



TE WHARE WĀNANGA O
AWANUIĀRANGI

TANGATA WHAIKAHA AND POLICY

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**“UN-LABELLING THE PAST: DETERMINING THE
FUTURE WELLBEING OF DISABLED PEOPLES:
INFORMING POLICY AND LEGISLATION
DECISIONS FOR TANGATA WHAIKAHA”.**

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DECLARATION

To the best of my knowledge and belief this thesis contains no material previously published by any other person except where due acknowledgment has been made. This thesis contains no material that I have submitted towards the award of any other degree or diploma in any other university or other institution.

This thesis represents research I have undertaken. The findings and opinions in my thesis are mine and they are not necessarily those of Te Whare Wānanga o Awanuiārangi.

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Mariana Morrison

Signature:

Date: 8 January 2024

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This research would not have been possible without the support of many people who deserve recognition. Firstly, I wish to acknowledge my daughters, Kahurangi and Te Rina, who provided unwavering understanding, patience, and love, without whom Mama would not have been able to complete this mahi.

To my partner Darryn and stepdaughter Aaliyah, thank you for your support. I would also like to acknowledge my Nan, Lady Kuia (Rangiwhata Anne) Morrison, for being my inspiration and heart, as well as for teaching me to never give up.

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To the participants of this study, it would not have been possible without your valuable knowledge and support, you are truly *taonga*.

It is noteworthy to mention that I worked full-time, raising many whāngai babies as well as my own, whilst completing a Bachelor of Laws (LLB) at the University of Waikato concurrently with my doctorate. This was no mean feat, and at times I was obviously distracted on assessments for the LLB, when I maybe could have worked on the thesis.

It is indeed somewhat unusual to thank my three examiners of this research, however, their careful reading and critique has allowed me to take the time to revise it,

to revisit the major arguments and to make it a better more robust thesis. I hope I have done justice to their concerns and issues.

In closing I thank my proofreader Faye Angelo who provided invaluable support in the structure and layout of the thesis, however, I note any small errors that remain, in argument, spelling, grammar and interpretation are entirely my own.



We have not often talked about mental asylums (psychiatric hospitals), psychiatric care, and institutions since the closing of many of these institutions in the early 1990s, one such example is Lake Alice. This doctoral research acknowledges all those who were segregated in asylums due to societal attitudes and never made it back to their haukāinga. Some of the issues of patient's treatment are currently being addressed in the ongoing *Abuse in Care Royal Commission of Inquiry* <https://www.abuseincare.org.nz/our-progress/reports/>¹

This research is dedicated to my cousin, Shannon, with my hopes and aspirations being to change the societal attitudes to creating more inclusive and empowering environments for Tangata Whaikaha (disabled) and whanau hauā to being able to access more equitable services within the communities of Aotearoa New Zealand.

¹ See for example: <https://www.abuseincare.org.nz/our-progress/reports/Beautiful-Children-Full-Report-PDF-v2.pdf>



PERSONAL POSITIONING

Like all academics, my own personal journey and background of Tangata Whaikaha has been through my own individual experiences. It is these which have influenced my mahi and passion in law, policy, and intellectual disability inclusion studies. My thesis is a living document.

On 23 June 2022, I successfully implemented the first Kaupapa Māori framework within a western-based framework in Elderly Aged Care. This was implemented based on the findings within this thesis. Due to my efforts and enthusiasm, I was appointed Head of Cultural Partnerships for Heritage Lifecare Limited. However, I have since left this role and worked on completing this thesis and working in Te Aka Whai Ora Māori Health Authority as Director of Localities, providing strategic leadership.

My personal position is from my own lived experience as whanau hauā, the thesis laid out in this study is informed by my subjective experience and the lived realities of myself and my whanau. These experiences have both guided the research topic and question(s) and informed the research from the outset. I talk more of my positioning within this thesis later in the introductory chapter.

Consequently, it is my view that deinstitutionalisation of Tangata Whaikaha, back in the early 1990s, was for political gains and agenda-based policies. It was not to meet the legislative obligations and person-centred human rights approach based on United Nations Conventions recommendations.

I, therefore, have argued that the social, political, legislative, and legal discourses that have been shaped and produced by the Aotearoa New Zealand Government since institutionalisation, have led to marginalisation and loss of cultural identity for Māori Tangata Whaikaha. This has been due to continued segregation from their families and communities. I further argue that this has led to associated and compounding socio-economic issues and challenges and these social determinants of disadvantage have compiled over the years. These inequities for Tangata Whaikaha, particularly Māori, have contributed to their not being able to live life as part of the community, nor to the provision of any sense of self-determining of their own health, wellbeing, and prosperity.

This research highlights the disadvantages people with disabilities have faced historically across various spheres - social, economic, cultural, and political. As many feminists have noted the personal is political and this is very much the case in this thesis.

ABSTRACT

It is difficult to comprehend the obstacles that Tangata Whaikaha and whanau hauā encounter, recent terms that have been used to describe peoples living with a disability and whanau that support a whanau member with a disability. The name Tangata Whaikaha was gifted by Maaka Tibble (Ngāti Porou) to shift from deficit negative labelling terms to more appreciative and enabling terms that focus on the strengths of disabled peoples. Such a history of naming can only remind us of the impact legislation, policies and institutions have had on our Tangata Whaikaha whānau.

The literature indicates that Tangata Whaikaha have been segregated from and marginalised by society since the closing of asylums (also known as mental or psychiatric hospitals) in the early 1990s. This marginalisation was primarily due to a lack of awareness of intellectual and other disabilities. This is highlighted in the literature and identifies multiple barriers and challenges for Tangata Whaikaha, for them to be able to live inclusive and flourishing lives in the community. This research asserts that, due to a lack of understanding and awareness of Tangata Whaikaha, contemporary society has failed to implement inclusive and enabling policy for Tangata Whaikaha, particularly Māori. However, it is not as simple to just say that raising awareness would result in a more egalitarian society.

This research uses Kaupapa Māori methodology and a combination of qualitative and quantitative data methods, more commonly known as a mixed methods approach. It compares the knowledge, attitudes and experiences drawn from the participants as well as the literature and draws new insights and understandings that might inform policy and decision-making in the future. The study consists of three data collection methods: E Likert scale survey, semi-structured interviews, and case study.

Sixty participants expressed their interest to engage with the Likert scale e-survey, however, only 54 participants completed the E-survey (a 90 per cent response rate). The purpose of the E-survey was to conduct an exploratory study. The intention was to assess the attitudes of whanau hauā, kaiāwhina and kaimahi surrounding culturally appropriate services' acceptability, based on the *New Zealand Disability Strategy*, then to compare the findings to a similar earlier study (Wiley, 2009).

Initially, twenty participants expressed their interest to participate in semi-structured interviews, however, due to tangihanga, barriers to travel and three participants

not attending, only 14 interviews were completed. The participants comprised four service managers, five support workers, and five whanau. All participants supported a whanau Tangata Whaikaha and were able to identify the inequities in providing culturally appropriate services in the Bay of Plenty Takiwa, and to inform and give breadth to the research question.

The third method was case study. The intention of the case study was to analyse the findings in the WAI 2575 memorandum-directions of the preliminary list of disability-related claims by investigating the stage two Health Services Outcomes, as well as the Kaupapa Enquiry and Māori Health Plan engagement findings conducted by the Ministry of Health (Ministry of Health, 2022) which give recommendations on more inclusive policy decisions.

In this study the intent was to highlight the disadvantages experienced by peoples with disabilities, specifically from a Māori perspective, and in so doing inform future decision-making around policies and legislation that are inclusive and enabling of all disabled peoples, particularly Māori, and so enhancing the mana of the people and name of Tangata Whaikaha. The main findings in this research are outlined throughout the three data chapters.

The significance of the WAI 2575 which highlights the equity gaps but highlights the need for further analysis if the legislative changes to the Public Health Act to Pae Ora have addressed the equity gap. Therefore, had limitations on assessing whether the needs of Māori have been reflected in changes to Māori.

The need for whanau haua and Tanagta whaikaha to be part and parcel of the decision making at all levels pertaining to policies that affect them, to make real inclusive change to their lives. The need for representation of Tangata Whaihaka on governance boards to create change and ensure that their voice is heard.

I conclude the thesis outlining its strengths, limitations, and the opportunity to challenge the current health system and an opportunity for further and future research.

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CHAPTER ONE

INTRODUCTION

1.0 Chapter introduction

The closure of asylums as well as health reforms have influenced the provision of services for Tangata Whaikaha. Discrimination, in the form of biases and negative attitudes, remains a significant challenge within healthcare systems. Deinstitutionalisation, while intended to support community-based care, has faced challenges in terms of planning and resources, impacting the transition from institutional settings. Marginalisation due to multiple factors, including disability, ethnicity, and socio-economic status, further exacerbates disparities in access to healthcare and support services for Tangata Whaikaha.

Notably, social policy has changed since the conclusion of this doctoral thesis and from when this thesis commenced in 2017. The government released three significant policy documents between 2018 and June 2022 and has suggested several far-reaching fair solutions for Māori to meet Treaty of Waitangi obligations. This chapter gives an overview and a background to the study.

1.1 Background to the Study

There have been significant changes and discrepancies in Aotearoa New Zealand's healthcare systems, policies, and regulations since the 1950s. Institutionalisation, on the other hand, is a global phenomenon. The reconfiguration to privatise asylums in New Zealand had ramifications for both state welfare and deinstitutionalisation. The funding arrangements in the late 1980s, as indicated in the literature, revolutionised how the health care system operated, combined with the privatisation of these asylums (Joseph & Kearns, 1999). Over the last three decades, Tangata Whaikaha, advocates and reformists have organised in numerous countries throughout the world to oppose the historical discrimination and marginalisation of disabled people (Shakespeare, 2006). In 1984, the Labour Government sought to make changes to New Zealand's healthcare system, and the stigmatisation of institutions indicated a redundant, inefficient, and inappropriate use of government funding.

Disabled persons not only have poorer health outcomes because of their impairment, but they also seek the same opportunities as other New Zealanders. Furthermore, disabled persons confront several obstacles, along with expenses, before they can achieve their dreams of living a regular life. There have been several costs linked with disability. Disabled people may

require additional resources to live a normal life. Their requirements differ depending on their circumstances, as well as the type and severity of their impairment.

Firstly, it is important to determine what an intellectual disability is. An intellectual disability (ID) is characterised as a significant impairment in both cognitive functioning and conceptual, social, and practical adaptive skills that began before the age of 18 (Ouellette-Kuntz et al., 2005). For defining and categorisation explanations, four broad techniques (social, therapeutic, intellectual, and dual criterion) have historically been utilised. These four methods are still visible in current discussions about who is (or should be) diagnosed as having an intellectual disability (Switzky & Greenspan, 2006). Every person who is or was eligible for a mental retardation diagnosis is also eligible for an intellectual disability diagnosis. The fact that intellectual disability falls within the broad category of disability helps to explain why the term 'intellectual impairment' has arisen as a preferred term to replace mental retardation (Schalock, et al., 2007).

Social historians have described the process of reforming mental health policy as a lever swinging between two opposing schools of thought: legalism, and professional discretion. Neither term lends itself to a simple definition. Traditional "legalism" appears to embody a set of principles requiring the use of compulsory powers in mental health, to be carefully limited by clear criteria and legal procedures; the term is frequently used to emphasise the importance of a judicial determination of the need for compulsory admission according to Gostin (1983). Rights-based legalism is a term used to describe a cycle that emphasises mental health laws and refers to the rights of individuals with mental health conditions as described by McSherry and Weller (2010).

In the early twentieth century, the New Zealand Government wanted to segregate people with physical and mental disabilities. New Zealand's Government and society believed that mental and physical diseases were caused by societal circumstances, criminality, and a poor socioeconomic class of individuals, and the government sought to segregate persons with physical and mental disabilities. Since the closure of institutes around the world, there have been substantial adjustments. Although institutionalised Tangata Whaikaha suffered tremendous institutionalisation and segregation, deinstitutionalisation has resulted in a massive shift in policy reforms.

In a study conducted by Wiley (2009), the findings suggested that there was a lack of accountability, consistency, and collaboration in implementing the *New Zealand Disability Strategy* objective 11 had failed on its intent to support Māori disabled to live more inclusive

culturally appropriate services. Although New Zealand has seen numerous changes to the Health and Disability sector since this study was conducted, a further report in the claim of WAI 2575 has also alleged that the Crown has breached Te Tiriti o Waitangi by failing to provide Māori with equitable health results and service provision (Ministry of Health, 2022). The proposed recommendation was that the legislation would provide a new organisational and accountability framework. Therefore, giving rise to and rationale for the research argument in this thesis to identify policy recommendations based on the attitudes, experiences that may inform policy recommendation surrounding accountability and equitable service provision for Tangata Whaikaha and whanau haua.

The changing landscape of the health system, based on the WAI 2575 recommendation, has seen the New Zealand Government implement new legislation with the introduction of the *Pae Ora (Healthy Futures) Bill*. The *Pae Ora Act 2022* aims to reduce disparities and variation within the publicly funded healthcare system. The *New Zealand Public Health and Disability Act 2000* was to be completely repealed and replaced by the *Nga Paerewa Health and Disability Services standard* (2022), which came into effect on 28 February 2022 and was implemented under the *Health and Disability Services (Safety) Act 2001*.

Further to the legislative changes, another common theme that has been identified is the disability social model. This is the fundamental political concept that both introduced and continues to sustain the rights of those with disabilities and challenge mainstream society. According to Shakespeare (2013), the term 'social model' indicates progressive approaches to disability, whilst the medical model encompasses everything that is backward-oriented and regressive policy framework. In comparison however to Tsakanikos and McCarthy (2014) state that policies in developed countries have supported autonomy, decision making, and enhanced access to services for individuals with Intellectual disabled that have implemented over the past 20 years.

Hickey (2006) and Durie (2012) both argue that the social model does not support Māori with disabilities, and they highlight the need to close the gap regarding the disparities experienced by the Indigenous peoples of Aotearoa New Zealand and the need for a more accessible holistic approach to care for disabled. However, there remains a dominant bias and stigmatisation of those with a disability that needs to be changed in New Zealand. Traditional ideologies and policies that support the social model are still preferred although they have been identified by some as drawn from backward thinking.

As well as the changes in legislative reforms, and the preferred use of the social model in policy setting and decision-making, Tangata Whaikaha have had to endure hegemonic societal perceptions that cultivate viewpoints and behaviours that lead to discrimination, segregation, and oppression. Simpson et al. (2019) argue that Tangata Whaikaha are no longer dominated by the physical infrastructure that once isolated them and the socially acceptable attitudes.

According to Lawson-Te Aho et al., (2019) there is also a direct impact on low socioeconomic concerns, as well as aspects that are widespread amongst disabled communities. There is a need for additional resources and support for Tangata Whaikaha to address social determinants that affect health such as homelessness, drugs and alcohol and offending according to Gulcur et al., (2003) These factors can impact overall health and contribute to higher rates of disability.

In Aotearoa New Zealand, one in five Māori report having a disability due to the high youth rate in Māori communities and the higher susceptibility of Māori to disabling health conditions as they age. These disparities can be attributed to a variety of factors, including socio-economic factors, access to healthcare, and historical and cultural determinants. Therefore, there is a need to focus on Māori with disabilities, especially given the existing policy's lack of accountability, consistency, and collaboration in conducting and successful implementation of the *New Zealand Disability Strategy* (Wiley, 2009). Notably, the incidence of disability is expected to increase, according to the Ministry of Health (2012). Te Arawa iwi has the third highest representation (18.1%) of Māori with an intellectual disability, as compared to the general population in New Zealand, stated by the Ministry of Health (2016). Highlighted in the statistics and demographic features are the relevance of the high rate of Māori service users. Furthermore, statistics indicate the youthfulness of the Māori population (half of the population is under 25 years of age). In addition, the Ministry of Health (2016) identify a disproportionate representation of Māori in low socioeconomic groups (two-thirds live in deprivation deciles 7-10).

These statistics indicate disproportionately high rates of Māori in Tangata Whaikaha, we also see a growing number of disadvantaged through disability. This is reflected in the literature, not just in legislation, policy, and social determinants. For example, as discussed in Humpage (2005), Māori are disadvantaged due to current and past policies that did not and do not reflect Indigenous people's right to self-determine or make their own decisions on how to support their most vulnerable.

Current policy settings have not benefited Māori and therefore there is a need for policy reforms that improve the experience of Indigenous peoples who have been subjected to general policy discourse in attempts to address the socio-economic issues raised for disabled peoples. Better outcomes through more inclusive Māori engagement in policy are required, of which, according to Came (2014), are due to the lack of poor consultation practices. In New Zealand, institutional racism continues to influence public health policymaking and, along with a history of colonisation and unequal access to health services, contributes to health disparities for Māori, and their ongoing limited use of primary health care services.

Therefore, as asserted by Eggleton et al., (2022), this raises the issue of culturally appropriate services for Māori and the need to be more responsive to ensure there is a development in the Māori health policy. This is in comparison to Hickey and Wilson (2017) who mention that there are still existing gaps in Māori participation planning and policy discussion decision making. They also disagree with the existing frameworks and assert they do not fit with a Kaupapa Māori framework.

The literature not only indicates the inequities of policy, and higher rates of disproportionate representation in health statistics, but also in Indigenous communities. Indigenous communities are typically considered to be at higher risk than non-Indigenous groups of experiencing chronic disease or sickness, injury, suicide, and death, according to social determinant theories of health. Dominant attitudes in health research associate racial discrimination with societal disablement, sustaining an 'Indigeneity as disability' narrative in which Indigenous peoples are disabled regardless of individual potential. This logic can divide lived experience and impede the formation of identity and community participation for Indigenous peoples with disabilities, according to Ineese-Nash et al., (2018). However, according to Fleurbaey and Schokkaert (2011) inequity in health care is a multifaceted problem.

Graham (2005) states that there is a continuum of connection between socioeconomic status and health, both over time and across main causes of mortality. Children and adults with Tangata Whaikaha are over-represented in the poorer and less healthy groups in society. However, research on health disparities and larger societal implications on health have yet to be incorporated into perspectives and policies for persons with intellectual impairments.

In summary, the literature indicates that further investigation is needed surrounding what recommendations are required for policy to address the inequities that are seen not only in Māori, but also in other Indigenous peoples. The themes in the literature indicate social

determinants of health, discrimination, and disproportionately high rates of health and disadvantages across a wide range of policies and leave Tangata Whaikaha more disempowered based on the already existing lack of awareness to their living inclusive lives.

There is still insufficient data and information surrounding the disabled in New Zealand. Research highlights a need to focus on disabled communities. Therefore, the importance to articulate the broader significance of your research in terms of informing policy, improving service provision, and enhancing the overall quality of life for disabled individuals. Highlight how your findings may contribute to positive societal change. By addressing these points, you can provide a comprehensive and compelling rationale for the importance of conducting research on disability in New Zealand, particularly focusing on the need to shed light on the experiences of disabled communities that may be underrepresented or overlooked in existing literature and data. to establish this topic's context, background, and importance. A new generation of research in this area need to address the extended question to how this research aligns with broader government objectives across agency to create a more inclusive and supportive society for people with disabilities. by identifying and finding more evidence. Based on identifying the concerns faced by the disabled, we can more than manage and provide better opportunities for Tangata Whaikaha and whanau hauā to ensure that they receive equitable service provision.

This research shows that an Indigenous perspective gives Kaupapa Māori validity and a voice for improving the policy and service delivery.

Therefore, the purposes of this study are:

1. To investigate the attitudes of whanau hauā, kaiāwhina, and kaimahi surrounding the New Zealand Disability Strategy implementation
2. exploratory investigation to assess whether the attitudes of whanau hauā, kaiāwhina, and kaimahi surrounding the New Zealand Disability Strategy are still the same compared to Wiley (2009)
3. To evaluate the effectiveness and barriers to equitable service provision of current government policy (Māori Health Strategy) analysing perceptions of whanau hauā, kaiāwhina, and kaimahi to inform recommendations for what inclusive policy is for Tangata Whaikaha.

1.2 Aim and Research Questions

The overall aims of the study are to identify existing barriers to equitable service provision, critically evaluate the New Zealand Government Disability Strategy Policy, and in so doing make recommendations for more equitable service provision for Tangata Whaikaha through policy changes. To achieve the aims as described above, this research seeks to first answer several questions:

- *What are the current obstacles that Māori face in obtaining disability services?*
- *What are the barriers to creating equitable service provision?*
- *What are policy recommendations for removing any such barriers?*

1.3 Significance

This study is both important and significant for several reasons. First, it will extend the study of Wiley (2009) and highlight significant breaches of *Te Tiriti o Waitangi* (1840) and the *Treaty of Waitangi Act* (1975) which gave life to the Waitangi Tribunal whereby iwi could contest grievances against State agencies and the governments of the day. In this instance the health sector is the field under scrutiny in this research in relation to, primary care, legislation, and health policy. Thus, it emphasises the importance of examining the implications for the Aotearoa New Zealand healthcare sector and the denationalisation of healthcare systems.

Second, it will provide up-to-date information, from a Māori perspective, on the New Zealand Disability strategy, and will inform the framework regarding insight into Māori. Therefore, as Creswell (2003) states:

Employ the methods that will best serve the theoretical perspective of the researcher... (it) may be able to give voice to diverse perspectives, to better advocate for participants or to better understand a phenomenon or process that is changing as a result of being studied. (p. 216).

This will ensure that the data collected adds to the breadth of new knowledge. where there has been an insufficient collection of data from the whanau voice and the implications this voice may have on Tangata Whaikaha and Whanau hauā.

The literature indicates that further investigation is needed surrounding how the attitudes toward creating better awareness and inclusive environments in policy for Tangata Whaikaha.

There is still insufficient data and information surrounding the disabled in New Zealand as indicated in Eggleton et al., (2022), therefore highlighting a need to focus on these communities and, therefore, emphasising the significance of and need to conduct such

research. Based on the experiences and concerns faced by disabled peoples, we can provide better opportunities for them in the workplace and in their everyday lives. The research is centered upon an Indigenous perspective of the experiences of disabled peoples, gives Kaupapa Māori validity as an appropriate research approach, and a Māori voice for improving policy and service delivery.

1.4 Overview of Methods

The research must follow Kaupapa Māori research methodologies. This is because there are one in four New Zealanders with a Tangata Whaikaha and one in five Māori. The aim and intention of this research is to investigate the ideas associated with disability and health service to attain equitable health care for whānau hauā supporting Tangata Whaikaha. The literature highlights recommendations to prioritise Māori health for Tangata Whaikaha to address longstanding inequities in policy and, therefore, the rationale for using Kaupapa Māori methodologies and approaches.

This study uses a mixture of methods to collate data and answer the research questions. Because Māori Tangata Whaikaha are currently under-represented in health and disability policy decision-making and service planning forums, the study will, therefore, contribute to the knowledge gaps in this area. The research methods used in this investigation were E-surveys, semi-structured interviews, and case studies. These methods were chosen because there are existing gaps in the literature and a dearth of data on the cultural impacts of policy on whānau who support their whānau members with Tangata Whaikaha. These gaps in knowledge, insights, and experiences from Tangata Whaikaha and their whānau require a wide range of methods to draw out and learn from them, if there is to be meaningful systemic changes and transformation for Māori Tangata Whaikaha and whānau hauā.

1.4.1 What are the inequities of service provision for Māori Tangata Whaikaha and whānau hauā?

An E-survey using a Likert scale was chosen for numerous reasons: it is fast, cost-effective, and efficient, straightforward to create, and is likely to yield a reliable scale, as stated by Taherdoost (2019). Furthermore, it enabled me to compare results with Wiley (2009) based on a similar study and, therefore, using the same method was preferred.

1.4.2 What are the attitudes of whānau hauā, kaiāwhina, and kaimahi?

The semi-structured interview is the method chosen to draw out insights and understandings. These will then aid the establishment of equitable service provision through policy where

there have been existing gaps in meeting the needs of Tangata Whaikaha, and the New Zealand Disability Strategy for whanau hauā supporting Tangata Whaikaha. Qualitative research enables the participants to participate in the research with either a structured or semi-structured interview, based on questions that have been derived to draw insights of the reality and practice, according to the participants (Morris, 2007).

1.4.3 What are recommendations for inclusive service provision?

A case study method was chosen to answer the second research question, what are the barriers to creating equitable service provision to evaluate the stage two *Health Services Outcomes Kaupapa Enquiry* and *Māori Health Plan Engagement* findings. According to Yin (1993), a case study design should be considered when: (a) the purpose of the study is to answer "how" and "why" questions; (b) you cannot manipulate the behaviour of those involved in the study. Therefore, for these reasons, I wanted to gain insights from the contextual conditions of the case studies, as they are relevant and integral to the phenomenon under study. In this case, these are the policies currently in place and the impact these have had on Tangata Whaikaha and whānau hauā, then to give policy advice and recommendations that lead to more equitable outcomes.

1.5 Overview of Thesis

Chapter One introduces the research topic and provides some background on how the closure of asylums and health reforms have influenced the provision of services for Tangata Whaikaha. Discrimination, in the form of biases and negative attitudes, remains a significant challenge within healthcare systems.

Chapter Two is critical a literature review that explores a wide range of literature to answer the research questions and to explore different methodologies and methods outlined in the literature.

Chapter Three discusses the research frameworks and methodologies on which my research is based. These are based on Kaupapa Māori methodology with the use of the Pōwhiri framework. The chapter also describes the methods I have used to seek answers to my research questions. They are E-survey, semi-structured interviews, and case study methods.

Chapter Four presents the findings / results of the Likert scale E-Survey questions to answer research question on What are the obstacles that Māori face in accessing culturally appropriate services in comparison to an earlier study of Wiley (2009),

Chapter Five presents the results of the semi-structured interviews to answer research question two, what are the barriers to accessing equitable services for Tangata Whaikaha and whanau whaua.

Chapter Six presents the finding results of the case study to answer research question three.

Chapter Seven is the discussion part covering the analysis of the research questions and the findings.

Chapter Eight is the thesis conclusion providing an overview, key findings, limitations, recommendations, and thesis closing.

This chapter introduced the thesis and the background to the study, highlighting the inequities of policy based on legislation. The next chapter reviews the literature with a particular emphasis on ascertaining what impact the government policy has had on Tangata Whaikaha and whanau hauā Māori, and to highlight the perspectives of indigenous people.

Researcher positioning

I noted on an earlier page my personal position in relation to the research, that is I am a proud Māori wāhine toa, a mama, a partner, a worker and advocate and an academic practitioner. I am also a warrior researcher. Throughout this thesis, I will declare my own personal and professional positioning within this deeply personal exploration of my chosen topic. Declaring one's position is important in both Feminist and Indigenous research, and this takes these standpoints as both theory and practice.

This research is underpinned by a commitment to 'practitioner' research, whereby educational research is conducted by one or more practitioner/professionals into either their own practice, or into the practices of their organisation (Wellington, 2000). The advantages of conducting this type of research include the prior knowledge and experience that participating practitioner/professionals afford concerning the setting and its context. They bring 'insider' knowledge to bear; they initiate easier access; provide improved insights into the situation and critical perspectives about the people involved; they contribute familiarity with situations and informants because of their history of personal relationships with contributing participants, e.g. with teaching/researching colleagues. Furthermore, practitioner insight may assist those from 'outside' with facilitating design validity, ethical integrity and a richer level of research reporting (Wellington, 2000, p. 20). Linda Tuhiwai Smith (1999, p. 139) provides the following enlightening argument on this topic:

Insider research must be ethical and respectful, as reflexive and critical, as outsider research. It also needs to be humble. It needs to be humble because the researcher belongs to the community as a member with a different set of roles and relationships, status and position.

Mutch (2005, p. 86) suggests a useful strategy is to utilise a critical friend or mentor outside the setting to debrief with. Because this is essentially mostly a qualitative research inquiry the researcher’s own biases and assumptions should be laid bare. My own beliefs about research in the health sector are coloured by experiences both positively and negatively.

In acknowledging my own research biases, I am stating my ‘subjective’ position in the research Wellington (2000), thus for me my worldview is that reality is subjective, and constructed and reflexivity is important. Advocating or declaring a position is common in qualitative research, whereby the researcher describes themselves theoretically in relation to the research being conducted, thus ‘declaring one’s position’ (Mutch, 2005). In terms of the researcher’s own reflectivity –thus reflecting on one’s own experiences and practices and also reflexivity – consider how one’s history and position influence current decisions will be recorded and at the fore in this research. I found the following literature helped me to carefully consider being reflexive and honest about my own position with the research. Therefore, I have included these authors here in a table format below along with my first reflection.

Table 1: Reflexivity and positioning

<i>Reflexivity and Self-reflection and issues in research</i>
Mutch, C. (2013). <i>Doing educational research: A practitioner’s guide to getting started</i> (2 nd ed.). NZCER Press.
Mutch, C. & Wong, M. (2005). Confessions from the field: Unpacking our research kete. <i>Waikato Journal of Education</i> , 11(1), 43-60.
Norsworthy, J. (2005). Changing expectations of research: Wrestling with the complex and unpredictable. <i>Waikato Journal of Education</i> , 11(1), 89-106
Petrie, K. (2005). Coming unstuck as an interviewer. <i>Waikato Journal of Education</i> , 11(1), 107-120.
Schmidt, C. (2005). Phenomenology: An experience of letting go and letting be. <i>Waikato Journal of Education</i> , 11(1), 121-133.
<i>Researcher positioning</i>
Lichtman, M. (2011). <i>Qualitative research in education: A user’s guide</i> . Sage
Merriam, S. & Tisdell, E. (2016). <i>Qualitative research: A guide to design and implementation</i> . Jossey-Bass.
Savin-Baden, M. & Major, H. (2013). <i>Qualitative research: The essential guide to theory and practice</i> . Routledge.
Yin, R. (2016). <i>Qualitative research from start to finish</i> . The Guilford Press.

(Source: Smith, n.d. published table provided in the Research Methods Prof. Doc paper, 2017)

CHAPTER TWO

LITERATURE REVIEW

2.0 Chapter Introduction

In the previous chapter, we explored the implications of health reforms, discriminatory practices, deinstitutionalisation, and marginalisation on the equitable service provision for Tangata Whaikaha (Māori individuals with disabilities). We discussed the ongoing challenges and the impact of these factors on their access to healthcare and support services.

The literature review highlights the gaps in the literature surrounding Tangata Whaikaha and whanau hauā to better understand the research problem. There is anecdotal evidence identified in the statistics which indicates a dearth of data surrounding accessible services for Māori Tangata Whaikaha. According to Joseph et al., (2009), this is due to Māori commonly taking care of their own. Māori Tangata Whaikaha and whanau hauā are usually located in rural areas and limited to accessible services. It is noteworthy to mention that a vast majority are unaware of the health service providers they have access to, according to the Ministry of Health (2016). There are also limited studies in the Aotearoa New Zealand literature surrounding the implications of inclusion and what the barriers are precisely, as well as a lack of specific iwi-based perceptions of services for the Tangata Whaikaha.

2.1 Key literature topics

The literature was broken down by themes into subsections with specific reference to Tangata Whaikaha, whanau hauā, and health professionals to get a good breadth of knowledge to compare the findings of this research project. The topics included are as follows: International literature surrounding the indigenous perspective of disability; Colonisation impacts of disability from an Indigenous perspective; post-colonialism; the Indigenous perspective of the policy of Tangata Whaikaha and indigenous sovereignty. The New Zealand literature review consisted of the following subsequent subheadings within this chapter.

2.2 International literature relevant to the topic (Iwi Taketake)

This section reviews literature from overseas relevant to the kaupapa of the thesis.

2.2.1 Indigenous Perspective of Disability

Indigenous tribes around the world have various views and interpretations of the impairment experience (Lovern & Locust, 2013). Many Indigenous languages of Turtle Island (North

America) do not include a word for disability. This could be explained by the fact that these languages tend to be context-based (Gross, 2016).

Indigenous peoples with disabilities are frequently regarded as too disadvantaged to engage in society and severely limited due to both disability and racial prejudice (Durst, 2006). Indigenous peoples with disabilities sometimes encounter geographic hurdles to getting support services in some states (Roberts et al., 2005), as well as systemic racism, indicated in Baxter et. (2006).

2.2.2 Colonisation Impacts of Disability from an Indigenous perspective

A historical perspective offers new light on the common origins of welfare and asylum policies, as well as disturbing beliefs about the exceptionalism of contemporary migration, the primacy of nation-state borders, and corresponding political and state norms of governance. The unresolved grief of Indigenous peoples around the world has been sobering based on historical critique and analysis of the assimilation policies and the segregation and marginalisation that took place with the American Indians. In these communities, state policies inflicted historical trauma that has led to poorer health and social status outcomes of its people (Heart, 2003).

The term disability is a colonial construct that contradicts Indigenous ideas of community and so perpetuates assimilation practices that cause and inflict harm. This is not to argue that Indigenous peoples are prone to having difficulties in surviving without intervention; rather, colonial history has developed a normative practice for the treatment of those psychologically challenged, particularly Indigenous peoples, which perpetuates institutional dependency (Ineese-Nash, 2020).

This history of discriminatory policies and practices towards Indigenous people has been one of neglect and exclusion, though there have been periods of intense surveillance, incarceration 'for their good,' medicalisation, including pathologising Indigenous cultures, lifestyles, and bodies, and eugenics through sterilisation or, more commonly, control of sexuality. In some cases, the same scientists and medics detained and trained Indigenous people in facilities that had previously served individuals deemed 'feeble-minded' or infected with contagious diseases (Evans- Campbell, 2008). This history encompasses the practices of colonial brutality and neo-colonial power, which imposed widespread ideas about those with disabilities as well as crippling moral and physical deficiency (Meekosha, 2006).

