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Āta whakarongo:

Understanding whānau experiences of audiology early intervention

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

Masters of Applied Psychology (Community)

at

The University of Waikato

by

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2022

Abstract

For tamariki with hearing loss, early intervention is of critical importance in maximising speech and language, socio-emotional and academic development outcomes. Better hearing outcomes can be achieved by minimising diagnosis delays and initiating intervention treatment as soon as possible. Preliminary data from Waikato District Health Board indicated an equity gap at the point of diagnosis with persisting inequities for tamariki Māori during the delivery of early intervention services. High rates of appointment non-attendance within this group (27% Māori vs. 8% for non-Māori) are a cause for concern when approximately 50% of total appointments are for tamariki Māori. This research seeks to understand the experiences of Māori whānau accessing Waikato's Audiology Early Intervention Service in order to identify changes the service can make to improve Māori engagement in the future. This study uses qualitative methodologies within a kaupapa Māori framework to investigate the access experiences of Māori whānau of tamariki identified with hearing loss. Interviews with six whānau from Hamilton city and rural Waikato provided rich narratives to inform changes to the Audiology Service to improve the hearing outcomes of tamariki Māori. Whānau shared systems and practical barriers that contributed to challenges with attending appointments including the location, appointment timing, travel and parking. From entering an unwelcoming waiting area, whānau described the added stress experienced to the depth of their emotional response to the hearing loss diagnosis. All shared positive interactions with staff and detailed what could have made their health experience better. After leaning into the kōrero and connecting to the whānau experience, a Manaaki-based pathway is proposed to support Māori ways of being, to ease whānau through the barriers and to combat the alienating experiences of engaging with the health system.

Acknowledgments

Ko te mihi tuatahi ki ngā whānau o ngā tamariki. It has been my honour to connect with six whānau to share their experiences and to capture their desires for the Audiology Service to support all whānau with tamariki living with hearing difficulties. Ngā mihi maioha ki a koutou katoa.

My supervisor, Associate Professor Bridgette Masters Awatere, tēnei te mihi ki a koe. As you know, over the past two years of writing this thesis, it has been a mission to finish this work and you have challenged me to do better when I would have settled for less.

To my work colleagues, my kaupapa whānau Dr. Nina Scott, Dr. Rose Black, Nicola Birch, Te Okahurangi Ngahana-Hartley and Justine Crittenden for their encouragement and equity expertise, Ngā mihi.

The Te Whatu Ora Waikato Audiology Service and in particular Emily Hunter who initiated this whole journey and has gently supported with information about processes and connecting to whānau. Thank you.

Thank you to the Eisdell Moore Centre for Hearing and Balance Research and the Waikato University Māori & Psychology Research Unit for their support to fund time off work to investigate this kaupapa and for the tools I needed to support my writing. Ngā mihi nui.

Ngā mihi MAI ki Waikato and the other Māori Masters and PHD students who gave moral support and encouragement during the writing retreats, in particular Pita Shelford, Nikki Barrett and Rangihurihia McDonald.

Finally to my whakapapa whānau, those who lived with me and on a daily basis shared in the weight of this journey with me. Ngā mihi aroha Arran, Arie, Tia and Romie. To my mum and dad, my sisters and whānau whānui, e mihi ana ki a koutou katoa. The reason I study is because I can but the reason I continue is because of my whānau.

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Glossary[1]

Āta Whakarongo	To listen carefully
Āwhinatanga	To assist, help, support, benefit
Aroha	Affection, sympathy, charity, compassion, love, empathy
Aroha-ki-te-tāngata	A respect for people
Hapū	Kinship group, clan, tribe, subtribe
Hapū	To be pregnant, conceived in the womb
Iwi	Extended kinship group, tribe, nation, people
Kanohi ki te kanohi	Face to face, in person, in the flesh
Karanga	Formal call, ceremonial call, welcome call
Kaupapa	Topic, policy, matter for discussion, plan, purpose, subject, programme, issue
Kōrero	Speech, narrative, story, news, account, discussion, conversation, discourse
Kōtiro	Girl, daughter
Kura kaupapa	School operating under Māori custom and using Te Reo Māori as the medium
Koha	Gift, present, offering, donation, contribution
Māmā	Mother, mum
Māori	Indigenous person of Aotearoa/New Zealand
Mātauranga Māori	Māori knowledge
Māmāe	Ache, pain, grief, hurt, guilt, injury, wound
Mana	Prestige, authority, control, power, influence, status
Manaakitanga	Hospitality, kindness, generosity, support
Pākehā	New Zealander of European descent
Pāpā	Father, uncle, dad
Pēpi	Baby, infant
Pihoi	Inattentively deaf
Pūwharawhara	Deaf
Tāhorehore	Deaf as if the ears were cropped
Taiao	World, Earth, natural world, environment, nature

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[1] Unless otherwise stated, translations are derived from Moorfield & Te Aka Māori Dictionary, 2022.

Tama	Son, boy, nephew
Tamaiti	Child, boy - used only in the singular
Tamariki	Children - normally used only in the plural
Tamāhine	Daughter
Tāne	Husband, male, man
Tangata Whenua	Local people, hosts, indigenous people
Te Ao Māori	The Māori world
Te Reo Māori	Māori Language
Te Tiriti o Waitangi	The signed Te Reo Māori version of the Treaty of Waitangi
Tika	To be correct, true, upright, right, just, fair, accurate, appropriate
Tikanga	Correct procedure, custom, habit, lore
Tino rangatiratanga	Self-determination, sovereignty, autonomy, self-government, rule
Wāhine hapū	Pregnant women
Waiata	Song, chant, psalm
Wairua	Spirit, soul
Wero	To challenge
Whakapakari tinana	Physical fitness, exercise
Whānau	Family group, familiar term of address to a number of people
Whānau ngatanga	Relationship, kinship, sense of family connection
Whakawhānau ngatanga	Process of establishing relationships, relating well to others
Whaikōrero	Oratory, oration, formal speech
Whakapapa	Genealogy, lineage, descent

Chapter 1: Introduction

Literature Review

> Āta Whakarongo
>
> To listen with reflective deliberation
>
> This requires patience and tolerance
>
> It gives space to listen and communicate to the heart,
> mind and soul of the speaker, kaupapa and environment
>
> It requires the conscious participation of all senses
>
> It signals the elements of trust, integrity and
> respectfulness of what is being shared.

(Pohatu, 2004, pp. 5-6)

The phrase "Āta Whakarongo" aligns perfectly with the kaupapa of this study since it is about listening with intention to whānau when examining Māori experiences. These words gently framed, guide kaupapa Māori researchers to cultivate respectful relationships. This Kaupapa Māori principle resonated with my desire as a researcher to produce a thesis that made people; particularly health service staff feel something, feel connected to whānau so that they would champion change. Āta Whakarongo means leaning into the kōrero with whānau and acknowledging a shared connection. It also beautifully articulates what staff need to be doing for all whānau engaging with health services. There is a synergy between listening and reflecting on whānau kōrero as they share their experiences of accessing hearing services.

This study is a response to Public Health physician Doctor Nina Scott's wero to address Māori inequities within Waikato District Health Board[2] (WDHB) Hospital and Community Services. The Audiology Early Intervention Service (AEIS) began an investigation into service inequities, including examining the equity gap between Māori and non-Māori access to their services. The service staff recognised the value of hearing from whānau about how to make their service more accessible and appropriate. Staff from the AEIS approached Te Puna Oranga (the Māori Health Service of WDHB) to support and design a research grant application to understand whānau experiences of the Audiology Early Intervention Services. In my capacity as a Māori strategy analyst, I supported the service to design the research project. At the time, a key responsibility of my role was working with health services to enhance Māori health outcomes. The audiology team demonstrated a sincere desire to address the inequities and to consult with the whānau about how to proceed. The result of which was a collaboration between audiologist Emily Hunter and myself to work together to advance the research. My role was the primary investigator and Emily's was to enable confidential engagement with whānau referred to the service and to provide audiology technical expertise. Our partnership presented an opportunity to serve whānau and to ensure that the study was undertaken safely and respectfully to facilitate service transformation.

Health in an inequitable landscape

All people, no matter where they live or what groups they belong to are entitled to health equity, that is, to have a fair opportunity to experience long, healthy and productive lives. Good health enables people to lead more productive lives, to contribute to the wellbeing of their whānau, to actively participate in and grow their communities (Commission on Social Determinants of Health, 2007). The World Health Organization (WHO), a global public health organisation committed to using evidence-based knowledge to improve the lives of vulnerable communities, defines health equity as

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[2] As a result of the health system reform from July 2022 the 20 DHBs were disestablished and two new national entities took on the responsibilities for the health system Te Whatu Ora – Health New Zealand and Te Aka Whai Ora – Māori Health Authority

“the absence of avoidable or remediable differences among groups of people, whether those groups are defined socially, economically, demographically, or geographically” (World Health Organization, 2021, para 1). Although it is widely acknowledged that the achievement of good health is a fundamental human right, these opportunities are often inequitable for many groups of people (Commission on the Social Determinants of Health, 2008). Inequity is driven by the systematic differences in economic, political, environment, and social status between groupings of people. The important feature of these health differences between groups is that they are unnecessary, avoidable, unfair and unjust (Reid & Robson, 2007). Further, health inequities as described by Hodgetts et al. (2016) are a "persistent feature of our societal landscape" (p. 425). Health inequities exist and have been explained as resulting from the combination of socially unjust policies, programmes and economic systems, which are evident even in some of the most affluent countries (Commission on Social Determinants of Health, 2008). According to Raphael (2012) health inequity results from social, economic, gender and racial inequity, which are all forms of power inequity. Navarro (2011) argues that the political context has a major influence on the health of populations, which is determined by social, economic and cultural factors. Further, those in positions of power maintain the politically unjust systems that are responsible for health inequities. To have any impact on health inequities it is important to understand how these conditions first arose and then continue to exist. A global focus on understanding and eliminating the conditions that lead to inequities is required to ensure that the poor health of vulnerable communities does not become so embedded in our lives that it becomes an accepted part of our society landscape. Realizing the unique challenges experienced by indigenous communities is crucial to addressing health inequities.

