Rights of the Child*. https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-rights-child

United Nations. (2006a). *United Nations Convention on the Rights of Persons with Disabilities Article 1 –Purpose*. https://social.desa.un.org/issues/disability/crpd/article-1-purpose

United Nations. (2006b). *United Nations Convention on the Rights of Persons with Disabilities Article 24 –Education.* https://social.desa.un.org/issues/disability/crpd/article-24-education

Valicenti-McDermott, M., Hottinger, K., Seijo, R., & Shulman, L. (2012). Age at diagnosis of autism spectrum disorders. *Journal of Pediatrics*, *161*(3), 554–556. https://doi.org/10.1016/j.jpeds.2012.05.012

VanBergeijk, E., Klin, A., & Volkmar, F. (2008). Supporting more able students on the autism spectrum: College and beyond. *Journal of Autism and Developmental Disorders*, *38*, 1359–1370. https://doi.org/10.1007/s10803-007-0524-8

Van Patten-Walsh, C. M. (2013). *The impacts of autism: Having a child with autism and the formation of mother's identity* [Master's thesis, Humbolt State University]. ScholarWorks. http://hdl.handle.net/2148/1669

Voysey, M. (1972). Impression management by parents with disabled children. *Journal of Health and Social Behavior, 13*(1), 80–89. https://doi.org/10.2307/2136975

Waddington, H., van der Meer, L., Sigafoos, J., & Ogilvie, E. (2020). Evaluation of a low-intensity version of the early start Denver model with four preschool-aged boys with autism spectrum disorder. *International Journal of Developmental Disabilities, 66*(4), 257–269. https://doi.org/10.1080/20473869.2019.1569360

Wagner, J. L., Mueller, M., Kellermann, T., Griffin, M., Smith, G., Soliven, M., Guilfoyle, S. M., Junger, K. F., Mucci, G., Huszti, H., Barrett, L., Zupanc, M., & Modi, A. C. (2019). Vulnerabilities to antiepileptic drug (AED) side effects in youth with epilepsy. *Epilepsy & Behavior*, *97*, 22–28. https://doi.org/10.1016/j.yebeh.2019.05.012

Waitoki, W., & Levy, M. (2016). *Te manu kai i te mātauranga. Indigenous psychology in Aotearoa, New Zealand.* New Zealand Psychological Society.

Walker, R. (2004). *Ka whawhai tonu matou – Struggle without end.* Penguin.

Walker, R. J. (1985). Cultural domination of Taha Māori: The potential for radical transformation. In J. Codd & R. Nash (Eds.), *Political issues in New Zealand education* (pp. 73–79). Allen & Unwin.

Wallace-Watkin, C., Whitehouse, A. J., & Waddington, H. (2021). Early intervention delivery methods for New Zealand children with autism: Current practices versus parental preferences. *Journal of Autism and Developmental Disorders, 51*, 3199–3211. https://doi.org/10.1007/s10803-020-04777-w

Warden, K. D. (2020). *A misfit's perspective: The lived experiences of mothers of disabled children* [Doctoral dissertation, University of Oregon]. Scholars Bank. https://hdl.handle.net/1794/26174

Warner G., Parr, J. R., & Cusack J. (2018). Workshop report: Establishing priority research areas to improve the physical health and well-being of autistic adults and older people. *Autism in Adulthood*, *1*(1), 6–12. https://doi.org/10.1089/aut.2018.0003

Weastell, K. (2017). *Raising a child with an autism spectrum disorder: The experience of stigma by association, its impact on caregiver wellbeing, the influence of signature strengths, and the experience of growth* [Doctoral dissertation, Massey University]. Massey Research Online. http://hdl.handle.net/10179/12150

Webb, S. J., Jones, E. J. H., Kelly, J., & Dawson, G. (2014). The motivation for very early intervention in infants at high risk for autism spectrum disorders. *International Journal of Speech Language Pathology*, *16*(1), 36–42. https://doi.org/10.3109/17549507.2013.861018

Whaikaha – Ministry of Disabled People and Ministry of Education. (2022). *Aotearoa New Zealand Autism Guideline: He Waka Huia Takiwātanga Rau: Third edition*. https://www.whaikaha.govt.nz/about-us/programmes-strategies-and-studies/guidelines/nz-autism-guideline