Over many decades, colonialism, and racism in Australia, as another example, have 'disabled' Indigenous people, regardless of their physical or mental incapacity (Hollinsworth,

2013). The overwhelming majority of disability service providers have yet to confront the ramifications of this history of government-imposed disablement on the programmes and services they deliver to Indigenous people (Smeaton, 1998; Danuletti, 2000; Nelson, 2009).

2.2.3 Postcolonialism

Disability and post colonialism are two crucial and interconnected discourses in the social formation of the nation and those individuals judged deserving of citizenship rights. We use the term 'post-colonial' to refer to all cultures impacted by the imperial process from colonisation to the current day (Ashcroft et al., 2003). There have been eleven preoccupations throughout the historical process that began with European imperial aggression. According to Ashcroft et al., (2003) state the discourse around the disablement caused by colonial history has evolved in recent years. In the 20th century we now consider the voices and perspectives that have emerged within academia, activism, and community narratives, shaping a more comprehensive understanding of the issues at hand. The new cross-cultural criticism that has evolved in recent years, as well as the discourse that has formed it, given that the history of colonialism (and its post/neo-colonial aftermath) is one of mass disablement. Thereby, thorough exploration of the connection between colonial history and disablement, acknowledging the complexity of this relationship within the context of cross-cultural criticism and contemporary discourse.

Although the notions and constructs of disability historically may be linked to larger patterns of dispossession—the loss of family, house, land, community, and employment. It is believed there is a compelling need to reject the all-too-easy condemnation of narratives that define disability as ‘a loss’ (Barker & Murray, 2010). Disability theorists who follow this path have argued that (post)colonial theorists frequently use disability as a metaphor, whereas for disability theorists, colonisation has become a key metaphor for describing the oppression, marginalisation, and exclusion to which disabled people are frequently subjected (Barker & Murray, 2010; Sherry, 2007). References to disability in (post)colonial theory are limited to the enactment of biopolitical processes that result in several types of oppression, marginalisation, or disenfranchisement under the conditionality of colonisation, empire, and imperialism (Sherry, 2007).

2.2.4 Indigenous perspective of the policy of Tangata Whaikaha

Despite the presence of legislation and services for the Intellectual disability population in South Africa, acknowledgment of and provision for their needs is given low priority (Adnams, 2010). In Australia policy and practice papers have mostly failed to address the requirements of people with disabilities in hospital contacts, (Iacono et al., 2014). These reviews have also indicated that some people with Tangata Whaikaha are afraid of hospital contacts, and that they rely on carers for the duration of their stays, furthermore, hospital staff have problematic attitudes and little knowledge, sometimes with disastrous results (Fitzsimmons & Barr, 1997; Bradbury-Jones et al., 2013).

There is little indication of the capability to deliver the types of accommodation requested by policy, and these elements are lacking in both health and disability service systems worldwide as identified in Australia and South Africa (Mencap, 2012; Iacono et al., 2014). The disability literature has investigated what constitutes appropriate adaptations, but evidence of consultation with mainstream services is scarce (Michael & Richardson 2008; Iacono et al., 2014).

2.2.5 Indigenous sovereignty

There is an absence of integration of culture, cultural practices, and experiences of culture into the analysis of data according to (Carroll et al., 2020). Thereby, in the absence of integration of culture, cultural practices, and experiences into the analysis of data is a significant limitation that can hinder the depth and accuracy of this research findings. Therefore, by highlighting the exposure to racism, isolation, marginalisation, and negative identity construction are all identified as aspects of the cultural landscape and Aboriginal experience that has had a detrimental impact on wellbeing (Daniel et al. 2011) enhance the integration of culture into the analysis of data, fostering a more inclusive, accurate, and respectful understanding of the phenomena under investigation.

In the early 1960s in Australia, a surge in Aboriginal and Torres Strait Islander voices drew attention to the lack of Indigenous rights in policymaking and the impact it had on the lives of people. Before 1967, states and territories had sole legislative and policy responsibility for Aboriginal and Torres Strait Islander peoples, as the Commonwealth was constitutionally forbidden from adopting laws affecting the people (Rainie et al., 2019).

Governments and international enterprises have, in the past, concentrated on legal authority issues (Kukutai & Taylor 2016). There needs to be a critique of current policy to highlight and investigate the depth of indigenous disadvantages in Australia in greater detail

as well as in New Zealand, Canada, and the United States. Therefore, this suggests a lack of understanding and intention behind self-determination and policy implications. The current framework fails to consider the view of Indigenous people which has meant that the policies have been unsustainable and inequitable to Indigenous people (Walter, 2021). Thus, involving Tangata Whaikaha in policy implementation allows them self-determination and to contribute to policies that impact them directly.

2.3 Aotearoa New Zealand literature relevant to the topic

This section reviews literature from New Zealand relevant to the kaupapa of the thesis.

2.3.1 A Narrative of the History of Asylums and Reforms in New Zealand

When searching for intellectually disabled, the terms used throughout the previous two hundred years have included idiocy, feeble-mindedness, mental deficiency, mental disability, mental handicap, and mental sub-normality (Goodey, 2005; Mercer, 1992; Schroeder et al., 2002; Stainton, 2001; Trent, 1994). The term mental retardation is now non-existent with the expression intellectual impairment increasingly being utilised as mentioned in Schalock et al. (2007).

An intellectual disability (ID) is characterised as a significant impairment in both cognitive functioning and conceptual, social, and practical adaptive skills that began before the age of 18 (Ouellette-Kuntz et al., 2005). For defining and categorisation explanations, four broad techniques (social, therapeutic, intellectual, and dual criterion) have historically been utilised. These four methods are still visible in current discussions about who is (or should be) diagnosed as having an intellectual disability (Switzky & Greenspan, 2006). Every person who is or was eligible for a mental retardation diagnosis is also eligible for an intellectual disability diagnosis. The fact that intellectual disability falls within the broad category of disability helps to explain why the term intellectual impairment has arisen as a preferred term to replace mental retardation (Schalock et al., 2007).

The *New Zealand Disability Strategy*, first published in The Office of Disability Issues in 2001, differentiates a disability from an impairment. Therefore, individuals do not have disabilities. Instead, they may have physical, sensory, neurological, psychiatric, intellectual, or other impairments (Office of Disability Issues, 2018). "Disability is the process which happens when one group of people create barriers by designing a world only for their way of living, taking no account of the impairments other people have" (Office of Disability Issues, 2018, p. 3).

In Te Ao Māori, the term whānau means to be born or to give birth. It, therefore, refers to the extended family network that may live within or outside of a home. Whānau differs from the commonly understood construction of the nuclear family and can be made up of either whakapapa whānau or Kaupapa whānau (Hickey & Wilson, 2017, p. 5). The term whanau hauā is referred to in this thesis and Tangata Whaikaha is the name given to the intellectually disabled. It is definitive in its name as is its translation, it merely states an aspiration to do well.

Furthermore, it is important to start the literature review by investigating the research, by assessing the attitudes and barriers to the intellectually disabled in policy. The starting point is the significance and importance of understanding the context of the history of asylums in New Zealand and the government mechanisms surrounding these ludicrous laws that were in place. Historically, for post-colonisation asylums the literature indicates that legislation was informed by society's attitudes and is reflected in the *Mental Defectives Act 1911*. The *Mental Defectives Act 1911* policy was implemented in New Zealand, following Great Britain and the United States, to segregate, institutionalise, and eradicate those deemed "unfit, troublesome and imbecile" from society, such as into psychiatric hospitals, with the last closing in 1998 in New Zealand.

Social control theory was the basis of asylums at their earlier conception and originated from "social orders. It is suggested that the implementation of social control theory was about managing care and controlling the service user. It is stated there was ambiguity surrounding care and control and what was reasonable to keep the public safe, according to Wiatrowski et al. (1981). The paradox of eugenics control theory was an implicit tension in a nineteenth-century asylum in Britain. It was mentioned that eugenics and social control theory occurred during the early 19th century, not only in Great Britain but also in New Zealand, according to Dale (2003). The Lunatic Act of 1883 also known as New Zealand Acts as enacted was another Act that was formed and implemented from the 1840s to the 1900s. According to *Lunatic Asylums 1840s-1900s* it was a colonial society that responded to managing mentally ill patients. In earlier times (the 1840s), the first asylum was set up in Wellington, with no treatment put in place, but to contain them and prevent them from harming themselves.

In 1871, at an inquiry into New Zealand's lunatic asylums, Legislative Councillor Dr. M. S. Grace offered this comment on the country's rate of mental illness: 'Insanity is much more common in [New Zealand] than it is [in Britain], chiefly on account of the limited range of sympathy which the isolation of individuals and families in the country gives

rise to, and also on account of the oppressive loneliness which many newcomers experience even in our crowded towns. Many immigrants, too, form the most extravagant anticipations of their new home and are proportionally depressed by the result of experience. (Brunton, 2005, p.5)

However, the first asylums did not have staff trained in mental health, but medical services were available, and they often practised restraint by using soft jackets with the higher complex cases. Patients who were able to work did so, inside and outside the asylum, where capable. Humanitarian movements pushed to see these asylums changed from initial confinement to a more rehabilitative framework. By the 19th century, the asylums were rehabilitative-based, housing much different for mental health and Tangata Whaikaha, including children, according to Brunton (2005).

Wanhalla (2007) explains that the eugenic movement was an inquest around an initial inquiry in 1924 in a debate into the *Mental Health and Mental Defectives Act* of sterilisation regarding a 1930s policy. Furthermore, in 1868, the *Lunatic Act 1868* (as enacted n.d) implemented regular inspections, and a report conducted by the 'Commission of Enquiry into the Constitution and Management of the Dunedin Hospital, and Lunatic Asylum' (1864) was mentioned in Brunton (2005). The Otago Provincial Council's Select Committee argued that the state ought to consider lunatics with sensitive concern and that no effort should be spared to enhance their situation. They categorically reject any treatment of them as captives or destitute. Fleming (1981) describes this period as looking to improve genetic personalities. The author mentions that the eugenic society's history reflects inclusive social issues. However, the author also mentions apparent contradiction and ambiguity compared to what happened:

Notwithstanding the development of civilising, Christianising, and educational institutions, crime, insanity, and pauperism are increasing rapidly. Proper care is to be found deep down in the biological truth society is breeding from defective stock. The best fit to produce their kind, while the fertility of the worst remains undisturbed"(Fleming, 1981, p. 12).

In the *Mental Deficiency Act* 'mental deficiency, now known as intellectual disability', was not officially recognized as a condition separate from lunacy until the early twentieth century. The *Mental Defectives Act* (1911), in New Zealand first acknowledged several categories, including; 'idiot,' 'imbecile,' and 'feeble-minded,' within the field of 'mental deficiency'. This legislation also sought to resolve the 'problem' of 'mental deficiency' The

Mental Deficiency Act's mental deficiency, now known as intellectual disability, was not officially recognized as a condition separate from lunacy until the early twentieth century.

In addition, it is crucial to have begun by highlighting, reviewing, and evaluating the attitudes and barriers associated with Tangata Whaikaha previously in the history of asylums about policy so as to give context. The history of asylums in New Zealand and the political structures were surrounded by absurd laws, informed by an ideology that they were imbecilic and idiots that needed to be segregated and marginalised from.

Society. That was a significant starting point for this literature review.

Furthermore, it has been 22 years since the last mental health inquiry in Aotearoa New Zealand, which was conducted by Judge Ken Mason in 1995–1996. The inquiry was conducted due to the deinstitutionalisation of committal patients to the community, with the closing of asylums in the early 1990s. However, there has not been a plethora of reviews and inquiries into the subject since. This, therefore, indicates the significance of this literature review.

The interconnectedness of institutionalisation and deinstitutionalisation with the *Mental Health Act 1992* is significant in highlighting further inadequacies and inequities in the policy. The intention is to define a connection between the closing of asylums and differentiated themes. Although Mental Health is not the scope of this research there is a need to highlight the recognition of Tangata Whaikaha and their mental health needs, especially those that have dual diagnoses.

However, the health reform in the early 1990s by the New Zealand Government sought to contract and privatise asylums. This was instigated for economic gain rather than reintegrating community well-being of Tangata Whaikaha mental health service users, according to Joseph et al., (2009). It is suggested that the implication of restructuring and privatisation of these asylums was not for state welfare so much as it was for deinstitutionalisation, which is argued by Joseph and Kearns (1999). Furthermore, it is argued that closing the mental health institutes had a dearth policy and strategies for supporting mental health and the community. Therefore, it is suggested that the theory of deinstitutionalization has been captured by the ideology of restructuring, which is why it is mostly referred to as having "failed".

Before 1992, in New Zealand, Tangata Whaikaha who posed risks to themselves or others, appeared before the criminal justice system to be treated under managed Mental Health. McCarthy and Duff (2019) mentioned that after the implementation of the *Mental*

Health Act 1992, there was a gap for Tangata Whaikaha, meaning those whose disabled behaviours were criminal and appeared in the justice system were seen under forensics and were admitted into places, such as Henry Bennett, in New Zealand, and imprisoned as special patients in prisons. Furthermore, due to the gaps in the legislation for Tangata Whaikaha, the *Intellectual Disability Compulsory Care and Rehabilitation Act 2003* (IDCCR Act), was introduced.

The purpose of the IDCCR Act 2003 was to “Establish a scheme which authorises the provision of compulsory care and rehabilitation to individuals with an intellectual disability who have been charged with, or convicted of an imprisonable offense” (McCarthy and Duff, 2019, p.8). However, Prebble et al. (2013) mentioned that there is a conflict between the needs of risk management, rehabilitation, and human rights; uncertainty regarding the "therapist" or "custodian" roles. Moreover, according to McCarthy and Duff (2019), there is little to no research surrounding the succession of a linear approach to the IDCCR Act 2003. This issue raises the point of whether the human rights of someone under the IDCCR Act 2003 is being managed consistently with their human rights.

Carroll et al. (2021) indicated that in our prisons there is still an unmet need surrounding psychiatric confinement and involuntary treatment of mental health incarceration. At the time of the study, it was a time of a rising trend in reporting of unmet needs of mental health patients in prisons and a potential breach of human rights surrounding involuntary treatment in the management of mental health. Although the findings that will be analysed pertain to the mentally impaired, the significance and importance of this study highlight and bring to light the gaps across agencies surrounding social determinants for mentally impaired and Tangata Whaikaha policy.

The apparent higher rates of Māori in the justice system with mental health need addressing. Particularly with regard to the *Treaty of Waitangi's* obligations of participation and partnership, so as to mitigate and ensure that the *Treaty of Waitangi* meets the Crown's obligations, according to Toki (2010). Wells et al., (2006) stated that Māori have a higher mental health rate than non-Māori and are disproportionately represented in the justice system. Matthews et al., (2018) indicated an overlap in mental health and neurodevelopmental disabilities. Therefore, there is a need for more specialised functions and systems for managing mental health needs of Tangata Whaikaha undergoing community and prison-based sentences.

Gibbeson (2020) discusses the stigma attached to asylums by highlighting that the negative action could look like a positive action for change based on their history. The qualitative study's findings explore the stigma attached to these hospitals and are perceived in a negative light. It is essential to analyse the negative and positive aspects of asylums for a better understanding.

The literature highlights that since deinstitutionalization there have been implications of legislation and disproportionate representation for individuals with Tangata Whaikaha in the community in society today, more specifically for Māori. The lack of implementation of reintegration and the dearth of study have impacted the lack of integration in the community of Tangata Whaikaha and mental health patients since the closing of Asylums, such as Tokanui Hospital. The literature indicates government policy has failed to address the institutionally oriented system, which was to deinstitutionalise. Therefore, there are still gaps in ensuring that the needs of the community of Tangata Whaikaha and mental health people in the community are met.

2.3.2 New Zealand Government Mechanism of Disability Strategy and legislative requirements

This section discusses: the *Mechanism of Government in New Zealand* legislation; the *United Nations Conventions*; the *New Zealand Disability Strategy*; *He Oranga Korowai Māori Health Strategy*; the *New Zealand Disability Act 2000*; the *New Zealand Health Disability Safety Act (2001)*; *Pae Ora Act 2022*; *Nga Paerewa Health and Disability* sector standards; and WAI 2575 claim.

The *Public Health and Disability Act (2003)* set out the provision under s 8 (2) that the Crown Minister is responsible for disability issues. Therefore, this act must determine a strategy for disability support services, called the *New Zealand Disability Strategy*. It is to provide the framework for the government's overall direction of the disability sector in improving disability support services and amend, or replace, that strategy at any time (p. 8). In 2009 the New Zealand Government established a ministerial committee to address issues related to disabilities, and the *New Zealand Disability Strategy* was put into effect the following year. The Chief Executives' Group on Disability Issues governs the current mechanism. Responsibilities are to monitor and implement the *New Zealand Disability Strategy* and to revise leadership and governance for implementing the United Nations Convention on the *Rights of Persons with Disabilities and the New Zealand Disability Strategy*. These United Nations Conventions and Covenants are part of the partnership with

different states around the world, and the rights of indigenous people through the global lens. They use the United Nations declarations on the rights of indigenous people to clarify the rights of Indigenous peoples. These stem from convenience in interventions, based on the United Nations and the Bill of Human Rights, in New Zealand. This is referred to in the *New Zealand Bill of Rights Act 1990*.

The WAI 2575 claim changed the legislation landscape in New Zealand. The claim alleged that the *Public Health and Disability Act 2000* is not Te Tiriti compliant and does not give Te Tiriti or its principles proper and complete effect. Furthermore, *He Korowai Oranga's Māori Health* strategy explanation of "partnership, participation, and protection" was said to fall short of accurately reflecting Te Tiriti or its guiding principles, according to the WAI 2575 claim. The *Waitangi Tribunal* (2019) inquiry into primary healthcare services and outcomes for Māori (the 'WAI2575 report') found detrimental colonial structures functioned in New Zealand's healthcare system. The Waitangi Tribunal highlighted the government's continued inconsistencies in applying the principles of the Treaty, "partnership, active protection and equity" (Waitangi Tribunal, 2019, p. 162), and failed to honour its obligations to provide equitable health outcomes for Māori.

The findings in the literature suggest that "reducing disparities" and "reducing inequality" are dominant rhetoric to achieve Māori health equity. The *Pae Ora Act 2022*, which was introduced to replace the *Health and Disability Act 2000*, has been introduced. A non-discriminatory approach to health and disability services in New Zealand and society is ensured by the Act, which enshrines the treaty principles and holds the New Zealand Health System accountable for monitoring and implementing them. This response to data collection findings that the Crown needed greater accountability to ensure the principles are followed.

Based on the findings in the WAI 2587 report on 28 February 2022, the Ministry of Health implemented the *Nga Paerewa Health and Disability Services* standard (Ministry of Health, 2022). The purpose of the sector standard is to implement a whanau-centric approach. The health and disability sector standards are reflective of the treaty and are reflective and responsive to the needs of Māori. They are part of the forty-seven new sector standards that were implemented based on the recommendations from the WAI 2575 claim in primary care. The *He Korowai Oranga Māori Health Strategy* is reflected in the *Nga Paerewa* sector standards for primary and community care, which were also put into effect as of July 2022 (Ministry of Health, 2022).

The case for more empowering alternatives to restrictive legal frameworks and reliance on unregulated informal support is embedded in the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). It continues to be made by the disability rights movement (Bach, 2017, p. 4). United Nations conventions set the obligations under these treaties and partnerships with different states around the world, and the rights of Indigenous people, through the global lens. The use of the United Nations declarations on the rights of Indigenous people is to clarify the rights of Indigenous peoples. These stem from conventions and interventions based in the United Nations and the *Bill of Human Rights in New Zealand*. Also, this is consistent with the *New Zealand Bill of Rights Act 1990* (NZBORA)

The significance of the *Treaty of Waitangi* and the United Nations *Declaration on the Rights of Indigenous Peoples* according to *Indigenous & Tribal Peoples' Rights in Practice* (2009) state that the United Nations conventions are essential when discussing the rights of Indigenous people of Māori descent. Therefore, this suggests that Māori are disproportionately represented in health statistics compared to non-Māori, according to King et al., (2009).

In summary, the WAI 2575 claim has highlighted breaches by the Crown to Māori in failing to meet the objectives of equitable health and service provisions. The Health and Disability Act has been replaced by the Pae Ora Act and ensures that equity and Te Tiriti are reflected and entrenched in legislation.

2.3.3 Disabled Statistics Overview New Zealand

The Ministry of Health (2016) says that Māori are reflected in the disability statistics with a disability between the ages of 15-64. Therefore, this recognises a significant issue for Māori. "One in five Māori report having a disability, and due to the youthfulness of Māori communities and the higher susceptibility of Māori to disabling health conditions as they age, the incidence of disability is expected to increase" (Ministry of Health, 2012, p. 1).

Ministry of Health (2022) asserts that Māori and European/Other individuals are over-represented among Tangata Whaikaha in New Zealand. Statistics from the Mātātuhi Tuawhenua; *Health of Rural Māori 2012*, mentioned in the Ministry of Health (2012), explained that the barriers to Māori accessing equitable service provision have been associated closely with linguistic, cultural barriers, and inequality, in the policy.

Measuring inequality for disabled New Zealanders 2018 statistics indicated key findings about inequality for disabled New Zealanders. In terms of a variety of outcomes

regarding their houses and neighbourhoods, as well as their economic and social life, disabled persons perform worse than non-disabled people.

Māori adults with a lived experience of disability were more likely to report they did not have enough money for everyday needs, such as accommodation, food, clothing, and other necessities, compared with Māori without lived experience of disability (25% and 8%, respectively) (Statistics New Zealand, 2015, p. 1) The disability survey reported on victims of crime experienced by a Māori with a disability. As the statistics indicate, 16% of Māori adults with lived experience of disability reported they had been victims of crime in the previous 12 months. Therefore, they were more likely to have been victims of violent crime than Māori adults without lived experience of disability (8% compared with 3%, respectively).

For Māori with lived experience of disability, there were no significant differences in age and gender- regarding the proportions of those who had experienced crime. The report states that overall, "Māori adults were almost twice as likely as non-Māori adults to have experienced any type of racial discrimination" (27.5% compared with 14.7%, respectively) (Ministry, 2015 p. 14).

The *Demographic Report of Disabled People* highlights the statistics as an overview and snapshot of where Māori sit statistically among the intellectually impaired compared to non-Māori. The data shows demographic data and trends for persons who need disability assistance services and are consistent with the findings of international studies. Demographic data indicated that of the 40,064 New Zealanders that access the Ministry of Health services, half of the service users had been Tangata Whaikaha, according to the Ministry of Health (2022). As indicated in the statistics, most recipients (63%) lived in New Zealand's largest number of districts, including the intellectually disabled.

Health statistics based on the Ministry of Health (2022) overview of the findings concluded the following:

- A disabled Tane compared to a non-disabled person will have a shorter life expectancy of 18 years.
- A disabled Wahine compared to a non-disabled person will have a shorter life expectancy of 23 years.

Those with Tangata Whaikaha were approximately 1.5 times more likely than those without intellectual impairment to obtain care or treatment for one or more of the six chosen chronic health disorders. They additionally were about 1.5 times more likely to receive chronic

respiratory disease care or treatment, about twice as likely to receive coronary heart disease diagnosis or treatment, and about 1.5 times more likely to receive cancer care or treatment.

People with intellectual impairments are more likely to be enrolled in a primary health care organisation, 1.5 times more likely to visit a general practitioner in three months, and twice as likely to be dispensed twice as many different types of prescription drugs from community pharmacies.

Persons with Tangata Whaikaha got \$3,001 in government-funded primary and secondary health care per person per year on average, about three times more than persons without intellectual impairment (\$1,028)

The report not only indicates the trends and statistics, but also indicates that New Zealanders with Tangata Whaikaha have poorer health and appear to be more vulnerable to illness, disease, and death than those without intellectual disability. This provides justification for the study, as the age range covered by the scope of this research is 44 to 65, and Māori have high and disproportionate rates of youth and young person contracts. study of aged care services.

Health status indicators in the Ministry of Health report (2018) highlighted that Māori statistics were under-represented and misinformed. Moreover, the mortality rate of Māori was due to the increase in different ethnicities from the 1980s to 1990s. Between the 1970s and 1990s, Māori life expectancy reports indicated an increase. Since the 1990s it has been similar to the life expectancy rate of non-Māori. Kingi and Pūtahi-a-Toi (2006), mentioned that the Treaty of Waitangi was the first strategic management health plan for Māori.

2.3.4 Mai Maketu ki Tongariro statistics

The Bay of Plenty (BoP) has 27% of the disabled population of Māori (73,000). The disabled population of Māori is prevalent compared to other age groups, with 32% of Māori with a disability and 65% aged sixty-five plus being highlighted in Statistics New Zealand (2015). Compared to the most recent report in the Ministry of Health (2020), indicators of Māori in the BOP have the third highest representation of Māori, with a principal I.D. of 2,766 clients engaged with disability support services. Of these individuals, 15.7% have an autism spectrum disorder.

In the Ministry of Health (2020) report, indicators for general Māori in the Bay of Plenty were engaged with behavioural support services and residential and community residences. Carer support with I.D. in the Bay of Plenty makes up 1,603 – 94 I.D. These

service users with client services. With 379 residents in the community, and 84.4% with an I.D., a total of 379 were identified as having autism.

In the Bay of Plenty, the youth residential services for Māori have a median age of 21. Of 7,151 disabled persons, 11.5% are Māori, and 59 live in the Bay of Plenty. 2766 people in the Bay of Plenty are supported by I.D. behavioural services, with a median age of eleven. Males heavily represent that ratio. Moreover, 21% of Māori disabled are accessing behavioural services, compared to the New Zealand population. Māori are again over-represented in the statistics, with 143 in the Bay of Plenty.

2.3.5 Intellectual Disability awareness for Primary Health Care Practitioners

The attitudes of health care professionals are an essential aspect to analyse. The Ministry of Health (2013) states that people with an intellectual disability are four times more likely than people without an intellectual disability to enter the hospital with an avoidable condition. In addition, the Ministry of Health (2013) suggests poor communication between primary healthcare providers, Tangata Whaikaha clients, and their caregivers. This highlights the importance of further analysing attitudes and intellectual disability.

Primary care providers and community support workers have been seen as providing inadequate care for these individuals, and a lack of training for working with Tangata Whaikaha, according to the Ministry of Health (2013). The findings in the Ministry of Health (2013) report poor communication between primary healthcare providers, Tangata Whaikaha and their caregivers. A survey undertaken by an Australian Medical Institute discovered; "training on knowledge of intellectual disability for working with people with intellectual disability was often inadequate" (Ministry of Health, 2012, p.1).

The Ministry of Health (2016) demographics of people with an intellectual disability report suggests recommendations for creating public awareness, further analysis of equal opportunities and investing further funding into implementation. The statistics highlighted the fact that there is a lack of awareness and implications of the New Zealand Disability Strategy on creating inclusive environments. Butterworth et al., (2015) conducted a study indicating that workplace culture was 83% successful in implementing disability culture inclusion in workplaces that employed the disabled. Butterworth et al., (2015) noted that barriers that prevented successful implementation were attitudes that disagreed that disability awareness was beyond the required responsibility of the organisation.

Stereotyping societal beliefs about the Tangata Whaikaha presupposes that a person with a disability is always associated with other impairments, thus carrying a stigma

regarding how they should be treated. An example of this would be a service provider who, presuming a wheelchair user is unable to communicate, does not address this person directly, but instead talks to the companion.

Block and Yuker (1977) and Gellman (1960) say that behaviour happens over time and is therefore learned. This stigmatisation and stereotyping are a result of the construction of what is "normal" or "abnormal," which is a process of socialisation. As a result, the shift from this medical model perspective, which constructs disability, to a social model perspective represents an important perspective. Both positive and negative prejudice, and frequently these attributions have little to do with the actual disability, according to Daruwalla and Darcy (2005).

The Ministry of Social Development (2023) highlights the importance of identifying what the responsibilities are in research when creating public awareness and mentioned the need for both further analysis of equal opportunities for the disabled, and investment in further funding for implementation. This would enable participation in the community and improve social inclusion. Research in the Ministry of Social Development (2023) identified the need for more inclusive environments, to face disparities that regularly contribute to barriers and the lack of inclusive environments, particularly in housing for mental health and the disabled.

Campbell et al., (2003) suggest that awareness training is successful if the attitudes change when confronted with a behavioural disability. Kastner et al. (1979) point out that disability surveys tend to elicit responses biased toward socially or politically correct views. Crates and Spicer (2012) mention that the difficulties implementing intellectually disabled workplace training programmes are the lack of funding, and no legislative framework to implement.

Successful implementation, as suggested in Peterson and Quarstein (2001) is where intellectual disability awareness in an organisation will enable inclusive environments. In the United States, the government implemented the *Disability Act in 1992*. Lack of sensitivity or awareness of the plight of the disabled in business and government continues to be a distinct problem requiring attitude changes and training, but this problem can become acute even for professionals in organizations dedicated to the care and education of the disabled. (Peterson and Quarstein, 2001, p.1) Peterson and Quarstein (2001) suggest having practical training surrounding disability awareness and not just theoretical training.

Studies have discovered that attitudes might be mitigated through an intervention programme; however, the suggestion is that this is over time, with more contact with the disabled, and providing more knowledge and awareness for the disabled. It has also been mentioned that repetitive exposure creates longer-lasting awareness, with no significance in demographics between males and females, according to Daruwalla and Darcy (2005). Therefore, societal attitudes change over time, with recommendations and awareness interventions being refreshed and offered more regularly to be effective. Disability is based on a reflection of attitudes and perceptions.

The integration model reflects beliefs and attitudes, and it is suggested that these attitudes can be changed, by the input of new information. For example, the introduction of information aimed at changing people's perceptions from a medical model to a social model. One interesting finding mentioned surrounding the attribution of positive and negative prejudice is learned and often these attributions have little bearing on the disability itself according to McCarthy et al., (2010, p. 216).

The literature suggests that disability reflects attitudes and, therefore, a suggestion of a perception integration model which would reflect beliefs and attitudes that are reflective of a more inclusive environment for Tangata Whaikaha. Therefore, information dissemination aimed at transforming public perceptions of intellectual disability awareness is not only necessary, but required, based on the frequency of how often Tangata Whaikaha visit primary health care practitioners.

The literature highlights evidence-based studies that support the need to raise awareness of training in the workplace. The findings concluded that although the policy may state inclusion with people with disabilities, it requires the attitudes through implementing intellectual disability awareness training, which is necessary to the success of changing attitudes towards Tangata Whaikaha.

2.4 Literature specifically relevant to Māori

This section reviews literature specific to Māori and relevant to the kaupapa of this thesis.

2.4.1 Māori and Indigenous socio-demographic epidemic

The definition of indigeneity is, therefore, inherently social and includes significant elements of cultural identity. However, does not determine Māori ethnicity but as a descriptor for describing indigenous being isolated from aspects of this identity is widely understood to harm indigenous health (Gracey & Kingsmith, 2009).

Although New Zealand has seen dramatic policy reform changes in social policy, there is still a gap in addressing the socio-demographic factors experienced by Māori and Indigenous peoples (natives to their country of origin) in the policy. For example, Eggleton et al., (2022, p. 2) identified that socioeconomic deprivation indicated over-representation of Māori in particular geographic areas. Durie (2004) highlights that socio-demographic epidemiological patterns of Māori are associated with land confiscation, language assimilation, health, and culture. Came (2014) conducted a mixed-method approach highlighting the issues of institutional racism, and states that this has been a contributing factor by the Crown to the effects on Māori being disproportionately over-represented.

In addition, Szlemko et al., (2006) describe how the effective treatment for addressing health inequities of indigenous peoples is in recognising and understanding the historical inequities and they recommend that researchers take heed in acknowledging this as part of their research. Therefore, Indigenous people have been affected by the lack of recognition of their cultural identity. Baxter (2008) highlighted the gap in socioeconomic factors that significantly contribute to the prevalence of Māori with mental health issues and disabilities, such as education and housing. King et al. (2009) asserted that inequality in health issues is related to socioeconomic issues. Reid et al. (2014, p. 4), Gracey and Kingsmith (2009), Lawson Te Aho et al., (2010) and Szlemko et al. (2006) all described the characteristics of poorer health status as an accumulative experience by Māori over generations, which has had adverse implications on psychological and physiological health outcomes.

Health issues have been associated with socioeconomic issues, according to Reid et al. (2014). They state that the impacts of colonisation have changed the landscape of Māori health. The study highlights socioeconomic status issues reflected in poor health. For preventable conditions, such as; skin infections, glue ear, dental caries, injuries, asthma, bronchiectasis, bronchitis, bronchiolitis, diabetes and its complications, hypertension, congestive heart failure, acute rheumatic fever, and chronic rheumatic heart disease, Māori have higher hospitalisation rates than non-Māori, according to Robson and Harris (2007).

Morgan et al., (2008) mention that one of the prevailing findings is that other family members of those with disabilities have higher hospitalisation rates. Thompson et al., (2014) raised the point that people with Tangata Whaikaha reported having higher rates of epilepsy and autism spectrum disorders associated with other underlying disability. The research participants comprised health care professionals and family members who cared for their Tangata Whaikaha, whanau hauā, and caregivers. Of the 133 participants from thirteen

different countries worldwide, forty-eight members (36%) of the cohort were paid family members. The data concluded that there was a need to develop service support that addresses these areas service support, practical overall restrictions to accessing accessible services that are less comprehensive and essential to improving the overall well-being.

Saunders et al., (2015) conducted an international study that looked at the financial burden on families having a child with an intellectual disability, specifically the autism spectrum disorder. In a cohort of 2,046 participants, 52% of the families stated that they had experienced financial difficulties, with 51% having to stop work to care for their child. The prevalence of ASD has steadily increased Internationally statistics indicate from one in 2000 children between 1960 and 1980 to one in 68 in 2010 (Saunders et al., 2015, p. 1).