Indigenous inequity within the global landscape

The United Nations recognised the rights of Indigenous Peoples to both sovereignty and health, which was affirmed in the Declaration on the Rights of Indigenous Peoples (United Nations General Assembley, 2007). However, on a global scale, Indigenous Peoples experience persistently poorer health outcomes compared to non-indigenous peoples (Berghan et al., 2017). Paradies

(2016) and Reid and Robson (2007) have drawn attention to further cultural and historical determinants of health that impact Indigenous Peoples. These include: negative experiences of colonisation and racism, alienation from land, identity, culture and historical trauma, grief and loss. The historical and contemporary settings of colonisation serve as the primary motivating force for the disparities experienced by indigenous communities (Reid & Robson, 2007). The global spread of colonisation has followed a systematic process of stripping away from indigenous people control over spirituality, land, law, language, education, health, family and community structures and culture (Glover et al., 2020). Taking control of the means of production—power, wealth, land, and resources—had an impact on not only the previous generation but also succeeding ones, leaving intergenerational health disparities and trauma in its wake. Colonisation is an intentional and ongoing process that is not limited to the historical experiences of indigenous people with systems and structures still in place causing indigenous disadvantage and ill-health. Conversely, the benefits of inherited cultural privileges are being enjoyed by the colonisers' descendants (Berghan et al., 2017; Paradies, 2016). These privileges are "enabled by layer upon layer of new systems established to determine how resources will be obtained, how they will be distributed and to whom" (Reid & Robson, 2007, p. 5). One of the ways that colonisation continues to enable the inequity of health of indigenous populations is by unjust processes such structural violence. Structural violence is a key determinant of health, which disadvantages and causes suffering from structures, policies and institutional practices that are innately unjust (Browne et al., 2016). Racism, as a social process of structural violence has a severe and negative impact on the health of Indigenous Peoples (Browne, 2017). A focus on addressing racism (and the systems that continue to support it) is needed as a key determinant of health equity for Indigenous Peoples. Social justice is critical to any systems change and actions to redress the effects of racism and colonisation on the health of indigenous people. Understanding Māori experiences of inequity is important as tangata whenua, Indigenous Peoples of Aotearoa New Zealand.

Health of Māori in Aotearoa

A focus on good health and wellbeing is essential to ensure Māori flourish. Whānau flourishing was proposed as an ideal goal for action to improve health equity by contemporary Māori scholars (Kingi et al., 2014). To understand the elements which accelerate flourishing, the authors explored determinants of whānau wellbeing. The social, economic, environmental, and cultural aspects of flourishing are all interconnected and contribute to whānau wellbeing. Whānau heritage, whānau wealth, whānau capacities, whānau cohesion, whānau connectedness and whānau resilience are six proposed markers of whānau flourishing (Kingi et al., 2014). In addition, Hodgetts et al. (2016) maintain that for whānau to flourish, changes need to be made to the features of society, which cause health inequities. These changes need to include targeted approaches for a more equitable allocation of resources, services, and healthier living conditions.

Colonisation has deeply harmed Māori. Māori have on average the poorest health status of any ethnic group in Aotearoa New Zealand (Reid & Robson, 2007)). Demonstrated as lower life expectancies, higher rates of disability and chronic health conditions than any other New Zealand population group, Māori also experience greater morbidity and severity of illness (Moewaka Barnes & McCreanor, 2019). Poverty, unemployment, educational underachievement, and youth suicide are all linked to poor health outcomes, which Māori are more likely to experience than non-Māori. (Glover et al., 2020). According to Reid & Robson 2007, these disparities are "consistent, comprehensive and compelling" (p. 3). More recently, academics have acknowledged that Māori whānau live in precarious circumstances due to insecure employment, insufficient income, and inadequate welfare support. (Standing, 2012; King et al., 2017). Historical systems and Acts put into force by the New Zealand Government have enabled this to occur with a legacy of land and resource loss, spiritual and cultural demise. The Native Land Act and the New Zealand Settlement Act enabled settlers to legally buy up and confiscate Māori land and the introduction of the monetary system are examples of past systems which have disadvantaged Māori and benefitted the descendants of settlers (King et al 2017; Reid & Robson, 2007).

Inequity is a whole of society problem and not just the responsibility of the beneficiaries of inequitable health outcomes (Smith, 2015). According to Reid et al. 2019, health professionals must engage critically with the history of power and disadvantage that led to these inequitable health outcomes to mitigate the effects of colonisation, notably the poor health of Māori. The conditions that have led to the health inequities of Māori have taken generations to create and may take a lifetime to restore.

Investigations into health inequities in Aotearoa New Zealand

There have been two significant national investigations into how the health system in Aotearoa New Zealand is operating and upholding its Te Tiriti o Waitangi obligations to Māori. The first was in 2016; the Waitangi Tribunal commenced an inquiry to determine whether the legislative and strategic framework that administers the primary health care sector is Te Tiriti o Waitangi compliant. The resulting report found that "the framework consistently failed to state a commitment to achieving equity of health outcomes for Māori" (Came et al., 2020, p. 209; Waitangi Tribunal, 2019). The second significant investigation was the Health and Disability System Review (2020), set up by Government in 2018 and tasked with providing recommendations to government for "a future health and disability system that is sustainable and well placed to respond to the future needs of all New Zealanders" (p.10). Regardless of the best intentions of those involved, the current health system was not working equitably for all and required significant change (Health and Disability System Review, 2020). As described here, both the Waitangi Tribunal 2575 inquiry Stage 1 (Waitangi Tribunal, 2019) and the New Zealand Health and Disability system Interim Report (Health & Disability System Review, 2019) identified a persistent failure of the Crown to deliver health equity for Māori. These investigations call on the Crown and their agents (which includes District Health Boards) to take urgent action to prioritise their Te Tiriti obligations to Māori.

The New Zealand Government's public health strategies and plans have also been reviewed and found wanting. According to Came et al. (2018), plans and strategies for public health have failed significantly to address Te Tiriti o Waitangi obligations to Māori. In addition, the authors argued that institutional racism has influenced how public health policies are developed in New Zealand and is, in fact, a factor in the health disparities experienced by Māori as a result of colonisation. Māori health inequities persist despite the strategic intentions of the New Zealand Government. Despite using equity frameworks in strategy and planning processes many District Health Boards struggle to put health equity into practice to address the inequities within their organisations (Sheridan et al., 2011). Notwithstanding good intentions and rhetoric, Government strategies and policies have yet to make a difference for Māori health gain. To ensure that Māori have access to high standards of health and wellbeing is the overarching goal of He Korowai Oranga Aotearoa New Zealand's Māori Health Strategy and its action plans (King & Turia, 2002). The latest Māori Health Action Plan 2020-2025 Whakamaua has taken the recommendations from the Waitangi Tribunal 2575 inquiry Stage 1 and the New Zealand Health and Disability System Report to design a framework for addressing Māori heath inequity (Ministry of Health, 2020). Whakamaua was developed in consultation with Māori communities and service providers across Aotearoa New Zealand. To achieve the goal of Pae Ora healthy futures for Māori, Whakamaua: Māori Health Action Plan 2020-2025 focuses on four high-level outcomes:

1. Iwi, hapū, whānau and Māori communities can exercise their authority to improve their health and wellbeing.
2. The health and disability system is fair and sustainable and delivers more equitable outcomes for Māori.
3. The health and disability system addresses racism and discrimination in all its forms.
4. The inclusion and protection of mātauranga Māori throughout the health and disability system (Ministry of Health, 2020, p. 23).

Evidence of how this new National Health Action Plan will affect Māori health outcomes is yet to be realised. For instance, the 2021 Rapua Te Ara Matua Waikato DHB Equity Report data shows the equity gap between Māori and non-Māori across a number of critical health indicators such as access to the social determinants of health and measures of child and adolescent health and avoidable deaths. It was highlighted that "Waikato DHB is party to the systemic failure to adequately address and eliminate equity gaps and provides services that are culturally competent and holistic for tangata whenua" (Waikato District Health Board, 2021, p. 2). Understanding the national and local context and its efficacy is crucial to determine future action to address Māori inequity. An important area of focus to redress the poor health outcomes needs to begin in early life.

Importance of early life experiences

Early life experiences are crucial for future health and wellbeing outcomes. Tamariki are the most vulnerable and disadvantaged group in Aotearoa New Zealand during the period from conception to age two, which is commonly referred to by health service providers as the first 1000 days. Pēpi and tamariki who grow up in households with high deprivation are more likely to experience social, economic, and physical health problems later in life (Simpson et al, 2016). Deprivation interferes with the healthy development of tamariki by limiting access to resources (such as healthy food and housing, education, and healthcare), as well as by placing stress on the whānau (New Zealand College of Public Health Medicine, 2017). In the Waikato region, there have been some overall health gains for pregnant women and babies. However, wahine hapū and pēpi Māori living in rural areas carry the greatest burden of socioeconomic deprivation and poor health (Becker, 2018). Although health services have consistently worked to improve the early years of tamariki, many barriers to opportunities that promote health, including access to healthcare, remain. (Becker, 2018). Health service access experiences for tamariki Māori during this critical period of health development, the first 1000 days is the context of this investigation.