White, J., McGarry, S., Falkmer, M., Scott, M., Williams, P. J., & Black, M. H. (2023). Creating inclusive schools for Autistic students: A scoping review on elements contributing to strengths-based approaches. *Education Sciences*, *13*(7), Article 709. https://doi.org/10.3390/educsci13070709

White, R. E., Prager, E. O., Schaefer, C., Kross, E., Duckworth, A. L., & Carlson, S. M. (2017). The "Batman Effect": Improving perseverance in young children. *Child Development*, *88*(5), 1563–1571. https://doi.org/10.1111/cdev.12695

Whitlock, A., Fulton, K., Lai, M. C., Pellicano, E., & Mandy, W. (2020). Recognition of girls on the autism spectrum by primary school educators: An experimental study. *Autism Research*, *13*(8), 1358–1372. https://doi.org/10.1002/aur.2316

Willis, C. (2009). *Creating inclusive learning environments for young children: What to do on Monday morning*. Corwin Press.

Wilson, S. (2001). What is an Indigenous research methodology? *Canadian Journal of Native Education*, *25*(2), 175–179.

Wilson, S. A., & Peterson, C. C. (2018). Medical care experiences of children with autism and their parents: A scoping review. *Child: Care, Health and Development*, *44*(6), 807–817. https://doi.org/10.1111/cch.12611

Wilkinson, S. (2001). Theoretical perspectives on women and gender. In R. K. Unger (Ed.), *Handbook of the psychology of women and gender* (pp. 17–28). Wiley.

Winitana, M. (2012). Remembering the deeds of Māui: What messages are in the tuakana-teina pedagogy for tertiary educators? *MAI Review*, *1*(1), 29–37.

Wirihana, L. A., & Barnard, A. (2012). Women's perceptions of their healthcare experience when they choose not to breastfeed. *Women and Birth*, *25*(3), 135–141. https://doi.org/10.1016/j.wombi.2011.08.005

Withers, R. (2009). The therapeutic process of interactive drawing therapy. *New Zealand Journal of Counselling*, *29*(2), 73–90.

Wolff, S. (2004). The history of autism. *European Child & Adolescent Psychiatry*, *13*, 201–208. https://doi.org/10.1007/s00787-004-0363-5

Woolfson, L. (2004). Family well-being and disabled children: A psychosocial model of disability-related child behaviour problems. *British Journal of Health Psychology*, *9*(1), 1–13. https://doi.org/10.1348/135910704322778687

World Health Organization. (2013). *Application for inclusion to the 19th Expert Committee on the Selection and Use of Essential Medicines: Risperidone*.

World Health Organization. (2019). *Autism spectrum disorders*. Regional Office for the Eastern Mediterranean. https://iris.who.int/bitstream/handle/10665/364128/WHOEMMNH215E-eng.pdf?sequence=3&isAllowed=y

Wright N., & Heaton, S. (2021). 'Hospitality', boundary crossing and thresholds applied in education: Embodying manaakitanga and whanaungatanga. *Hospitality & Society 11*(1), 71–85. https://doi.org/10.1386/hosp_00032_1

Wylie, C. (2000). *Picking up the pieces: Review of special education 2000*. Ministry of Education.

Yilmaz, K. (2013). Comparison of quantitative and qualitative research traditions: Epistemological, theoretical, and methodological differences. *European Journal of Education*, 48(2), 311–325. https://doi.org/10.1111/ejed.12014

Yingling, M. E., Hock, R. M., & Bell, B. A. (2018). Time-lag between diagnosis of autism spectrum disorder and onset of publicly-funded early intensive behavioral intervention: Do race–ethnicity and neighborhood matter? *Journal of Autism & Developmental Disorders*, *48*(2), 561–571. https://doi.org/10.1007/s10803-017-3354-3

Zuckerman, K., Lindly, O. J., & Chavez, A. E. (2017). Timeliness of autism spectrum disorder diagnosis and use of services among US elementary school–aged children. *Psychiatric Services*, *68*(1), 33–40. https://doi.org/10.1176/appi.ps.201500549

Appendix 1: Diagnostic Criteria for Autism (DSM-5-TR)

The diagnostic criteria of Autism Spectrum Disorder as per the *Diagnostic and Statistical Manual of Mental Disorders 5th Text Revision Edition* (DSM-5-TR) (American Psychiatric Association, 2022) includes:

A. Persistent deficits in social communication and social interaction across multiple contexts, as manifested by all of the following, currently or by history.

1. Deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions.

2. Deficits in nonverbal communicative behaviors [sic] used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication.

3. Deficits in developing, maintaining, and understanding relationships, ranging, for example, from difficulties adjusting behavior to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers.

B. Restricted, repetitive patterns of behavior, interests, or activities, as manifested by at least two of the following, currently or by history.

1. Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypes, lining up toys or flipping objects, echolalia, idiosyncratic phrases).

2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take the same route or eat the same food every day).

3. Highly restricted, fixated interests that are abnormal in intensity or focus (e.g., strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interests).

4. Hyper- or hypoactivity to sensory input or unusual interest in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).

C. Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities, or may be masked by learned strategies in later life).

D. Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.

E. These disturbances are not better explained by intellectual developmental disorder (intellectual disability) or global developmental delay. Intellectual developmental disorder and Autism spectrum disorder frequently co-occur; to make comorbid diagnoses of Autism spectrum disorder and intellectual developmental disorder, social communication should be below that expected for general developmental level (American Psychiatric Association, 2022, p.56, 57).

DSM-5-TR included changes in the diagnostic criteria sets or specifier definitions in criterion A for Autism. The criterion A phrase *"as manifest by the following"* was ambiguous and could be interpreted to mean "any" of the following (one of three). The revision for criterion A now reads *"as manifested by all of the following"* (three of three) to make the intention of the criterion clearer and maintain a high diagnostic threshold for Autism (First et al., 2022).

A publicly funded diagnosis of Autism starts with a General Practitioner (GP) referral to a specialist diagnostic assessment. An ideal team for making a diagnosis of Autism includes a paediatrician, psychiatrist, psychologist, speech-language therapist and an occupational therapist (New Zealand Guidelines Group, 2010). Additionally, the process entails interviews with the person being assessed at an appropriate level for their age and an interview with whānau or primary caregivers that is associated with information about development and whānau history. An individual assessment will take place to determine levels of communication and socialisation in structured and unstructured settings. Once a diagnosis is confirmed the person with Autism has the right to access the health system for various types of funding depending on accessibility to services where they reside.

Appendix 1a: Interview Questions

Think about your life with your loved one with Takiwātanga. I want you to consider all the things that you do as a mother/caregiver during the day, the night, at home, school and the community that facilitate the way you manage the lived experience of Takiwātanga. What do you do as a mother/caregiver to navigate your day, Other responsibilities and support other whānau members?

Tell me about your family/whānau

Tell me about your children (Your son/daughter who has Takiwātanga)

What has life been like for your family?

The really good things?

The challenges?

The School System

What has it been like supporting your child/adolescent/adult in the school system?

What have you done?

What has been good about school?

What has been challenging about school?

In what ways have your experiences with the school system shaped your perspective about Autism (tōna anō Takiwātanga) and your life?

The Health System

What has it been like for you supporting your child/adolescent/adult in the health system?

What have you done?

What has been good about the health system?

What has been challenging about the health system?

In what ways have your experiences with the health system shaped your perspective about Autism (tōna anō Takiwātanga) and your life.

At Home

What has it been like for you supporting your child/adolescent/adult in the home environment?

What have you done?

What has been good at home?

What has been challenging at home?

In what ways has your experiences at home shaped your perspective about Autism (tōna anō Takiwātanga) and your life?

Appendix 2: Letter for Organisations

MASSEY UNIVERSITY
TE KUNENGA KI PŪREHUROA
UNIVERSITY OF NEW ZEALAND

A Māori woman's perspective of mothering a child/adolescent/adult with Autism.

CCS Disability Action
17 Claudelands Road
Hamilton

Dear Sir Madam

Kia Ora, my name is Jan Hastie and I am a student researcher currently completing a Doctor of Philosophy degree with Massey University. My supervisors for this research are Dr Vijaya Dharan and Dr Pania Te Maro.

I would appreciate your support in accessing participants through your organisation.

My research aims to capture Māori mothers' perspectives of Autism. I am interested in exploring a culturally responsive and positive view of Autism through an indigenous and feminist perspective. As a Māori mother of a daughter with autism and as a scholar, I have found that such a positive view is often missing in the research literature.

My research focuses specifically on Māori woman's' lived experience of raising a loved one with Autism. The criteria for participating in my study are:

- Women who identify as Māori and who are mothers or primary caregivers of children/adolescents/adults with Autism.

In terms of being culturally responsive I am conducting an arts-based research method in which participants talk about their experiences while creating a piece of art that is meaningful to them. I believe that this method is appropriate for research that involves Māori women.