As indicated in the findings of the literature, there is a clear connectedness and significant elements of cultural identity with socio-deprivation and social determinants in health. Mitra (2006) asserts that to determine disability it is harmful to break down social and economic findings to a rural area or region. There have been investigations from four major disability models for a better understanding of the writing of policy that fits with disabilities.

Saunders et al., (2015) asserts that the inclusion of disability should be viewed at the level of capability, and actual disability, by implementing the capability approach for a better understanding of what disability is. They suggest that policies should be based on the capabilities of the disabled, not their functioning. Although there are identifiable dramatic changes to social policy in New Zealand reflected in dramatic reforms to social policy, there is still a gap in the policy's treatment of the sociodemographic issues that Māori and Indigenous people face in general. For instance, socioeconomic deprivation is indicated in an over-representation of Māori in specific geographic areas of health. There is a need to address these issues in policy reform to close existing gaps and ensure that Māori are reflected in social inclusion and to create equitable inclusion to eliminate disparities barriers in socio-demographic statistics.

2.4.2 The Treaty of Waitangi, the Crown, and the Conundrum of Jurisprudence

Since 1840, the New Zealand Crown has confronted a fundamental contradiction between colonial capitalism and the rights of tangata whenua, and that of the Crown's own political and economic sovereignty, according to Kelsey et al., (1990). There is enormous inequality for Māori surrounding health, incarceration, and land confiscation reflected heavily in tyrannical Acts and omissions historically, and a lack of Crown obligation and accountability

to Te Tiriti. This has impacted Māori by their being disproportionately represented and reflected in higher socio-deprivation, social determinants, and incarceration.

The impact of prejudice Acts and omissions historically has caused cultural injustice. As seen in the case *R v Symonds*, due to tyrannical laws, the Crown attempted to confiscate land, however, the Doctrine of Aboriginal Title meant the Courts could not abolish Aboriginal title without the consent of the Crown and the Indigenous people of New Zealand. This is in contrast to the case of *Wi Parata v Bishop of Wellington* where the Treaty was described as a 'null'. This case is an example of tyranny by the Crown and its injustice to Māori amongst confiscation of land.

A further case in point is where the Crown attempted to abolish the Māori language, with the attempt to suppress Te Reo through colonialism. An example of language assimilation implications was highlighted in Fortune (2013) who conducted a literature review on the implications of policy and legislation for Māori children with special needs. The participants mentioned emphasis on the loss of their identity due to this loss of language as having a devastating effect on Māori. The findings indicated that Te reo Māori's current standing among its people has been significantly impacted by legislation that forbade its usage. In 1987 New Zealand saw the enactment of the Māori Language Act 1987⁴. However, the implications of tyrannical legislation have severely impacted the education system due to language suppression and land confiscation post colonisation.

In most recent times, the extinguishment of the aboriginal title and customary rights of Māori is shown in the case of *Ngati Apa v Attorney General*. This case sparked controversy between a legal landmark decision around the customary rights of Indigenous people and the Crown. The Crown stated that Aboriginal Title did not cover the customary rights of Indigenous peoples consistent with the Treaty of Waitangi. However, Aboriginal Title states that the Crown cannot abolish Aboriginal Title without the pre-emptive right of the indigenous people, in partnership with the Crown. *New Zealand Māori Council v Attorney-General* (1987) mentions that the Crown needs to be responsive to the Treaty of Waitangi's obligation in deciding policy and legislation. For example, as discussed in Rolleston et al., (2020) much disparity and disproportion of Māori health representation is due to the lack of acknowledging and recognising the implications of colonisation.

The discourse of equity in Acts and omissions, land confiscation, and the attempt to assimilate Te Reo have all led to social determinants of health and poorer quality of life for Māori. King et al., (2009) mentioned that the implications of policy have contributed to

disproportionate representation in health statistics of Māori compared to non-Māori, and that the Crown has failed to implement the Treaty of Waitangi and meet the obligations of Māori.

It is also noteworthy to mention as reflected in the incarceration rates of Māori, as indicated in the most up-to-date statistics, that 17% of the total incarcerated population are Māori, according to the Department of Corrections (2020). Moreover, Māori are said to be 3.3 times more likely to be apprehended by Police and, therefore, more likely to be incarcerated, according to Doone (2000). Indigenous Native Americans also have been highlighted as being a disproportionate over-representation of Indigenous people. It was indicated that 15% of the population of Native Americans, and 37% of the overall population, were imprisoned, according to Camplain et al., (2019). In New Zealand, incarceration rates of Māori are highlighted in Statistics New Zealand (2020) and identify a disproportionate representation in Māori incarceration rates of 4,392 Māori incarcerated in 2020, compared to 2,952 in 1999. The statistics highlight examples of inequity of Māori and Indigenous and their disproportionate over-representation.

The statistics and case law identify the difficulty surrounding self-determination and what that looks like in an indigenous context, furthermore, how Māori were treated and subjected to due to the impacts of colonisation. There is a clear indication of the failure to ensure jurisprudence by the Crown consistent with the Treaty of Waitangi principles. The lack of obligation by the Crown and, therefore, a conundrum surrounding the over-representation of Māori in our prisons, on social welfare, and among the disabled is indicated in Upston-Hooper (1998).

Self-determination is an important aspect that needs to be considered when writing policy. We also note that the approach fails to recognize the rights of Indigenous people. It has denied Indigenous people the right to self-determination and autonomy. This has been a managed approach rather than enabling Indigenous peoples to be part of the decision-making, especially with things that affect them (Kukutai & Taylor, 2016). "A central tenet of Indigenous self-determination is that Indigenous Peoples have an inherent right to be in control of their destinies and to create their own political and legal organizations" (Kukutai & Taylor, 2016, p. 27).

The legislative powers and constitutional framework, especially in New Zealand, have contributed to the separation of Māori from the land. However, despite the constitutional changes that have developed over time in the New Zealand Government, there is insufficient data and insufficient evidence to imply that, despite the continuous constitutional amendments

pertaining to New Zealand's sovereignty, Māori rights in the country are still unsupported. Unfortunately, Indigenous peoples worldwide are still struggling not only to obtain sovereignty over their land but also to have self-determination when it comes to political autonomy and recognition of their rights, and how we can measure that to move forward. Therefore, it is argued that the tyrannical laws that were implemented have a clear interconnectedness with the discourse of land confiscation and assimilation of cultural identity for Māori. This, I argue has led to cultural discourse and inequality for Tino rangatiratanga.

2.4.3 The inequity of inclusion in Policy

The issue of inclusion is particularly relevant to Indigenous peoples, who are often victims of marginalisation and exclusion from society. "Indigenous group membership is all too frequently concomitant with racial prejudice, religious intolerance, poverty, disempowerment, and language loss" (Bevan-Brown, 2013, p. 2). The meaningful discourse of social inequalities and loss of cultural identity (as discussed in the introduction to this thesis) indicates an association between colonisation and cultural discourse due to assimilation, all of which have led to the health issues of Māori. Inequality surrounding health issues is subject to socioeconomic issues. Research has highlighted the disadvantages people with disabilities face across various social, economic, cultural, and political spheres. There are, however, still existing gaps in the literature regarding Tangata Whaikaha and the accessible service provision of Māori in policy.

Hassankhan et al., (2020) mentioned that the New Zealand disability strategy failed to meet the needs of inclusivity in the policy. The research highlights gaps in policy and the social barriers to the disabled and their decision-making. This illustrates a political viewpoint that is divided and one that advocates for both the disabled and the non-disabled. Consequently, there is a gap that has to be filled between putting policy into action and making sure it serves the interests of those with disabilities.

The way that persons with disabilities are viewed as a group is influenced by how disability is viewed and diagnosed from a scientific and social perspective (Kingi & Bray, 2000). Accessing services is an important aspect of removing barriers for people with intellectual disabilities, as highlighted in Dyall and Marama (2010). Harris et al., (2006) mentions the importance of allocating appropriate health funding to eliminate barriers to accessible services to mitigate the discrimination that is already reflected in the literature. Jones (2019) describes how populations have been discriminated against with their human rights and indigenous rights, and this in New Zealand is reflected in colonisation and the

implications of this can be seen in the poor health outcomes in Māori, with the disproportionate statistics.

Kingi and Bray (2000) explain that society has a propensity to think of disabled people as being in wheelchairs, but from what I understand, disabilities are caused by a lack of understanding of whakapapa and how it relates to whanau, hapū, and iwi. Therefore, the meaningful discourse of social inequalities and loss of cultural identity, as discussed in the introduction, indicates an association between colonisation and cultural discourse due to assimilation, all of which have led to the health issues of Māori. Inequality surrounding health issues is subject to socioeconomic issues. Research has highlighted the disadvantages people with disabilities face across various social, economic, cultural, and political spheres. The literature also highlights disparities between indigenous and non-indigenous people through implications of colonisation and historical health issues that pertain to indigenous people. Māori, in particular, have also been affected as have other indigenous people worldwide who have faced significant social inequity and loss of cultural identity due to colonisation. Cultural assimilation has led to the health issues for Māori today.

2.4.4 Social Model and social policy

The medical model and the social model are the two main northern hemisphere approaches to working with impaired people, according to disability frameworks. These models have an individualistic perspective on disability, which is irrelevant for many Indigenous people with disabilities, whose worldview is holistic, relational, and collective in character. The social model of disability emphasises how societal barriers cause impairments, people with disabilities are referred to as "disabled persons." The term "person with disabilities" is used to describe those who have disabilities because the traditional medical model ignores personal experiences and instead places emphasis on a person's disability and the deficits caused by impairments that are to be "fixed". Came (2014) mentions better outcomes for Māori participation in policy with flawed consultation practices.

Barwick and Siegel (1992) suggest that a social policy recommendation surrounding the inclusion of the disabled addresses the variable socioeconomic issues for better outcomes and the necessity for a succession of healthcare reforms in the policy. However, Māori remain seen as still disadvantaged. Furthermore, there is a lack of self-determination in policies that are not reflective of Indigenous people, with the current implications of policy having not benefited Māori, according to Humpage (2005). A critical review of the Māori mental health policy by Durie (1999) recommended there be more participation by Māori, more Māori-

centric frameworks, and evidence-based practice. Therefore, it is apparent that Māori are still disadvantaged, that there is a lack of self-determination in policies that are not reflective of Indigenous people, and that the current policy implications have not benefited Māori. Hickey and Wilson (2006) and Hoskins and Jones (2012) argue that the social model does not support Māori with disabilities and highlights the need to close the gap in the disparities.

Policy inequality on Indigenous peoples that safeguard the significance of Māori participation are required to ensure better outcomes for Māori in the health sector and an essential aspect that needs to be reflected in the policy about Tikanga, as indicated in the *Takamori v Clarke* case. In our standard legal system in New Zealand, we have seen an implementation of Tikanga in both the courts and the United Nations treaty. However, there are still gaps surrounding policy inequality among Indigenous peoples. Therefore, not having safeguarded the significance of Māori participation required to ensure better outcomes for Māori in the health sector is an essential aspect that needs to be reflected in the policy.

Furthermore, in assessing the current health model and the implications of the Treaty of Waitangi, Kingi (2007) states that as a result, there are at least two major methods of thinking about how the Treaty which may be applied to health. One is based on the Treaty's text or terminology, and another is founded on more expansive and interpretive ideas, such as those that are mentioned in the *Waitangi Tribunal Act* and the *Treaty of Waitangi*. Māori are still disadvantaged, and there is a lack of self-determination in policies that are not reflective of Indigenous people, and the current implications of policy have not benefited Māori, according to Humpage (2005).

According to Walter et al., (2020), there needs to be a critique of current policy to highlight and investigate the depth of indigenous disadvantages in greater detail in Australia as well as in New Zealand, Canada, and the United States. This, therefore, suggests a lack of understanding and intention behind self-determination and policy implications. This suggests the formulation which has been implemented has been based on individualism. Therefore, this framework fails to consider the view of Indigenous people. This has meant that the policies have been unsustainable and inequitable to Indigenous people.

Indigenous people have been segregated and disadvantaged. This has meant that there has been a lack of connectedness in implementing the policy. The literature highlights the lack of opportunity for participation by Māori and Indigenous people in terms of, responsibility, autonomy, and self-determination. Durie (2004) highlighted; socio-demographic, epidemiological patterns of land confiscation, language assimilation, health, culture, and the

implications of indigenous people's well-being that have been affected due to the lack of cultural identity, a common theme in the literature. Therefore, it is evident there is a need to discuss restorative justice for cultural rehabilitation and cultural competence, as essential factors for identifying the underlying issues for Māori.

The issue of inclusion is particularly relevant to Indigenous peoples, who are often victims of marginalisation and exclusion from society. "Indigenous group membership is all too frequently concomitant with racial prejudice, religious intolerance, poverty, disempowerment, and language loss" (Bevan -Brown, 2013, p. 2). Boulton (2005) and Toki (2010) assert that Treaty principles have failed to meet the needs of Māori.

Therefore, based on the literature there is a need to investigate the current policy issues. Policy should entail appropriate methodological approaches that may apply to Māori, especially those surrounding perspectives of Indigenous people. This highlights a need to investigate the current policy issues to ensure that policy and frameworks entail appropriate methodological approaches that apply to Māori, especially surrounding perspectives of Indigenous people. This will ensure policy participation regarding Indigenous people and Māori.

2.4.5 Data sovereignty

Māori have paid the price for citizenship in New Zealand, dating back as early as the 19th and 20th centuries, due to Colonisation. Historically, Māori were discriminated against for living in Pa and had significant historical entitlement rights compared to the Pakeha, especially regarding social welfare rights. Māori have been estranged from their Turangawaewae because of Colonisation and have experienced land discrimination and language assimilation. Compared to Pākehā, they have been disadvantaged and alienated from society and, historically, earlier land confiscation and segregation due to disparities in policy. Moreover, indigenous people have not participated in the interventions concerning data collection surrounding themselves, their land, and their culture.

The policy implications of data sovereignty, suggested by Walter et al., (2020), state that the current implication of policy legislation and Indigenous perspective, in practice fail due to the lack of integration. The literature describes the connectedness with other indigenous peoples surrounding health disparities, that have been derived as a common trend. Therefore, there is an increasing demand for data surrounding policies and decision-making. There is a need to change the current interventions, that have had little to no input from Indigenous

peoples. This is to ensure the aspirations of self-determination is from their own knowledge and information, and that this information is shared when it comes to policy making.

The importance of these injustices, as argued by Cheyne et al., (2005), is that historically, the importance of acknowledging welfare was for Pākehā's gain. However, social policy is more than just social welfare and, since the 1980s, has undergone significant changes in New Zealand. Dalley and Tennant (2004) mention that Māori faced applying for a benefit that did not address the public perception. Māori were still criticized by the public and seen as an easy target set for social security as 'welfare spenders'. There is a need to investigate the current policy issues. Policy should entail appropriate methodological approaches that may apply to Māori, especially surrounding perspectives of Indigenous people, which will ensure policy participation regarding Indigenous people, their communities, and their land.

We interpret the validity of a numerical value as a representation of these communities, where policy fails to determine and interpret the statistical interpretation from the person's perspective. The interpretation of data collected about this group of people, whether Māori, or Indigenous people around the world, has been made to fit based on numerical variables. Policy fails to consider the subjective view and has a one-size-fits-all approach.

The health policy and the *New Zealand Disability strategy* policy issue and all current health policies before WAI 2575 have been based on numerical data, is not the issue and therefore the assumption based on this data does not correlate with the appropriate methodology in the policy from a Te Ao Māori perspective (Walter et al., 2020). The underlying issue is that policies fail to reflect an Indigenous perspective and or to consider the communities' culture. Yet, these policies are being implemented and applied to society.

In conclusion, Māori have faced and continue to face discrimination over the years and are still fighting the Crown for their sovereignty. There needs to be accountability for addressing the years of discrimination Māori have faced and the implications of this. Though New Zealand has seen dramatic policy reform changes in social policy, we are still not addressing the poverty and socio-demographic factors affecting Māori.

There has been a lack of connectedness in implementing policy. They lack opportunity for greater responsibility, autonomy, and self-determination for Indigenous people. One way of regaining rights is through data sovereignty and having autonomy over decision-making, therefore, giving an Indigenous perspective. In practice policies fail due to the lack of integration and understanding in policy legislation.

2.5 Brief overview of methodologies literature relevant to this study

This section describes the research methodology and methods. The methodologies that will be assessed in this research are as follows; qualitative and quantitative research methodology, culturally responsive methodology, decolonising methodology, Kaupapa Māori methodology, Pūrākau methodology (see Lee, 2009), and post- colonial research methodologies. The methods that will be analysed will be based on being able to answer the research question, giving rationale to use the most appropriate methods for collecting and analysing the data, and being culturally appropriate, to ensure that it maintains the integrity of the rangahau and the participants.

The next section expands on the methodologies and the specific methods of data collection analysis.

2.6 Qualitative and Quantitative methodologies and a mixed methods approach

The following is the analysis of qualitative and quantitative mixed methods research methodology. According to Morris (2007), a structured or unstructured interview is based on questions derived to describe reality and practice, to obtain perspectives based on a set of questions and topics to address. Moreover, a qualitative study is one where the participant can participate in the research using qualitative methods.

Morgan (1993) explains the use of open-ended questions when conducting a semi-structured interview as opposed to semi-structured questions. There are different perceptions of the interpretation of the question, and, therefore, a collaborative approach to a mixed methods approach may be more appropriate according to Jick (1979) and Mark et al., (1997). However, Johnson and Onwuegbuzie (2004) suggest the need to eliminate the researcher's biases. Therefore, remaining emotionally distant and uninvolved with the object of study and testing empirically justifies the stated hypotheses, according to quantitative purists. However, Johnson and Onwuegbuzie (2004) suggest a more constructed view. They disagree with having multiple-constructed realities, and that time and context-free generalisations are neither desirable nor possible. They argue that qualitative methodology is value-bound, that it is impossible to fully distinguish between causes and effects, and that logic flows from the specific to the general statements, and further, that the known cannot be separated because the subjective knower is the only source of reality.

2.7 Indigenous paradigms

Traditional paradigms for education research are challenged by culturally responsive methodology, which also value many forms of involvement and knowledge. These kinds of cross- and intracultural research collaborations offer new avenues for the development of rich educational and social science research since they are grounded in critical theory, ethnology, and post-colonial studies. Culturally responsive research methodology is both distinctive and inclusive of numerous postmodern research methodologies. Indigenous epistemology is axiologically embedded, which means that it includes an ethical spiritual foundation associated with human-nature-cosmos relationships (Guba & Lincoln, 1994).

The purpose of an Indigenous research paradigm in research is to dispute the pathological determinants of the previously colonised as well as deficit thinking. Furthermore, to build a body of knowledge that inspires hope and fosters transformation and social change among historically oppressed people. Such a paradigm is philosophically informed by neo-Marxist theories, feminist theories, critical race-specific theories, post-colonial discourses, and indigenous knowledge systems (Chilisa, 2012)

2.8 Culturally responsive research methodology

There is no single definition of a culturally responsive methodology. Culturally responsive methodology encompasses cultural and epistemological pluralism. According to Berryman et al., (2013) it disassembles Western colonial traditions of research and acknowledges the importance of connections within a power-sharing dialogue. It is mentioned that culturally responsive methodology has three separate, and frequently simultaneous, phases of the research: getting to know the subjectivities of the participant(s); making the researcher's positionality explicit; and taking part in relational dialogue, according to Berryman et al., (2013).

Culturally responsive research methodology is both distinctive and inclusive of numerous postmodern research methodologies. Researchers using feminist approaches that apply these methodologies include Harding (2004), Denzin and Lincoln (2008), Mutua and Swadener (2004). All these authors, according to Berryman et al. (2013), originate from different historical backgrounds, speak across multiple languages, and share similar approaches. They want to place those who have been marginalised at the forefront of study as co-constructors.

2.9 Post-colonial research methodologies

Each of the cultural practices that are connected to tangihanga share a corpus of language and discourse. Kinship within the tribal polity, the marae, and the institution of the tangi were the strongholds of cultural conservatism for Māori. However, according to Moreton-Robinson (2004), post-colonial methodologies when you are being educated from the perspective of the colonists, means that we can no longer keep our traditional identities, and indigenous educational empowerment is reduced to the preservation of those identities. This presumption conceals the notion that we cannot adapt or devise survival tactics that allow us to expand on the various subject positions we have established through family and local politics (Moreton-Robinson, 2004).

Post and anti-development theorists contend that there is more evidence of continuity in the preservation of Western-centred attitudes than of a break from the colonial attitudes of the past. In addition, to an arrogant confidence in the indisputable reliability of science and Western knowledge (Escobar, 1995; Pretty 1994; Nustad, 2001). However, many authors now dispute if scientific methods are the best or the only way to solve development-related issues. They contend that alternative knowledge, such as the indigenous knowledge of people who live in certain locations, may be of equal or more worth (Ellen & Harris, 2000; Kalland, 2000; Leach & Mearns, 1996; Sillitoe, 1998).

2.10 Pūrākau methodology

Pūrākau methodology is a storytelling relationship and a narrative (see Lee, 2009). Storytelling kindles reciprocity, the story transforms accountability by way of determining where there is respect, a story to be a gift. However, because knowledge sharing with the practice of storytelling differs from culture to culture, we must be aware of the nuances of storytelling within indigenous culture. Moreover, of the responsibilities hearing the story carries, since both the techniques and the depiction seem to be used to storytelling that is separated from its origins, lacking the important message of the powerful according to (Kovach, 2021). Data cannot be compared to things that are living connections, it does not animate the transfer of the story when indigenous episteme is applied to indigenous methodologies in data collection. Pūrākau, however, is more about connection in indigenous storytelling. It is essential to indigenous cultural sustainability for a story to be the most powerful intergenerational manifestation of hope (Kovach, 2021). The narrative is multi-layered, weaving a tapestry of indigenous culture while reflecting on a story, pedagogy, and

research. Hearing stories in indigenous research is more than just data collection bounded by the sharp discoveries of an interview (Robin, 2015).

2.11 Decolonising methodologies

Decoloniality is a critical theory at the cultural intersection, according to Freire (1972) and Horkheimer (1993), who assert that Indigenous Studies within the world of academia challenge and strive to transform "Indigenous" relationships to "the Western" academy. Critical Theory, with its emphasis on emancipation or liberation, as well as its arguments for participatory knowledge-making and activities that empower and transform Indigenous individuals and collectives, is widely accepted in Indigenous inquiry. For example, focusing on decolonizing knowledge in the disciplines to free colonised peoples and restore Indigenous worldviews is a current trend in the learning and teaching of Indigenous Studies in the Australian higher education sector (Walker, 2000; Mackinlay, 2005; Phillips & Whatman, 2007).

2.12 Kaupapa Māori Methodology

A Kaupapa Māori position in research enables and promotes an epistemological version of validity, one where the authority of the text is "established through recourse to a set of rules concerning knowledge, its production, and representation" (Bishop, 1999, p. 6). It has been highlighted that Kaupapa Māori methods incorporate a range of methods and "It is generally accepted that a Kaupapa Māori approach is inclusive of a range of methods; however, those methods need to be firstly interrogated for their cultural relevance and appropriateness concerning researching with Māori" (Jones et al., 2010, p. 7).

Kaupapa Māori research will be guided by a set of principles: Aroha ki te tangata (a respect for people); Kanohi kitea (the seen face, present yourself face-to-face); Titiro, whakarongo ...korero (look, listen ... speak); Manaaki ki te tangata (share and host people, be generous); Kia tupato (be cautious); Kaua e takahia te mana o te tangata (do not trample over the mana of the people); and Kaua e mahaki (do not flaunt your knowledge) (Smith, 1999).

In conducting this research, it is important to understand the barriers as an indigenous researcher when conducting indigenous research and when using Kaupapa Māori methodology. This research aims to ensure that the indigenous participants are not left voiceless and are not marginalised. Furthermore, that they are represented to achieve and contribute self-determination consistent with the principles of the Treaty of Waitangi. Battiste and Henderson (2000) assert- "Most existing research on Indigenous peoples is contaminated

by Eurocentric prejudice and this the development of ethical research must begin by replacing Eurocentric prejudice with new premises that value diversity over universality" (pp. 132-133). Therefore, addressing the implications will give purpose and rationale to highlighting the importance and significance of using the kaupapa Māori methodology.

Indigenous peoples residing in settler societies have long expressed concern at the impact on their communities of the social research activity carried out by government agencies and academic institutions, according to Battiste and Henderson (2000), Smith (1999) and Tauri (2018). They argue that indigenous approaches should be conducted and considered within ethical research. This is because of the issues of informed consent required to ensure indigenous approaches are consistent with constructing and disseminating the research that needs to be informed by the participants. Universalism has been suggested as an indigenous critique on the research of ethical boards, and authors suggest a process from a euro-centric perspective is inconsistent with what constitutes and what does not constitute ethical research conduct, according to Battiste and Henderson (2000) and Wilson (2004).

Research ethics boards have been identified as contributing to marginalisation and the continuation of colonisation when it comes to indigenous academic research, according to Absolon (2008), Glass and Kaufert (2007), Smith (1999) and Wax (1991). Smith (1997) and Tauri (2014) argue that ethical research boards lack epistemological indigenous methodology research knowledge expertise and, moreover, fail to understand the socio-political impacts on indigenous peoples. This is due to their lack of understanding and knowledge around how these research issues impact indigenous research and its participants.

Case studies in indigenous studies using traditional Western research methods to investigate Indigenous perspectives is frequently perceived by Indigenous peoples as inappropriate and ineffective in gathering information and promoting discussion. Using traditional storytelling as a research method, on the other hand, connects Indigenous worldviews, shaping the research approach, theoretical and conceptual frameworks and epistemology, methodology, and ethics (Datta, 2018). Indigenous methodology is known as the "paradigmatic approach" (Kovach, 2010). Indigenous methodology's relational accountability is an inherent responsibility in learning how individual knowledge systems interact with the whole and how a human expresses different forms of knowledge (Wilson, 2008).

The conversational method in Indigenous research differs from its use in Western research in several ways: a connection to Indigenous knowledge; a location within an

Indigenous paradigm; a relational nature; a purpose (which is often decolonising); following a specific protocol that reflects Indigenous knowledge; a flexible nature; collaboration; and reflexivity (Kovach, 2010).

Traditional storytelling is an important way for Indigenous peoples to express their knowledge, culture, and oral traditions. It values holistic interconnectedness, collaboration, reciprocity, spirituality, and humility, and it has a positive impact on practice (Kovach, 2010). Traditional storytelling, narrative, and the relationships between these concepts are widely understood, but formal definitions are scarce (Thompson and Barnett, 2008).

Indigenous scholars express that some stories, because of their sacredness, should not be revealed because this strips them of their spiritual and sacred elements. A story session, for example, could include a story about a success or failure. To engage a multidisciplinary team of academics in community-based research, a story could also describe the difficulties encountered and overcome, in full or in part. Traditional storytelling can vary depending on the culture and tradition of a particular community (Wilson, 2008). Indigenous ontology and epistemology are intertwined with storytelling as Indigenous ways of understanding and acting are linked to a specific ontology and epistemology known as relational ways of knowing (Hart, 2010; Wilson, 2008).

The practice of telling stories is important to Indigenous communities for several reasons: Stories can range from the sacred to the historical; some focus on social, political, and cultural issues; others are entertaining, even humorous; some tell of personal, family, community, or national experiences; some are owned by specific clans or families and can only be told by a member of that group; others can be told by anyone who knows and cares for them; stories reflect the perceptions, relationships, beliefs, and attitudes of a specific people (Datta, 2018; Dei, 2011; Denzin & Lincoln, 2008).

Since the 1930s, the case study methodology has been evaluated and criticised on numerous occasions. Moreover, it has not been listed as a research tool in the major research texts in the social sciences (Tellis, 1997). Research bias has been a source of concern and has been mentioned as an ongoing issue because it can occur in a variety of ways. The following are examples of how to address these biases to ensure that they are minimised. The first is research bias, which refers to the various theories, hypotheses, and perceptions that the researcher holds when conducting the study. As a result, the researcher may only see these biases through their perception, failing to examine the research and data collected objectively rather than subjectively. The researcher's background and experience may also introduce bias

into the study. The problem of case selection and the danger of selection bias, which can have more severe consequences in case studies than in statistical studies, are recurring trade-offs in the use of case study methods. This is the tension between consistency and richness when selecting the number of variables and cases to be studied.

The importance of this research is to ensure that the research participants have a voice that is led through informed consent processes and is an informed decision-making process that they can be part of. The concept of individualism involves giving preference to self-governing research subjects, a tendency that might cause issues with informed consent procedures and collaborative decision-making. (Ellis & Earley, 2006; Glass & Kaufert, 2007; Piquemal, 2000; Wax, 1991).

Tauri (2018, p. 5) states that the standard consent process in New Zealand is a Western framework where participants sign a piece of paper and are informed of their role within the research. However, the process of informed consent does not always necessarily mean that the research is collected in an ethical manner and/or that the researcher is an ethical researcher, according to Butz (2008).

Tauri (2014) based their research on the inequality and inconsistency of institutions that contradict the treaty principles in the ability to be able to recognise indigenous people and interpret the principles applicable to the Treaty of Waitangi. Arthur Smith (1997) asserts:

It is self-evident that Indigenous people now want their voice in research, and they want it to be heard and understood ... The right to establish and control the terms and conditions of cultural research is an inalienable right for all peoples of the Earth. The colonial era is dead, if not yet buried. (pp. 25-26).

My hope and aspiration of this research was to ensure that institutional structures as mentioned in the literature review, and consider how your background, experiences, and perspectives may shape your understanding of the research and not to minimise and avoid perpetuating biases or stereotypes present in the existing body of research.

The voice of the indigenous participants that are part of this research, therefore, give rationale for the need to use this kaupapa Māori methodology. The use of this methodology is to protect the knowledge in the first instance and control the narrative of this research and its significance. It is specifically about the empowerment of the research participants and giving them value to ensure that the ethical obligation from a Tikanga perspective is maintained. Ratima et al., (1994) assert that there needs to be cultural-specific measures that encapsulate hapū, iwi, and whānau in defining and understanding what is reflective of a Māori context specify cultural appropriateness for Māori when collecting data.

In this research, it is essential to understand the barriers as an Indigenous researcher when conducting indigenous studies and using the Kaupapa Māori methodology. This research aims to ensure that the Indigenous participants are not left voiceless, are not marginalised, but are represented to achieve and contribute self-determination consistent with the principles of the Treaty of Waitangi. Battiste and Henderson (2000) assert that most existing research on Indigenous peoples is contaminated by Eurocentric prejudice, and thus the development of ethical research must begin by replacing Eurocentric prejudice with new premises that value diversity over universality (Battiste & Henderson, 2000, pp. 132-133). Indigenous scholars have, however, closely examined indigenous research methodologies. Indigenous peoples living in settler countries have long expressed worry about how social research activities carried out by governmental organisations and academic institutions may affect their communities (Battiste & Henderson 2000; Smith 1999; Tauri, 2014).

For this research it is essential to ensure that the research participants have a voice which is demonstrated in the findings. In addition, participants need to feel informed by consent processes, an informed decision-making process that they can be part of. Individualism: privileging autonomous research participants leads to informed consent processes that problematize collective decision-making and informed consent protocols (Ellis & Earley, 2006; Glass & Kaufert, 2007; Piquemal, 2000; Wax, 1991; Tauri, 2018).

Tauri (2014) argues that ethical research boards lack epistemology. Due to the lack of understanding and knowledge of these research issues, indigenous methodology and research expertise fails. They fail to understand the sociopolitical impacts on Indigenous peoples and how it impacts indigenous research and its participants. It has been suggested that Research Ethics boards have contributed to the continuation of colonisation when it comes to indigenous academic research (Absolon, 2008; Glass & Kaufert, 2007. Smith, 1999; Wax, 1991).

According to Battiste and Henderson (2000) and Wilson (2004), universalism is an indigenous critique of the research of ethical boards, and the authors suggest that a process from a euro-centric perspective is inconsistent with what constitutes moral and what does not constitute ethical research conduct. Tauri (2018) argues that indigenous approaches must be controlled and considered within ethical research. This is because of the issues of informed consent required to ensure indigenous methods are consistent with constructing and disseminating the research that needs to be informed by the participants.

2.13 Māori education

Recognising colonial influence in knowledge and paradigms necessitates being always mindful of the history of colonialism (Coburn, 2015). This historical process, which took place in New Zealand between 1840 and 1900, resulted in a structural relationship in which Pakeha dominated and Māori were subordinate. This structural link was maintained by later institutional structures, such as Parliament and the state apparatus (Walker, 2016). Anglican missionaries who came to New Zealand in 1814 were the first wave of the invasion of another culture. Pakeha had the goal of bringing the Māori people "from barbarism to civilisation," which was based on ideas of racial and cultural superiority. They believed they had a divine right to replace the culture of those they were displacing and impose their worldview on them (Freire, 1972). The Bible was first published in Māori in 1837, and rapidly gained popularity among the tribes. The New Testament writings, according to Māori, were the source of information about European culture and material things (Barrington & Beaglehole, 1974). In most New Zealand settlements, several Māori had learned to read and write Māori within a decade.

The indigenous Māori language, its associated culture, and the Māori classical literature that endures today have all been preserved and nurtured through the marae and the institutions of tangihanga (funeral customs). On these occasions, the Māori worldview is fully expressed in a modern, authentic atmosphere. Therefore, tangihanga (or tangi) is crucial for maintaining Māori identity (Edmonds, 2016). The cultural practices that are related to tangihanga are specific and each has a unique language and discourse. For the Māori, kinship within the tribal polity, the marae, and the institution of the tangi were the bulwarks against cultural conservatism (Walker et al., 2006).