Health service loss of engagement with patients

When patients are unable to attend health appointments, it can result in significant social, financial, and health burdens affecting their health outcomes. Studies have shown that patients with chronic health issues who missed appointments were more likely to require emergency admissions and had higher mortality rates in comparison to those who had not (Delgado Guay, 2014; Nielsen, 2008). In addition, missed appointments to health services also have a financial cost to the health system. This can take the form of inefficiencies of staff time, lengthy waiting lists and clinical costs that limit access for other patients (Deloitte Access Economics, 2017; Ratnayake & Lim, 2020). The non-attendance rate is an indicator of inequity because it highlights services' inability to attend to a patient's health needs. The drivers of non-attendance are multifactorial but can be grouped into health system factors, information system factors, clinical factors, socio-economic and patient related factors (Tamatea & Ruka, 2020). Several studies have found that social deprivation is directly linked with inequities in health service attendance rates including paediatric services (Aarts et al., 2011; Hirani et al., 2016; Johnson et al., 2004). According to Johnson et al. (2004), factors such as low education, employment, and poverty influenced child and adolescent attendance at follow-up cancer appointments. They identified a significant trend of decreasing attendance with increasing social deprivation. A Dutch study found that despite the absence of financial barriers to breast cancer screening, socioeconomic disparities in attendance rates persist. In that study, women with low socio-economic status had significantly worse health outcomes and survival rates (Aarts et al., 2011). Other international studies on non-attendance found that system factors such as incorrect patient contact information, a lack of reminders and follow-up contributed significantly to low attendance rates (Hasvold & Wootton, 2011; Roberts et al., 2011).

Māori experiences of accessing healthcare

Numerous studies have examined how whānau in Aotearoa New Zealand, experience access to and through healthcare. These studies have documented a number of barriers to whānau accessing health services. Walker et al. (2008) and Jansen et al. (2008) identified factors such as the financial costs associated with attending appointments including travel and taking leave from work. Whānau experienced difficulties managing practical considerations, such as organising childcare, as well as the additional costs related to attending hospital or clinic appointments (Gilmour et al., 2016; Stevenson et al., 2016). Another concerning theme identified in the research was the impact that staff attitudes and behaviour have on whānau experiences (Kidd et al., 2013; Masters-Awatere & Graham, 2019). Negative attitudes, overt racism, discrimination, and whānau perceptions of staff were encounters with staff that caused barriers to engagement. A general lack of understanding of spiritual and cultural practises was also described by whānau, which led to requests to leave health services earlier than was ideal (Graham & Masters-Awatere, 2020). The combination of these factors meant that whānau were less likely to utilise their right to access healthcare.

When whānau do not access healthcare when needed it is assumed and without sufficient information, that they do not care about their health or their health of their whānau. A literature review on initiatives to increase Māori whānau access to healthcare completely rejected this argument (Cram, 2014). In this review, it was not a lack of care by whānau about their health but costs of health services, lack of transportation and health service features which were identified as barriers to Māori accessing healthcare. Consequently, it was interventions that addressed the financial and logistical barriers, which were highlighted as being most effective for increasing Māori access to health services.

It is concerning to note how vulnerable whānau experience their journey through healthcare when it is critical that their health needs are met. A longitudinal study of young Māori mothers' journeys through pregnancy to motherhood found that current system issues negatively impacted on their health experiences. The impact of this negative experience contributes to alienating the whānau from further engagement with services in the future. Whānau support and promoting positive communication was critical to keeping the whānau feel engaged and supported by the service (Stevenson et al., 2016). Another study investigated the experiences of whānau with tamariki Māori admitted to the Paediatrics Ward of Waikato Hospital. Similarities in all of the whānau experiences were found, including financial strains, hunger, isolation, concern and engagement in the care of their tamariki. The implementation of the Harti Hauora Tamariki tool, a kaupapa Māori-centred intervention, mitigated earlier alienating interactions with the healthcare system (Masters-Awatere & Graham, 2019). The 'one size fits all' model of health services tends to suit the needs of the majority, who are rarely the group in most need of help. Even when whānau can access mainstream support, Māori often found the service not appropriate or so alienating that they prefer to disengage (Waitangi Tribunal, 2019).

Further, a recent analysis of two decades of studies on the experiences of 326 Māori users of the public health system determined that the existing health system is considered "hostile and alienating" by many Māori (Graham & Masters-Awatere, 2020). Organisational structures, staff interactions and practical considerations were common themes identified as contributing to healthcare barriers. Facilitators to engaging with healthcare included whānau support by way of practical assistance, emotional support and navigation through the health system (Graham & Masters-Awatere, 2020). The researchers challenged public health service providers to “find ways to ensure Māori consistently experience positive, high quality healthcare interactions that support Māori ways of being” (Graham & Masters ‐ Awatere, 2020, p. 193).

Several studies have shown how focusing on enhancing interactions, communication, and physical barriers can significantly affect whānau access to healthcare. For example, a Māori-led action research study of whānau with heart disease found that the sharing of whānau experiences with healthcare professionals had a significant positive impact on lowering access barriers for whānau including financial costs and non-judgmental engagement (Digby et al., 2020; Kerr et al., 2010).

Based on the growing body of research on Māori access to healthcare, it is clear that there is evidence of the specific action needed to enhance the healthcare experiences of whānau. It is therefore important to understand what has been done locally in the Waikato region to address inequity in access to health services.

Local response to inequity in access to health care

The local Waikato District Health Board Health System Plan, Te Korowai Waiora describes the strategic goals and actions of the organisation to aspire to a future health system that will improve health outcomes for whānau particularly for Māori to enable them to achieve their full health potential (Waikato District Health Board, 2019). Consultations were held with Māori communities across the Waikato region to incorporate Māori goals and perspectives into the Te

Korowai Waiora plan. The prevailing evidence of health inequity for Māori within the Waikato region warranted the need to radically change and be more responsive and improve health outcomes for Māori. This calls for health services to overcome their own internal barriers to address the structures and policies that lead to inequity. Te Korowai Waiora acknowledged that access is a critical factor to improving Māori health outcomes. Barriers to access include cost, distance, time of day a service is scheduled, inappropriate facilities such as hospitals, lack of local services and a lack of choice available to whānau (Waikato District Health Board, 2019). In order to address the inequities, Te Korowai Waiora proposed two key recommendations. Firstly, that the Waikato DHB needs to be whānau centred by listening to the experiences of whānau, and secondly to improve access and choice for whānau. Being whānau centred requires decision makers within health services to prioritise the needs of whānau first and not those of the organisation or the mainstream majority Pakēhā. Prioritising whānau is significant in terms of this study because it is focuses on asking Māori how to improve their access to a health service.

At Waikato District Health Board Māori overall non-attendance rates are significantly higher than non-Māori patients. In 2019, the overall clinic non-attendance rate for Māori was 22% and 6% for non-Maori. Some outpatient clinics with high annual non-attendance rates for Māori include diabetes outpatient clinics (37%), paediatric medicine clinics (27%), and paediatric surgery clinics (39%). Although there have been numerous attempts to reduce these disparities in clinic attendance, isolated small 'fixes' have not addressed the root cause of the inequity (Tamatea & Ruka, 2020). To understand the root causes and systems failings that contribute to attendance inequities, a clinic attendance road map project Te Ara Hauora, was initiated in 2020 to undertake a system wide stocktake and gap analysis. The project aims to develop an equity focused patient and whānau-centred outpatient clinics attendance Roadmap, co-designed with patients, whānau, clinicians, booking clerks and referrals staff. It will include a pathway within the roadmap to identify and support high priority patients (Tamatea & Ruka, 2020). The project's learnings and roadmap have the potential to influence inequities across all outpatient clinics in Waikato Health Services.

These studies argue that initiatives to address non-attendance are critical to improving health outcomes particularly for the most vulnerable including Māori and tamariki. Understanding the specific impact of inequity of Māori with lived experiences of disabilities is an important aspect this study.

Inequity of Māori with lived experiences of disabilities

Pākehā settlers reported very little about Māori with disabilities or hearing difficulties. Therefore, some generalisations have been proposed based on evidence of te reo Māori words associated with deafness such as pihoi – inattentively deaf, pūwharawhara – deaf, tāhorehore – deaf as if the ears were cropped (Williams, 1985). Having hearing loss was most likely recognized and accommodated for within Māori communities (Forman, 2003). Although hearing is required for essential traditional Māori protocols such as waiata, karanga, and whaikōrero, the author proposed that whānau with hearing difficulties would have been regarded as valued members of pre-contact Māori community life (Forman, 2003).

Nowadays within health services, people who experience a range of barriers and impairments that restrict their full access and participation in society are often referred to as disabled or persons with disabilities (Shakespeare, 2013). Traditional medical approaches to support those experiencing disabilities have focused on breaking down social barriers including access to services or improving their functional abilities to participate in daily life. Indigenous researchers argue that this focus fails to take into account indigenous cultural perspectives, which are holistic, collective and relational in nature (Hickey & Wilson, 2017). More recently, for Māori with a disability, tangata whaikaha is the term proposed as it describes whānau who have the ability to do well. Maaka Tibble, founding member of the Māori Disability Leadership Group explains:

> Tāngata whaikaha means people who are determined to do well, or is certainly a goal that they reach for. It fits nicely with the goals and aims of people with disabilities who are

> determined in some way to do well and create opportunities for themselves as opposed to being labelled, as in the past (Ministry of Health, 2018, p. 4).