I have attached the full information sheet for prospective participants in electronic form. I can provide a printed version of this information sheet. I would appreciate it if you could disseminate it through your data base. I have asked the prospective participants to contact your organisation to release their contact details or me directly. I am happy to discuss any of the details of my research with you so please feel free to contact me.

I look forward to hearing from you.

Yours faithfully

Jan Haste

Institute of Education
Private Bag 11222, Palmerston North 4442, New Zealand
06 356 9099 \ massey.ac.nz

Contact details:

Jan Hastie

Phone: 0273468002 (Please text).
Work: 07 346 8633
Email: jan.hastie@toiohomai.ac.nz

Address: Toi-Ohomai Institute of Technology (Formerly Waiariki Institute of Technology)
Mokoia Drive
Rotorua 3015

Primary Supervisor

Dr Vijaya Dharan

Phone: (06) 356 9099 ext. 84315
Email: V.M.Dharan@massey.ac.nz
Senior Lecturer

Address: Massey University
Tennent Drive
Palmerston North 4474

Supervisor

Dr Pania Te Maro

Phone: (06) 356 9099 ext. 84459
Email: P.Temaro@massey.ac.nz
Senior Lecturer

Address: Massey University
Tennent Drive
Palmerston North 4474

This project has been reviewed and approved by the Massey University Human Ethics Committee: Southern A, Application 19/70. If you have any concerns about the conduct of this research, please contact Dr Negar Partow, Chair, Massey University Human Ethics Committee: Southern A, telephone (04) 8015799, extension 63363, email humanethicsoutha@massey.ac.nz.

Appendix 3: Participant Invitation Letter

A Māori woman's perspective of mothering a child/adolescent/adult with Autism.

Ko Mauao te Maunga
Ko Tauranga te moana
Ko Taakitimu te waka
Ko Ranginui te Iwi

Kia Ora, my name is Jan Hastie and I am a student researcher currently completing a Doctor of Philosophy degree with Massey University. My supervisors for this research are Dr Vijaya Dharan and Dr Pania Te Maro.

I would like to invite you to participate in my research project on Autism. I am interested in increasing the knowledge about Māori women's perspectives about Autism in relation to:

- the school system
- the health system
- home
- Whanau

The aim of my research is to explore and *offer* a different way of thinking about autism, one that is culturally responsive and presents a positive view of Autism. As a mother of a daughter with autism and as a scholar, I have found that such a positive view is often missing in the research literature.

Who can take part in the research?

I am seeking Māori women who are mothers and/or caregivers of children/adolescents/adults with autism.
What will you be asked to do?

If you agree to be a participant in this research you will be asked to be part of a focus group to come and discuss your experiences about school, the health system and home. The korero in these sessions will be alongside artwork that you will be creating.

This is called arts-based-research and has been found to be more user-friendly than the traditional question and answer type of focus groups. You do not have to be an artist. It is about getting together with up to four other Māori women to share stories about your perspectives of Autism, while creating a piece of artwork. This should take around 3-4 hours to complete. These sessions will be audio recorded and photographs will be taken of the art activity and art pieces. The photographs may be used in academic publications with your permission. The art pieces are your property and when the research is completed, they will be returned to you by the researcher. I am aware that conversation can switch between te reo and English so I may ask for the English translation to check for the meaning of what is being said. Transport will be arranged to and from the hui if needed.

After completion of the focus group narratives and activities, each one of you will be given a $35 petrol or grocery voucher as koha. In addition to the voucher is a small personal gift for each participant. As a participant you will be invited to support the process of analysing the themes within the transcribed

transcripts after the focus groups have concluded. There is unlikely to be any discomfort through participation in this research. However, it is recognised that this research may cause participants some discomfort regarding a lack of access to services for you or your loved one with Autism. Therefore, a list of local support services in your area will be provided for you.

What will happen to the korero data?

- The recorded focus group discussions will be transcribed into a written document that will be used to answer the study questions and to write a thesis about the findings.
- Your name will not be linked to the written document. All discussion of what you say in the focus groups or tell me will only be identified by a numerical, alphabetical or pseudonym identifier.
- All transcripts will be stored in a secure locked location as the responsibility of the researcher.
- Data will be stored for a period of 5 years at which time it will be disposed of.
- A summary of the main findings will be offered to all participants and a copy of the completed thesis will be made available after the thesis has been examined. Once I have done this, all names and contact details will be destroyed.