2.14 Methods

2.14.1 Case study method

Two key approaches to case study methodology are proposed by Stake (1995) and Yin (2003). Both approaches aim to ensure that the topic of interest is thoroughly investigated, and that the essence of the phenomenon is revealed, but the approaches are quite different and deserve to be discussed. To begin, both Stake (1995) and Yin (2003) base their case study approaches on a constructivist paradigm. Truth, according to constructivists, is relative and dependent on one's perspective. This paradigm "acknowledges the importance of subjective human creation

of meaning but does not reject some notion of objectivity outright." (Baxter & Jack, 2008, p 3).

In determining a case versus case study, a case is frequently described as a "phenomenon for which we report and interpret only a single measure on any relevant variable." (Eckstein, 1975, p 2.). However, this incorrectly implies that each case has only one observation on the dependent variable, but many independent variables. If this were true, it would create a problem of indeterminacy, or the inability to choose between competing explanations for a case (Bennett, 2004). However, because each "case "has a potentially substantial number of observations on intervening variables and may allow several qualitative measures of various dimensions of the independent and dependent variables, case studies are not necessarily indeterminate, according to King et al. (1994) and Campbell, (1975).

According to Yin (2003), a case study design should be considered when: (a) the purpose of the study is to answer "how" and "why" questions; (b) you cannot manipulate the behaviour of those involved in the study; (c) you want to cover contextual conditions because you believe they are relevant to the phenomenon under study; or (d) the boundaries between the phenomenon and context are not clear.

Case studies themselves may be of interest in the most limited sense of the concept. For example, a study for an organisation to improve its functioning, when applied as a research method case, is usually carried out to generate findings of relevance beyond the individual's case. A research method case is appropriate for investigating phenomena when a wide range of effectors in relationships are included, and where no basic laws exist to determine what factors have significance to the relationship, and the factors and relationships can be directly observed, according to Fidel (1984).

A case study is expected to capture the complexities of a particular case, and the methodology for doing so has developed within the social sciences. This methodology is used not only in social sciences, such as psychology, sociology, anthropology, and economics, but also in practice-oriented fields, such as environmental studies, social work, education, and business studies (Johanson, 2007). The concept of a case is not well defined and is still being debated. The case might pertain to a bounded object or a process, theoretical, scientific, or both (Ragin and Becker, 1992).

The "case" should be the object of study in the case study. The "case" should be a complex working unit that is investigated in its natural context using a variety of methods, and it should be contemporary (Yin, 1994; Merriam, 1988; Stake, 1995,1998; Miles &

Huberman, 1994). There are three types of case studies: exploratory, explanatory, and descriptive. The relevant strategy is determined by the research questions "who", "what", "where", "how", and "why" (Levy, 1988). Both the study and the proposed study, being exploratory, do not require nor have a proposition (Yin, 1994). Gathering of information principles for case studies is recommended.

An explanatory case study would be used to answer a question regarding presumed causal links in real-life interventions that are too complex for survey or experimental approaches. In evaluation terms, the explanations would connect programme implementation to programme effects (Yin, 2003).

Exploratory case investigation is used to examine situations in which the intervention being evaluated does not have a clear, single set of outcomes.

Descriptive: this type of case study is used to describe an intervention or phenomenon as well as the real-life context in which it occurred.

Multiple-case studies: a series of case studies allows the researcher to investigate differences between and within cases. The objective is to replicate findings across cases. Because comparisons will be made, the cases must be carefully chosen so that the researcher can predict similar results across cases or predict contrasting results based on a theory, according to Yin (2003).

Intrinsic: the definition of intrinsic means that researchers with an authentic stake in the case should use this approach to better understand the case. It is undertaken not primarily because the case represents other cases or illustrates a specific trait or problem, but because the case itself is of interest in all its particularity and ordinariness.

The goal is not to comprehend some abstract concept or generic phenomenon. The objective is not to create theory (though that is an option) (Stake, 1995). **Instrumental:** is applied to purposes other than comprehending a specific situation. It sheds light on a problem or aids in the development of a theory. The case is secondary in importance; it serves to aid our understanding of something else. The case is frequently examined in depth, its contexts scrutinised, its everyday activities detailed, and because it assists the researcher in pursuing the external interest. The case may or may not be considered typical of others (Stake, 1995). **Collective:** multiple case studies are similar in nature and description to collective case studies (Yin, 2003).

Therefore, it can be concluded that case study methods have inherent limitations, including their inability to make judgments on the frequency or representativeness of specific cases, and their poor ability to estimate the average "causal weight" of variables. These are inferential processes for which case studies are not designed and can only be used rudimentarily. Fortunately, these inherent limitations perfectly correspond to the comparative advantages of statistical methods, which provide various measures of frequency and can estimate the expected causal weight of a variable (Bennett, 2004).

2.14.2 Mixed methods

Mixed methods have emerged with the integration of qualitative and quantitative approaches being used more widely as a strategy for reporting, controlling the methods, and analysing the data. Mixed methods studies are products of the pragmatist paradigm and combine the qualitative and quantitative approaches within different phases of the research process (Tashakkori & Teddlie, 2008, p. 22).

The advantages of using a mixed methods approach enables the research to be integrated with the primary purpose of gaining a broader perspective and an overall predominant collection of data. The use of mixed methods, as opposed to one method, enables an embedded method that can address different research questions. It also enables the research to be collected simultaneously as both provide quantitative and qualitative perspectives, the advantage of using mixed methods. However, the disadvantages of mixed methods, as described by Terrell (2012) are that the amalgamation of the data analysis may lead to discrepancies surrounding the data interpretation and differing biases based on the research design.

The use of mixed methods in this research will help enhance and enrich the current data. We are also gaining an extension to the body of knowledge surrounding the subject of the research, which is the lack of equality of policy that supports Māori. It has been identified in the literature that no rationale indicates that there are neither more nor less specific approaches. Mixed methods is more appropriate compared to any other research methods: however, thought has been given surrounding the application to this research.

2.14.3 Survey questionnaires method

There are roughly four distinctive styles of survey questionnaire design, according to Goode and Hatt (1952): Contingency Questions (Cascade Format), Matrix questions, Closed-ended questions, and Open-ended questions. The primary tool for gathering quantitative primary data is a questionnaire. A questionnaire makes it possible to collect quantitative data consistently, ensuring that the results are internally consistent and coherent for analysis (Roopa & Rani, 2012). Although it is currently under-utilised for this purpose, online data collection provides a quick and easy replacement for the more commonplace way of information gathering, according to Mertler (2002).

Contingency Questions/Cascade Format is a question that may only be answered if the respondent provides a certain response to an earlier question. By doing this, inquiries about subjects that do not concern them are avoided. Matrix questions provide multiple questions

that are given the same response categories. The questions are stacked one on top of the other to create a matrix, with question lists on the side and response categories across the top. The responders' time and page area are being used effectively. Closed-ended questions; answers from respondents, are restricted to a predetermined set of options, scales are typically closed-ended. Open-ended; there are no recommended alternatives or present categories. The respondent responds on their terms without being limited by a predetermined range of answers, according to Mertler (2002).

Following are recommendations when deciding on questions. To avoid creating an inaccurate picture of the actual situation, the question should be clear and objective. The series of questions must be unambiguous and fluid. A good question order minimises the likelihood that any one inquiry will be misunderstood. The initial few inquiries are crucial since they are questionnaire-making plans for a survey to sway respondents' perspectives, according to Roopa and Rani (2012).

Online gathering of data requires all participants to have simple access to surveys. Additionally, web surveys need to be simple to complete. Furthermore, web surveys need to have a built-in security system to assure validity and anonymity, and lastly, only the barest minimum of computer knowledge should be needed to complete web surveys (Carbonaro & Bainbridge, 2000). Researchers further emphasise that online data collection safeguards against data loss and makes it easier to upload data into a database for analysis (Carbonaro & Bainbridge, 2000; Ilieva et al., 2002).

Online data collecting can potentially give researchers access to a sizable, geographically dispersed population, while also saving them time and money. Web-based surveys provide researchers special opportunities for Internet data collection, notwithstanding their limitations. They can be especially helpful for gathering preliminary data, pre-testing research design, and determining how well people understand questions. Online data collection can be beneficial for internal school projects including gathering information from students, teachers, staff, and parents for school improvements, in addition to being favourable for outside researchers (Lefever & Matthíasdóttir, 2007); however, it is the most challenging sort of questionnaire to develop. Information communicated via the internet may be difficult to follow up, difficult to get a probability sample, and like postal surveys, there is poor control over respondent selection.

The barriers to the use of surveys are fraudulent respondents to web surveys, which is a source of concern. In contrast to surveys conducted using paper and pencil, respondents to

online surveys have the potential to lie or pretend to be someone else. It was crucial to approach data collection, especially involving personal identification, with careful consideration of ethical principles and privacy concerns. There is inconclusive evidence that suggests that replies from online surveys and self-completed mail surveys differ from one another (Ilieva et al., 2002). Evidence, however, indicates that participant responses in email surveys may be more thorough than those in paper-and-pencil surveys (Schaefer & Dillman, 1998). Furthermore, every questionnaire should have a specific goal connected to the study's goals, and it should be made clear upfront how the results will be used (Mackay, 2001). The use of a questionnaire will ensure that participants can participate as fully as possible, and protect the participants' privacy, as participants will respond honestly only if their identity is hidden, and confidentiality is maintained. Corroboration with other questionnaires findings can also be useful confirmation (Roopa & Rani, 2012).

2.14.4 Likert-scale questionnaire

A Likert scale is a psychometric tool that allows respondents to select from a variety of categories to express their ideas, attitudes, or feelings regarding a specific topic. Likert-scale questionnaires have been utilised most frequently in the field of Survey Likert scale when examining personal differences such as drive, anxiety, and self-assurance. The use of Likert-scale questionnaires has several benefits, including the ability to quickly gather data from many respondents, the ability to estimate a person's ability with high reliability, the ability to establish the validity of interpretations drawn from the data, and the ability to compare, contrast, and combine the data with qualitative data-gathering methods such as open-ended questions according to Nemoto and Beglar (2014). To quantify and evaluate one component of a person's effect or reasoning, Likert-scale instruments are most used to measure psychological constructs, according to Messick (1989).

Most Likert scales should have four or six points. Studies have revealed that scales with more than six categories are rarely tenable, due to constraints in the capacity of working recollection. One of the many measures that gauge a person's propensity towards a certain person, thing, or phenomenon, these scales are often more sophisticated and multi-item scales compared to rating scales. Scaling creates a continuum, or continuous sequence of values, upon which the measured items are positioned. To select the best scaling method for a questionnaire, a variety of things should be considered, according to Smith et al. (2003). One of the most popular measurement tools is the attitude and rating scale, which is utilised in a variety of sectors including; sociology, psychology, information technology, politics, and

economics. However, research methodology studies haven't offered any concrete advice on how to choose the right rating scale for research projects, according to Krosnick and Fabrigar (1999).

As a psychometric tool, this scale contains several statements that represent this study's hypothesis. In the survey, respondents are asked to rate the statements' level of agreement on a scale from strongly agree to strongly disagree. Although the Likert scale's five symmetrical and balanced points were part of its initial design, it has been employed over time with measurement ranges from two to eleven points, depending on the number of response alternatives (Simms et al., 2019).

The Likert scale is straightforward to create and is likely to yield a reliable scale. Aside from that, it is simple to read and finish from the viewpoint of the participants. On the other hand, there is a lack of reproducibility and validity in this scale that may be challenging to prove. Additionally, participants may avoid extreme response categories, which could result in central tendency bias, which is another drawback of the Likert scale, according to Taherdoost (2019).

2.15 Reliability

The reliability of the Likert scale's cognitive structure produced from the results is not significantly influenced by the number of response categories, according to Schutz and Rucker (1975). Therefore, it is suggested that it has little impact on the outcomes, but employing six or seven points will maximise information retrieval, according to Green and Rao (1970). Therefore, even if reliability scores from 7 to 11 points are quite comparable, it can be said that reliability increases as the number of response alternatives increases.

2.16 Validity

While reliability and validity do not rely on the number of scales (Matell & Jacoby, 1971) it is argued that reliability and validity would not be affected by a reduction in the number of response options. However, Loken et al. (1987) argue that 3-point and 4-point scales are weaker than 11-point scales, as opposed to Matell and Jacoby (1971) who state validity and reliability would not suffer. The 6-point scales were shown to have greater convergent validity coefficients than the 4-point scales, but both were found to have identical criterion validity, according to Chang (1994). Colman and Preston (1997) state scores from five to eleven points have largely equal criteria validity, but nine points has the highest creation validity.

2.17 Preference

Jones (1968) mentioned preferences for the 2-point and 7-point scales among respondents, stating that the 2-point scales are more user-friendly despite the 7-point scales being more accurate, intriguing, and confusing. Preston et al.'s (1997) study results show that the three scales with the highest simplicity of use ratings were the five-point, ten-point, and seven-point scales. On the other hand, shorter scales containing the phrase "quick to use" obtained the highest preference rating. The most popular rating scales were three-, two-, and four-point scales. Therefore, their findings showed that scales with six or more response categories have stronger convergent validity. Overall, validity will rise as the number of scale points increases.

Regarding odd and even number responses, Kulas and Stachowski (2013), Nadler et al., (2015) and Krosnick and Fabrigar (1999), recommend employing midway scales. It is suggested that individuals who want to satisfy their desires will look for a means to do so, and if it is not at once apparent to them, they will choose the optimal option. It was concluded that if the midpoint is not given, the respondent will select the best option, but that scales with a middle choice may deter respondents from adopting a side. Therefore, it is argued that even if midpoint scales are less dependable, they will make it easier to gather more useful data. Furthermore, Colman and Preston (1997) add that if they allow the middle category to be understood as a neutral point, odd numbers of response categories have typically been preferred to even numbers because they give the choice to a person who has a neutral opinion. Regarding the choice of scale, according to Menold and Bogner, (2016), there is no recommendation, and it makes no difference according to the standards for the validity of psychometric measurements. Therefore, to organise rating scales, researchers might do it either in ascending or descending order which will stop persuasion into choosing a side.

In conclusion, Colman and Preston (1997) concluded that although the internal consistency did not vary significantly amongst scales, reliability, validity, and discriminating power indices were significantly greater for scales with more response categories; up to approximately seven.

On the other side, the 7-point preference came in a close second, with respondent preferences being highest for the ten-point scale, according to Preston and Colman (1997). Despite Matell and Jacoby's (1971) claim that the number of response alternatives has no bearing on reliability and validity, some studies have shown that reliability rises as scales go from two to six or seven points. Additionally, research shows that using six or more response scales increases validity (Chang, 1994; Colman and Preston, 1997).

However, Colman and Preston (1997) recommend that the use of the five-point, seven-point, and ten-point scales is comparatively simple. Despite being perceived as being easy to use, scales with 10 and 11 possibilities were strongly preferred to adequately reflect respondents' feelings. The literature recommends applying a seven-point rating scale, and a six-point scale is best if the respondent must be guided toward one side.

2.18 Chapter Summary

This chapter explored a wide range of literature to help answer the research questions and suggest suitable research methodologies and methods. The literature review highlighted the gaps in the literature surrounding Tangata Whaikaha and whanau hauā to better understand the research problem. There is anecdotal evidence found in the statistics which shows a dearth of data surrounding accessible services for Māori Tangata Whaikaha. According to Joseph et al. (2009), this is due to Māori commonly taking care of their own. Māori Tangata Whaikaha and whanau hauā are usually found in rural areas and limited to accessible services. It is noteworthy to mention that a vast majority are unaware of the health service providers they have access to, according to the Ministry of Health, (2016). There are also limited studies in the New Zealand literature surrounding the implications of inclusion and what precisely the barriers are. The next chapter analyses selected methodology and methods to examine and evaluate the strengths and weaknesses.

The next chapter provides an outline of the various methodologies chosen, plus the specific methods of data collection, as well as how I analysed the data.

CHAPTER THREE

METHODOLOGY AND METHODS

3.0 Chapter Introduction

The previous chapter analysed relevant research and statistics about Indigenous- disabled, Tangata Whaikaha. The broad range of literature aimed at defining the barriers of Tangata Whaikaha, Tangata Whaiora, and Whanau Hauā, as well as methodology and methods.

This chapter analyses the selected methodology and methods. The literature review provided insights into commonly employed methodologies and helped identify potential approaches for this research. From there was selected methodology and methods to examine and evaluate the strengths and weaknesses of a range of methods, to combine the strengths of both quantitative and qualitative research to provide a more comprehensive understanding of the research questions.

3.1 Methodology Overview

Kaupapa Māori methodology is chosen for this research as it focuses on Māori perspective knowledge, values, and aspirations. It is a research approach rooted in Māori cultural principles and aims to challenge Western research paradigms that may perpetuate colonization and marginalisation of indigenous peoples. Highlighted is the rationale for the use of the Kaupapa Māori methodology in this research.

Indigenous-centered research: Kaupapa Māori methodology, places indigenous knowledge, experiences, and voices at the forefront of the research process. It seeks to empower Māori communities and challenge the historical dominance of Western research approaches, which have often marginalised indigenous perspectives. Therefore, adopting the Kaupapa Māori methodology creates a more inclusive and equitable research process. The outcomes that honour Māori perspectives, experiences, and aspirations. This methodology is not limited to research with Māori communities but can also inspire and inform research with other indigenous groups seeking to centre on their own cultural perspectives and knowledge systems and collecting and preserving the mauri of Whānau in the data collection and analysis process.

The reason I chose to use Kaupapa Māori methodology in my research is that I believe it best fits with the research question and is best able to answer the research question. Kaupapa Māori research also advocates for research for Māori, by Māori and with Māori, as well as drawing on solutions and transformative actions that effect real change for Māori.

The research questions about Māori people are therefore consistent with that of Kaupapa Māori principles. Therefore, it meets the criteria and best fits with how the framework and the thesis of this research have been conducted and is divided into sections, accordingly, based on this rationale. The purpose of using this methodology is to be able to see the how and why in gathering the information. It further enables identifying how the phenomena are within the context of attitudes and experiences of whanau to give recommendations to Kaupapa Māori.

This section sets out the research questions, how Kaupapa Māori methodology informs my research; how it is conducted, who with and why. I also discuss the importance of Kaupapa Māori not only in this research, but in general, and how it guides the process of collecting and analysing the data in this research in ethically and indigenous ways. This section explains how the Kaupapa Māori methodology will be used through the pōwhiri process, and, moreover, how the pōwhiri process will be used as the narrative and framework for collecting the data in the method of the data collection process.

The outcome of this project will include ethnically relevant results completed by Māori, for the benefit of Māori, with an indigenous Kaupapa Māori perspective. The data collected will provide recommendations for engaging Māori and will identify areas of improvement by providing culturally appropriate services. The section also covers triangulation and the research questions.

3.2 Methods

This section describes the methods I used in the research. Each research question links to the research method used to answer the research question.

The methods applied in this research are not constructed by Western traditions. The methodology applied was Kaupapa Māori methodology and methods that were relevant to the setting and participants within the research they are working in. Three methods were applied in this data collection: E-survey, semi-structured interviews, and case study.

3.2.1 Research question one

The semi-structured interviews consisted of fourteen participants, which included five whanau hauā of Tangata Whaikaha, four service managers, five support staff, from across five service providers in the Bay of Plenty Takiwa. The aim of conducting this E-survey is to undertake an exploratory study to determine what whanau hauā, kaiāwhina, and kaimahi attitudes are and their perceptions on whether they receive culturally appropriate services,

based on the New Zealand Disability Strategy. A previous study of a similar nature was carried out by Wiley (2009).

One of the weaknesses is the time between when the study of Wiley (2009) was completed and the interviews in this data collection, as well as the legislative changes that have occurred since this study was conducted. However, I have mitigated this by comparing the attitudes and not analysing the policies in answering this question.

3.2.2 Research question two

The purpose of using an E-survey Likert questionnaire was to determine the frequency or prevalence of barriers to accessing cultural appropriate service provision according to the participants within the Te Arawa Takiwa. For logistical and financial considerations and purposes, the survey was only open to a sample that was characteristic of whanau hauā, kaimahi and kaiawhina where there has been no existing data. This quantitative research data was collected through an online survey with the use of Survey Monkey.

One of the weaknesses of using this research method was that a question may only be answered if the respondent provides a certain response to an earlier question. However, the questions were answered using a Likert scale and based on attitudes. By doing this, inquiries about subjects that do not concern them are avoided according to Mertler (2002).

3.2.3 Research question three

A case study was the third method that was used to examine four claims in the stage two health Services Outcomes Kaupapa Enquiry and Māori Health Plan Engagement findings. The case study intends to analyse the findings in the WAI 2575 memorandum-directions of the preliminary list of disability-related claims that the Tribunal is investigating in stage two of Health Services and Outcomes Kaupapa Enquiry (Ministry of Health, 2022), under the disability section.

3.3 Ethics (Tikanga Matatika)

Ethics approval was sought and approved by the institutional Ethics Committee and process Te Whare Wānanga o Awanuiārangī. Consent was given from the participants/whanau/hapū/iwi, once they were happy to do so, and were fully informed about their participation in the study, its purpose and how their important contributions would be used regarding the objective of the study. The Pōwhiri framework, provided both a culturally responsive and an ethically tikanga-based approach to working with whānau and conducting

research of this kind. The outcome of this project included ethnically relevant or specific results completed by Māori, for the benefit of Māori, with an indigenous Kaupapa Māori perspective.

The ethical and tikanga considerations around the methods used in Kaupapa Māori research was discussed at great length with my supervisors. Furthermore, the dearth of literature espouses the importance of indigenous informed frameworks of engagement. One of the key ethical considerations, is the care and safety, and upholding of the mana of all those involved in the research. This was always a key reflection for me as I conducted this study and in searching for a better understanding of the areas of improvement required by providing more culturally appropriate and responsive services for our Tangata Whaikaha.

All the participants signed consent forms to participate in the research and will all be given a PDF copy of the thesis and its findings upon completion of this research.

3.4 Overarching Methods adopted in this research.

Three methods have been chosen to collect data. The case study method, E-survey Likert scale questionnaire, and semi-structured interviews are explained below for the purpose and rationale outlined below.

3.4.1 Case study method

Case study method was chosen for this thesis to analyse with a deep and holistic understanding and specifically to answer what the existing barriers are to using secondary data analysis. The qualitative research method adopted in this research allows for complex and real-life situations in their natural context. Following are some tailored insights into the reasons why the case study method has been chosen. Yin and Heald (1975) state that the bulk of empirical evidence and literature is based on case studies which makes it difficult to analyse the data when it comes to policy. The significance of conducting an E survey enables the researcher to source some initial insights, before creating a framework based on the data collected and to better inform analysis of the research gathered. The surveys that are conducted will be able to be analysed based on experience in the frequency that they have occurred over the collection of the participants and then themed accordingly. The case study then seeks to explore in more depth the themes and findings from the surveys, and so would be used to answer questions regarding presumed causal links in real-life interventions that are too complex for survey or experimental approaches. In evaluation terms, the explanations would connect programme implementation to programme effects (Yin, 2003).

Exploratory case investigation is used to examine situations in which the intervention being evaluated does not have a clear, single set of outcomes. Descriptive: this type of case study is used to describe an intervention or phenomenon as well as the real-life context in which it occurred. Multiple-case studies: a series of case studies which allow the researcher to investigate differences between and within cases. The objective is to replicate findings across cases. Because comparisons will be made, the cases must be carefully chosen so that the researcher can predict comparable results across cases or predict contrasting results based on a theory.

Therefore, the case study method is useful for exploring uncharted or new areas of study. It allows the researcher to gain a comprehensive understanding of a phenomenon, which may then serve as a basis for further research. However, although it is noteworthy to mention that while case study methodology offers numerous advantages, it also has limitations. Generalizability to broader populations can be a challenge, and the subjective interpretation of data by researchers can introduce bias. Therefore, by ensuring that the method is applied and used appropriately with a clear research purpose, the case study method will provide valuable insights and contribute to knowledge in various fields which is the rationale for choosing this method.

3.4.2 Qualitative research semi-structured method

Semi-structured interviews are a common qualitative research method chosen for research when in-depth, nuanced insights and perspectives from participants are desired. This approach for this research allows for flexibility in questioning, while providing a framework for consistent data collection. Following are some insights into semi-structured interviews and the reason for why they have been adopted in this research.

Before the engagement of participants through semi-structured interviews, creating an environment conducive to open and honest communication in this approach allows participants to feel heard, respected, and protected throughout the research process. Therefore, the semi-structured interviews offer a flexible and participant-centred approach to gathering qualitative data, enabling me to capture detailed insights and perspectives. By carefully designing interview protocols and actively listening to participants, researchers can uncover rich and nuanced information that contributes to a deeper understanding of the research topic.

3.4.3 E-survey method

A Likert scale questionnaire was used with the use of an E-survey to collect data. This is to identify perceptions about barriers of inequitable service provision that is set out in the New Zealand Disability strategy, but also highlighting inequities for Tangata Whaikaha and whanau hauā. This will add a new breadth of knowledge as, according to the literature, there is a dearth in the data about whanau voice and lived experience.

The advantages of using an E-survey are, firstly, the faster response time for getting feedback from the participants and, secondly, the cost. This is as compared to getting people to fill out a form and having to collect it from the participants. E-Survey is characterised by Jansen and Corley (2007), who state that “[w]e define an electronic survey as one in which a computer plays a major role in both the delivery of a survey to potential respondents and the collection of survey data from actual respondents” (2007, p. 2).

Therefore, E-survey research allows me to reach a large and diverse audience, potentially including participants from different geographical locations, demographics, or populations. This method provides an opportunity to gather data from a broad sample, increasing the potential for generalizability and capturing diverse perspectives.

Lazar and Preece (1999) and Sproull (1986) encourage researchers to use mixed-mode surveys (Mixed-Mode Surveys: surveys that offer alternative response formats e.g., e-mail solicitation with an option to print and return a paper-and-pencil survey) (as cited in Jansen and Corley, 2007, p. 8). Cook and Campbell (1979) argue there are limitations to the validity of the use of surveys. Instrumentation is a threat when an effect might be due to a change in the measuring instrument between pre-test and post-test, rather than due to the treatment's differential effect at each time interval (Cook & Campbell, 1979). Therefore, conducting surveys online can be more cost-effective compared to traditional paper-based surveys. Researchers can save on printing, postage, and data entry costs. E-surveys can also be automated, reducing the need for manual data collection and analysis.

In assessing the appropriate sample size, Martin and Bateson (1986) suggest the bigger the sample the better. It is, therefore, important to ensuring that the sample size is reflective of the population. However, Alreck and Settle (1995) dispute this. Gay and Diehl (1992) state it does not need to be large enough to meet the saturation of data to contribute to new knowledge. Roscoe (1975) highlights some key rules and considerations that should be applied when conducting the sample size of a survey to ensure that it is big enough. It is not

recommended having fewer than ten participants when conducting a survey, surveys that are conducted between 10 to 20 people are sufficient, however, thirty or more is recommended.

In assessing the sample size, it is recommended by Martin and Bateson (1986) that the researcher split the research in half, then the researcher is required to analyse the data of both sets and come up with the same conclusion. In this way the sample size has been met and is sufficient. Gay and Diehl (1992) mention that the size of the data collected needs to be dependent on what type of research is being conducted.

However, Isaac and Michael (1995) suggest that a small sample is sufficient, as it may not be economically feasible or viable to conduct a large study, and therefore a smaller sample may be required. So, where there is an exploratory study that needs to be conducted participants between 20 to 30 would be sufficient or where the research requires an in-depth case study analysis, a small sample size would also be sufficient. Time efficiency: E-surveys can be administered quickly, with data collection occurring in real time. For my research, this meant I could gather a large amount of data within a brief period, enabling efficient analysis and timely research outcomes.

The aim of using the Likert scale is to measure the attitudes, opinions, perceptions, or preferences of participants. This method employs a rating scale where participants indicate their level of agreement or disagreement with a statement or their assessment of a particular attribute. Following are some insights into why Likert scale questionnaires are often chosen: To ensure the measurement of attitudes and opinions: Likert scale questionnaires provide a structured approach to measure participants' attitudes, opinions, or perceptions on a specific topic. The scale allows participants to indicate their level of agreement or disagreement with a statement, providing researchers with quantitative data for analysis.

While Likert scale questionnaires offer several advantages, it is essential to consider potential limitations, such as response bias, limited scale sensitivity, and the inability to capture complex or nuanced opinions. Researchers should design their Likert scales carefully, pilot-test them, and consider complementary research methods to address any limitations and gain a comprehensive understanding of the research topic.

3.5 Scope

The perceived limitations of this study are minor. However, the area scope includes the following: Te Arawa iwi has the third-highest representation (18.1%) of Māori with an intellectual disability, compared to the general population in New Zealand, according to the

Ministry of Health (2015). Moreover, Te Arawa has the highest number of Māori with disabilities (285). As highlighted in the literature review there is an enormity of issues surrounding Māori with disabilities and though this is an indigenous problem and affects the whole of New Zealand, it is important to understand the issues applicable to the research question to make recommendations. Other areas, as they are not in the scope of this research, surrounding institutionalization, compulsory treatment orders, and the Mental Health Act will be looked at as this research evolves.

3.6 Research design

The outcome of this project will include ethnically relevant results completed by Māori, for the benefit of Māori with an indigenous Kaupapa Māori perspective due to the use of a Pōwhiri framework. The data collected will provide a recommendation for engaging Māori and identify any areas of improvement by providing culturally appropriate services. The aim is to analyse the cultural impacts and barriers that whānau members face by comparing the primary data with a triangulation method for better outcomes and improvement of services for people with intellectual disabilities. This research seeks to apply a quantitative case study methodology, which sets out to understand the ‘how’ and ‘why’.

3.7 Participants

I conducted a Likert scale survey of whānau hauā (n-30) support workers of Tangata Whaikaha (non-whānau members) (n-10), managers of non- Government-funded organisations (n-10) and Government-funded organisations (n-10), that work/reside in the Bay of Plenty area. The semi-structured interviews consisted of two whanau hauā support workers, two kaimahi coordinators, and kaiāwhina two service managers.

3.8 Materials

This study conducts quantitative research data collection through Survey Monkey (Appendix D)

3.9 Procedures

Ethics: All information is collected for statistical purposes and used for academic purposes only. All information is kept in full confidentiality. No information, data collection, or feedback will be disclosed to anyone other than the academic board for assessment and will be filed securely. No information will be shared with any other parties and all provisions are

under strict confidentiality under the Privacy Act. An application to the ethics committee will be made and it is likely an ethical application to the National Health Council will be required as well.

3.10 Kaupapa Māori framework

“Kaupapa Māori research is an attempt to retrieve space for Māori voices and perspectives, methodologies, and analysis, whereby Māori realities are seen as legitimate” (Cram, McCreanor, Smith, Nairn, & Johnstone, 2006, p. 50).

It has been highlighted that Kaupapa Māori methods incorporate a range of methods and “It is generally accepted that a Kaupapa Māori approach is inclusive of a range of methods; however, those methods need to be firstly interrogated for their cultural relevance and appropriateness for researching with Māori” (Jones, Ingham, Davies & Cram, 2013, p. 7).

The Kaupapa Māori research will be guided by a set of principles:

- Aroha ki te tangata (a respect for people).
- Kanohi kitea (the seen face, present yourself face-to-face)
- Titiro, whakarongo ...korero (look, listen ... speak).
- Manaaki ki te Tangata (share and host people, be generous).
- Kia tupato (be cautious)
- Kaua e takahia te mana o te tangata (do not trample over the mana of the people)
- Kaua e mahaki (do not flaunt your knowledge) (Smith 1999).

Kaupapa Māori methodology was applied in this research in applying the pōwhiri framework. “Kaupapa Māori research is an attempt to retrieve space for Māori voices and perspectives, methodologies, and analysis, whereby Māori realities are seen as legitimate” (Cram et al., 2006, p. 50)

3.11 The specific elements of pōwhiri applied in the data collection process are karanga, mihimihi, whaikōrero, and koha.

The word pōwhiri is often translated to mean ‘welcome’ (Williams, 2019). The pōwhiri framework in McClintock et al., (2012) is where Māori participation is more likely if an indigenous approach is applied. It increases the engagement process and suggests that the pōwhiri process ensures that it enhances positive engagement.

Karanga – the initial call and intention of this process in the data collection will be implemented through contacting potential participants, both in semi-structured interviews and

e-surveys. Initial contact will be via *kanohi ki te kanohi* (face-to-face) and *whānau* networks will be used to access participants. In a research context, this protocol has alignment with the return of the consent form, which signals acceptance to participate in the research (McClintock et al., 2012).

Mihimihi – Following the *karanga* is the *mihimihi*. This is a time to make connections as well as acknowledge the reason for the meeting (McClintock et al., 2012). Following on from the *karanga* process is the explaining in more detail the reason for and significance of the research. This will be done by email to confirm participation, accompanied by a letter of confirmation of the date. The survey link will be sent as a letter explaining the purpose of the survey, and a signed consent form. Where applicable, and when the organisations are accessible, the *mihimihi* stage will be done face-to-face to implement the *whanaungatanga* process which contributes to the success of research with Māori (Bishop, 1999). It is a fundamental part of the data collection process; however, this process will be dependent on location and accessibility.

Whaikōrero – In the *whaikōrero* phase, the social controls of respect, *tapu*, and *noa* play a significant role when considering these principles (Durie, 2001). Although the data collection is via the quantitative and not qualitative method, O'Leary (2019) sets out eight points when considering the research design that will be applied – population and sample respondents, access, biases, skills, ethics, data, and contingencies. To ensure the survey is implemented successfully, to minimise sample error and biases, and any ambiguities in the questions and lack of understanding, the survey will be piloted on a sample group. This group will be similar to the respondents in the survey to enable the opportunity to gauge understanding and to make any requirements possible that need to be considered for social controls.