When it comes to Māori concepts of disability, perspectives, and attitudes towards whānau with disability are inextricably linked to Te Ao Māori. These beliefs and values include whānau ngatanga, aroha-ki-te-tangata, wairua, āwhinatanga, and manaakitanga (Bevan-Brown, 1994). These concepts are important for health service providers to understand as Māori experiences of disabilities are at a higher rate (33%) than any other population group (24%) in Aotearoa New Zealand (Statistics New Zealand, 2014). Hickey and Wilson (2017), contend that Māori with disabilities have less access to support including health and disability services. As with other Indigenous Peoples, the lived experiences of Māori with disabilities are compounded by “additional and diverse historical and contemporary impacts of disablement arising from colonisation, societal discourses about racism, subjugation and dysfunction that are in themselves disabling” (Hollingsworth, 2013 as cited in Hickey & Wilson, 2017, p. 85).

Inequities for Māori whānau are exacerbated by the intersectionality of multiple barriers and disadvantage including inadequate income to meet daily needs, unmet needs, less access to funding, health and disability services and special equipment (Hickey & Wilson, 2017). Additionally, whānau encounter racism, discrimination, and a lack of access to the determinants of health. (Hickey & Wilson, 2017; Minsitry of Health, 2016a; Statistics New Zealand, 2014, 2015). Further, a report on the Health of Māori Children and Young People with Chronic Conditions and Disabilities in New Zealand stated that for tamariki Māori, being young, being Māori and experiencing a disability are critical indicators of risk of social exclusion in our society (Craig et al., 2012). The literature highlights that this significant burden of health inequities on Māori with lived experience of disabilities needs urgent attention by health services.

As part of the Waitangi Tribunal for Stage Two of the Wai 2575 Health Services and Outcomes Kaupapa Inquiry 2019 a report was commissioned to examine the lived experiences of

Māori with disabilities. In the report, King (2019) argued that District Health Boards are not responsive to Māori with lived experiences of disabilities and are failing in their Te Tiriti o Waitangi obligations. DHBs do not have the systems in place to collect and monitor whānau health needs. They are therefore unable to provide appropriate services to meet whānau needs or to report their own performance to support whānau. For tamariki Māori with lived experiences of disabilities, critical gaps were also identified in addressing inequities in health and disability services (King, 2019). Considering that the Māori population are younger than non-Māori, the evidence of inaction on inequity is concerning given the significance of addressing health issues early in life.

The review of literature on health inequity for Tāngata whaikaha demonstrates that significant action is required to address the significant burden on whānau. Additionally, a deeper understanding of Māori concepts, values and perspectives about disability is needed by health services. This study is investigating whānau access experiences of a health service designed to address the specific needs of tamariki with a hearing loss in order to improve hearing outcomes.

Understanding hearing loss

A crucial element in the growth and development of tamariki is good hearing health (World Health Organization, 2022). When tamariki are diagnosed with hearing loss, it means that their hearing thresholds are greater than 20dBHL. Hearing loss is experienced on a continuum and can be classified from mild to moderate, severe, or profound for those with no hearing or very little. It might affect either one or both ears. Hearing loss of any severity can impair the ability to perceive speech sounds and interfere with the proper development of speech and language (World Health Organization, 2022). Those with a mild to severe hearing loss, who may be referred to as hard of hearing. Whānau with this level of hearing loss often converse verbally and benefit from hearing aids and other assistive technologies. Those who have substantial hearing loss or severe hearing impairment, may be referred to as deaf and/or utilise sign language to interact with others. People with severe hearing loss may benefit from cochlear implants, surgically implanted electronic devices attached to the ear delivering the sensation of sound (Digby et al., 2020; World Health Organization, 2022).

Understanding the etiology (causes) of tamariki hearing loss can support whānau engagement in early intervention (Audiology Service Waikato DHB, personal communication, February 2, 2021). Hearing loss can be congenital or acquired. Congenital causes are those that occur at or shortly after birth. Hearing loss can be caused by inherited and non-hereditary genetic factors, as well as difficulties during pregnancy and childbirth, such as maternal rubella, syphilis or other infections during pregnancy, or low birth weight. Infectious disorders such as meningitis or measles, persistent ear infections, fluid build-up in the ear, and the use of certain drugs, such as those used to treat newborn infections, can all cause acquired hearing loss at any age (World Health Organization, 2022). Hearing loss can have a significant impact on the health of tamariki and whānau social, educational, and financial wellbeing. This may include health service costs, informal care and whānau productivity and access to hearing aids and education and support services (Deloitte Access Economics, 2017).

Importance of early intervention for good hearing health

For tamariki with hearing difficulties, early intervention is of critical importance in maximising speech and language, socio-emotional and academic outcomes (Downs, 1995; Downs & Yoshinaga-Itano, 1999; Johnson & Newport, 1991). Minimising delays in diagnosis and starting intervention early means better outcomes can be achieved. Māori are more likely to be diagnosed with permanent bilateral hearing loss than Pākehā, accounting for 39-43% of all hearing loss nationally among those under the age of 19 (Digby et al., 2014). Additionally, the hearing loss severity profile is known to differ for Māori (compared to non-Māori) with a higher proportion of hearing losses in the mild to moderate range and a higher proportion of bilateral hearing losses (Digby et al., 2019).

Data for tamariki notified to the New Zealand Deafness Notification Database reported to have had delays in hearing loss diagnosis indicated that:

- Māori whānau are considerably more likely not to attend appointments or to delay these, for any reason (30% of Māori whānau compared with 10% of Pākehā families).
- Waikato has a higher than average proportion of whānau who are unable to attend appointments, at 49% compared with a national average of 29% (Digby et al., 2020).

Preliminary data for Waikato DHB indicated an equity gap at point of diagnosis with persisting inequities for tamariki Māori during the delivery of early intervention services. There are higher rates of appointment non-attendance within this group (27% Māori vs. 8% for non-Māori); and Māori account for approximately 50% of total appointments booked. Additionally, national data indicates lower rates of device use (hearing aids/cochlear implant) for Māori, with 46% of children with known hearing loss having low/inconsistent or no device use (Digby et al., 2019), a finding which is also reflected at Waikato DHB. 2020 data shows that Māori pēpi are less likely than non-Māori/non- Pacific to have a completed audiology diagnosis by three months of age (Audiology Service Waikato DHB, personal communication, February 2, 2021).

Hearing Screening and Audiology Early Intervention Services

From 2007, the Universal Newborn Hearing Screening and Early Intervention programme (UNHSEIP) was implemented by the Ministry of Health to ensure the early identification of pēpi with hearing loss so that they can access timely support and interventions in order to reduce inequities and improve whānau health outcomes. Every pēpi born is offered hearing screening. The core goals of the UNHSEIP are known as 1-3-6; which includes a hearing screen for all newborns by one month of age. They are all offered screening in the hospital/birthing unit before discharge. If this opportunity is lost then screening is offered in outpatients' clinics. Diagnosis of hearing loss by three months of age and by six months of age for those pēpi identified with permanent hearing loss. It is then that the national guidelines specify an early intervention programme begins (Minsitry of Health, 2016b). Typically, this includes fitting of devices (hearing aids and/or cochlear implants) and regular appointments with local audiology and Advisor on Deaf Children (AODC) services. These advisors work to support the whānau and the schools from birth to five years old (Audiology Service Waikato DHB, personal communication, September 28 2020). An important aspect of the programme is monitoring the proportion of incomplete screens due to non-attendance at the screening appointments or other losses of engagement with whānau to follow-up services (Minsitry of Health, 2016b). This information is essential to understanding any equity gaps and where to focus support for whānau engagement.

Waikato DHB Audiology Service

The Waikato DHB Audiology Service is located at Waikato Hospital Meade Clinical Centre with outpatient visiting clinics also provided at the rural hospitals in Tokoroa, Thames, Te Kuiti and Taumarunui. Audiologists within the service provide paediatric diagnostic and early intervention services to whānau across the Waikato region for infants (pēpi) up to 3 years referred through the New Zealand Universal Newborn Hearing Screening and Early Intervention Programme (UNHSEIP). Early intervention support is also provided jointly through the Ministry of Education (Learning Support) by the Advisors on Deaf Children (Audiology Service Waikato DHB, personal communication, February 2, 2021).

Newborn hearing screening is an inpatient service at the Waikato Hospital or in the birth centres within the Waikato region. It is also offered in the community through outpatient clinics. Hearing screening and diagnosis is undertaken by Auditory Brainstem Response (ABR) testing. While the pēpi is sleeping, stickers (electrodes) are placed on the head to record the minute responses of the auditory nerve in response to sounds of different loudness and pitch. In this way it is possible to accurately estimate the degree and configuration of hearing loss. A complete diagnosis can take from one to three appointments of one and a half hours depending on how well pēpi sleeps. Once there is a complete diagnosis of a pēpi with hearing loss, then early intervention services are offered. When a pēpi does not pass the hearing screen, the service actions what is called a "refer result". The refer result can be unilateral (one ear) or bilateral (two ears). Once there is a complete diagnosis of a pēpi with a hearing loss, diagnostic appointments are offered at the audiology services at Waikato

Hospital outpatient department in Hamilton due to the specialist equipment needed. The service is currently unavailable to whānau in their own home, as the equipment used by staff to conduct the test is not transportable (Audiology Service Waikato DHB, personal communication, February 2, 2021).