Participants' Rights

You are under no obligation to accept this invitation. If you decide to participate, you have the right to:

- decline to answer any question.
- withdraw from the study prior to the analysis of the research data.
- ask any questions about the study at any time during participation.
- provide information on the understanding that your identifiable information will be made anonymous.
- be given access to a summary of the project findings when it is concluded.

Thank you for reading this information.

Should you wish to participate in the study, please contact the organisation who sent you this invitation or you can contact me via phone (07) 346 8633 or text (027 3468002). If you prefer to e-mail me, you can do so at: jan.hastie@toiohomai.ac.nz.

Please do not hesitate to contact me if you have further questions about the study.
You can also contact my supervisors using the contact details below if you have any questions.

I look forward to hearing from you.

Kind regards

Jan Hastie

Contact details:

Jan Hastie

Phone: 0273468002 (Please text).
Work: 07 346 8633
Email jan.hastie@toiohomai.ac.nz

Address: Toi-Ohomai Institute of Technology (Formerly Waiariki Institute of Technology)
Mokoia Drive
Rotorua 3015

Primary Supervisor

Dr Vijaya Dharan

Phone: (06) 356 9099 ext. 84315
Email: V.M.Dharan@massey.ac.nz
Senior Lecturer

Address: Massey University
Tennent Drive
Palmerston North 4474

Supervisor

Dr Pania Te Maro

Phone: (06) 356 9099 ext. 84459
Email: P.Temaro@massey.ac.nz
Senior Lecturer

Address Massey University
Tennent Drive
Palmerston North 4474

This project has been reviewed and approved by the Massey University Human Ethics Committee: Southern A, Application 19/70. If you have any concerns about the conduct of this research, please contact Dr Negar Partow, Chair, Massey University Human Ethics Committee: Southern A, telephone (04) 8015799, extension 63363, email humanethicsoutha@massey.ac.nz.

MASSEY UNIVERSITY
TE KUNENGA KI PŪREHUROA
UNIVERSITY OF NEW ZEALAND

Appendix 4

PARTICIPANT CONSENT FORM

A Māori woman's perspective of mothering a child/adolescent/adult with Autism.

I have read the Information Sheet and have had the details of the study explained to me. My questions have been answered to my satisfaction, and I understand that I may ask further questions at any time.

I agree to the focus groups/interviews being sound recorded.

I agree that the focus group activity is a confidential space for all participants.

I agree to taking photographs for purposes of the research.

I wish/do not wish to have my recordings returned to me.

I agree to participate in this study under the conditions set out in the Information Sheet.

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

Full Name - printed .....

Institute of Education
Private Bag 11222, Palmerston North 4442, New Zealand
06 356 9099 | massey.ac.nz

MASSEY UNIVERSITY
TE KUNENGA KI PŪREHUROA
UNIVERSITY OF NEW ZEALAND

Appendix 5

A Māori woman's perspective of mothering a child/adolescent/adult with Autism.

AUTHORITY FOR THE RELEASE OF PARTICIPANT INTERVIEW TRANSCRIPTS

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

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

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

Full Name - printed .....

Institute of Education
Private Bag 11222, Palmerston North 4442, New Zealand
06 356 9099 | massey.ac.nz

Appendix 6: Ethics Approval

MASSEY UNIVERSITY
TE KUNENGA KI PŪREHUROA
UNIVERSITY OF NEW ZEALAND

Date: 18 December 2019

Dear Jeanette Hastie

Re: Ethics Notification - **SOA 19/70 - A Māori woman's experience of mothering a loved one with Autism.**

Thank you for the above application that was considered by the Massey University Human Ethics Committee: **Human Ethics Southern A Committee** at their meeting held on **Wednesday, 18 December, 2019**.
On behalf of the Committee, I am pleased to advise you that the ethics of your application are approved.

Approval is for three years. If this project has not been completed within three years from the date of this letter, reapproval must be requested.

If the nature, content, location, procedures or personnel of your approved application change, please advise the Secretary of the Committee.

Yours sincerely

Professor Craig Johnson
Chair, Human Ethics Chairs' Committee and Director (Research Ethics)

Research Ethics Office, Research and Enterprise
Massey University, Private Bag 11 222, Palmerston North, 4442, New Zealand **T** 06 951 6841; 06 95106840
E humanethics@massey.ac.nz; animalethics@massey.ac.nz; gtc@massey.ac.nz