Koha – The final element of the *pōwhiri* process is the *koha*, a physical demonstration of appreciation offered to those who have both shared their knowledge and hosted the investigator (McClintock, 2010). Data analysis in this research involves utilising the triangulation method (Keeves & Snowden 1997).

All data were collated in spreadsheet format for interpretation, and appropriate data will be allocated in subsections to interpret data more effectively. Case surveys can contribute to this triangulation, which “heightens qualitative methods to their deserved prominence and, at the same time, demonstrates that quantitative methods can and should be utilized in complementary fashion” (Jick, 1979, p.2): Bennett and Liu, 2018).

3.12 Participants

Before the outset of the study the researcher engaged with a Kaumatua to seek cultural guidance surrounding the data collection and whanaungatanga with the identified participants in the Te Arawa region. The purpose of this method was to ensure that there was biculturalism surrounding the culturally appropriate analysis and to ensure that the research was conducted in a culturally appropriate manner, with guidance. Before the data collection was conducted the researcher contacted the local intellectually disabled community and sought participants for this research. Participants were identified, then sent an email, with their identified email address, and an email was sent with a link. The link contained the consent and the survey questionnaire.

3.13 Considerations to be undertaken when deciding upon accepting participation.

All information is collected for statistical purposes and used for academic purposes only. As previously mentioned, all information is kept in full confidentiality. No information, data collection, and feedback will be disclosed to anyone other than the academic board for assessment and will be filed in a filing cabinet under lock and key, then destroyed upon completion of its purpose. No information shall be shared with anyone other than parties, and all provisions are under strict confidentiality under the Privacy Act 1993

All consent to participate in this survey was at the discretion of the participant. There was a 7-day withdrawal process if they chose not to participate. They will give information on the outcome of the activity in the form of the findings that will be available to their organisation upon request.

Participants are not considered vulnerable in participating in this study.

The participants surveyed are managers that implement management processes, support workers, and whanau that have whanau with an identified intellectual disability.

The risk of participating is always minimised, with the discretion of any feedback collected, will only be used for this study and guarantees no harm.

In the case of qualitative research and interviews conducted, all information taken was double-checked before interpreting any ambiguous text and ensure that what has been collected is true and correct. The consent form was held at Te Whare Wānanga o Awanuiārangi and under the control of my supervisor.

3.14 Data analysis

A Likert scale was used to measure and interpret survey data, which is used to generalize the different information of diverse cultures, ages, sex, and demographics through a survey to better analyse the data. All data was collated in a spreadsheet format for interpretation, and appropriate data was allocated in sub-sections to interpret data more effectively.

The Likert scale questionnaire method was used to identify the participant's specific relatable opinion or perception towards the question being asked. This enables the researcher to capture the feelings, actions, and opinions of the participant to give more to the study. The analysis methods used for individual questions were themed and displayed in pie graphs, with the median and mode - not the mean. The subjectivity of people's perceptions and attitudes in the study were quantified into a conventional measurement using a Likert scale. The research design was a clustered sample to ensure that the region has been proportionately represented in the data collection. A limitation to the use of this method is the illustration of my own experiences and cultural perspective, therefore I had to compare my experiences with that of other research to give the research validity. The implementation of triangulation supports the descriptive survey method sample by giving the research descriptive understanding of culture for the non-indigenous and facilitating their understanding of culture.

Semi-structured interviews were conducted with a total of twenty participants that were selected by whanau hauā of Whaikaha, kaiāwhina, and kaimahi non-government and government participants. Semi-structured interviews were conducted based on questions similar to those of Wiley (2009). This decision was under consultation with my supervisor. The data collected was analysed against previous findings in Wiley (2009) and compared with the attitudes of whanau hauā, kaiāwhina, and kaimahi surrounding the *New Zealand Disability Strategy*.

Participants included: 30 Māori whānau that support their whānau with an intellectual disability; ten support workers; ten non-government funded service managers; and ten government-funded service managers in Te Arawa. The findings were analysed, themed, and described, then organised and clustered into typologies grouping commonalities across themes and analysed with the use of triangulation. This study conducted quantitative research data collection. This method was applied using probability sampling to identify the barriers and needs of the stakeholders to better understand the attitudes of the sample group representative of that population. The number of respondents should meet saturation to provide reliable and valid results. All these aims were achieved thanks to the overarching

methodological approach in which questionnaires consider the diversity of the cultural background of the New Zealand population, with special emphasis on engaging Māori.

The case study method was analysed against the literature review with recommendations based on the findings. Data was analysed using the nominal scale observing the categories based on the association to specific themes and observing and ranking the measure of each of the relationships between each of the findings. These findings indicate and reflect meaningful relative points, and these points were used to identify whether we met the needs of modifying information based on the findings of the attitudes of whanau supporting intellectual disability. The themes were identified in the secondary data analysis obtained from Health Engagement for the development of *Whakamaua Māori Health Action Plan* findings (Ministry, 2020), and the Waitangi 2575 preliminary list of claims (Ministry of Health, 2022). The analysis of the findings identified key themes to answer the question of existing barriers to policy and were assessed against the literature to inform the implementation of operating policy and answer the research question.

3.15 Pōwhiri framework

The Kaupapa Māori method that was applied in this research is the use of the Pōwhiri process. “Kaupapa Māori research is an attempt to retrieve space for Māori voices and perspectives, methodologies, and analysis, whereby Māori realities are seen as legitimate” (Cram et al., 2015, p. 50). The specific elements of Pōwhiri applied in the data collection process are Karanga, mihi, whaikōrero, and koha. The word pōwhiri is often translated to mean ‘welcome’ Williams et al., (2017). Staps et al., (2019) conducted a qualitative study on Māori service users with bipolar disorder and mentioned they make up 27% of the mental health services in New Zealand. They also highlighted that it was overpopulated compared to the general population engaged in mental health services. Staps et al., (2019) state that “The colonization of New Zealand by European settlers and the consequent impacts led to the undermining and undervaluing of Māori culture and the Māori worldview” (p. 2). .

3.16 The application of the pōwhiri framework

As previously mentioned, McClintock et al., (2012) state that Māori participation is more likely if an indigenous approach is applied, which increases the engagement process and suggests that the Pōwhiri process ensures that it enhances positive engagement. The practice of Aroha ki te Tangata (respect for the person) and Kaua e takahia te mana o te Tangata (do

not trample over the authority of the person) increases the chance of a positive outcome for engagement (Smith, 1999).

3.17 Mihimihi

Following the karanga was the mihimihi. This is a time to make connections as well as acknowledge the reason for meeting McClintock et al. (2012). Following on from the Karanga process to explain in more detail the reason and significance for the research, this was done by an email to confirm participation accompanied by a letter of confirmation of the date the survey link was sent and a letter with the purpose of the survey and a signed consent form. Where applicable the organizations accessible to the mihimihi stage were done face to face to implement the Whanaungatanga process that contributes to success in research with Māori (McClintock, et al., 2012) and was a fundamental part of the data collection process. However, this process was dependent on location and accessibility.

3.18 Whaikōrero

In the whaikōrero phase, the social controls of respect, tapu, and noa have a key role (Durie, 2001) considering these principles and, although the data collection was via the quantitative method and not qualitative, O’Leary (2017) sets out eight points when considering the research design and they were applied. To ensure the survey was implemented successfully to minimize sample error and biases, the ambiguity of the questions, and lack of understanding, the survey was piloted on a sample group similar to the respondents in the survey to enable the opportunity to gauge understanding and make any changes as necessary and consider social controls.

3.19 Koha

The final element of the Pōwhiri process is the koha, a physical demonstration of appreciation offered to those who have both shared their knowledge and hosted the investigator (McClintock et al., 2012).

Jones (2000) explored Māori concepts of Kaupapa Māori methodology to examine Tikanga in common law, with the use of a pōwhiri framework. “Kaupapa Māori- centered research is inherently connected to Māori self-determination. The author explains that it is important for the researcher to be a part of the community to be able to support and author their research from a Kaupapa Māori perspective. As the researcher I currently work with within the community space working with stakeholders specifically about this research and

therefore have good experience in ensuring that I was working closely with the research participants.

While I was using Kaupapa Māori methodology I was aware that I needed to create spaces in using the framework applied in this research to ensure that the appropriate ethical cultural practices were implemented when collecting data and working with the stakeholders in this research. I used the collection of data and the pōwhiri processes framework to collect my findings for analysis and implementing of my findings in conclusions within the framework.

3.20 Pōwhiri framework in this research

This research has used this framework to follow the method and methodology but also used it as a narrative to write the thesis. The importance and significance are the ability to frame this within a Kaupapa Māori approach. I have sectioned the methodology framework in which I collected the data into four sections, and I will illustrate each section in how this process was conducted below, based on Mead, (1993) and my own experiences as a Māori.

Wero: the challenge was identifying how I was going to achieve the research using the appropriate methodology, consistent with the need to meet the objectives set out for this research. The first section of this thesis pertained to the introduction of this research project which entailed the introduction of the background to the research.

The aim of this research is examining the attitudes of whanau, support workers, and service providers that support Māori with an intellectual disability (in the Bay of Plenty); to discover what cultural services are available (in the Bay of Plenty), and to identify the extent of Māori whanau accessing these services and the areas of improvement for engaging Māori. Therefore, I applied a pōwhiri framework as the narrative to collect data through surveys, in a culturally appropriate context.

The outcome of this project included ethnically relevant results, completed by Māori for the benefit of Māori, with an indigenous Kaupapa Māori perspective. The data collected provides a recommendation for engaging Māori and identifies any areas needing improvement in providing culturally appropriate services for informing policy by creating an indigenous framework specific to Te Arawa.

Karanga: the next part of this thesis looked at the literature review and it was analyzing what had already been written to identify and ascertain gaps in the research. This literature review aimed to analyse the most up-to-date research and statistics about indigenous people with Tangata Whaikaha and to clearly define the barriers of Tangata Whaikaha and

their families. This research project sought to inform and identify the policy recommendations by comparing the literature with the findings in the research. It also endeavoured to identify gaps in the research surrounding the barriers to an inclusive policy by the unequal impacts that policy has to date on cultural barriers and the impacts of accessing services for Māori Tangata Whaikaha.

The literature review aimed to distinguish and recommend appropriate service supports in policy that is reflective of the needs of Tangata Whaikaha to better understand the research problem. As there is anecdotal evidence identified in the Ministry (2013), Māori commonly take care of their own and are not aware of the health service providers that they have access to, based on the findings within this literature review. Therefore, this highlights the need for further focus in these communities, and the significance of conducting this research.

3.21 Whaikōrero

The implementation of this phase enabled the participants to have an active voice in conducting the surveys which gave breadth of knowledge to the research to identify gaps that had already been mentioned in the literature. The importance and significance of this section was the implementation of Kaupapa Māori methodology in the overarching framework which was used to collect the data. This also saw the sharing of information between agencies, and whanaungatanga where I saw different agencies contacting other agencies to see if they would be interested and sharing via email.

Whaikōrero was subdivided into three sections. The first section was about the non-government agencies that support people with intellectual disabilities. The second section was government agencies government-funded that support people with Tangata Whaikaha and in the third section was whanau members that support a member with an intellectual disability. Three subdivided sections represent the three speakers.

Speaker 1: non-government-funded intellectually disabled coordinators and support workers.

The importance of non-government not-for-profit agencies gave a different context, however, although everyone was required to abide by objective 11, it added a different perspective from a not for profit on their attitudes towards whether intellectually disabled are supported in the community. There is no funding or limited funding for people with Tangata Whaikaha in the community. However, it is still to be concluded whether their attitudes are because of lack of funding. This was not measured in this research but can be explored further in another research

study. The research aim was to look at attitudes, not to assess the organizations that participated, but in general whether the objective meets the needs of the disproportionately represented numbers within the community.

I classed a non-government agency by identifying whether they provided a service for the intellectually disabled, whether that be a day service for people with disabilities or a supported living environment. They also needed to be located within the parameters of the scope of the research – this was from Maketu to Tongariro – and they had to be registered as a not for profit charitable or incorporated organisation. The scope of the participants did not look at how many they serviced, and the triangulation did not compare the areas other than the area of scope. Thus, all participants that were non-government agencies, but provided services, were all measured against the attitudes of each person, as opposed to organizations. Service providers did not have to have a limited number of employees and employers. The governance structure did not have any implications on their participation in this research in their level of funding and it did not have an impact on whether they could participate in this research. Support workers were not measured by the number of hours that they worked, and their time employed within the organisation.

Speaker 2: Nongovernment and government funded kaimahi, kaiāwhina of Tangata Whaikaha and whanau hauā support workers.

The significance and scope of government-funded intellectually disabled coordinators in support workers give the breadth of knowledge to the research because it looked from an aspect of what the current attitudes are, to meet triangulation.

However, again, as well as non-government- funded agencies, the study did not investigate whether this was due to funding or if there was enough literature to suggest that there is not enough funding being distributed to intellectually disabled organizations. Like non-government agencies, the same approach was taken with government-funded agencies in selecting participants, whether they be coordinators and/or support workers and participating in this research.

Speaker 3: whānau hauā. Speaker 3 highlights the importance of this thesis on whether we meet the needs of Māori with Tangata Whaikaha in the community. The results have been quite a cannon in that they have a very objective view compared to that of the literature. This was measured against the non-government agencies in government agencies editors to whether objective eleven was met. The scope of this research did not segregate to a certain group; however, it did specifically look at ethnicity. It did not, however, look at

demographic, or socio-economic factors that may have influenced people's attitudes which, again, is another further extension that can be explored later. The participants were more than willing to participate in this research and understood the methodology that was being used which made it a lot easier to gauge participation and completion of surveys.

3.22 Waiata

This section was documented through the different speakers, and they all seemed to emerge with different perspectives of thinking. With the use of triangulation, I have been able to identify a key point in identifying the research question. Numerous themes were highlighted differently as in perspectives, and this is what created the basis of the framework based on the three sections and the feedback that was ascertained from the data collection. The findings were broken down into two main sections. The first was the policy recommendations, the second whether we have met the needs of Māori with the intellectual disabled in the community, and, again, this was triangulated and themed accordingly. The combination of all the subdivided sections collaboratively comes together and forms a framework with recommendations and addressing the research question.

3.23 Scope

The research aimed to identify whether we have met the treaty obligations under objective 11. Furthermore, how we are working with whanau to recommend policies by assessing the attitudes of whether we meet the needs of Māori currently. These are themed accordingly in the findings and by the collection analysis in the next chapter.

The scope of this study is that the method of data collection and analysing of statistical data did not look at analysing asylums and or institutionalization; this is something that can be further investigated at a later stage. This could have been used as a comparative analysis, or if we are still institutionalizing the procedure of measuring and comparing the analysis with the way we currently meet with this research to determine if any themes emerge.

Based on the findings of this research I argue that there is a need to address the treaty obligations within common law. There is also still a need to measure and identify whether tikanga is appropriate. Furthermore, analysing how this is measured and how we support Māori with the intellectual disabled. The importance of using this research framework within the narrative of the research was to ensure that a Māori worldview was applied throughout this research.

3.24 Pōwhiri structure in collecting data.

Identifying suitable participants was also implemented by contacting non- government agencies, government agencies and whanau members of people with Tangata Whaikaha. This was to identify whether they would participate in such research in the first instance.

"Kaupapa Māori Research aims to avoid Māori knowledge being simplified or commodified, as has often been the case with much earlier research" (Bishop, 1999, p. 50). Bishop (1999) explains that there are four components to the implementation of this principle: identifying the families, creating the report, and fostering relationships for them to participate, and lastly the researcher participating in the research.

I contacted whanau non-government agencies in the community and government agencies to ascertain the stakeholders and identify the research participants. This was conducted via telephone and then followed through with hui to explain the purpose of the research. Some participants were happy with receiving emails with the information. This highlights the importance of the interest in sharing this research, due to the dearth of data surrounding family members and organisations that support people with intellectual disability in the community.

Conducting numerous hui with the participants allowed me to engage in rapport and answer any questions they had. I was also able to ensure that they were aware and part of the process of collecting the data, and that the method was implemented within this process of identifying participants. The most important aspect of this principle in working with the families was being able to establish that they were leading the research and that without their participation this research would not be possible. The significance of this was that I was able to capture a greater scope in the area by sharing some information and having face-to-face hui with different whanau.

The three non-government agencies and government agencies were happy to receive the information via email. Of the family members of those that had an intellectual disability, 6 of 17 whanau wanted to have a face-to-face to discuss what the purpose of the research was and how they would be participants in it. Of the thirty identified families contacted, only 17 participants identified were happy to participate in the research. Three of the final, explicitly did not want to participate and gave no reasons. 6 had barriers to completing the surveys and 4 lived rurally and did not have access for completion of the surveys.

3.25 The Karanga- The call was made.

The initial karanga was made and it was initiated in whanaungatanga in establishing the research participants, as stated above. The purpose of the implementation of this framework was to work within a structure in an easy-to-follow research format. This enabled me to follow a process and to work within a culturally appropriate way of collecting data, consistent with the literature in collecting Māori research. The use of this framework was particularly successful in that the participants were Māori and in highlighting various aspects of the method of data collection and data analysis. I was able to articulate this in a way that they understood in the hidden appreciation of using Kaupapa Māori methodology, and an appreciation from a cultural perspective.

From the literature, as stated in this chapter, Māori tend to not participate in qualitative research due to the barriers and attitudes. Because the use of this framework has been researched, it was a lot easier to interpret what I was doing and what the process is, where to get the buy-in and participation in the research. With the use of this stage in the process of data collection, I did not have any barriers to communicating with the families involved in the research. Of the thirteen participants from families that did not want to participate, this was due to not having access to the Internet or not knowing how to use SurveyMonkey. They decided that it was a barrier to them completing this research questionnaire. This is something that needs to be looked at through the wide research findings with whanau members, to access in their view how accessible services are. The survey are for collecting qualitative research, specifically for whanau members that support their adult children with an intellectual disability.

Also, another barrier to participation was families that live in rural areas were not able to come and have face-to-face hui to gain more information about what they were participating in. This created a barrier for them to participate in this research. Therefore, the barriers can be summarized as access to the Internet, understanding how to use SurveyMonkey, and access from rural areas.

3.26 Whaikōrero

After the initial karanga was sent in emails, we sent out conversations we had with different participants and the participants had the opportunity to engage in conversations via email, telephone, or face-to-face. They were able to ask for more information about why this research was important. This was a pivotal opportunity for me to share information regarding what

Kaupapa Māori is with the whanau, NGOs, and government funded organization participants, and the importance and significance of the impact this research would have. This was important for the scope of this research because it needed to be accessible. I also needed to be accessible to the participants to be able to make this method of data collection successful, not only for the participants, but for this research to be successful.

Participants were sent a link with the participant's disclosure statement, ensuring that they were to be kept anonymous, and that all information collected was only for statistical purposes. No information collected could identify them as participants in this research. The statistical data that was collected represents a percentage of the identified intellectually disabled within the Te Arawa catchment. However, this did not meet the original requirement of representing the demographic to meet full saturation for this research; therefore, this was made up of non-government agencies and government-funded agencies support workers to meet the saturation of conducting a sound assessment with the use of comparing and contrasting their findings using the triangulation method.

The data collection has given the participants the voice to be able to share their views surrounding whether the treaty obligations have been met. This supports the point and significance of Kaupapa Māori and the role that it plays in collecting data. This allowed participants in this research to identify whether we are currently meeting the need and gave their perspectives surrounding what was important for them. This is also consistent with the literature of what is important in collecting and applying the principles of the wellbeing of Māori.

However, this application of the principles may be a question of how Tikanga is applied. It is important to note that, in order to maintain the participants' mana, Tikanga principles and whanaungatanga were implemented throughout the data collection procedure.. The significance that this data has to the researchers is phenomenal, although it may only be a small sample of the demographic. It creates an opportunity to investigate further surrounding the intellectually disabled and the inequalities that we face in legislation, specifically looking at Tikanga and how this is applied.

3.27 Data analysis

All data was themed accordingly, consistent with each subdivided group. The first group being non-government-funded intellectually disabled coordinators and support workers. The second group was government-funded intellectually disabled coordinators and support workers, and the third group whanau members of service users with intellectual disabilities.

Each question was broken up into different sections, then each section allocated using the Likert scale, then analysed using triangulation against the three participant groups. All data was analysed and graphed accordingly using the SurveyMonkey application. The purpose of using this app is that it is user-friendly and populates all the answers and themes. This saved time creating graphs to analyse the data, which makes it more readily available. Once data has been interpreted, themed, and categorised accordingly, it was written up in the findings, in the conclusion section of the next chapter.

3.28 Chapter Summary

This chapter sought to explain the rationale behind why this specific process was used to collect the data and give a rationale for its purpose in answering the research question. I would like to also take this opportunity to thank the participants that participated in this research, for without your participation this research could not have been completed. Also, acknowledging that the integrity of the research was upheld, consistent with the principles applied throughout the data collection of this research.

The purpose of this section is to ensure that Kaupapa Māori concepts have been implemented strategically. Furthermore, to ensure that the methodology and Tikanga principles have been applied correctly throughout this research and to identify the process the researcher has taken to implement this. As identified in the literature was the highlighting of the significance, or end importance, of Kaupapa Māori recommendations in promoting methodology to make promote recommendations. The significance and importance of using the Pōwhiri framework is to ensure that the integrity of the research, by way of the participants, is managed in a way that is sufficient, and the ethical obligations consistent with Tikanga. The implementation of the Powhiri narrative in the framework of writing up this thesis, in sectioning it off into different sections, applies to this research as it ensures that is articulated in a way that can be easily understood and interpreted by the participants. The next chapter uses E-surveys to determine the frequency or prevalence of barriers to accessing accessible and equitable service provision among the participants within the Te Arawa Takiwa. For logistical and financial considerations and purposes, the survey was only open to a sample that was characteristic of the intended group. It was conducted as an exploratory investigation to assess the attitudes of whānau hauā, kaiāwhina, and obstacles that Māori face in obtaining disability service.

CHAPTER FOUR

E -SURVEY FINDINGS / RESULTS CHAPTER

4.0 Chapter Introduction

The previous chapter outlined the overarching framework and significance of the use of Kaupapa Māori in this thesis, as well as how the data was collected with the use of the Pōwhiri framework as the narrative. It also indicated the methods and methodology that were used in this research thesis.

Likert scale questionnaire as well as descriptions of the interpretation of the results. This research aims to conduct an exploratory quantitative case study of three groups (whānau hauā of Tangata Whaikaha in the Bay of Plenty Community, Māori, and non-Māori local government, hapū, and iwi service providers).

4.1 Data interpretation

An initial karanga was conducted via existing networks within the health and disability sector, as well as emails to government and non-government providers of Tangata Whaikaha in the Te Arawa Takiwa. The purpose was to gauge the interest of service providers and whānau hauā in participating in an E-survey and contributing to this research. Once the initial karanga was made, I initiated phone calls and had face- to-face interviews with service providers and whanau hauā to explain in further detail the purpose of the research and the research objectives.

Sixty participants wanted to participate. They were all sent a survey monkey link via email and/or text message. Location and accessibility were taken into consideration, as well as time limits. However, only 90% of participants agreed to participate. The other 10% declined to participate and therefore the analysis is reflective of the 54 participants that completed the survey (refer to Appendix A for the questions). All the data was populated in an Excel spreadsheet, with respondents on the right, and each question was reflective of the data collected and can be seen in Appendix E.

Each question was broken up into different sections, then each section was allocated using the Likert scale questionnaire. A Likert scale questionnaire was used to measure and interpret survey data, which was used to generalise the variety of information of diverse cultures, ages, sex, and demographics. All data was presented in spreadsheet format, and appropriate data allocated in subsections to interpret data more effectively.

The questions were closed ones Mertler (2002) closed-ended questions and answers from respondents are restricted to a predetermined set of options scales, therefore the rationale for choosing closed questions was to compare the findings to the literature. Although collecting data does not fit within a Māori context, the process of collecting and engaging has been applied with the use of a Pōwhiri approach and therefore adheres to the principles outlined in the methods and methodology section.

The graphs in appendices A to D reflect the visual format of the data collected with the use of the Survey Monkey collection data tool. The survey conducted a Likert scale survey of whānau hauā support workers of Tangata Whaikaha (TW) (n=18); community support workers of Tangata Whaikaha (CS) (n=18); community coordinators (CC) (n=9) and service managers (SM) (n=9).

4.2 Discussion

Question 1. Do you give consent to use this information, and do you agree to participate in this research E-Survey? If you decide that you would like a copy of the findings, please let the researcher know and this will be made available to you on completion of examination.

All participants agreed to participate in the survey and acknowledged by agreeing that all information is collected for statistical purposes and used for academic purposes only and kept in full confidentiality. No information, data collection, and feedback will be disclosed to anyone other than the academic board for assessment. Data were filed in a filing cabinet under lock and key, and will be destroyed upon completion of its purpose. No information shall be shared with any other parties, and all provisions are under strict confidentiality under the *Privacy Act 1993*.

Question 2. Highlighted in the literature mentioned, the Ministry of Health (2015) stated the findings in the analysis of the demographics surrounding barriers that intellectuals face in the community. The findings in the report indicated the need and recommendation for intellectual disability public awareness, examining equal opportunity issues more thoroughly, and allocating more money for the implementation of creating more inclusive access to services. However, according to the statistics, there is a lack of understanding and application of the *New Zealand Disability Strategy's* goal of fostering inclusive environments. This is particularly so in housing for mental health and the disabled and that indeed based on the attitudes of the participants there are still existing gaps.

The Ministry of Social Development (2023) asserts the need for more inclusive environments to address disparities that regularly contribute to barriers and the lack of inclusive environments. Creating more inclusive environments for Tangata Whaikaha (disabled people) in the community is crucial for promoting equity, and social cohesion and ensuring that everyone has equal opportunities to participate and contribute. Therefore, this gives rationale to measure the attitudes of the participants. This is to assess whether they believe there is a need to create inclusive environments for disabled people in the community (Appendix B).

The findings of the question for accessing the attitudes to question two are indicated as follows. WH (n=18) results indicate they strongly agree and believe there is a need to create inclusive environments for disabled people in the community. CSW (n=18); the average results of the Likert scale survey results strongly agree that there is a need to create inclusive environments for disabled people in the community. CC (n=9) and SM (n=9); results strongly disagree that there is a need to create inclusive environments for disabled people in the community.

Therefore, in comparing the findings with the literature, it can be determined that both cohorts of support workers, mainstream and whānau members that support their whānau with an intellectual disability suggested that there is a need to create more inclusive environments. Based on the results it is suggested that those on the front line see more, as they are working in the community with the service user. They are more likely to see the barriers in the community and have reflected the gaps that are also highlighted in the literature. Therefore, based on the findings in the data collection, there is a need to create more inclusive environments to empower Tangata Whaikaha. This is by providing opportunities for their active participation in decision-making processes, community activities, and social interactions. Inclusion enables them to exercise autonomy, express their opinions, and contribute their talents and expertise. As highlighted in the literature, attitudes reflect beliefs and attitudes that are reflective of a more inclusive environment for Tangata Whaikaha will contribute to the overall health and well-being of Tangata Whaikaha.

Question 3. The literature indicated that Māori Tangata Whaikaha have experienced a breach of equity in health. Furthermore, significant concerns exist in the literature about disparities and challenges they face. Several factors contribute to this breach, including historical and systemic issues, socio-economic disparities, cultural barriers, and inadequate access to healthcare resources in health which is a significant concern that highlights the

existing disparities and challenges they face. Several factors contribute to this breach, including historical and systemic issues, socio-economic disparities, cultural barriers, and inadequate access to healthcare resources.

Therefore, the purpose and intent of assessing whether participants felt that their organisations provide a culturally appropriate policy to meet the needs reflective of Māori Tangata Whaikaha. (Appendix B)

The findings of question three for accessing the attitudes to the question are indicated as follows. WH (n=18) and CSW (n=18) average results of the Likert scale survey results indicate they neither agree nor disagree that their organisation provides a culturally appropriate policy to meet the needs reflective of Māori with Tangata Whaikaha with their current service provider/service offered. CC (n=9) and SM (n=9) results show that they strongly disagree that their organisation provides a culturally appropriate policy to meet the needs reflective of Māori with Tangata Whaikaha with their current service provider/service offered.

In comparing the findings, it can be determined that both cohorts of support workers, mainstream and whānau hauā with Māori Tangata Whaikaha average of both cohorts suggested that they neither agree nor disagree that their service provider provides culturally appropriate policy to meet the needs reflective of Māori Tangata Whaikaha with their current service provider/ service offered. This could show that they are not aware of the policy or are not familiar with the policy, as indicated in the results from the Service Community Coordinators and Service Managers cohort. This indicates they strongly disagree that they are not aware of the policy.

Question 4. International literature, indicated in Adnams (2010), highlighted that in Australia, the needs of people with disabilities in hospital contacts have gone unmet by policy and practice papers. According to these reviews, some people with Tangata Whaikaha are afraid of hospital contacts, they depend on carers for the duration of their hospital stays, and hospital staff often behave disastrously due to their poor attitudes and lack of knowledge (Fitzsimmons & Barr,1997): Bradbury-Jones, 2013). There is little evidence that the systems for health and disability services have what is necessary to supply the kinds of accommodations that are called for by policy, according to Mencap (2012). Although this study pertains to Māori the significance and importance is highlighting inequities of indigenous Tangata Whaikaha and policy.

Kukutai and Taylor (2016) mention there is a need to critique current policy to highlight and investigate the depth of indigenous disadvantages in Australia in greater detail than in New Zealand, Canada, and the United States.

Therefore, it is suggested that existing policies are unsustainable and unfair to Indigenous people (Walter et al., 2020). Therefore, the significance and importance of identifying whether the participants feel that their organisation provides a culturally appropriate policy to meet the needs reflective of Māori with Tangata Whaikaha, with their current service provider/service offered (Appendix B).

The findings of question 4 in assessing the attitudes to the question are indicated as follows. WH (n=18) average results of the Likert scale survey results in a 2.2 average strongly agree, overall, that we provide culturally appropriate services for the intellectually disabled Māori in the Bay of Plenty Community. CSW (n=18) average results of the Likert scale survey results indicate an average of 2.22 that strongly agree, overall, that we provide culturally appropriate services for the intellectually disabled Māori in the Bay of Plenty Community. CC (n=9) and SM (n=9) average results of the Likert scale survey results with 3.61 strongly disagree, overall, that in the Bay of Plenty community, there are culturally appropriate services for intellectually disabled Māori in the community.

In comparing the findings, this question looks at the Bay of Plenty collectively and not the organisation. It therefore indicates that on a macro level a majority of the cohort of all three groups, overall, believe that there are culturally appropriate services.

However, one-third of the sample group is representative of Māori whanau. It is not clear whether there is any bias due to the representation of Māori ethnicity in Service Community Coordinators and Managers. The purpose of the survey is in assessing the attitudes. The majority suggested that there are culturally appropriate services for Māori intellectually disabled in the community.

The findings indicates that a lack of recognition for Tangata Whaikaha, referring to individuals with disabilities who are also Māori, may face a lack of recognition and understanding in policy frameworks. Policies often fail to acknowledge and address the specific needs, challenges, and aspirations of this unique population, resulting in inadequate support and limited inclusion in decision-making processes. The literature indicates that policies may not align with the cultural values, practices, and aspirations of Tangata Whaikaha. This disconnect can lead to a disempowerment of Māori identity and a failure to promote culturally appropriate approaches that recognize and respect their rights and

perspectives. Therefore, ensuring effective policy development requires collaboration and meaningful engagement with Tangata Whaikaha and their whānau as key stakeholders. However, the lack of genuine consultation and participation can result in policies that do not reflect their voices, experiences, and priorities, leading to a disconnect between policy intent and the lived realities of Tangata Whaikaha.

Question 5. Overall, do you feel satisfied with disability service support for Māori with an intellectual disability in the Bay of Plenty region (Appendix B).

The findings of question 5 for assessing the attitudes to the question are indicated as follows. WH (n=18) average results of the Likert scale survey results indicate a 4.44 average. This cohort strongly agrees that they are satisfied, overall, with the disability service support for Māori with Tangata Whaikaha in the Bay of Plenty region. CSW (n=18) average results of the Likert scale survey result indicate an average of 4.44. This cohort disagrees that they are satisfied, overall, with the disability service support for Māori Tangata Whaikaha in the Bay of Plenty region. CC (n=9) and SM (n=9) Likert scale survey results with an average of 3.66 strongly disagree, overall, that they are satisfied with disability service supports for Māori Tangata Whaikaha in the Bay of Plenty region.

From the results of the three cohorts, a similarity is drawn in the suggestions of both mainstream service providers, Service Community Coordinators, and Service Managers. They believe they are not satisfied with the support services for Māori and yet Whānau hauā indicate that they are satisfied. The difference to draw upon in this comparison is that Whānau members support their whānau hauā's use of individualised funding and are self-managing. Therefore, it can be concluded that the majority of the three.

cohorts are not satisfied with disability service supports for Māori with Tangata Whaikaha in the Bay of Plenty.

Question 6. Do you believe that your organisation meets objective eleven? – "Objective 11: Promote participation of disabled Māori, promote opportunities for disabled Māori to participate in their communities and access disability services. Disabled Māori should receive an equitable level of resource that is delivered in a culturally appropriate way". In that, your organization promotes the participation and promotion of Māori with an Intellectual disability (Appendix C).