Investigations of Māori experiences of hearing loss

One of the only comprehensive reviews of the impact of hearing loss on Māori was the Whakarongo Mai report (New Zealand Review Team to Consider Hearing Impairment Among Maori People, 1989). The review team was tasked with advising the Minister of Māori Affairs "on the most appropriate means to achieve the needs of Māori in policy planning and service delivery for the hearing impaired" (New Zealand Review Team to Consider Hearing Impairment Among Māori People, 1989, p. 1). The investigation concluded that Māori hearing loss was closely associated with socioeconomic deprivation such as low income, poor housing, underemployment, and poor health and education outcomes. The report found "unacceptably high levels of Māori hearing impairment" (New Zealand Review Team to Consider Hearing Impairment Among Māori People, 1989, p. 47), necessitating deliberate prevention, early detection, and intervention strategies. Further, the authors emphasised that Māori should have greater access to audiology services by providing more flexibility in referral procedures (New Zealand Review Team to Consider Hearing Impairment Among Māori People, 1989). Despite the clear findings of this review, the inequities for Māori with hearing loss are still unacceptably high and health services have yet to operationalise the majority of the recommendations almost 32 years later.

More recently, Masters student Aroha Crisp conducted a study in which she interviewed 12 whānau on the decisions they make after receiving a hearing loss diagnosis within their whānau. She found that the whānau experienced similar difficulties in receiving a diagnosis and treatment with hearing aids/cochlear implants as Pākehā. However, these difficulties were further exacerbated by socio-economic factors including financial, transport and access issues (Crisp, 2010). From the literature on whānau access to healthcare, these barriers would have undoubtedly contributed to inequitable whānau health outcomes. At the time of writing this thesis, apart from these two studies, there has been no other research to understand Māori whānau experiences of hearing services in Aotearoa. In light of this, it is acknowledged that this study in 2022 is long overdue.

This study

According the review of the literature, Indigenous Peoples experience persistently poorer health outcomes compared to non-indigenous peoples. As tāngata whenua, Māori have been deeply harmed by colonisation, having on average the poorest health status of any ethnic group in Aotearoa New Zealand. The health system and the Waikato DHB have fallen short in their obligations to address this inequity for Māori whānau. In addition, inequities for tāngata whaikaha are significant and exacerbated by the intersectionality of multiple barriers and disadvantage. Despite their efforts, health services have not been able to close the equity gap in access or to deliver services that are appropriate for whānau. Studies showed that Māori are having poor experiences of the public health system and a number of barriers and facilitators to engagement were identified. For tamariki with hearing difficulties, access to early intervention services is of critical importance to improving health outcomes. The Waikato DHB Audiology Early Intervention Service identified an equity gap for tamariki Māori with access to early intervention appointments. They requested support to understand the experiences of whānau engaging with their service. There has been very little research in Aotearoa New Zealand to understand Māori whānau experiences of hearing services. This study will investigate whānau experiences of engagement the Waikato DHB Audiology Early Intervention Service. In this way, whānau centred solutions can be identified by Māori to better meet their needs for audiology early intervention.

The aim of this research is to understand the experiences of Māori whānau when accessing and engaging with the Audiology Early Intervention service at Waikato DHB.

To pursue this broad aim answers to the following specific questions will be sought:

1. What were the positive or negative experiences of processes and interactions when engaging with the Audiology Early Intervention Service?

2. How can the service change to better meet the needs of Māori whānau as they access audiology early intervention services?

Chapter 2: Research Approach

Methodology

Māori Centred Research within a Kaupapa Māori Paradigm

This study was initiated by the Audiology service staff to address the inequities in health service engagement. While the study focusses on improving Māori health outcomes, the Waikato District Health Board will ultimately have control over whether the research findings translate into transformational change and is therefore considered Māori- centred research (Hudson et al., 2010). However, good practice in Māori-centred research means that Māori play a significant role in the research, not only as participants but as active members of the research team. Māori were also involved in the research design and analysis, which will influence the outcomes of the research (Hudson et al., 2010). Further, engagement with Māori in the research means it is more likely to have beneficial outcomes for Māori whānau in the future.

This study followed a Kaupapa Māori paradigm as it prioritised Māori centred philosophies, understandings and practices with the intention of improving Māori wellbeing. Kaupapa Māori research has a kaupapa (purpose) and acknowledges a range of influences impacting on Māori including: their historical experiences and perceptions, perspectives, values, expectations and practices, knowledge and the status of contemporary Māori, language and culture in Aotearoa (Pihama et al., 2015). The strength of Kaupapa Māori research is that it supports Māori researchers connecting with Māori whānau to privilege Māori voice to improve Māori wellbeing.

Kaupapa Māori methodological principles guided this research. Acknowledging the significance of whānau and whānaungatanga for Māori and sharing whakapapa (genealogy) was an intrinsic part of all engagement with whānau participants. Te reo and tikanga (Māori language and protocols) were also used where appropriate when engaging with whānau. This included in written communication, invitations, emails and text messages and kanohi ki te kanohi (face to face) interviews. The whānau had control over their own kōrero, how the interviews were conducted, including the location and timing, ensuring alignment to the principle of tino rangatiratanga (self-determination). It was also important that whānau had autonomy and control over their data (recorded interviews) and their proposed solutions (Kukutai, 2019). The principle of kaupapa refers to the collective vision, aspiration and purpose of Māori communities. Although a small number of whānau were interviewed, the researcher and the whānau participants acknowledged the potential impact of the research to be able to improve the early intervention services for other whānau (Smith, 1999). Another key principle of Kaupapa Māori theory is Te Tiriti o Waitangi. This was a fundamental feature of this research as it was investigating the health services provided by the Crown agency to serve tangata whenua. A Te Tiriti focus ensured a critical analysis of the effects of the relationships between the Crown and Māori and the drive to challenge the identified inequity (Pihama et al., 2015).

One of the core functions of Kaupapa Māori theory is to address issues of injustice and of social change. Kaupapa Māori researchers advocate for research to be transformative to influence positive change on the lives of those who are most disadvantaged (Smith, 2015). In this way, the identification of strength-based opportunities can inform transformative change for participants in this study. With the Audiology Service's commitment, it is hoped that access for whānau who took part in this research and future whānau engagement with the service will be transformed.

Qualitative Phenomenological Approach

This research uses a qualitative phenomenological approach as it seeks an understanding of common meanings across and between whānau participants who have all experienced a similar phenomenon. In this approach, information is collected about what the whānau experienced and how they experienced it to understand ‘the essence’ or nature of the phenomenon, which was “accessing early intervention” in this instance. It is only through gaining this understanding that improvements can be made to the phenomenon in the future (Creswell & Poth, 2017; Thompson, 2009). The scope is of the inquiry focuses on a period where whānau share and describe their experiences of accessing the Audiology early intervention service for the hearing health of their tamariki. Although not a kaupapa Māori approach, studies have shown that it has been effectively used with other Indigenous Peoples across Northern America (Jones et al., 2010).

Practitioner Research

As a staff member of the Waikato District Health Board working within the Māori Equity Strategy and Research Directorate my role is to work with health services and within the health system to improve health outcomes for Māori and eliminate inequities. It is a challenging place to be. Being a Māori health professional within a government organisation with a system designed to improve the health of the non-Māori majority currently does not achieve equity for Māori. As part of my role, I support health services with advice, frameworks and planning to enable them to improve the inequities for Māori whānau. Practitioner research recognises that the researcher holds a dual position as a staff member and a researcher. This allows for opportune conditions to collaborate with the Audiology Service as well as to connect and engage with whānau from the service (Dahlberg & McCaig, 2010). This dual role also increases the likelihood that the outcomes of the research translates into action with someone working within the system to ensure this happens.

Methods

Recruitment of Participants

The study used purposeful sampling to recruit Māori whānau with tamariki identified as having hearing loss via the Newborn Screening Programme. Purposeful sampling is a technique used in qualitative research to identify and recruit participants who have specific information and rich knowledge on the subject being investigated when there are limited resources (Palinkas et al., 2015). The members are more likely to be willing to participate and communicate their experiences on the subject, as it is immediately relevant to them (Dahlberg & McCaig, 2010). This type of sampling is appropriate for Kaupapa Māori qualitative inquiry as it directly targets the whānau as experts in their own experiences. In order to recruit whānau, the concept of whānau in contemporary Māori society needs to be understood. Māori scholars have recognized two different types of whānau unit.

Whakapapa whānau are those who descend from a common tupuna (ancestor) with shared traits, responsibilities and obligations. The other is the kaupapa whānau where the members share a common goal, purpose or bond, which is not necessarily genealogically connected (Cunningham et al., 2005). For the purposes of this study, the identification of the whānau unit of tamariki with a hearing loss was defined by the parents or caregivers caring for them during the period of research i.e. diagnosis and early intervention.

It is critical for health service improvement that the experiences of whānau who have experienced difficulties with access to the service are included in order to fully understand the challenges and barriers. Consequently, solutions will be more appropriate for whānau who are most in need of the services. To make certain that whānau were able to recall their experiences with the Audiology Early Intervention Service whānau were invited to participate with the following inclusion criteria:

- Tamariki up to three years of age
- who had been identified as having hearing difficulties via the Newborn Hearing Screening Programme and
- who had experienced barriers to accessing the Early Intervention Service appointments

Whānau in this group have had some contact with the Audiology Service, and will be able to provide more insight into what works, or does not work in the way services are delivered from referral to diagnosis to subsequent early intervention.

A confidential invitation to participate in the research was sent out through the Waikato District Health Board Audiology Services to Māori whānau who met the inclusion criteria (See Appendix 1). The invitation was mailed to all whānau with tamariki up to three years and who had been identified as having hearing difficulties via the Newborn Hearing Screening Programme. Although a mailed invitation from the Audiology Service was not an ideal method of engagement with whānau, this was the only confidential means of connecting to the whānau. Therefore, an invitation letter that was culturally appropriate and engaging to Māori whānau was designed after consultation with cultural advisors. Following discussions with the clinical equity advisor and the Audiology Service, it was decided that whānau would determine whether they had encountered barriers to attending early intervention service appointments. This provided the opportunity for whānau self-determination, rather than focusing recruitment solely on those who had not completed or had only partially completed the early intervention programme. The invitation was also distributed through other appropriate avenues to recruit whānau including through the Māori Midwives Association (Ngā Maia) and Whānau Ora service providers. Whānau were invited to contact the Audiology Service through text, phone, or email to express their interest in participating in the study. No information was shared until participants indicated to the audiologist their interest in the study and consented to disclose their contact details.

Six whānau accepted the invitation despite engagement beginning a mailed invitation from the Audiology Service. Four of the six whānau interviewed in this study were mothers and two were with mothers and fathers/male caregiver. Encouragingly, the first two whānau responded quickly to the invitation and responded within a day of the receiving the invitation. The remaining four whānau accepted after a follow up phone call from the audiologist who gained their approval for the researcher to call them. In preparation for the interviews it was noted that those who have disengaged from the service may require more support to participate. Therefore, the researcher offered to conduct the interviews in their homes, workplaces or nearby and whānau support was available to care for tamariki if needed so that the whānau could be fully involved in the interviews.

A koha was also provided to acknowledge and value whānau time and in recognition of their expertise as patients and whānau members with experiences to share. Providing koha is also an implicit practice within Māori practices of manaakitanga (showing care and respect for others). Within a Kaupapa Māori research methodology it is also culturally appropriate to bring kai to share with whānau at each research interview. It can be considered unethical to expect whānau to provide their time and expertise for free. This is particularly important in terms of equity in the research methods when the research is funded and the research team members are paid for their time. The main motivation for whānau engagement was to support other whānau with tamariki with hearing difficulties. The koha was accepted with humility and was not seen as a key element in determining their participation. However, the koha for whānau support with their tamariki from a trusted carer was an additional bonus that helped them to participate fully in the interview.

Consent

Participation in the research was voluntary and informed consent was obtained from all whānau members. The participant information sheet and consent form were mailed out by the Audiology Service after whānau expressed interest in the study by replying through email or phone to the invitation (see Appendix 2 and 3 for participation information sheet and consent form). They were then contacted to explain further details of the study. Research contact details were also provided on the information sheet if the participants had any questions to raise later. The whānau were offered time to consider their participation before follow up. Once they agreed to participate, an interview meeting time was arranged, and the research and consent process discussed prior to the signing of the written consent form. Prior to any interviews, whānau gave written consent by signing the consent form. Consent to interview the participants in their homes and to record the conversation was also gained at that time.

Ethical considerations

The research was conducted in accordance with the Code of Ethics for Psychologists Working in Aotearoa New Zealand and guided by the Ethical Conduct in Human Research and Related Activities Regulations of the University of Waikato Human Research Ethics Committee. The study received ethical approval from the University of Waikato Human Research and Ethics Committee prior to commencing data collection HREC (Health)2021#32 (see Appendix 4). The Waikato District Health Board Māori Research Review Committee also gave local health service approval for the research to be undertaken.

This study adhered to Kaupapa Māori ethical considerations to ensure that research engagement with whānau took place in culturally appropriate ways. Te Ara Tika guidelines for Māori research ethics guided the study (Hudson et al., 2010). Specifically this included aligning to the four tikanga-based principles Whakapapa, Tika, Manaakitanga and Mana. Whakapapa is about developing and maintaining meaningful relationships throughout the entire research process. The focus of the engagement was to connect with whānau. For this study, this meant taking time to share whakapapa and understanding the context of their everyday lives in order to ensure safe collection of their experiences. Tika aims to ensure that the research's design achieves its intended outcomes to transform the experiences of Māori. Although initiated by a health service, this qualitative research was designed to contribute to outcomes to support the transformation of the Audiology Service to address current access inequities for Māori whānau. Manaakitanga emphasises respect for the whānau and honouring social and cultural obligations. Interactions with whānau were respectful and mana enhancing with guidance from cultural and Kaupapa Māori advisors. Mana in research ensures that responsibilities, risks, benefits, and outcomes are equitable and just. This study acknowledged whānau as the experts in their own experiences, challenged victim blaming in reporting experiences, and looked to address unjust access issues (Hudson et al., 2010).

Interviews

Whānau experiences were mostly gathered via a series of kanohi ki kanohi (face to face) interviews with whānau living in Hamilton central and in rural localities. As a qualitative method, interviewing allows for a deeper understanding of the social realities of whānau in order to focus attention on the experiences, the behaviours and impacts of engagement with the audiology service (Flick, 2009). The interviews offer a critical opportunity for whakawhānaungatanga (building trusting relationships) between researchers and participants as part of the relational fabric of the research interactions (Furness et al., 2016). The interviews were a semi-structured kōrero (conversation) with open-ended questions and prompts to elicit further information. An interview schedule was created for each interview with key questions to cover (see Appendix 5 participant interview questions).

Each interview was recorded and transcribed (see Appendix 6 for confidentiality agreements). Whānau members were offered the opportunity to review the transcript or a summary of their interviews and request any amendments. This was often the first time they had been asked about their experiences with the service. This meant that whānau not only to recall the experience but also to reflect on their feelings during that period of time.

Data analysis

After each interview, it was important to transcribe and reviewed the whānau kōrero. The process of transcribing and reviewing the kōrero allowed for a continuous connection to their experiences. Similarities and differences were noted and batched into themes in a flexible and adaptive way (Dahlberg & McCaig, 2010). As a Māori researcher and māmā, my intention was to engage with their experiences on a holistic level; from listening, to understanding, to connecting to the feeling of their responses. This study used an interpretive phenomenological approach (IPA) to guide the analysis of the interviews where the focus is determined by the review of whānau kōrero (narrative) of their experience of the early intervention service. Thus, meaning is interpreted from the analysis of whānau commonalities and differences (Stevenson et al., 2016). IPA is a tool often used in research to understand patient experiences of healthcare (Biggerstaff & Thompson, 2008). By concentrating on the health experiences and barriers this liberates whānau from blame for non-attendance (Stevenson et al., 2016). My intention with the analysis was to let the kōrero determine the themes, feeling confident to āta whakarongo, to trust in myself that my mind, heart and experiences would be able to present the essence of whānau kōrero into the findings.

Strengths and Limitations

The strength of this study is the collaboration between Māori practitioner researcher with a health service to hear from whānau how they can improve access to their services. Although this is a study about barriers to access and engagement the intention and design of the processes ensured that whānau, including rural whānau, volunteered to participate in the research. The data collection phase encountered some issues, which caused delay with some interviews. Waikato District Health

Board was subject to a cyber-attack that shut down all clinical information systems. Consequently, contacting whānau was impossible, as patient data was inaccessible as the whole information system was shut down for three months following the cyber incident. Waikato region also experienced a COVID-19 lockdown that impacted on the kanohi ki te kanohi (face to face) interviews. This affected interviews with the final two whānau and although not ideal, they agreed to being interviewed by virtual means.

A limitation to this study was in the recruitment of whānau who may have had very little engagement with the Audiology Service. The invitation to participate came from a mailed invitation from the Audiology Service, which could have been a deterrent to participation in the study for those who had previous negative experiences with the health service. The whānau in this study were able to access the Audiology Service at some point of the early intervention for their tamariki. Recruitment of whānau to the study who had no access to the Early Intervention Service was not achieved despite connecting with other Māori providers and Māori midwives. This may have provided insight about why whānau completely disengaged from a service or elaborated on the findings from the participating whānau.

Chapter 3: Findings

The first section of the findings is an introduction to each whānau and a brief summary of their experiences with the Audiology Early Intervention Service. Experiences of engaging with other hospital services are also sometimes captured in this section as the kōrero shared often intertwine and are not distinct experiences from their whole health system experience. It was important to this study to understand who the whānau are and their unique experiences with the service before looking to uncover themes in their shared experiences. The second section reports on themes uncovered in the shared experiences of accessing the Audiology Service describing commonalities and differences across the whānau kōrero.

Section 1: Introduction to each whānau

Whānau Tahi

This whānau is a single māmā who works fulltime and her tamaiti who was 19 months old at the time of the interview and lives with a syndrome. As a pēpi, her tamaiti was born prematurely and spent significant time in the Newborn Intensive Care Unit at Waikato Hospital. He currently attends day care and an early childhood intervention centre. The whānau live in Hamilton city and have other whānau living close by for support with attending appointments and caring for each other. This includes the maternal grandmother, who lives with hearing and vision loss, and an aunt. The whānau regularly engage with an extensive team of health professionals including a General Practitioner, Waikids (children's health services), the eye clinic, audiology, physiotherapy and the children's' osteoclinic.

Experience of the Audiology Service and Health Service

The whānau have had a challenging experience in their engagement with the Audiology Early Intervention Service and the other health services. Following the birth of her pēpi born with the syndrome māmā felt, from the outset that the newborn screening team failed to provide adequate information to her. Māmā wanted to make sure that everything was fine with him but was informed by the screener that she did not need to do the test as he had a syndrome, not giving an explanation about why or what happens next. Māmā likened her experience to that of being on a roller coaster when you have a newborn pēpi and the emotions, the ups and downs that you go through. Feeling like she has had to change the way she engaged with the Audiology Service in order to navigate the challenges she faced, māmā recalled “pushing” and “being bossy” for the service to meet her needs. She shared her concern that many other Māori would not feel comfortable asking for what they needed. On one occasion, she had to attend an audiology appointment on one day for her tamaiti and then come back again the next day for another appointment for herself, which meant taking two days off work. When she tried to ring to rearrange appointments for the same day, there was no response to her attempts to reschedule. The whānau attend many different health services for specific health issues associated with her tama’s syndrome. Māmā felt that going to separate health services for each of his health issues is not the best way to meet the needs of her tamaiti and recommended Māori models of care as more appropriate for whānau with disabilities or multiple health issues.