WH (n=18) average results of the Likert scale survey result in an average of 4.33 that strongly disagree that they are aware of the New Zealand Disability Strategy. CSW (n=18) average results of the Likert scale survey results with 4.33 who disagree that they are aware

of the New Zealand Disability Strategy. CC (n=9) and SM (n=9) average results of the Likert scale survey results in an average of 1.1 that agree that they are aware of the New Zealand Disability Strategy. In assessing all three, Whānau members that support their whānau with an intellectual disability and Mainstream Support Workers of Intellectual Disabled compared to Service Community Coordinators and Service Managers are not aware of the New Zealand Disability Strategy. These findings are an important indication in answering the research question, as these are the strategy guides of how policy should be reflectively implemented.

The findings indicate the lack of implementation and awareness consistent with the literature highlights; that the New Zealand Disability policy frameworks may inadvertently perpetuate discrimination and bias against Tangata Whaikaha, leading to unequal treatment and systemic disadvantages. This can be exacerbated by intersecting factors, such as disability, ethnicity, and socio-economic status, resulting in compounded marginalization and limited opportunities for Tangata Whaikaha to thrive.

Question 7. The literature indicates the need for a more culturally responsive policy. Therefore, what is the importance and significance of measuring the attitudes of participants to ascertain whether they believe there is a need for organisations that support Tangata Whaikaha and be culturally responsive to the needs of Māori (Appendix D)?

WH (n=18) results of the Likert scale survey indicate an average of 4.11 strongly disagree they are culturally responsive to the needs of Māori. CSW (n=18) Likert scale survey results indicate an average of 3.09 neither agree nor disagree that their organisation is culturally responsive to the needs of Māori. CC (n=9) and SM (n=9) Likert scale survey results indicate an average of 3.94 strongly disagree that their organisation is culturally responsive to the needs of Māori. Ministry of Health (2012) explained that the barriers to Māori accessing equitable service provision have been associated closely with linguistic and cultural barriers, and inequality in the policy. Therefore, in comparing the three cohorts, it is apparent that there is still a gap in attitudes about cultural responsiveness of services, according to the perspective of Whānau hauā.

Question 8. How old are you? WH (n=18) Likert scale survey results indicate that the average age range of participants was between 44 and 54 years. CSW (n=18) Likert scale survey results indicate that the average age of participants was between 54 and 64. CC (n=9) and SM (n=9) average results of the Likert scale survey result the average age of participants was between 44 and 54. In comparing the three cohorts the average age of participants is between 44 and 54 years (Appendix D).

Question 9. What is your gender? Likert scale survey results of all three groups indicate that the average gender of participants was females. Appendix D indicates that females are the predominant gender that care givers.

4.3 Chapter Summary

This chapter produced quantitative research data derived from E-Surveys with Likert scale questionnaires.

The outcome of this data collection highlighted ethnically relevant results completed by Māori, for the benefit of Māori, with an indigenous Kaupapa Māori perspective. The Pōwhiri framework was applied to the karanga through to the engagement process and all were conducted within a Te Ao Māori context. A Likert scale was used to collect the data and interpret the attitudes of the participants.

The findings of three groups (whānau hauā of Tangata Whaikaha in the Bay of Plenty Community, Māori, and non-Māori local government, hapū, and iwi service providers) identified the existing and continuation of barriers to accessible services that are culturally appropriate among the participants are consistent with the literature. Therefore, the findings conclude that there are still inequities in the policy framework of implementing the New Zealand Disability Strategy within the Te Arawa Takiwa.

The key findings are as follows.

- The need to ensure policymakers and service providers have a deep understanding of Māori culture, values, and perspectives. Training in cultural competency is essential to avoid biases and to respect the unique needs of Tangata Whaikaha.
- The need to engage Tangata Whaikaha and their whānau (family) in the development and review of policies that directly affect them. This co-design approach ensures that their voices and experiences are included.

The next chapter presents the findings of the semi-structured interviews to answer question 2. It presents the findings from the interview questions and themes and displays the results of the following participants: Māori and non- Māori support worker caregivers, service managers, and coordinators. This study will be compared to an earlier study conducted by Wiley (2009). Wiley (2009) conducted a qualitative data analysis to show the attitudes to inequities of service provision for Māori that are set out in the New Zealand Disability strategy. The research indicated that the social model was not effective for Māori and strategy needed to be developed to look at the implementation from an indigenous context surrounding policy.

CHAPTER FIVE FINDINGS / RESULTS

FROM SEMI-STRUCTURED INTERVIEW METHOD

5.0 Chapter Introduction

The previous chapter discussed and presented the findings of the E-survey Likert scale questionnaire. This chapter presents the findings from the interview questions and themes and displays the results of the following participants: Māori and non-Māori support worker caregivers, service managers, and coordinators. This study will be compared to an earlier study conducted by Wiley (2009). Wiley (2009) conducted a qualitative data analysis to show the attitudes to inequities of service provision for Māori that are set out in the New Zealand Disability strategy. The research indicated that the social model was not effective for Māori and the development of strategy needed to look at the implementation from an indigenous context surrounding policy.

Therefore, the semi-structured interviews will be compared to the findings of the earlier study by Wiley (2009), and the literature, to answer the research question: Are the attitudes of inequities of service provision for Māori set out in the New Zealand Disability strategy still the same compared to Wiley (2009)?

5.1 Interview Contributors/Participants - Karanga

The initial karanga was made to intellectual disability services in the Te Arawa rohe from Maketu to Tongariro, via email, to gauge the interest of the service providers and their service users' whānau. Once the initial karanga was made, I started phone calls and had face-to-face interviews with the service providers to explain, in further detail, the purpose of the research and the research objectives. Fourteen participants were contacted and agreed to take part, however, due to availability and tangihanga four were unavailable at the time of the interviews, meaning only ten interviews conducted.

Hui was the process of initiating and finding the potential participants for this research. The hui that took place allowed the service provider and their whānau to ask questions and seek clarification. Location and accessibility were taken into consideration as well as time limits. Whānaungatanga was implemented throughout the process of the initial hui with the whānau and service providers:

- 1) Two Coordinators – one non-Māori and one Māori- each covered the Eastern Bay of Plenty and Western Bay of Plenty. Both were from government organisations mainstream firms.
- 2) One Māori Service Delivery Manager of a Māori Organisation, and non- Māori Mainstream Service Delivery Manager.

In this phase of applying the Pōwhiri process, as the narrative for conducting semi-structured interviews, the social controls of Tapu and Noa were seen during this period. All hui began with a karakia, and Tikanga was implemented and followed through the duration of the hui with each participant. All participants were invited to bring whānau support as well.

A total of fourteen respondents were initially selected, however, only six interviews were conducted due to availability. Participants were selected in relation to availability and contacted via telephone. Interviews were recorded using an audio device. Upon consultation with the supervisor, and having reviewed the transcripts, evidence suggested there was enough to compare the findings to meet the saturation of data collected.

All interviews ranged, on average, for 60 minutes. The interviews were one on one and face-to-face. The taped interviews were input into an Excel spreadsheet, reviewed against each category (Coordinators, caregivers, and Service delivery Managers), and put into themes accordingly.

Participants consisted of a 2:1 ratio of female to male. The youngest participant interviewed was forty-two with the average age of participants being 50 to 60, with 18.5 years average experience in the Health and Disability sector. Māori to non-Māori participants of 1:1, and 1:3 participants were whānau hauā with Tangata Whaikaha and 1:2 mainstream non-government to Māori organisations.

5.2 Koha

All participants were allowed to review the findings of the interviews as a way of showing appreciation for their contribution. They were also told that their participation would contribute to those that have whānau members affected. Although the concept of koha is a physical demonstration, in this context it was the ability to participate and therefore contribute. This was a reciprocal approach, where they are given back with regards to their contribution to more accessible services, and the recommendations will enable more inclusive environments for their whānau.

The findings are measured against secondary data analysis of the findings of Wiley (2009). Moreover, the literature review is used to identify whether gaps continue to exist and to ascertain more information to answer the research question.

5.3 Participants

Each Coordinator (CO) interviewed was from two separate organisations; one serviced the Eastern Bay of Plenty and the other the Central Lakes districts. Interviews conducted took an

average of 55 minutes, with 19 years of experience between each coordinator. Both coordinators are funded by government-contracted agencies that delivered the same or similar services. One of the coordinators had a child with an intellectual disability.

Two separate interviews were conducted with service delivery managers (SM) who work in the Health and Disability sector, both from separate organisations. On average, the interviewer spoke with each participant for 60 minutes. These participants had an average of 20 years of experience in the Health and Disability sector. Both worked for government-contracted agencies that delivered the same or similar services.

Two separate interviews were conducted with community support workers (CSW) that are whānau hauā, from two separate non-government mainstream organisations, with an average of 34 years' experience between the two. Both were employed by contracted agencies. Each interview took on average of 58 minutes.

5.4 Analysis of Findings

Question two: All respondents mentioned that they were familiar with the New Zealand Disability Strategy and could explain what it was, however, they did not know what objective 11 was. Both COs suggested that there was a need for more accessible services for service users in the community. SM1 and SM2 both mentioned that there are not enough alternative services. Comparing the findings, the CSWs suggested that there are adequate services and support.

Question two findings highlight the following: CSW 1, CO1, and CO2 say their organisation delivers bicultural training three times a year. SM1 and SM2 say their organisations deliver every quarter. CSW 2 is aware that they deliver bicultural training, yet in the four years, with the current employer has never participated in bicultural workplace training. The two whānau hauā participants were unaware if staff received training and mentioned they assumed that they would. Whānau hauā further expressed their concerns regarding the lack of cultural support for their whānau member. However, they expressed concerns surrounding the lack of whānaungatanga from their provider and providers in the past:

We have received insufficient information and guidance and we struggle to navigate complex service systems due to a lack of clear and accessible information. Understanding eligibility criteria, available services, and how to access them can be overwhelming for us as a whānau and the inadequate guidance and support from service providers or government agencies can further hinder equitable service provision for our whānau is not reflective of whānaungatanga” (Whānau Hauā Support Worker).

Stigma and social isolation: Stigma associated with intellectual disabilities often leads to social exclusion and isolation, impacting both individuals and their families. These negative attitudes can hinder the development of inclusive communities, limit social opportunities, and impede access to vital resources and services.

Question three findings highlight the following: Surrounding culturally appropriate services for Māori Tangata Whaikaha; CSW 1, CO1, CO2, and SM1 suggest that they implement culturally appropriate services and programmes. However, CSW 2 and SM1 say that their organization is aware there is a need; however, they have not implemented Māori Culture programmes at present. This suggests there is a lack of appropriate cultural awareness and being unsure of where they can access these services of knowledge.

For question three: attitudes towards access, CO 1 & 2, and SM 1 & 2 had ambivalent arguments and both suggested there are limits to Māori being able to access services. They identified the need to form bridging between physical supports to access the services.

From the findings it can be concluded that although the policy may state inclusion with people with disabilities, and attitudes may be changed by implementing awareness training, this may not necessarily be as successful in changing attitudes towards I.D. In question eight, findings from the data collected suggest that all participants feel that there needs to be more accountability for implementing more effective support services. The common trend that appeared in the findings from semi structured interviews of participants CO 1 & 2, SM 1 & 2 surrounded the lack of funding as well as in (Wiley, 2009).

There needs to be accountability in addressing the years of discrimination Māori have faced and the implications of this. Though New Zealand has seen dramatic policy reform changes in social policy, we are still not addressing the poverty and socio-demographic factors affecting Māori.

Wiley (2009) identified common trends in the findings of 34 semi-structured interviews, which were conducted to evaluate the effectiveness of Objective 11. Wiley (2009) suggests that accountability, for Objective 11 had not been implemented and the *New Zealand Disability Strategy* has failed to support individuals (Appendix E).

The literature highlighted that there are significant barriers to equitable service provision for Tangata Whaikaha. Therefore, the findings seek to determine and highlight the barriers to accessible services and inequity in policy for accessing equitable services for Tangata Whaikaha.

Question 1. The *New Zealand Disability Strategy*, like any policy framework, may have limitations in meeting the specific needs of Tangata Whaikaha in New Zealand. The

following are some reasons why the strategy might fall short of adequately addressing their needs, as highlighted in the data. The findings indicate the opinions of how the participants felt; whether the New Zealand Disability Strategy Objective 11 has successfully met the needs of 1 in 4 New Zealand Tangata Whaikaha and 1 in 5 Māori Tangata in the Bay of Plenty.

The study by Wiley (2009) found that the *New Zealand Disability Strategy* does not have structured accountability and is insufficient for incentives of Ministries that are contracted to implement the *New Zealand Disability Strategy*. The findings seek to identify whether collaboration and accountability have been a barrier to more inclusive environments for Tangata Whaikaha. They further identify where there are existing gaps in implementing the *New Zealand Disability Strategy*. These are indicated in the findings as follows: The literature and findings in Wiley (2009) compared to the current findings have discovered that Māori felt that traditional values were not adhered to. Moreover, they felt that they were being compromised to fit with a mainstream context. It is suggested, however, that Māori were part of the NZDS. In comparison to the most recent qualitative data findings, which identified Māori versus the Mainstream, they questioned the *New Zealand Disability Strategy*. The *New Zealand Disability Strategy* has been mainstream delivered and has not been culturally responsive to the needs of 1 in 5 Māori (SW1). Whānau that were interviewed all stated that they felt Māori had to fit in with the Pākehā context and mentioned that the New Zealand Disability Strategy does not fit with Māori.

We have experienced major issues as a whanau that have involved economic advantages, and lack of inclusivity for a whanau member from the community as a whole. We would suggest that organisations like the Ministry of Social Development need to look at their current policies as they are not reflective of equal access to employment, and economic opportunities for Tangata Whaikaha, fostering economic growth and innovation. We need laws and policies in place that mandate inclusivity and prohibit discrimination based on disability. Creating inclusive environments and opportunities for all members of society. By actively embracing inclusivity, communities can create spaces where Tangata Whaikaha can thrive, contribute, and be valued as equal members of society. (SW 1).

An example of our whanau member is unable to work more than 10 hours a week otherwise it will affect his benefit. His benefit is more than his rent and he is not entitled to an accommodation supplement. Our Mum must sleep on the couch to help keep our whanau member from being homeless. (SW 1).

Highlighted in Wiley (2009) at the time the research was conducted, there was no collaboration and consistency across ministries that were implementing support and had failed to address the needs of Māori. Further investigation is needed for analysis. This is also reflected in the literature and is still apparent today. In comparing the findings of Wiley (2009)

to the current data it was suggested that the strategy may not have involved meaningful consultation and engagement, with Tangata Whaikaha and their whanau, throughout its development and implementation processes. Their voices, experiences, and priorities are not sufficiently considered, leading to a strategy that does not fully capture their needs and aspirations.

The barriers that we have faced have been experienced surrounding discrimination, prejudice in policy that are reflective of perceptions that are not reflective of Tangata Whaikaha and great bigger hurdles to access resources, funding and especially as we are rural that is even a bigger barrier as we have to travel and we do not receive any further funding to attend OT, Dr and or specialist appointments for our child. We have been advised that due to our age, limited whanau support, and the fact that we live in rural that we should think about transitioning our child to Idea Services residential living. We have used respite in the past and they do not fit well with our child, it, is very pakeha and does not fit with our way of supporting our baby.

We would like to see more Kaupapa Māori services for Tangata Whaikaha and more whanau-centric frameworks. (SW1).

Participants indicated that they felt there has not been enough discussion around the relationship between service providers and the government. This is especially so regarding suggestions around policy and/or the appropriate type of Kaupapa Māori framework applied, to which they are being supported. The researcher specifically targeted Māori whanau, in comparison to the quantitative and quantitative research that was conducted in this research project. They found there was a comparison between Māori and non-Māori in the overall findings. This was highlighted and there is a need to address inequalities that continue to exist for Māori with health issues, especially for Māori whānau supporting their disabled whānau in the community.

It is noteworthy to mention that the *New Zealand Disability Strategy* pertains to health, however, there are inconsistencies across the Ministry's collaboration which are consistent with the findings in Wiley (2009). The *New Zealand Disability Strategy*, according to the findings, is not sufficiently incorporating cultural responsiveness to address the unique needs, perspectives, and aspirations of Tangata Whaikaha. There are still gaps and inconsistencies within the *New Zealand Disability Strategy* that inadvertently overlook or do not adequately address the needs of Tangata Whaikaha and social deprivation. This has resulted from a lack of comprehensive understanding of the intersecting factors of different Ministries that shape their experiences. Factors, such as disability, ethnicity, culture, and socio-economic status still need to be addressed to create inclusive environments as the issue still remains.

Question 2. The literature highlights the need for addressing barriers and limitations to Tangata Whaikaha in the policy. Indicated is the need for a critical review and potential revision of the *New Zealand Disability Strategy*, ensuring that it incorporates cultural responsiveness, meaningful participation, explicit equity goals, adequate resourcing, and an integrated approach to meet the needs of Tangata Whaikaha. It is crucial to actively engage with Tangata Whaikaha and their whānau, collaborate with Māori community leaders and organizations, and prioritize their voices and experiences in the policy development and implementation processes, to ensure that their needs are effectively addressed. Therefore, question two seeks to understand and to give recommendations for the current barriers to whaikaha accessing services in the community, in the Bay of Plenty takiwā.

Their independence, have on ownership and choices over their lives for people we support. services that support Māori service users are extremely limited to what funding that they can provide, as they are limited to finding restraints. We have to say that our child is schooling in Hamilton to get extra funding so that we can live and pay our mortgage" SW 2. In comparison to Comparing to Wiley (2009) suggests that caregivers and consumers were not happy with access to services and mention that they felt the organizations were not aware of their culture. Both caregivers agreed that neither participant felt that they needed emotional support, and the organisation was aware of their culture. (SW1)

I am aware of a whanau that we support in our service that has high needs and requires 24/7 support. Their child has high medical costs, however, their entitlement by NASC is only 12 hours per week, and therefore the mother must stay home. Both parents have poor health and require medication themselves, however, they cannot afford prescriptions as they are a one-income family with a high need's child with complex needs. As an organisation is our role to advocate for Tangata Whaikaha and whanau hauā however we are at capacity for what we can do as we are a non for profit. We have sourced collaborations with other entities however the needs are too high for our organisation to manage, and the funding is minimal it does not meet the need of those that need our services. There is a need to address financial barriers and more financial support for families like these. We are a not-for-profit organisation, we are only 30% Government funded, the funding structures constantly change, and we are heavily reliant upon Community grants. (SM1).

SM2 stated that the service provider is constantly battling with funding, "we are unsourced and understaffed". This suggests that there are limits to being able to provide accessible services for all cultures and ethnicities. "Training, education, and pay parity are not glamorous aspects to gaining new staff, and due to the lack of funding this means it's not an attractive space to work in". All participants felt some level of frustration surrounding satisfaction with the Health and Disability sector. In comparison, common trends and qualitative data

collection suggest that funding and awareness is an issue. "Consumer and caregiver respondents referred to bureaucracy in terms of delayed service access. Often the structure of the service system (i.e., paperwork, estimates and appraisals, progressive levels of intervention) prevented timely access of services." (Wiley, 2009, p. 5). Therefore, there are still existing trends surrounding funding when comparing both studies.

These inadequacies can contribute to limited access to appropriate and quality services for Tangata Whaikaha. This includes barriers in healthcare, education, employment, housing, and other essential domains, which can further perpetuate inequities and disparities in outcomes. In comparing the findings with Wiley (2009) the data indicates there is still a gap in the services that we provide to Māori service users. Attitudes towards the way we support Māori have not changed based on the findings.

Effective policy development requires collaboration and meaningful engagement with Tangata Whaikaha and their whānau (family) as key stakeholders. However, the lack of genuine consultation and participation can result in policies that do not reflect their voices, experiences, and priorities, leading to a disconnection between policy intent and the lived realities of Tangata Whaikaha. CC 1.

In Wiley (2009), the findings suggested that those writing policy do not understand how the policy affects the service user. "What's the use of having someone driving it that has no idea about the people he or she is dealing with? It is probably inappropriate" (Wiley, 2009, p. 4). Therefore, in comparing the findings in Wiley (2009) and findings from the literature review, it appears that current policy frameworks have inadvertently perpetuated discrimination and bias against Tangata Whaikaha, leading to unequal treatment and systemic disadvantages. This can be exacerbated by intersecting factors, such as disability, ethnicity, and socio-economic status, resulting in compounded marginalization and limited opportunities for Tangata Whaikaha to thrive. Policies have failed to allocate adequate resources and funding to meet the specific needs of Tangata Whaikaha. Insufficient investment, support systems, and infrastructure can impede progress toward equitable outcomes and hinder the full realization of Tangata Whaikaha potential.

Common factors that are apparent across all the research highlights socioeconomic factors associated with social economic issue according to Wiley (2009). The gap between better health reforms and policy still shows a huge disadvantage of Māori Tangata Whaikaha in the community, especially surrounding the Treaty of Waitangi principles highlighted in the literature review. Therefore, addressing these gaps and ensuring policies meet the needs of Tangata Whaikaha requires a commitment to inclusive policy development processes. This

includes actively involving Tangata Whaikaha and their whānau, promoting cultural competency among policymakers, and allocating resources that prioritise culturally responsive services and support systems. By recognising and addressing the unique needs and aspirations of Tangata Whaikaha, policies can contribute to the empowerment, inclusion, and well-being of this important population.

Question 3. The literature has indicated a lack of recognition of Tangata Whaikaha. This refers to individuals with disabilities who are also Māori who have faced a lack of recognition and participation in policy frameworks. Policies have been highlighted to acknowledge and address the specific needs, challenges, and aspirations of this unique population, resulting in inadequate support and limited inclusion in decision-making processes. The prior study by Wiley (2009) mentioned that caregivers' attitudes towards disability services at the time, felt they had to use an aggressive approach to ensure culturally appropriate services. However, in reviewing the literature no data was found on the association with the findings of Wiley (2009). Therefore, the rationale for question four is to identify whether the participants felt that they believe that what they are being offered is culturally responsive to the needs of Māori Tangata Whaikaha.

SW in this study indicated that they felt their values were compromised when it came to the current services that were being provided and agreed with the statement in Wiley (2009). The findings are indicated as follows.

My whānau do not feel that we get adequate training and are not explained what service are available to use. We do not have Treaty of Waitangi training and or cultural training on what supporting a Māori service user looks like. Our recommendation is, that organisations that support Tangata Whaikaha should provide culturally appropriate services that recognize the significance of whānau. Services should involve and support whānau strengthen family connections, promote collective responsibility, and foster culturally grounded care. This approach acknowledges the importance of the wider whānau network in providing support and contributes to positive outcomes for Tangata Whaikaha. (SW 1)

Our organisation does not have Māori management and lacks cultural awareness. I do not feel that we work in partnership with the treaty principles and being Māori I am used as the default and feel that it is tokenistic" They provide kittle learning aids for disabled in Māori; we open and close with a Karakia before meetings and usually conducted by a Māori. Which is the only traditional value upheld. There is a need for a culturally competent workforce that understands and respects Māori cultural values, practices, and perspectives. Investing in cultural competency training and workforce development ensures that service providers can deliver services that are responsive to the needs of Māori Tangata Whaikaha, leading to improved outcomes and experiences. (CC1)

There are not enough of services that are implementing appropriate services to Māori in particular. There is a need for culturally appropriate services to recognize and respect the unique cultural identity of Māori Tangata Whaikaha. Embracing their cultural values, language, customs, and practices allows individuals to maintain a sense of belonging and self-determination. Cultural identity plays a crucial role in overall well-being and can positively impact outcomes for Māori Tangata Whaikaha. This has not been reflective in our organisation. SM2)

In our whanau perspective as whanau hauā, there is a need for Culturally appropriate services to ensure effective communication and engagement with Māori Tangata Whaikaha and their whānau (family). This includes the use of Te Reo Māori (Māori language) and culturally sensitive communication approaches. By understanding and respecting Māori ways of communication, service providers can build trust, foster meaningful relationships, and enhance service delivery outcomes. (SW 2).

I believe that there is a need to address disparities and inequities about culturally appropriate services as they are critical in addressing the disparities and inequities experienced by Māori Tangata Whaikaha. These disparities can stem from historical and ongoing systemic factors, including colonization, marginalization, and discrimination. By tailoring services to meet the specific needs and experiences of Māori Tangata Whaikaha, these disparities can be addressed, promoting equitable outcomes. There is no legislative requirement and or compliance for organisations to ensure that they are culturally responsive, and this is required. (SM1).

None of the participants felt that working with Māori families is difficult but suggested that implementing better communication processes would eliminate any barriers that may exist at present. All participants are working in partnership with agencies and Māori families to access services in isolated and rural areas. Surrounding attitudes towards barriers that affect Māori accessing services, it was suggested that there is ignorance towards what services are available; respondents felt that current services are culturally appropriate. CC 1 says, "*Māori families tend to look after their own from experience. There are a lot of prehistorical, preconceived ideas that Māori families have regarding support services, this may suggest why they access services.*"

Based on the findings from the data collection, in comparison to the findings of Wiley (2009), there are still existing gaps, and as indicated in the findings, currently there are no legislative compliance standards. There is a need, as indicated, for culturally appropriate services to empower Māori Tangata Whaikaha to become active participants in decision-making processes, self-advocacy, and service planning. By involving Tangata Whaikaha and their whānau in the design and delivery of services, they can shape and influence the support they receive, leading to increased empowerment and self-determination.

5.5 Themes and trends

Keywords that are frequently mentioned are:- Awareness, Biculturalism, Funding and *New Zealand Disability Strategy*, Barriers to Communication, and Māori. The most common reoccurring statements from all participants were funding and lack of services for Māori in the BOP area. SM 1 says:

There are limited services to what can be accessed, lack of choice, and barriers surrounding funding to access services to enable empowering lives for people that we support.

Common themes that were identified in the interviews are how their main roles and responsibilities were to connect with service users and service delivery agencies, collaboratively, to implement the NZDS. All organisations implement the *Treaty of Waitangi* in their Policy/Strategic Plan. This highlights that the NZDS has been effective in supporting Māori to a certain extent. However, there is the suggestion that there needs to be regular assessment surrounding its implication.

5.6 Recommendations

There is still a relative distinction that runs throughout all the literature within the things that have been identified in the data collected from the quantitative and qualitative findings. This is, that there is still a need to implement services that eliminate the gaps and disparities experienced by indigenous peoples. The importance of the interviews was in highlighting the need for; policy reform, the continued effects of colonisation for many Māori, and the lack of giving effect to Treaty of Waitangi principles, all of which are not apparent in the current implementation of supporting Māori whānau in the community.

The findings have identified the issue that Māori do not ‘fit in a box’; the needs of Māori have not been addressed and are not culturally appropriate. When writing policy there is a need to reduce further discussion about socioeconomic culture in society and reviews of disabled people when it comes to policy. Thus, ensuring that we address the disparities that Māori have faced and still face today with high disproportionate rates compared to those of other New Zealanders. Therefore, there is a need for a culturally responsive framework for implementing and measuring the New Zealand Disability strategy against current policy, which is reflective and self-determined by that of Māori.

5.7 Chapter Summary

The data collection findings inform a new breadth of knowledge investigating the research questions. On further analysis, the data collection highlighted inequities of implementing and failing to meet the New Zealand Disability Strategy objectives for 1 in 4 people in New Zealand Tangata Whaikaha, and 1 in 5 Māori in New Zealand.

The purpose of this data collection was to investigate the attitudes of whānau hauā, kaiāwhina, and kaimahi surrounding the *New Zealand Disability Strategy* implementation, in comparison to Wiley (2009). Wiley (2009) argued that there was a lack of accountability, consistency, and collaboration in implementing the New Zealand Disability Strategy. In comparison to the current qualitative semi- structured interview data collection, the findings indicate the need to address barriers to equitable service provision with collaborative efforts between policymakers, service providers, advocacy groups, and communities. This is so as to create inclusive systems that promote equity, accessibility, and support for Tangata Whaikaha and Whānau hauā in the policy. This argument is also supported by the literature and statistics. The next chapter presents the findings of the case study method to answer the final research question.

CHAPTER SIX

FINDINGS FROM CASE STUDY METHOD

6.0 Chapter Introduction

The previous chapter presented the findings from the semi-structured interview questions and themed results. It displayed the results of the following participants: Māori and non-Māori caregivers, service managers, and coordinators. This chapter uses the case study method to analyse the findings of the preliminary hearing of the WAI 2575 hauora report, and secondary data presented by the Ministry of Health surrounding the implications of implementing the Māori Health strategy.

6.1 Analysis of findings

Health policy is one mode of addressing disparities and protecting Indigenous peoples' access to the universal human right to health. The core principles of both Te Tiriti and the convention will be reflected in how the *New Zealand Disability Strategy* will be implemented. The principles serve as a foundation for developing constructive relationships between disabled persons and the government. (Office for Disability Issues, 2016). Despite assurances in the strategy that disability services will be accessible and culturally suitable for Tangata Whaikaha, Māori and whānau hauā, there are significant differences in the experiences and outcomes of both Māori with impairments and disabilities and those of non-Māori (Manson et al., 2022). Despite convincing evidence of vast inequities, there has yet to be a systematic national effort to identify Māori disability assistance requirements and to implement a strategy to fulfil those needs in an integrated way (Ratima & Ratima, 2007).

It was determined from the findings that the *New Zealand Public Health and Disability Act 2000* is not Te Tiriti compliant and does not give Te Tiriti or its principles proper and complete effect. It was also discovered that He Korowai Oranga's explanation of "partnership, participation, and protection" falls short of accurately reflecting Te Tiriti or its guiding principles. Instead of a dedication to achieving equity of health outcomes for Māori, we observed that "reducing disparities" or "reducing inequality" is the dominant rhetoric in the legislative and policy framework. We stress that it ought not to be arguable to include an explicitly expressed, stand-alone commitment to achieve health equity. One of the ultimate goals of any just health system should be to achieve health equity (Ministry of Health, 2022).

There was inconsistency in public policy engagement with Te Tiriti and Māori health at the time the New Zealand Disability Strategy was developed (Came et al., 2018)

6.2 Māori Health Action Plan

The term 'disability' has long been problematic in the sense that Māori do not easily identify with it or even the notion behind it. To fully understand disability from a Māori perspective, terminology about impairment must be relevant to Māori. Māori require the terms that they identify with. Not terminology assigned to them, but ones derived from their ideas and experiences (Hickey & Wilson 2017).

He Korowai Oranga, the Māori Health Strategy, was developed into an action plan by the Ministry of Health in 2014. However, WAI 2575 claims highlighted that the Crown had breached Tiriti obligations and gave recommendations. The Ministry of Health has sought to collaborate with Māori and the health and disability sector to address inequity to support and implement the Māori Health Strategy. Ministry of Health conducted four wānanga in Tāmaki Makaurau, Rotorua, Te Whanganui-a-Tara, and Ōtautahi. Wānanga were conducted to give Māori and the health and disability sectors a chance to shape and contribute to the creation of the Māori Health Plan that would direct the advancement of the health system over the following five years, from 2020 to 2025. The purpose of the wānanga was to hear whakaaro on current Māori health concerns and action priorities to enhance Māori health. Participants were asked to consider what they believed should be the top priority for Māori health, followed by two or three crucial steps to support these priorities. The primary concerns presented also required the participants to offer creative, "out of the box," feedback on their non-negotiable priorities and activities.

The 370 participants consisted of: hapū and iwi, hāpori Māori from Non-Government organisations to non-Māori agencies, Whānau Ora Commissioning Agencies, Māori academics, kaiāwhina and kaimahi in the health sector, District Health Board Māori Staff and non- Māori, researchers, and Primary Health Organisations.

To give stakeholders the chance to offer detailed comments on the discussion document, an online survey was created for those who were unable to attend a wananga. The survey enabled those that could not attend, an opportunity to contribute input through the survey, and those who did attend could make additional comments. Ninety respondents participated in the survey and represented a variety of communities, including the general

population, healthcare professionals, Māori health providers, iwi governance members, and non-Government agencies.

Written submissions were also accepted. Unlike the online survey, paper comments did not include pre-set questions, allowing people and organisations to offer comments on any component, or all the discussion document, in addition to on Māori health more generally. Twenty-two written submissions were received in total, including five from members of the public and seventeen on behalf of organisations, such as providers, non-Government organisations, and professional associations. The written submissions underwent a thematic analysis after initial data coding, as part of a qualitative study.

6.3 Treaty of Waitangi claim

On 27 February 2020 in the Waitangi Tribunal concerning the *Treaty of Waitangi Act 1975* and the Health Services and Outcomes Kaupapa Inquiry, the Court ordered the disabilities component of stage two of Wai 2575 to outline a preliminary list of claims that this Tribunal would investigate. Claimants' claims that were selected for this case study have been selected. These are based on three themes that were indicated in the literature review; lack of participation in policy for Whaikaha and Whānau hauā and lack of equitable service provision in policy for Māori Whaikaha.

The *Health Services and Outcomes Kaupapa Inquiry* (WAI 2575) in the case of Tauranga Tibble WAI 2109, the claimant represented himself, a Kapo Māori (Māori blind, vision impaired, and deaf-blind persons), their whanau, and Kapo Māori New Zealand/New Zealand Incorporated. The claimants argued that in terms of Whaikaha and their health, their wellbeing, their capacity to live full and active lives among their whānau, hapu and iwi, Tangata Whaikaha are in terrible circumstances due to the Crown's actions and omissions. In the Health Inquiry (WAI 2575) in the case of Wilson and Pointon WAI 21423, according to the complainants, the decisions or inactions of the Crown have already adversely affected Tāngata Turi o New Zealand (Māori Deaf). These actions, or inactions, contradicted Te Tiriti o Waitangi and its principles of collaboration, cooperation, self-determination, active security, equity, development, and options, and they continue to do so.