Whānau Rua

Whānau Rua are young rural farming workers who both work and live on the farm approximately one and a half hours away from Hamilton city. This whānau consists of māmā and step pāpā and a three year old kōtiro diagnosed with a rare syndrome. They also have a live-in nanny/whānau support for when they are working on the farm. The whānau had only recently moved to a Waikato farm from the Bay of Plenty region, which has meant that they are able to compare the different services that they received in the different localities. The parents felt more supported by services within the Bay of Plenty region. The whānau have had numerous stays in hospitals including Starship with their pēpi who required hospital care for several months after birth. Māmā was unprepared when her pēpi was born with a disability and felt scared, deeply saddened and in shock. In their previous locality, a social worker supported the whānau to acquire household goods and baby necessities, which they appreciated. They do not currently have this support in their new home in the Waikato.

Experience of the Audiology Service and Health Service

This whānau experienced many challenges in accessing health services in general for their pēpi. The māmā will not attend appointments alone, as both she and pēpi, need the support of the pāpā to navigate the system as previous hospital experiences have left pēpi and māmā feeling anxious and traumatised. Issues such as finding appropriate parking, clinical clothing of the staff and interacting with staff are all areas that the whānau say contribute to the stress around appointments. Their tamaiti is terrified of anyone in a nurse's uniform and tries to run as soon as they enter the hospital. They make sure she is occupied with a tablet, lunchbox, books and colouring pens but they find the waiting area unwelcoming and unsafe for their child with the stairs close by and nothing available for little ones to play with.

The whānau often have a number of specialist appointments at Waikato hospital due to the health issues associated with their child's syndrome. They have to take lengthy blocks of time off work to attend appointments, as well as leave early morning due to travel distance yet much of their time is spent waiting for extended periods of time for their appointment. At times, this is not well received by their employer. The whānau previously had access to a speech therapist who has now moved roles and they feel the loss of her support for appointments, information and advice on the care of their tamaiti.

Whānau Toru

This is a Hamilton city based whānau where the parents live in the household with four children ranging from ages 3-15 years old, noting the 15 year old is extended whānau studying at a tertiary institution. Their three-year-old tama experiences hearing difficulties however, the whānau recognise and acknowledge times when he does show signs of hearing. Although living in the city the whānau have regular rural connections to their whānau land. Māmā is studying and working in health and papa works in construction. The tamariki attend kura kaupapa (school teaching in te reo and tikanga). The whānau are linked in with a speech therapist from the Ministry of Education to ensure that their tamaiti is reaching his milestones and provides support to connect with the hospital services. They recognise the speech therapist as the one who provides the most useful information to the whānau like how to get new batteries and new ear moulds in between appointments. Having the speech therapist come to their home made the whānau feel better about going to the hospital appointments and to understanding why they needed to keep going for their son's sake. The whānau decided that they would use their connection to te taiao (the environment) and whakapakari tinana (exercise) to support their tamaiti to learn to use his other senses in order to connect with the environment and each other; they see this connection with te taiao as part of his development and their whānau healing.

Experience of the Audiology Service and Health Service

At the birthing centre, pēpi was given the newborn hearing screening and the whānau were told that there was something wrong with the equipment so thought nothing more of it. They had 'no inkling' that anything was wrong with his hearing. However, a couple of months later they received an appointment for the audiology early intervention service which is where they found out that pēpi had hearing difficulties. Māmā felt distraught, guilty and sad for her tama upon hearing the diagnosis. She was so overwhelmed with emotion that she couldn't take in much of the information following the diagnosis about her pēpi having hearing loss; she left the appointment in tears to 'apologise' to her tane. She felt she needed to leave, as she was aware of others waiting for their appointment therefore, she didn't have time to process everything before leaving the appointment. The whānau recognise the pre-planning required for their audiology appointments including care of other tamariki, which parents will be attending with pēpi and navigating the parking issues. At times, the service sends out appointments to the whānau without consultation of appropriate day or time. However, there are instances when they are asked to schedule an appropriate time for their next appointment while they attend the clinic. The whānau expressed that the audiology service is not very whānau friendly or culturally friendly. Māmā questioned the degree of hearing loss of their tamaiti as the testing uses Pākehā concepts that their tamaiti may not have recognised being brought up in a te reo speaking household. During their journey, the whānau have made a connection with an audiologist in the service and have asked to have them for all future appointments; although non-Māori, it was the way she interacts with them that helps break down whānau reservations to attending.

Whānau Whā

This whānau is a single māmā with two young tamaiti aged six and three years old who live in a flat in Hamilton City. Both tama have hearing loss. Māmā is currently studying full time and works part time at a rest home. She has support with the tamariki from their paternal grandparents who live close by and no connection with pāpā. The whānau will soon all move in together to share support. The tamariki are assisted by a resource teacher for the deaf at school and a hearing advisor who comes out to the home who refers them to all the resources and strategies for the tamariki learning and development. Māmā appreciates all the access to the support people as she initially felt lost and ill prepared. She acknowledges the hearing advisor who has linked her to all the support people needed.

Experience of the Audiology Service

When the second tamaiti was born, he didn’t pass the newborn hearing screening so they were referred to the Audiology Service. As Māmā was waiting for her appointment, she read pamphlets about milestones and realised that her older tama had not reached them. After raising this with the audiologist her older tama was tested and diagnosed with hearing loss. This was around two and a half years old when first diagnosed. Having no concerns with his hearing, māmā recalled “being a new mum who really didn’t really know anything” and thought his “mumbly” speech was normal as she could understand it. Māmā felt sad when she heard the diagnosis noting that other tamariki in the extended whānau also had hearing difficulties. Māmā felt easily able to access all the information and supports for her tamariki including the type of hearing loss, access to hearing aids and connecting with a hearing advisor. She shared the information from the service with their extended whānau so that they too could understand the boys hearing difficulties. After the first appointment māmā had to return to the Audiology Service a couple more times as pēpi wouldn't settle to complete the diagnosis. The staff were very nice and interacted well with the tamariki and some of them used te reo. The service booked early appointments that suited the tamariki so they were not tired and irritable. Māmā felt that booking staff acknowledged the whānau needs and made the bookings accordingly. If an appointment is mailed out and it isn't suitable then māmā feels comfortable ringing up and changing it. Māmā now requests Saturday appointments because they suit the whānau better and there are fewer people around the hospital with more access to parking. She keeps the tamariki amused while they wait for their appointment using the Wi-Fi to watch YouTube and taking them for walks up and down the stairs. Māmā believes that this work to attend appointments is just one of those things you have to just deal with. The hearing advisor also comes to some of the appointments to support the whānau which māmā finds helpful.

Whānau Rima

This is a whānau living in a small rural remote Māori community approximately one and a half hours from Hamilton with whakapapa connections to the land. Theirs is a tight knit community where everyone has connections with each other. They have three tamariki; a six year old who attends the local kura, a two year old and pēpi is one month with hearing difficulties and māmā is hapū with another. Pāpā works fulltime in the local industry considered the hub of the community. As their community is so remote, the whānau often expect to travel for health appointments which māmā attends with pēpi so that pāpā can be available to look after the other tamariki. The whānau don't request or expect anyone to travel to their community to provide health services as "it's just too far". Therefore, when they come into Hamilton city there is an opportunity to visit whānau or do shopping for groceries or household needs. This whānau has had support from a hearing advisor who came to one of the appointments and gave information about resources and entitlements.

Experience of the Audiology Service and Health Service

When pēpi did not pass the hearing screening after having a water birth at a birthing centre the whānau were told that she might have just had water in her ears. However, they were given some pamphlets and referred to the Audiology Service. At the first appointment, māmā ended up staying for approximately three hours as pēpi would not settle but despite the long wait still felt that the staff were kind and caring. The staff showed an interest in her tamariki names but she didn't feel that the service provided any particular Māori world view, despite this she still felt comfortable with staff interactions. Though māmā wasn't prepared for the extended time of the first appointment, she was offered a quiet room to put baby to sleep where she felt calm and no pressure from the staff to put pēpi into a deep sleep. When māmā received the diagnosis of hearing loss, she cried on the way home in the car, crying for her tamaiti and the challenges that she would face in the future. Māmā noted that the parking is terrible in the hospital and the waiting area is not very child friendly; because of this, she has only taken her other tamariki along to one appointment and stated she would never do this again. As the whānau lives remotely, they are offered appointment times to suit them. In this way, they felt the service is being very accommodating to their needs. The whānau recommended that the service could mail out the ear moulds as the pēpi grow out of them rather than wait for the next appointment. The whānau feel fortunate to have the audiologist's mobile phone number so that they can communicate directly which is far easier than going through the main reception.

Whānau Ono

This is a rural remote farming whānau with two tamariki; a tama and a kōtiro who is two and a half years old with a mild hearing loss in both ears. They live approximately one and a half hours from Hamilton. The whānau found out that their pēpi had hearing problems after the newborn hearing screening and further testing at the audiology service. They felt upset by the diagnosis as they believed that their kōtiro could hear as she reacted to sounds in her everyday life. Later on, they learned that it was quite high-pitched sounds that she was unable to hear. They have access to support from a hearing advisor who comes to their home and sometimes to their audiology appointments. The whānau found her support very helpful with understanding the type of hearing loss that their child has.