In the *Health Services and Outcomes Kaupapa Inquiry* (WAI 2575) in the case of Washbrook WAI 2672, the claimant resides in Hokianga. There, the healthcare services for Māori have been drastically different than they are in the major urban areas of New Zealand. The claimant claimed her child, who has spina bifida, and their whānau have been adversely

affected by the different Acts and Crown policies, practices, acts, or omissions that the Crown or its agents have chosen for themselves or on behalf of the Crown.

In the Health Services and Outcomes Kaupapa Inquiry (WAI 2575) in the case of Kingi WAI 2894, the claimant alleges contradiction of the Te Tiriti principles of active protection, good faith, and collaboration. Furthermore, that the Crown has failed to give Māori who have experienced disability adequate economic support, on behalf of Ngai Tāhū O Mohaka Waikare (“the Claimants”).

6.4 Findings and key themes

The key findings and themes have been collected from the Ministry of Health Engagement for the development of *Whakamaua Māori Health Action Plan* findings (Ministry, 2020), and the Waitangi 2575 preliminary list of claims (Ministry of Health, 2022). The analysis of the findings identified key themes and were assessed against the literature to inform the implementation of operating policy recommendations based on findings in the data.

6.5 Discussion

The findings of the Ministry (2020) indicated that strategy and policy should be integrated and be the responsibility of the entire health and disability sector for the system to achieve its strategic objectives. Thus, they must be held accountable for reaching each component. Also highlighted was the critical significance of Te Tiriti o Waitangi as a foundation and lever for the progress of Māori health.

Effective Māori-Crown relationships including understanding the rights, interests, and perspectives of Māori meaningfully engaging and building relationships with iwi, hapū, and Māori communities, and embedding Māori Tiriti perspectives into policy programs and services (Ministry, 2020 p. 34).

In the case of Tauranga Tibble WAI 2109 “The failure by the Crown to ensure an adequate role was and is provided for Tangata Whaikaha in the design, establishment, management, and implementation of policies and services affecting Tangata Whaikaha”. (Ministry, 2020, p.30). Similarly in the case of Health Inquiry (Wai 2575) in the case of Wilson and Pointon.

In Health Inquiry (Wai 2575) it was heard in WAI 21425 claim that numerous Acts and Crown policies, practices, acts, and omissions adopted by or on behalf of the Crown or its agents have adversely affected Tāngata Turi in the past and are still doing so today. “The Ministry of Health has failed to involve Tāngata Turi in formal consultation; information

gathering, defining, and identifying issues; deciding on solutions; and implementing health and disability sector policy.” Wilson and Pointon WAI 21426.

Therefore, the key indications from analysis of policy and strategy findings indicated the need for the health and disability system to demonstrate and reflect delivery on Māori-specific outcomes in health. The Ministry must pledge to hold underperforming District Health Boards and Primary Health Care organisations accountable and impose penalties and consequences accordingly. However, the priority areas identified recognise the need to address the long-standing mistrust between Māori and the Crown. Respondents identified institutional racism and the impact of colonisation as some of the challenges that could be resolved through improved and strengthened Māori-Crown relations: “We need to ensure that the ways we review and evaluate the extent to which the Crown is meeting obligations, giving effect to equitable health outcomes, is through a Tiriti framework” (Ministry, 2020, p.30).

Crown obligations under Te Tiriti have been emphasised throughout the health and disability system, as well as in the government in general. Therefore, based on participants' feedback there is suggestion that a Tiriti framework should be observed and for it to be ingrained across the system, it needs to be supported by legislation and stricter accountability.

We need to ensure that the ways we review and evaluate the extent to which the Crown is meeting its obligations, giving effect to equitable health outcomes, is through a Tiriti-based framework. (Ministry, 2020, p.30).

The claims reference past prejudice in the legislative system, as mentioned in the case of WAI 2575- Tauranga and Tibble WAI 2109. In the past, providing health and disability services to Tangata Whaikaha has mostly emphasised isolation, assimilation, suppression, and paternalism at different points in time. More specifically, before the 1980s, Tangata Whaikaha were frequently segregated from their families and communities and given institutional care. The experience of institutionalised Māori children was particularly distressing and frequently caused them to feel cut off from their whānau and their cultural identities. Tangata Whaikaha were institutionalised, which led to their separation from their families and whānau. They frequently lost their reo and connection to their rohe inside such institutions. Evidence suggests that when Māori were deinstitutionalised in the 1980s, their rohe and people were not given any consideration.

The findings of the Ministry (2020) indicate that addressing historical grievances should be a priority area that offers a chance to recognise and address the longstanding mistrust between Māori and the Crown. People mentioned institutional racism and the legacy

of colonisation as some of the challenges that could be resolved through improved and strengthened Māori Crown relations. However, the increased vulnerability and exclusion linkages have been attributed to disconnections brought on by institutionalisation, and having to travel for health, disability, education, and other services. This is reflected in the claims and the implications of institutionalisation, particularly in the claim of Kapo Māori.

Institutionalisation, racism and discrimination were also identified as key themes in the data collected. The proposed objective of eliminating racism and discrimination in all its forms received a lot of support. This was emphasised as being essential to reducing Māori health inequalities throughout all engagement initiatives. The consensus was that this objective requires a wide variety of integrated plan-wide measures to be supported, while also acknowledging the linkages of racism and discrimination with other key areas (such as workforce, service commissioning, accountability, and finance) and racism and discrimination. People pressed the Ministry to retain this goal at the forefront of the strategy. "How can we avoid tokenism and ensure that the principles are applied meaningfully or become entrenched in the health systems culture? We need to be explicit in how we hold the health system accountable to uphold their obligations to the treaty.

Equitable service provision for Māori was also another common theme that was highlighted in the data. Many participants stated that equity should be the primary objective of the entire health and disability system, supporting the goal of Māori health equity. People were strongly in favour of the decision to involve equity in the proposed Tiriti framework because they believed that Māori health equity should always be considered alongside Te Tiriti. Use framework built by Māori to better understand our aspirations and solutions with better accuracy Quality standards need to recognise, where appropriate, Tikanga Māori and Mātauranga Māori. Particularly services with high Māori users and engagement, or services where the engagement should be high but is not." In the case of Kingi WAI 2894 as seen in WAI 2575:

The lack of government support for Whānau Ora and other initiatives that are targeted to improving the integration of health and disability services for Māori is a breach of the Crown's duty of active protection, in that it sustains and exacerbates the poor health outcomes suffered by the Claimants. (p. 1). "Addressing Māori health without addressing the root causes of poor health narrows the capacity of the system to respond to Māori illnesses and limits the effect the health and disability system can have in improving health equity for Māori". (Ministry, 2020, p.45).

A framework for Māori disability information suggested that Māori-specific data collection include not only ethnic data but also cultural data, such as hapu and iwi affiliation, access to Māori networks and whānau support. These, along with other information related to those factors that strengthen Māori identity and may reflect positive functioning within Māori cultural contexts. Additionally, data about Māori preferences for support services and understanding of disability should be gathered. This more comprehensive cultural information would guide the creation of disability assistance programmes catering to the unique needs of Māori (Robson & Harris, 2007)

The findings highlighted a need to ensure Mana Motuhake and Tino rangatiratanga visibility in a Māori health plan. These concepts were seen as the fundamental principles of Māori health improvement and ought to be incorporated into every component of the system-wide plan.

The principle of power sharing is an entitlement under the Treaty. Māori must be given the resources and authority to enable us to manage our health. Crown (DHBs) must provide resources in that context. We must move past aspirations to actions. (Robson & Harris, 2007, p. 2)

The findings / results indicated in the data are in line with the literature. The impact of impairments and disability varies between Māori and non-Māori, with Māori being more severely affected. The effects of disability for Māori go beyond the affected person to their whānau, who may lack the resources or capacity to offer the care and support that is required. In this situation, ensuring that Māori receive high-quality disability support services is essential to reducing the negative effects on Māori people as individuals, families, and communities (Robson & Harris, 2007).

Many participants advocated for Mātauranga Māori to be enhanced across all elements of the plan. This is due to it being highlighted as a crucial enabler of Māori wellness. The elevation of Mātauranga Māori was highly valued. This included Rongoa Māori service delivery and expansion in primary and community health settings (Ministry, 2020):

This priority sets out a standard of accountability for providers that aims to give people receiving the service a deliberate, safe experience of care that upholds the rights of any person receiving a health and/or disability service. Raising the bar on what is good practice health services for Māori so they can build trust and feel culturally safe at a time of great vulnerability. (Ministry, 2020. P.52).

It was acknowledged that intentional and concerted measures to redistribute resources were necessary to ensure equity for Māori. Emphasised was the importance of financing and

investment as a guiding force for advancing Māori health, both in terms of the overall investment in Māori health and the equitable funding and commissioning of services. Additionally, there was support for increasing specific spending for Māori health in a transparent manner that is geared towards promoting whānau outcomes and overall wellbeing (Ministry of Health, 2020). “Often underfunded ventures are doomed to fail, and Māori are blamed for the failure. [There needs to be] investment and appropriate funding to enable success.” (Ministry, 2020, p.34).

It was strongly agreed that it was important to create a workforce in the health sector that was both culturally competent and safe, and they supported the need for this both among all health practitioners (both regulated and unregulated), as well as for clear performance expectations and mechanisms for correcting underperformance. Many individuals agreed that the non-Māori health workforce needs to be prioritised because Māori health is still the entire health system's duty (Ministry, 2020). “It is vital to the safety of care for Māori patients and whānau that we have Māori involved in the delivery of care – this will lead to improved engagement with the health system and better health outcomes.” (Ministry, 2020, p 46).

It was widely agreed that improving accountability practices within the system was essential to advancing Māori health development. There was a request for repercussions when performance standards are not fulfilled, with a clear emphasis on improving accountabilities for District Health Boards and other contractual providers to fulfil *Te Tiriti o Waitangi* responsibilities. Others have expressed the need for more representation in iwi and Māori governance organisations for ensuring cultural practice and oversight (Ministry, 2020).

Māori influence the system from within when they are in the system.” An expanded Māori workforce employed in a system designed and measured by Pākehā needs and success factors is only one small part of the puzzle. That system needs to also reflect diverse values and adopt wellbeing outcomes that focus on equity for Māori (Ministry, 2020, p.48).

A ‘whānau- centric’ model of care was also a key theme throughout the data analysis. Expressed was the need to provide whānau, hapū, and iwi greater access to a wide range of services supported by Māori philosophy. People indicated an interest in greater investment in Kaupapa Māori and whānau-centred services. Furthermore, there was indicated the need for the iwi and Māori regulating groups to have greater resources to support Māori by offering services that suit the requirements of their communities; typically stated as “by Māori, for Māori, with Māori” (Ministry, 2020).

The core message of this submission is that fundamental change in our health system will be required to advance Māori health outcomes and achieve health equity for Māori, and the Ministry has a crucial role in driving the change required (Ministry, 2020, p. 59).

The legislative changes highlight and identify a fundamental shift from a Western framework to a more inclusive Māori-focused and whānau-centred approach. The principles that are applied in the sector service standards are an informed approach, which aims to achieve Māori health equity based on treaty principles. Moreover, to create a more accessible health service that ensures a non-discriminatory approach for accessible services to health and disability services in New Zealand and society. The sector standards are reflective of the *He Korowai Oranga Māori Health Strategy* (Ministry of Health, 2022) and the strategy aims to create better outcomes in the health and disability sectors for Māori.

Under Article 1 of the *Universal Declaration of Human Rights 1984*, New Zealand has obligations to seven of the treaties under the core framework of the United Nations' human rights and the *Convention of the Rights of Persons with Disabilities 2006*. In 2007 the New Zealand Government adopted the *United Nations Declaration on the Rights of Indigenous People*. The New Zealand Government is committed to achieving the rights of indigenous people concerning the existing legal, constitutional framework and implementation of the Treaty of Waitangi, which is demonstrated in *the Public Health and Disability Act 2001*.

Although the New Zealand Government has claimed implementation of Article 1, the claims in stage two of WAI 2575 are still being investigated. The claims do however highlight that due to the Crown's inadequate investigation of Māori-specific impairments and disability, the Crown's response, or lack thereof, is culturally inappropriate. This has led to more disparities for Māori and increased the burden on Māori who are attempting to support their whānau with impairment and disability. Recommendations in the case of Tauranga Tibble WAI 2109 mentioned that partnership: According to the treaty, both parties must "act towards each other reasonably and with the utmost good faith." That Kawanatanga and Tino rangatiratanga notions must be balanced to uphold the partnership is preferred.

The New Zealand Government has implementation of the health and disability service sectors. However, it is important that in the first instance, when considering and reviewing policies and strategies, they are done so in ensuring that whānau hauā and Whaikaha have accessed an integrated approach and the bigger context, from an indigenous perspective. This does not mean just providing culturally appropriate services for Whaikaha. As indicated in the literature and the findings there is a need for a collaborative and collective approach, not

only by the service users, but also involving whānau hauā and lived experience at all levels of decision making in policy. This will ensure Whaikaha have access to culturally appropriate services and that they understand the policies that are reflective of the health and disability service sector standards and are strategically and operationally sound.

However, although the transformative changes are based on the recommendations of *the United Nations Convention* and legislative health reform in New Zealand, there is still a need for a comprehensive effort to identify unique Māori disability support requirements nationally. Moreover, to put that strategy into action to serve those needs in a coordinated manner, is evident despite overwhelming evidence of significant inequities.

Based on the findings in the data analysis it is suggested that Primary and Community care, District Health Boards and Primary Health organisations, and other stakeholders are encouraged to have cultural safety policies. These are not only for services and staff development policies, but also as a recommendation that they are reflective in ensuring that Māori representation is reflected in the governance of the organisational structure and participation in policies. This is not limited to just staff, but also pertains to Māori Whaikaha and their whānau, as well as staff development. Also, creating sustainable relationships with Iwi and hapu as well as Māori entities within their community. This is also a sector standard.

6.6 Key trends

Key themes that were indicated in the Ministry's (2020) findings were the need to address the lack of accountability and monitoring, cultural competence, address racism, and Māori health equity. There was a repetition of the need to clarify what "authority" means in this context, noting that "true authority" to them would entail government agencies delegating power to Māori, to create equity for Māori. The findings were gathered from differing stakeholders, which included and were not limited to Non-Government and Government agencies, Primary Health Care organisations, iwi, hapu, and other services. Whānau hauā that support Whaikaha are still Māori and engage with these services within the health care sector and therefore their feedback from a Te Ao Māori perspective is invaluable and contributes to new knowledge where there has been a dearth of data.

There was a consistency about the lack of an accountability and measuring tool for District Health Boards and Primary Health Care Organisations. The suggestion was that there needs to be a monitoring tool. There was a frequent mention of what District Health Boards and Primary Health Care providers are not currently being held accountable for; not upholding

their Tiriti duties to improve Māori health outcomes. It was suggested that there is a need to implement penalties and repercussions for poor performance in meeting the needs of Māori health outcomes for the levers of change to measure against. It was also mentioned that participants had shown that Māori have been over scrutinised, and the intent of current legislation is not reflective of its intention. However, the purpose of this thesis is not to analyse the law and investigate the legislative arguments of the claims. It is noteworthy to mention that the claims have the basis of recommendation for this research. They give context to the arguments that have been analysed to show the gaps in existing implementation and to answer the research questions.

Nevertheless, the key themes that were indicated in the WAI 2575 preliminary claims were: prejudice, failure to provide adequate disability and Kaupapa Māori services rurally, institutional racism, failure to collect data, institutionalisation, lack of access to services and education, and inconsistency among policies and procedures. Further themes were: the failure to uphold the obligation of te Tiriti o Waitangi, and the reflection that National Policy does not fit within a local and regional level of implementation. The blanket approach to policy is not reflective of the disabled as a minority group and does not meet the needs and aspirations of Whaikaha to live a full life consistent with Article 12 of the *United Nations Convention or the Bill of Rights Act*.

6.7 Recommendations

The key recommendations from the data analysis for policy recommendations for removing barriers for Whānau hauā and Whaikaha, are cultural competence, eliminating barriers to equitable service provision, and accessing quality.

The key points and recommendations

- Policies should prioritise the importance of the extended family and community in the support and care of Tangata Whaikaha. It should acknowledge the role of whānau as primary caregivers.
- Create policies that address the unique barriers faced by Tangata Whaikaha, such as accessible public spaces, healthcare, and education. Ensure all services are designed to be inclusive and accessible.
- Collect data that is disaggregated by both disability and ethnicity, ensuring that the unique challenges and needs of Tangata Whaikaha are recognized. Transparency in reporting is crucial for accountability.

6.8 Chapter Summary

Highlighted in the data is an indication that by addressing these barriers and promoting culturally appropriate services, we can work towards creating inclusive and equitable systems. Systems that respect and support the diverse needs and aspirations of individuals with intellectual disabilities, their families and, specifically, Māori Tangata Whaikaha in New Zealand.

This chapter analysed the findings of the preliminary hearing of the WAI 2575 hauora report and secondary data conducted by the Ministry of Health surrounding the implications of implementing the *Māori Health strategy*. The data analysis delved into highlighting the barriers to equitable service faced by Tangata Whaikaha and whānau hauā. It also highlighted a lack of culturally appropriate services for Māori Tangata Whaikaha in New Zealand. These barriers hinder access to necessary support and opportunities, limiting the wellbeing and inclusion of these individuals. By understanding and addressing these challenges, we can strive towards creating more inclusive and equitable systems that meet the diverse needs of individuals with intellectual disabilities and promote cultural responsiveness for Māori Tangata Whaikaha.

The next chapter is the Discussion.

CHAPTER SEVEN

DISCUSSION

7.0 Chapter Introduction

The previous chapter analysed the findings of the preliminary hearing of the WAI. 2575 hauora report and secondary data collected by the Ministry of Health surrounding the implications of implementing the Māori Health strategy. This was to answer the research questions. This chapter discusses the research questions and the findings in answering the research questions. The study's findings were influenced by specific contextual factors, such as cultural, social, or political dynamics, which are unique to the study setting by disseminate the findings in answering the research questions.

7.1 Research questions

My research questions were:

1. *What are the current obstacles that Māori Tangata Whaikaha face in obtaining disability services?*
2. *What are the barriers to equitable culturally safe service provision for Tangata Whaikaha?*
3. *What are policy recommendations for removing any such barriers for Tangata Whaikaha?*

7.2 Discussion about question one

The research method used in answering this question was an E-survey Likert scale questionnaire to investigate the attitudes of whanau hauā, kaiāwhina, and kaimahi surrounding the New Zealand Disability Strategy implementation. Since the closure of asylums and the implementation of various health reforms, there have been implications for fair service provision for Tangata Whaikaha. These implications relate to discrimination, deinstitutionalisation, and marginalisation. These have been discussed as themes and trends that have been highlighted in the literature and the findings in answering the research question What are the current obstacles that Māori Tangata Whaikaha face in obtaining disability services?

Despite efforts to promote equitable service provision, discrimination against Tangata Whaikaha persists within healthcare systems. This discrimination can manifest in various forms, including negative attitudes, stereotypes, and biases held by healthcare professionals.

Discrimination may lead to unequal treatment, dismissive attitudes, and limited access to appropriate care, affecting the health and well-being of Tangata Whaikaha.

Deinstitutionalisation was also indicated in the literature and in the data collection of the semi-structured interviews. The following was indicated. The closure of asylums and the movement towards deinstitutionalisation aimed to promote community-based care and support for individuals with disabilities, including Tangata Whaikaha. However, the process of deinstitutionalisation has not always been adequately planned or resourced, resulting in challenges and shortcomings. Some implications include a lack of appropriate community-based services, limited access to housing and employment opportunities, and fragmented support networks. These factors can contribute to difficulties in transitioning from institutional settings and lead to potential gaps in care and support.

Therefore, Tangata Whaikaha has often faced marginalisation within broader society, even within the context of health policy and service provision. Marginalisation can stem from a combination of factors such as disability, ethnicity, socio-economic status, and cultural barriers. This marginalisation can result in limited access to healthcare services, lower quality of care, and reduced opportunities for meaningful participation, and inclusion in decision-making processes. Marginalisation further perpetuates disparities in health outcomes and worsens the inequities experienced by Tangata Whaikaha, as identified in the literature. Researchers have sought to determine how Indigenous Māori models of health and wellbeing's fundamental ideas, tenets, and values may guide the creation of a relational care model that is centred on the needs of Māori people.

In the literature are described three dimensions of health and well-being: whanaungatanga (connectedness), Whakawhanaungatanga (building relationships), and socio-political health context (colonisation, urbanisation, racism, and marginalisation). These are recognized as three overarching themes. For Māori, the concept of health and well-being is holistic and relational.

Whānau hauā must be able to effectively take part as stakeholders with the proper government agencies. This change in thinking would necessitate representation of the various categories of disabled people with disabilities, according to Mittler (2015). According to Hickey and Wilson (2017), the Ministry of Health and the Ministry of Social Development have adopted "tokenistic" methods of consultation and decision-making regarding Māori, in which people are chosen by a minister rather than the disability community.

Policies often do not acknowledge and address the specific needs, challenges, and aspirations of this unique population, resulting in inadequate support and limited inclusion in decision-making processes. The literature shows that policies may not align with the cultural values, practices, and aspirations of Tangata Whaikaha. This disconnect can lead to a disempowerment of Māori identity and a failure to promote culturally appropriate approaches that recognise and respect their rights and perspectives. Therefore, ensuring effective policy development requires collaboration and meaningful engagement with Tangata Whaikaha and their whānau as key stakeholders. However, the lack of genuine consultation and participation can result in policies that do not reflect their voices, experiences, and priorities, leading to a disconnection between policy intent and the lived realities of Tangata Whaikaha.

Therefore, the following suggestions are recommended. Having an inclusive policy development process, by setting up inclusive and participatory policy development processes that actively involve Tangata Whaikaha and their whānau. This can be achieved through engagement strategies such as community consultations, focus groups, and co-design approaches that enable their voices, perspectives, and lived experiences to be heard and integrated into policy formulation. Furthermore, ensuring that there is a meaningful representation of Tangata Whaikaha in policy-making bodies, advisory groups, and committees at local, regional, and national levels. This representation should be inclusive of diverse subgroups within the Tangata Whaikaha community to ensure diverse perspectives are considered. The key findings are as follows:

- Establishing inclusive and participatory policy development processes that actively incorporate Tangata Whaikaha and their whānau.
- Community consultations, focus groups, and co-design approaches that allow their views, perspectives, and lived experiences to be heard and incorporated into policy creation.
- Ensure that Tangata Whaikaha are represented meaningfully in policy-making bodies, advisory groups, and committees at the local, regional, and national levels. To ensure that multiple opinions are considered, this representation should include diverse subgroups within the Tangata Whaikaha community.

7.3 Discussion about question two

This section discusses the findings and answers the research question: *What are the barriers to equitable culturally safe service provision for Tangata are whaikaha in the Bay of Plenty, Te Arawa Takiwā?* The data collection method that was used to answer this question was semi-structured interviews. The findings highlight that there is a need for more accountability for

addressing the years of discrimination Māori have faced and the implications of this. Although Aotearoa New Zealand has seen dramatic policy reform changes in social policy, we are still not addressing the poverty and socio-demographic factors affecting by Māori.

Levack et al., (2016) mention that discrimination is rarely acknowledged. However, the health care system does not address its policy's effectiveness and contribution to the disparity. Tawhai and Gray-Sharp (2011) mentioned that there has been inequity in Māori health in the public sector. The author states that the Crown has failed to meet its obligation of rights to Māori under the Treaty. Jones (2019) describes how populations are discriminated against for their human rights and Indigenous rights, and this in New Zealand is reflective of colonisation. The implications of this can be seen in the poor health outcomes for Māori, with disproportionate statistics.

The data collected highlights Tangata Whaikaha, whanau hauā, and service providers facing various obstacles in accessing and delivering equitable service provision. These obstacles have contributed to disparities in healthcare, support services, and opportunities for inclusion. The literature and data collection have indicated discrimination and bias within healthcare systems and service providers. Negative attitudes, stereotypes, and unconscious biases can lead to unequal treatment, dismissive attitudes, and limited access to appropriate care and support services.

A key theme in the findings was communication; this was shown in the findings. Indicated was the lack of coordination and integration among different service providers which can create barriers for Tangata Whaikaha. Fragmented services can lead to gaps in care, challenges in navigating the system, and difficulties accessing comprehensive support across various aspects of their lives, especially barriers for whanau hauā. Nolan (2010) recommends placing whānau at the centre ensuring whānau needs as and when necessary and often working beyond the parameters of their job description or contract. The length of time and effort that providers put into working with whānau signifies the level of disempowerment and disadvantage amongst whānau. However, the consequence of this for the provider can result in 'burnout' putting more pressure on others in the organisation to resume responsibilities.

Comparing and contrasting the findings highlights the lack of implementation of meeting Treaty obligations from 2009 to 2020. The overall recommendations suggest an improvement for more inclusive environments for accessible services in the community. There is still an identifiable gap between the policy reflective of treaty obligations and those of the service users and their whānau. There is an obvious lack of funding, the implication of having

high needs that affect families financially, and the stress accompanying such concerns. As found in the literature review, Māori is the most prevalent ethnicity affected by an intellectual disability in New Zealand, making up 25% of the healthcare system in New Zealand. Therefore, in assessing whānau hauā access issues, an alternative Indigenous Māori framework has been described. This is a Māori perspective on disability, informed by te ao Māori. Spiritual, holistic, relational, and environmental dimensions are all significant components of an Indigenous Māori worldview, according to Hickey and Wilson (2017). I agree with Hickey and Wilson (2017), that to better serve the needs of whānau hauā, policies regulating the rights of disabled people must take a Māori perspective on wellness and disability.

Therefore, in answering the research question of how to assess the current obstacles that Māori Tangata Whaikaha face in obtaining disability services, it can be determined that Tangata Whaikaha and whanau hauā are absent in the decision-making when it comes to the New Zealand Strategy. This has been significantly highlighted in the Likert scale questionnaire and is consistent with the findings.

However, addressing these obstacles requires a comprehensive approach that involves improving cultural competence among service providers, allocating sufficient resources, promoting effective communication strategies, enhancing coordination and integration of services, addressing socio-economic inequalities, and empowering Tangata Whaikaha through education and advocacy. By overcoming these obstacles, equitable and fair service provision can be fostered, leading to improved health outcomes, increased inclusion, and enhanced well-being for Tangata Whaikaha.

In conclusion, the following recommendations are made. Firstly, ensuring that there is a capacity for building initiatives for Tangata Whaikaha and their whānau to enhance their knowledge, skills, and confidence in engaging with policy processes. This can include providing training on policy advocacy, communication, and decision making to empower them to actively take part in shaping policies that affect their lives. Furthermore, establishing robust monitoring and evaluation mechanisms to assess the implementation and impact of policies on Tangata Whaikaha. Regular review and feedback loops can ensure that policies are still responsive to their needs and aspirations and facilitate iterative improvements based on evidence and lived experiences. Lastly, fostering collaboration and partnerships between government agencies, non-governmental organizations, and Tangata Whaikaha-led organisations. Such collaborations can enhance knowledge-sharing, resource pooling, and collective advocacy efforts to influence policy development and implementation.

The key recommendations are as follows:

- Recognise that the experiences of Tangata Whaikaha are not solely defined by their disability and ethnicity. Intersectionality should be considered in policies, addressing issues related to gender, socioeconomic status, and more.
- Ensure that all health and social service providers receive training in cultural safety to prevent inadvertent harm or discrimination and to foster a more inclusive environment.
- Establish mechanisms for continuous policy evaluation and feedback from Tangata Whaikaha and their communities to ensure that policies remain responsive and relevant.

7.4 Discussion about question three

This section answers the research question conducted to evaluate the effectiveness and barriers to fair service provision of current government policy (Māori Health Strategy) by analysing perceptions of whanau hauā, kaiāwhina, and kaimahi. Then, from these, to inform recommendations for what inclusive policy is for Tangata Whaikaha.

The introduction of this thesis highlighted the inequalities that Indigenous people face surrounding policies that help an inclusive way of living, and policies that contribute to self-determination in its broader context. Therefore, it is crucial for Indigenous people's rights and, furthermore, to develop a better way to manage and want progressive data, especially Indigenous data sovereignty, to ensure that Indigenous people are no longer being depressed by colonial ideology.

Therefore, how do we address the continuation of Māori still being disadvantaged in the health and social services sectors regarding policy, which is reflected in the literature? The literature has found disparities in policy for Māori, but how do we evaluate the conundrum of policy in establishing Tino rangatiratanga to be more inclusive to the Treaty of Waitangi principles, as indicated in the trends, for example? The data showed that Māori health staff's role as "cultural monitors" for the non-Māori health workforce raises concerns about issues of cultural competency. Therefore, Whitinui (2011) mentions that to be responsive to implementing successful strategies for Māori with disabilities, we must align them with social, cultural, and political factors, to address culturally appropriate services successfully. Ratima and Ratima (2007) state several general principles, strategies, and processes that are relevant to ensuring that programmes need to be not only culturally appropriate but must ensure incorporation of a te ao Māori lens.

It is also noteworthy to mention, that there is a need for increased Māori employment, as indicated in the findings, to meet the requirement across the board in the health and disability systems in general. Pay parity, employee retention, and cultural competency in compensation are further problems. The Ministry of Health, as the steward of the Crown, are accountable for improving the workforce's cultural competency. However, based on the findings we see that contracted DHB service providers were not providing adequate training for Māori and were not creating inclusive environments for Māori surrounding education and pay parity. This highlights the issue of cultural safety.

In the context of cultural safety, the term "culture" is used in its broadest sense and refers to a variety of factors, including a particular way of life, attitudes, behaviours, links, and relationships with others (Papps & Ramsden, 1996). When assessing the importance and relevance of cultural safety, cultural safety practice, as a response to the poor health of Māori, has the purpose assessing the communication issues and 'access to the health service.' Therefore, it is helpful to look at how the concept of cultural safety implementation can be applied and assessed by service providers in terms of better health outcomes for Māori (Wilson et al., 2021).

Service providers have been found in the case study analysis as having lacked cultural competence. This means they may not have the necessary knowledge, understanding, or skills to effectively engage and support Tangata Whaikaha. This lack of cultural competence can result in miscommunication, misunderstanding of cultural needs and values, and inadequate delivery of culturally appropriate services. Wilson et al., (2021) highlighted the value and applicability of relational approaches for encouraging Māori and their whānau to access healthcare. This would mitigate and create more inclusive environments for Tangata Whaikaha and whānau hauā. Wilson et al., (2021) indicates the necessary groundwork for health professionals to develop bonds of trust with Māori. The process of forming relationships using tikanga (cultural protocols and processes) that are informed by cultural values of aroha (compassion and empathy), manaakitanga (kindness and hospitality), mauri (binding energy), and wairua (importance of spiritual wellbeing) are key components of a Māori-centered model of relational care.

Indigenous people with disabilities, Whānau Hauā, have a poor uptake of access to resources for people with disabilities, in a setting with a lot of unmet needs. Despite whānau Hauā having the right to fair access of high-quality assistance and services on a national and international level, this continues. Indigenous disability identities are recognized within the

framework of a dominant northern hemisphere, Western ideology and are shown in the findings. According to Williamson and Harrison (2010), most of the literature focuses on the cognitive aspects of culture and recommends learning about the culture of specific groups, which is presumed to apply to everyone. This generic approach can lead to stereotyping and a failure to identify the needs of the individual receiving care. The second approach incorporates culture within a more comprehensive, structural framework, focusing on social position to explain health status, rather than individual behaviours and beliefs. It includes perspectives on the impact of the colonial process on the ongoing relationships of Indigenous and non-Indigenous people and how this affects health and health care.

Therefore, the findings show the need for more integration of Māori competencies for staff that is reflective of working with Māori service users. It is essential to ensure that service providers, Primary Health Care, Primary Care, and hospital and specialist services are meeting the Treaty of Waitangi principles and effectively creating more culturally inclusive workplaces. The significance and importance of having a Māori workforce and ensuring that we are meeting the obligations under the Nga Paerewa sector service standards, ensures that organisations are committed to culturally responsive workforce development and training.

Bennett and Liu (2018) discuss the importance of following the process of whānaungatanga when working with Māori. The author discusses the importance of whakapapa, a connection to whānaungatanga. Roberts (2013) mentions that whakapapa is the basis of the connectedness of whānau. Bishop et al., (2003) explains that whānau is the kinship and the process by which fundamental relationships should be. Bennett and Liu (2018) mentioned that the Western framework contradicts that of working with Māori. This also reflects and reinstates the position of the data and the significance of this research.

Durie (1997) explains the importance and relevance of Māori and the implementation of collaborating with Māori. The author highlights four significant matters: (1) physical (taha tinana); (2) emotional and mental health (taha Hinengaro); (3) family (taha whānau); and (4) spiritual (taha wairua) and explains that this moves away from the western framework and focuses on a centered and holistic approach. Therefore, the recommendation is to ensure an integrated approach to support Māori from a clinical mental health perspective underpinned by the four predominant factors.

The findings from both the submission and summary report indicate strong support for the objective of acknowledging the connection between self-determination, Mana Motuhake, and partnership with Te Tiriti. Respondents emphasised the importance of defining the concept

of "authority" in this context. They expressed that "true authority" would involve granting Māori greater power within government organisations. The delivery of community engagement would depend on the size of the service provider and its capacity to implement it, which in turn would be determined by the number of employees involved. However, regardless of the number of unelectable disabled individuals and Māori, there should still be some form of community engagement that represents Māori entities, iwi, and/or hapu.

The findings from both the submission and summary report indicate a significant level of support for an objective that recognizes the strong connection between self-determination, Mana Motuhake, and partnership with Te Tiriti. Respondents emphasized the importance of defining the concept of "authority" within this context, with many expressing that "true authority" would involve granting Māori greater power within government organizations.

There needs to be an importance placed on defining the concept of "authority" in this context. According to them, "true authority" would involve granting more power to Māori by government organizations. The delivery of community engagement would depend on the size of the service provider and its capacity to implement it, which in turn would be determined by the number of employees. However, regardless of the number of unelectable disabled and Māori individuals, there should still be some form of community engagement representation with either a Māori entity, iwi, and/or hapū. The delivery of community engagement initiatives would vary depending on the size of the service provider, as well as its capacity to implement such initiatives, which in turn would be influenced by the number of employees involved. However, regardless of the number of unelectable disabled and Māori individuals, it is crucial to ensure some form of community engagement that involves Māori entities, iwi, and/or hapū.

Overall, these findings underscore the imperative for a fair and inclusive approach to governance that acknowledges and honours the rights and aspirations of Māori communities. By empowering Māori and cultivating meaningful partnerships, governmental organisations can strive towards a society that is more equitable and just.

The data also identified community engagement by the service providers and ensured a more inclusive environment for eliminating barriers for Māori accessing accessible services for the intellectually disabled in the community. Since the closing of the asylums in the early nineties there is still a gap within the attitudes surrounding intellectual disability awareness, as indicated from the literature review. The research project also highlights there is still a lack of awareness of intellectual disability in the community.

This is also highlighted in Wiley (2009), it is still apparent when compared to the findings in this research. There is still a lack of cultural training for staff to ensure that service providers are culturally safe and appropriate. Although the findings highlight this lack of implementation of bicultural training, there is still a gap in cultural training awareness and practice.

It is, therefore, important that service providers are responsive and have accessible services for all staff and Māori service users surrounding their community engagement. Based on the findings in this research, developing a bilingual workplace and the use of signage to increase the visibility of Te Reo Māori in workspaces, thereby increases the usage of Te Reo Māori in everyday conversation as well as practicing tikanga in the day-to-day running of the operation. Having an increase in Te Reo will create equity of language in the workplace. Also, increasing awareness of intellectual disabilities in the community would support the visibility and increase awareness in the community.

The findings indicated a strong need to recognise and empower Māori, iwi, and hapu communities to use their authority to enhance their health and well-being. A greater emphasis on self-determination, Mana Motuhake, and collaboration with a strong Te Tiriti connection would reinforce respondents' statements that it's critical to define "authority" in this context and that, in their opinion, "true authority" would include the government.

In assessing quality, we must also look to section 4 of the *Health and Disability (safety) Act 2021*, which sets out the *Treaty of Waitangi* and the obligations that service providers have toward Māori. In New Zealand, these are set out as the new legislative requirements and are consistent with the objectives that are set out in Nga Paerewa.

Servicing the standards is another requirement by the Ministry to ensure that the service providers are meeting best practices and ensuring that they are consistent with the Treaty of Waitangi. Measuring accessibility to and quality of services can easily be measured against the Treaty of Waitangi principles and Nga Paerewa sector standards.

The service sector standards are upheld by the Treaty of Waitangi Tribunal and underpinned by the understanding of the obligations under the treaty by the Ministry of Health. These principles are guided by objectives that each service provider is required to ensure when they are providing primary health care. The service provider should be assessing what the current implementation of assessing the policy is with that of an indigenous context based on the following: How the organisation is currently assessing the implementation of policy, and what the legislative requirements are; and assessing how they are currently implementing and

assessing policy against the health and disability sector service standards. When assessing the potential of service providers' policies and procedures for implementation of the health and disability service sector, we need to first assess matters with an integrated approach and the bigger context, from an indigenous perspective. This does not mean just providing culturally appropriate services for Tangata Whaiora, it is about using a collaborative and collective approach, not only for the service users, but also the staff, to ensure that they have access to culturally appropriate services. Furthermore, that they understand the policies that are reflective of the health and disability service sector standards and are strategically and operationally sound.

Therefore, in answering the research questions some key recommendations for addressing the obstacles in accessing equitable service provision for Tangata Whaikaha in policy have been suggested as follows: Coordination and integration among service providers and agencies involved in supporting Tangata Whaikaha.

This can be achieved through improved communication, information sharing, and collaborative approaches to ensure seamless and comprehensive service delivery. As well as addressing socio-economic inequalities that hinder access to services poverty should be assessed, as well as providing transportation options, and improving housing conditions. However, implementing these recommendations requires collaboration among policymakers, service providers, Tangata Whaikaha, their whānau, and community organizations. By addressing these obstacles, equitable service provision can be enhanced, leading to improved health outcomes, increased inclusion, and enhanced well-being for Tangata Whaikaha.

In conclusion, it is recommended that policy communications are written in plain language and made accessible to Tangata Whaikaha and whanau hauā, reflective of the four phases as indicated. The information should be disseminated through various channels including community meetings, online platforms, and audio-visual formats, to reach diverse audiences and facilitate informed participation. By implementing these recommendations, policy processes can become more inclusive, participatory, and reflective of the needs and aspirations of Tangata Whaikaha. This will contribute to the development of policies that address their specific concerns, promote equity, and facilitate their active participation in decision-making processes which affect their lives. The key findings are as follows.

- Policies should acknowledge and respect the Treaty of Waitangi, recognizing Māori as a Treaty partner and ensuring that Tangata Whaikaha are guaranteed their rights under the Treaty.

- To ensure that the multiple decision makers that are affected by policies are considered, this representation should include diverse subgroups within the Tangata Whaikaha community.

7.5 Chapter Summary

This chapter discussed the research questions and the findings in answering the research questions. The next chapter presents the concluding chapter and discusses the following. The thesis overview, the key findings of the thesis, the limitations, and the thesis closing.

The data collection sought to identify barriers to equitable service provision and give policy recommendations, for addressing the obstacles in accessing equitable service provision for Tangata Whaikaha in policy. The recommendations are indicated as follows. Firstly, recommendation in policy to ensure that it is reflective of improving cultural competence among service providers and ensuring that appropriate cultural training is provided on Māori culture, values, and practices. This will enhance their understanding and ability to provide culturally appropriate care and support. It will foster better coordination and integration among service providers and agencies involved in supporting Tangata Whaikaha. This can be achieved through improved communication, information sharing, and collaborative approaches to ensure seamless and comprehensive service delivery. Ultimately, engaging with Tangata Whaikaha and their whānau at all levels of policy will ensure that Tangata Whaikaha and their whānau are actively involved and can participate in the design, implementation, and evaluation of services.

This engagement will ensure that services are aligned with their needs, preferences, and aspirations. However, implementing these recommendations requires collaboration among policymakers, service providers, Tangata Whaikaha, their whānau, and community organisations. Therefore, by addressing these obstacles, equitable service provision can be enhanced, leading to improved health outcomes, increased inclusion, and enhanced well-being for Tangata Whaikaha. Based on the findings, this will create equitable service provision in policy and mitigation of inequities to service provision for Tangata Whaikaha and whānau hauā in policy, and a robust monitoring system. The next chapter discusses the thesis overview, the key findings of the thesis, the limitations, and the thesis closing.

CHAPTER EIGHT

CONCLUSIONS

8.0 Chapter Introduction

The previous chapter discussed the research questions and the findings in answering the research questions. This chapter provides the thesis overview, the key findings of the thesis, the limitations, and the thesis closing.

8.1 Thesis Overview

Chapter one introduced the thesis and the background to the study of asylums and inequities of policy based on legislation in deinstitutionalization implications of Tangata Whaikaha. In conclusion, deinstitutionalization, while intended to support community-based care, has faced a challenge, and further exacerbates disparities in access to healthcare and support services for Tangata Whaikaha today.

Chapter two discussed the literature relevant to this study, analysing research and data regarding Indigenous people of New Zealand with disabilities, Tangata Whaikaha. The objective of a wide range of literature is to define the Tangata Whaikaha and whanau hauā barriers. Highlighted in the literature review were barriers to equitable service for Tangata Whaikaha and whanau hauā, as well as the lack of culturally appropriate services for Māori Tangata Whaikaha in New Zealand. Numerous factors were indicated as contributing to barriers and therefore a failure to meet the needs of Tangata Whaikaha through policy.

Chapter three outlined the Kaupapa Māori methodology and methods adopted in the research. This chapter aimed to justify the data collection process that was used, as well as an explanation of how it served to answer the research questions. While acknowledging that the integrity of the research was maintained by the principles applied throughout the collection of this research.

Chapter four presented the findings of the E-survey Likert scale questionnaire to answer research question one. In this study, three groups—the whanau hauā of Tangata Whaikaha in the Bay of Plenty Community, the hapu and iwi service providers, and Māori and non-Māori local government—were the subject of an exploratory quantitative case study. In this chapter, e-surveys with Likert scale questions were used to conduct quantitative research. The results of this data collection highlighted ethnically relevant work done by Māori with an indigenous Kaupapa Māori perspective and for the benefit of Māori. (The Karanga through the engagement

process were all conducted within a Te Ao Māori context, and the Pōwhiri framework was applied.) This process identified the ongoing barriers faced by participants, which is consistent with the literature. The results led to the conclusion that the New Zealand Disability Act's policy framework still has inequities.

Chapter five presented the findings from the semi-structured research questions, to answer research question two. In conclusion, the data shows that we can work to develop inclusive and equitable systems. Systems that respect and support the diverse needs and aspirations of people with intellectual disabilities and their families, particularly Māori Tangata Whaikaha in Aotearoa New Zealand. This can be done by addressing these barriers and promoting culturally appropriate services.

Chapter six presented the findings from the case study analysis, to answer research question three. These barriers hinder access to necessary support and opportunities, limiting the wellbeing and inclusion of these individuals. By understanding and addressing these challenges, we can strive towards creating more inclusive and equitable systems that meet the diverse needs of Tangata Whaikaha and the need to create cultural responsiveness for Māori Tangata Whaikaha in policy.

8.2 Key findings

The key findings in the research indicate barriers to equitable service for Tangata Whaikaha. These include limited availability of specialised services, financial constraints, lack of comprehensive support systems, stigma, social isolation, communication and language barriers, inadequate transition planning, bias and discrimination, and policy gaps.

Highlighted in the literature and reflected in the data is the need for culturally appropriate services for Māori Tangata Whaikaha. This is crucial for respecting their cultural identity, promoting holistic wellbeing, ensuring effective communication and engagement, addressing disparities and inequities, empowering self-advocacy, strengthening whānau connections, and fostering a culturally competent workforce. Therefore, the data has addressed the need for recognizing and addressing these barriers to ensure equitable access to services and support for Tangata Whaikaha and whanau hauā.

More specifically, the findings pertain to the Te Arawa Takiwā and contribute to new knowledge of Tangata Whaikaha whanau hauā from that region. Overall, findings highlight the implication of policy and inequity of Māori in government policy. This highlights the need to raise awareness in policy surrounding discrimination, promoting Tangata Whaikaha and their

whānau in decision-making processes. Therefore, by recognizing and addressing these challenges, society can work towards achieving equitable health outcomes, reducing discrimination, fostering inclusion, and improving the overall wellbeing of Tangata Whaikaha.

The key recommendations are as follows:

- Develop and fund services that are culturally appropriate for Tangata Whaikaha. This includes support services that are accessible, welcoming, and culturally sensitive.
- Integrate anti-discrimination policies and practices into the broader policy framework to counter any bias or discrimination faced by Tangata Whaikaha.
- Allocate resources in a way that addresses the disproportionate impact of disability within the Māori population. Ensure equitable funding for health, education, and other support services.
- Adopt and promote the use of traditional Māori models of health and wellbeing, such as Te Whare Tapa Whā, which recognizes the holistic nature of health and wellness.

8.3 Limitations

There were notable limitations of this research. Firstly, the sample size and representativeness; due to practical constraints, the study had a limited sample size and therefore only focused on Te Arawa, a specific region. This could have limitations on the generalisability of the findings and limit the ability to draw broader conclusions about the population. Also, the thesis was subject to time and resource limitations. The constraints could have limited the depth and scope of the study, potentially limiting the ability to explore all relevant aspects of the topic or conduct extensive data collection and analysis.

Strengths of the thesis

This these has contributed to new knowledge by (i) critically examining the international and local literature on the topic area. (ii) Provided a critique of the policies and documents from the Ministry of Health from an outlining document in 2004 through to relatively recently 2022/23 and incorporated these into the literature review. (iii) I developed a wholistic model and proposed ways forward to better understand and address the issues into the future. E Likert scale surveys, semi structured interviews and case study method (iv) Utilising multiple methods to collect and analyse the data has provided a rich source of information, even though it may have been limited in terms of small numbers of participants. (v) I utilised the best possible available methods drawing from Indigenous and Māori theories and research practices and combined these with some familiar western research practices from qualitative research (14

interviews) and one from quantitative (54 e-Survey) benefit of this thesis for potential clients with disabilities going into the future.

8.4 Recommendations

The recommendations are based on this research and disseminating of the findings. It is recommended further analysis be carried out on policy development and support for the creation of more inclusive and equitable service provision to examine the social, economic, and health outcomes for individuals facing these barriers and the broader implications for their quality of life.

8.5 Future research

I want to publish from this large project in practitioner journals, so they are readily available and accessible for practitioners in the field, and also perhaps a series of booklets of key highlights for the participants and people with disabilities and their whanau. I challenge other researchers and policy makers to pick up this mahi and develop this in their own rohe and regions.

8.5 Thesis closing

The purpose of this research was to address the knowledge gap and provide new insights regarding Tangata Whaikaha and whanau hauā by identifying the barriers they face in accessing equitable service provision in policy. The research aimed to contribute to the existing literature by shedding light on these barriers and proposing solutions that can inform policy development and create more inclusive service provision. This thesis has contributed to this by highlighting policy recommendations to address these barriers, enhance responsiveness and service provision, and foster inclusivity in policy frameworks. The overall thesis has provided evidence-based insights to inform policymakers, service providers, and stakeholders about the importance of addressing these barriers. The research contributes to the potential benefits of equitable service provision and has participated in mitigating barriers to inclusion in policy and enhancing the well-being and opportunities available to Tangata Whaikaha in Aotearoa New Zealand.

However, as well as having whanau voice for Tangata whaikaha representation can contribute to the development of policies that are more effective in addressing the needs of disabled individuals. Additionally, as important is the recommendation of Tangata whaikaha on governance boards. This sends a powerful message about the value of diversity and inclusion. It empowers individuals with disabilities and encourages others to see their potential

and capabilities rather than focusing on limitations. Representation on governance boards would identify and address systemic inequities and barriers that Tangata whaikaha may face. This can lead to the creation of more equitable opportunities and outcomes.

Therefore, in conclusion the recommendation for this thesis is the representation of Tangata whaikaha on governance boards to ensure that decision making is inclusive, diversifies the system, and creates equity in decision-making and contributes to more comprehensive and culturally sensitive governance, ultimately benefiting the entire community.

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Appendix One – Likert scale questionnaire

Question 1. Do you give consent to use this information, and do you agree to participate in this research E-Survey? If you decide that you would like a copy of the findings, please let the researcher know and this will be made available to you on completion of examination.

Question 2. Do you believe there is a need to create inclusive environments for disabled people in the community?

Question 3. Overall, do you feel that your service provider for intellectual disabled in the community meets the need of Māori with an intellectual disability in the Bay of Plenty Community?

Question 4. Do you feel that your organisation provides culturally appropriate policy to meet the needs reflective of Māori with Intellectual Disabled with your current service provider/ service offered?

Question 5. Overall, do you believe that we provide appropriate culturally appropriate services are for Intellectually disabled Māori in the Bay of Plenty Community?

Question 6. Overall, do you feel satisfied with disability service supports for Māori with Intellectual disability in the Bay of Plenty region?

Question 7. Are you aware of the New Zealand Disability Strategy and the significance it has to you and your mahi and or whanau member?

Question 8. Do you believe that you organization meets objective eleven?

Question 9. Does your organization promote the participation and promotion of Māori with an Intellectual disability? “Objective 11: Promote participation of disabled Māori Promote opportunities for disabled Māori to participate in their communities and access disability services? Disabled Māori should receive an equitable level of resource that is delivered in a culturally appropriate way”.

Question 10. Do you believe that your organisation is culturally responsive to the cultural needs of Māori?

Question 11. Please indicate your age group.

Question 12. What is your gender?

Appendix Two - Participant Form

Thank you for taking the time out to undertake this interview.

Consideration to be undertaken when deciding upon accepting participation.

Please provide as information, all information is collected for statistical purposes and used for academic purposes only and all information is kept in full confidentiality.

No information, data collected, and feedback will be disclosed to anyone other than the Academic/Research Ethics Committee for assessment and will be filed in a filing cabinet under lock and key in my supervisor's office and will be destroyed upon completion of its purpose. No information shall be shared with anyone other parties, and all provisions are under strict confidentiality under the Privacy Act 1993. Please note that and allow 20-30 minutes to conduct this interview process and preferably uninterrupted to obtain best results.

All consent to participate in this survey is at the discretion of the owner/ operator. There is a 7 day withdraw process if you choose not to participate. You will give information of the outcome of the activity in the form of the findings that will be available to your organisation upon request.

Participants are not considered vulnerable in participating in this study.

The participants that will be surveyed and interviewed are Managers that implement management processes and decision makers in the organisation's policy processes. Risk of participating is always minimised, with discretion of any feedback collected and will only be used for the purposes of this study and guaranteed no harm.

In the case of qualitative research and interview conducted all information that will be taken will be, double checked before interpreting any ambiguous text and to ensure that what is been collected is true and correct to ensure that what is been documented correctly.

This consent form will be held at Te Whare Wananga o Awanuiārangi under the control of my supervisor and will be the only one that views this form and has the ability to destroy as well.

Signature:

Date:

Appendix Three - Doctoral thesis E-survey whanau hauā support worker participants

Respond	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Q11	Q12	Qu	Range	Interpret
1	1	1	2	1	1	3	1	2	1	4	18 - 24	M	Q1	1.0	Agree
2	1	1	2	1	1	3	1	2	1	4	24 - 34	M	Q2	2.30	Strongly agree
3	1	1	2	1	1	3	1	2	1	4	34 - 44	M	Q3	3.0	Neither agree nor disagree
4	1	1	1	1	1	3	1	2	1	4	34 - 44	M	Q4	2.2	Strongly agree
5	1	1	1	1	1	3	1	3	1	4	34 - 44	M	Q5	4.44	Strongly disagree
6	1	1	1	1	1	5	1	3	1	4	34 - 44	M	Q6	4.33	Strongly disagree
7	1	1	1	1	1	5	1	3	1	4	34 - 44	M	Q7	1.2	Agree
8	1	2	1	2	2	5	1	3	2	4	44 - 54	F	Q8	3.78	Strongly disagree
9	1	2	1	2	2	5	1	3	2	4	44 - 54	F	Q9	2.18	Strongly agree
10	1	3	1	2	2	5	1	5	2	4	44 - 54	F	Q10	4.11	Strongly disagree
11	1	3	3	2	2	5	1	5	2	4	44 - 54	F	Q11	24-46	Average age
12	1	3	3	3	3	5	1	5	3	4	44 - 54	F	Q12	F	Average gender Female

13	1	3	3	3	3	5	1	5	3	4	44 - 54	F			
14	1	3	4	3	3	5	1	5	3	4	44 - 54	F			
15	1	3	5	3	4	5	1	5	3	3	44 - 54	F			
16	1	5	5	4	4	5	1	5	4	5	54 - 64	F			
17	1	5	3	4	1	4	1	5	4	5	54 - 64	F			
18	1		3	1	5	4	5	5	5	5	54 - 64	F			
Average	1.0	2.3 0	3	2. 22	4.4 4	4.3 3	1.2	3. 78	2.1 8	4.1 1	24 - 36	F			

Appendix Four - Doctoral Thesis E – Māori, Non-Government and Government kaimahi and kaiāwhina, hapu and iwi agency participants.

Respond	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Q11	Q12	Q13	Question	Range	Interpret
1	1	1	2	1	1	1	1	2	2	2	2	F	44-54	Q1	1.0	Agree
2	1	1	1	2	2	2	2	2	1	1	1	F	44-54	Q2		
3	1	3	2	3	3	4	1	3	4	3	2	F	34-44	Q3		
4	1	3	2	3	3	4	1	3	4	3	2	F	34-44	Q4		
5	1	3	2	3	3	4	1	3	4	3	2	F	34-44	Q5		
6	1	3	3	3	3	4	5	3	4	3	3	M	44-54	Q6		
7	1	3	3	3	3	4	5	3	4	3	3	M	54-64	Q7	1.0	Agree
8	1	3	2	3	2	4	5	2	4	3	3	F	34-44	Q8		
9	1	3	2	3	2	4	5	3	4	4	3	F	54-64	Q9		
10	1	2	2	3	3	4	5	3	4	4	3	F	44-54	Q10		
11	1	2	2	3	3	4	5	3	4	4	3	F	34-44	Q11		
12	1	2	2	3	3	4	1	4	4	4	3	M	24-34	Q12		
13	1	2	2	2	3	4	1	3	4	4	3	F	24-34	Q13	Female	Average Female
14	1	2	2	2	2	4	5	4	4	4	3	F	54-64			
15	1	2	2	3	2	4	5	4	4	4	3	M	54-64			
16	1	2	3	3	2	4	5	4	4	4	3	F	44-54			

17	1	2	3	3	2	4	5	4	4	4	3	F	44-54			
18	1	2	3	3	3	3	5	4	4	4		F	44-54			
Average	1.0											F				

Appendix Five Doctoral Thesis E – Non-Māori, Non-Government and Government kaimahi and kaiāwhina agency participants.

Respond	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Q11	Q12	Q13	Question	Range	Interpret
1	1	4	1	1	1	1	1	3	1	5	1	F	24-34	Q1	1.8	Agree
2	1	5	1	1	1	1	1	3	1	5	1	F	34-44	Q2	4.05	Strongly disagree
3	1	5	1	1	1	1	1	3	1	5	1	F	54-64	Q3	3.8	Strongly disagree
4	1	5	1	1	5	1	1	3	1	4	1	M	34-44	Q4	3.61	Strongly disagree
5	1	5	5	5	5	3	1	3	1	4	1	M	44-54	Q5	3.66	Strongly disagree
6	1	5	5	5	5	3	1	1	3	4	1	M	44-54	Q6	3.27	Strongly disagree
7	1	5	5	5	5	3	1	1	3	4	1	F	44-54	Q7	1.0	Agree
8	1	5	5	5	5	4	1	1	3	4	3	F	44-54	Q8	2.94	Neither agree nor disagree
9	1	5	5	5	5	4	1	1	4	4	3	F	24-34	Q9	2.53	Strongly agree
10	1	5	5	5	5	4	1	5	4	4	3	M	54-64	Q10	3.94	Strongly disagree
11	1	5	5	5	5	4	1	4	4	4	3	M	44-54	Q11	4.41	Disagree
12	1	5	5	5	5	4	1	4	4	4	3	F	44-54	Q12	1.21	Average female
13	1	3	5	5	3	4	1	4	5	4	4	F	44-54	Q13	44-54	Average age
14	1	3	5	3	3	4	1	4	5	4	4	F	44-54			
15	1	3	5	3	3	4	1	3	5	3	4	F	54-64			

16	1	2	3	3	3	4	1	3	3	3	4	F	54-64			
17	1	2	3	3	3	5	1	3	3	3	5	F	44-54			
18	1	1	3	3	3	5	1	3	2	3	5	F	34-64			
Average	1.0	4.05	3.8	3.61	3.66	3.27	1.0	2.94	2.53	3.94	4.41	1.21	44-54			

Appendix Six – Semi Structured Interview Questions

Question 1

All participants will not be identifiable, therefore, by completing this survey you will not be identified. This is made explicit in the information sheet and consent form that you agree to at the time of completing this survey by choosing 'agree'.

No information will be shared with any other parties and all provisions are under strict confidentiality under the Privacy Act, and survey software will support the anonymity of the participants. All information is collected for statistical purposes and used for academic purposes only and is kept in full confidentiality. No information, data collection, and feedback will be disclosed to anyone other than the Academic board for assessment and will be filed securely.

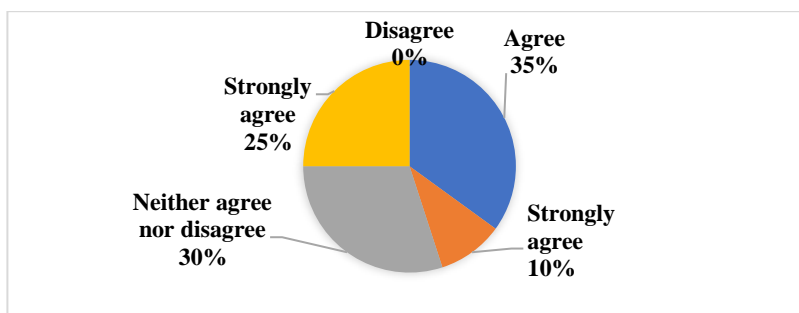
Question 1: Do you give consent to use this information, and do you agree to participate in this research E-Survey? If you decide that you would like a copy of the findings, please let the researcher know and this will be made available to you on completion of examination.

- Agree
- Disagree

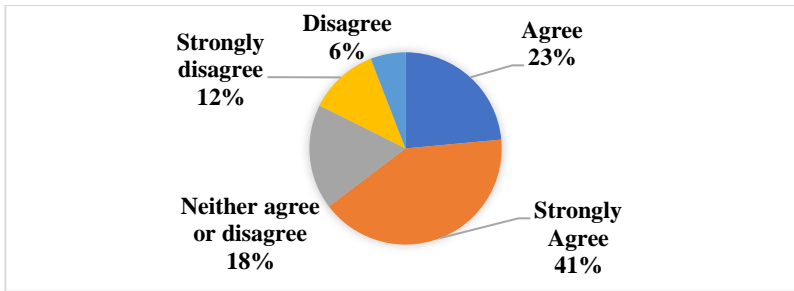
Question 1. E-Survey Findings of Whānau Support Workers consent to participate in E-Survey

Ninety percent of participants agreed to participate and 10% declined.

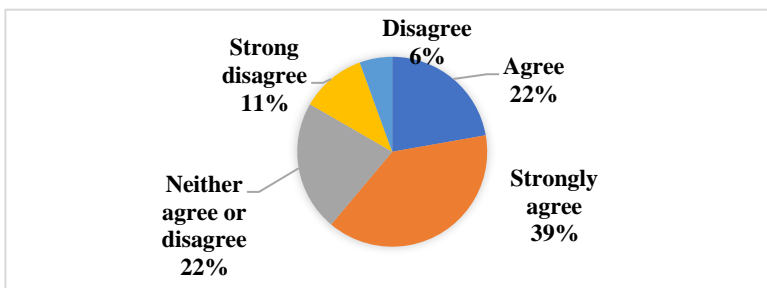
Question 2. Do you believe there is a need to create inclusive environments for disabled people in the community?



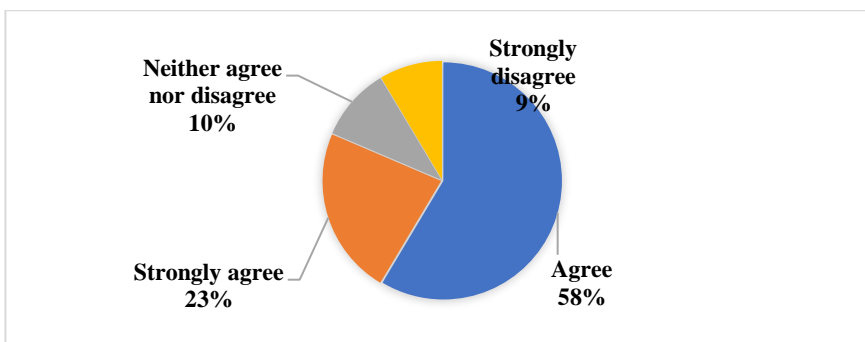
Question 3: Overall, do you believe that we provide culturally appropriate services for Intellectually.



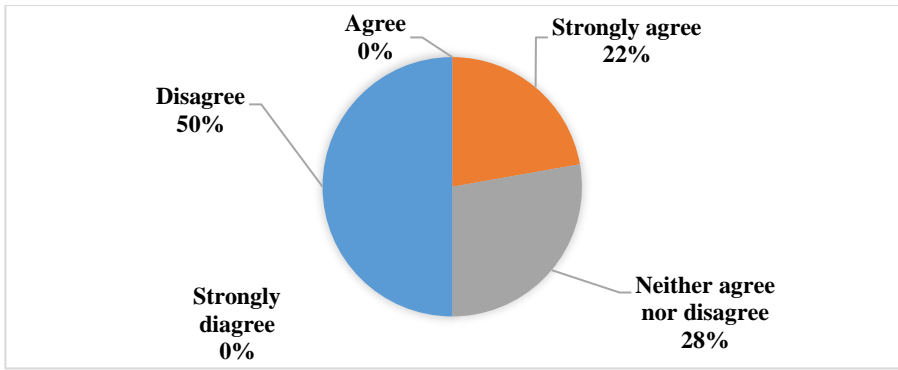
Question 4: Do you feel that your organisation provides culturally appropriate policy to meet the needs reflective of Māori with the Intellectually Disabled with your current service provider/ services offered?



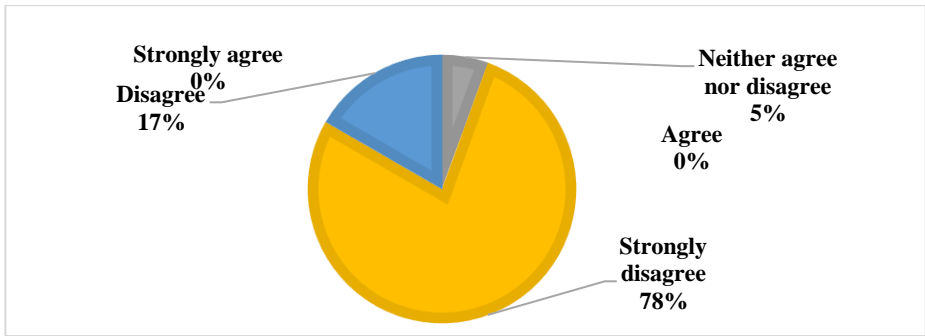
Question 5: Overall, do you feel satisfied with the disability service supports for Māori with an intellectual disability in the Bay of Plenty region?



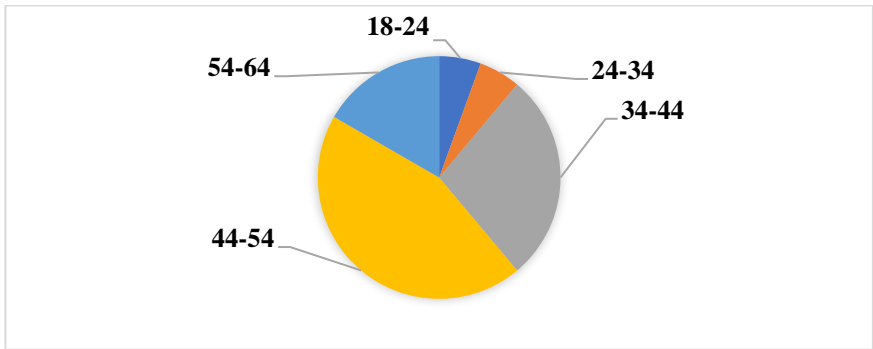
Question 6: Do you believe that your organization meets objective eleven “Objective 11: Promote participation of disabled Māori Promote opportunities for disabled Māori to participate in their communities and access disability services? Disabled Māori should receive an equitable level of resource that is delivered in a culturally appropriate way”. In that your organization promotes the participation and promotion of Māori with an Intellectual disability.



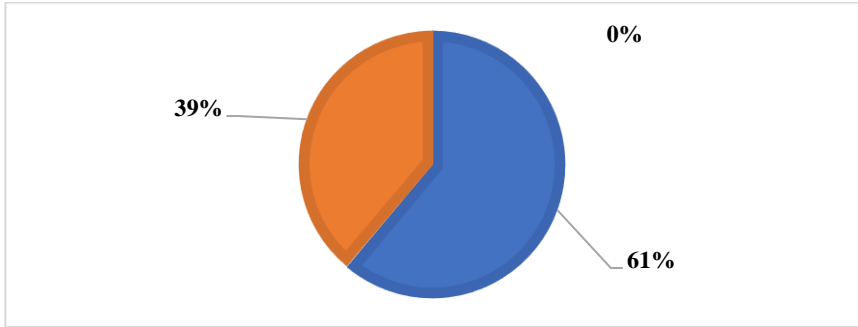
Question 7: Do you believe that your organisation is culturally responsive to the cultural needs of Māori?



Question 8: How old are you?



Question 9: What is your gender?



Appendix Seven - Ethics Approval



EC2020.13

TE WHARE WĀNANGA O
AWANUIĀRANGĪ

27/10/2020

Student ID: 2081879

Mariana Frances Morrison
134 Fairy Springs Road
Rotorua
3010

Tēnā koe Mariana

Tēnō koe i roto i ngā tini āhuatanga o te wā.

Ethics Research Committee Application Outcome: Approved

The Ethics Research Committee met on Wednesday 14th October 2020 and I am pleased to inform you that your ethics application has been approved. The committee commends you on your hard work to this point and wish you well with your research.

Please contact your Supervisor Dr Naomi Simmonds as soon as possible on receipt of this letter so that they can answer any questions that you may have regarding your research, now that your ethics application has been approved.

Please ensure that you keep a copy of this letter on file and use the Ethics Research Committee document reference number: EC2020.13 in any correspondence relating to your research, with participants, or other parties; so that they know you have been given approval to undertake your research. If you have any queries relating to your ethics application, please contact us on our free phone number 0508926264; or e-mail to ethics@wananga.ac.nz.

Nāku noa nā
Kahukura Epiha
Ethics Research Committee Administrator

Ethics committee document reference number: EC2020.13

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