Experience of the Audiology Service

The whānau reported having positive experiences of accessing the Audiology services. They found the staff to be supportive and welcoming. They reported that they felt well informed about the kinds of tests that their tamaiti would take at the hospital and were provided with further information about hearing loss and hearing aids. However when making recommendations for other whānau they said it was important to inform them about the testing so that whānau can be fully prepared when attending appointments. Living so far away from the hospital, they had problems with the diagnosis assessment as their tamaiti would sleep all the way in the car and be awake during the testing requiring additional appointments for a diagnosis. The next time the whānau travelled up earlier and a room was provided to get the pēpi into a deep sleep. They recounted that the service has always been accommodating for them with appointments checking what time suits them as they live so far away and are understanding if they need to rebook because of unexpected issues on the farm. At times, they are busy on the farm and appointment times don’t suit with the travel but the whānau feel that they can communicate well with the service. Māmā mostly attends appointments with the tamaiti so that the pāpā can do the school run although sometimes the maternal grandmother comes for support and to gather information for the whānau.

Section 2: Themes within whānau experiences

The aim of this study was to understand the experiences of Māori whānau when accessing and engaging with the Audiology Early Intervention service at Waikato DHB. This section reports on key themes of the whānau access experiences including some of the positive and negative experiences of processes and interactions of the engagement.

Reviewing the transcripts, it was important to connect with what the kōrero of a significant life experience of learning that something is amiss with their tamaiti during an emotionally and physically demanding period in their whānau life. Having a hearing problem is not something that can be easily recognised by whānau in the first few months of birth. As such, it required interactions with health professionals, newborn screeners and audiologists with whānau who were continuing to make sense of the diagnosis and early intervention processes. My focus of the analysis was to connect with the experiences of whānau during this intense time. What did they say? How did they show the impact of the engagement with the service? What were some of the differences and similarities across whānau experiences? And finally how could their kōrero be presented this in a mana enhancing way?

Whānau experience of māmāe

As a Māori researcher and a māmā one of the most significant experiences that I heard, felt and understood from some of the whānau kōrero was a sense of māmāe (to be hurt, upset, experiencing trauma). Whānau spoke of the heartfelt experience of māmae surrounding the initial diagnosis of their pēpi having hearing difficulties. Feelings of grief were recalled by whānau at being informed there was something wrong with their child's hearing. Some also described a sense of guilt and responsibility for the hearing loss; questioning whether it was something that they had done wrong. Māmā Toru left the initial diagnosis appointment in tears saying she needed to go home to her partner to "apologise" for her child's hearing loss, not knowing if it was something she had done:

> thinking nothing of it and then getting told your son is deaf and I was sitting in there, overwhelmed with emotion, teary eyed as and I just grabbed him and then you couldn't even have a moment to comprehend or go through those emotions, because they obviously had another appointment and you're gone… you and your teary eyes and everything walk out in public. With that, I get in the car, drive straight to (partner), and apologise to him about my son.

Māmā began crying as she recalled her feelings during this time, and we both cried. Although it was an upsetting memory shared, I was extremely grateful to her for allowing me to understand the depth of the emotion tied to this experience. I checked in with her to ensure that she wasn't still carrying this sense of guilt and having a kōrero about evidence of the causes of hearing loss. Another whānau shared a similar experience. When Whānau Rima were referred to the Audiology Early Intervention Service, they had no idea that their child's hearing could be of concern. Consequently, the diagnosis came as a shock. Māmā shared her feelings of fear for the future of her tamaiti and what that could mean for her growing up:

> When I was told, yeah I had a little cry. Had a cry at first, I cried on the way home in the car, once I got in the car, I just starting crying for her. I guess I jumped ahead a few years, thinking I don't want no kids teasing my baby all that sort of stuff

This finding is significant because it reveals the impact of this experience was kept from the audiology staff. There was a sense from whānau that they had to leave the service and keep their feelings to themselves. Whānau did not feel comfortable sharing their feelings and experiences of māmāe with the service and therefore no further support could be given.

Whānau newborn experience

It is important to note that at the time of diagnosis the whānau have a newborn, which in itself can be a very emotional and stressful time. Newborn hearing screening occurs within the first month of birth, after which the pēpi is referred for an audiology diagnostic assessment, usually within three months of birth. Māmā Tahi recalled her experience of having to deal with the challenges of being a new parent:

> I think too, you know how it is when you've just had a kid, and all the rollercoaster you're going through

Understanding from the whānau that having a newborn pēpi and the diagnosis of hearing problems carries a heavy emotional burden that they are dealing with at this critical time in their lives.

Additional burden of multiple health issues

For two of the whānau, there was as the additional emotional burden of dealing with other significant health conditions of their tamariki. Māmā Rua was in shock and disbelief and was emotionally struggling with the unexpected and overwhelming diagnosis that her pēpi was born with a rare syndrome:

> She had no ears whatsoever and it just started growing, little bit by little bit… yeah, it was sad… she looked different, we could tell, we're like-what the?, what's wrong you know… yeah and I just cried and cried, no that's not my baby, nope.

Having problems with hearing was one of many health issues that some of the whānau were dealing with in this early period with their new pēpi. For the two whānau with tamariki living with a syndrome, it was evident that their health experiences shared were often extremely distressful. Māmā Rua explained the difficult experiences they face at each hospital visit:

> She's terrified of anyone in a nurses uniform… she runs, we've got to keep her occupied or put her on the tablet so she doesn't see we're in the hospital and wheel her to audiology as fast as possible and when we have to wait it makes it harder because she is trying to run, she's trying to get out of there.

The tamariki health issues are often complex, requiring multiple visits to specialised health and social services for each of the health issues associated with the conditions. Whānau reported how challenging this can be. Whānau Tahi and Rua described the many services they need to navigate:

> So he had quite a big team around him I guess you'd say because of [the syndrome], he has our regular GP but he also has [a] doctor up at Waikids, then we've also accessed audiology, the eye clinic, we've also accessed the children osteo clinic and he sees an

> osteopath. At the… centre he has a physio therapist and we can also access a psychologist there.
>
> Yep, they try to jam them all in one. So if we have an audiology appointment, we'll see her plastic surgeon in one day, she'll see her specialist in one day and her speech and language therapist all in one.

Māmā Toru asked that staff be more understanding of their situation and the emotion that comes with what is, in its first instance, distressing news about the health and wellbeing of their tamaiti.

> To be more like, empathetic, when you can, you as a clinician can stop an appointment and check in, instead of oh I've got to get this and this done. Can we just be humans again? And knowing that these emotions are attached to you. Because I'm sure eardrums can be done at the next appointment. Let's just check in and see how a new mum is.

A recognition of this, and support from staff of the mamāe that whānau may be experiencing during the diagnosis and testing can go a long way to encouraging whānau attendance at future appointments.

Whānau experiences of systems and processes

Waikato Hospital serving the whole Waikato region

Waikato Hospital in Hamilton is the only place where tamariki from across the region can receive diagnostic and early intervention services. This is likely to be a three-year commitment from whānau to attend regular early intervention appointments for their tamaiti. This is a significant barrier for those living rurally. Rural Waikato whānau can travel up to three hours for an outpatient appointment. Three of the six whānau interviewed lived rurally with one whānau living so remotely that they had no expectations that any services would come to them. Even with the interview for this study, the whānau offered to meet in Hamilton rather than have others travel the winding rural roads to their home. Going in 'to town' was described by whānau as a necessary part of their lives and was often linked in with shopping or visiting other whānau. Whānau Rima shared:

> Whenever I get her appointments I kind of, whenever we come into town I make it worthwhile, so I do the groceries and pick up others that need to be picked up. So I'm not just shooting in for the one thing so yeah it always kind of works out you know I always grab things before we head back.

Even when offered an appointment at a closer rural hospital the whānau declined because they had extended whānau in Hamilton to support with looking after their other tamariki. Travel time, work and caring for other children were all factors that rural whānau described as needing to organise in order to attend health appointments.

Siloed health services not culturally appropriate

Māmā Tahi stated that the health system's approach of providing separate services for different health issues does not work for Māori whānau. This is particularly significant for whānau with tamariki living with a syndrome or multiple health issues. She recommended more holistic culturally appropriate models of care to support tamariki and to ease the stress on whānau dealing with various services.

> This audiology department they deal with ears, but this is a whole person and… I am Māori, Māori models deal with the whole person holistically… cause he's got [a] syndrome and he has been diagnosed with some eye thing as well as his heart, also his hearing then maybe… I don't have to explain everything when I go to appointments.

Māmā Toru described how connecting to te taiao (the environment) was a key component of their health journey for their whānau. This was something that was not a feature of their early intervention journey with the health service.

> So when T was diagnosed, I quickly learnt, like, shit I need to get into his other senses then. I thought it was important for me to look at our taiao (environment) and what was around us. You can't communicate with me verbally (tama), but if I can give you the world and you can feel the breath of Tāwhirimatea, you can feel the sand and all of those different sensory [experiences], then I'll give it to you as much as we could… you can only sit and dwell inside your own four walls, but then you got to pick yourself up for the rest of your family so, it's healing for both.

The whānau recognised that early intervention for their whānau was not just about attending the Audiology Service appointments but also adapting with their tamaiti to his hearing loss through connecting to Te Ao Māori.

Practical Barriers

There were multiple practical barriers cited by whānau that contributed to the challenges of attending appointments. These included having to organise whānau support for other tamariki, taking time off work, travelling to Waikato hospital and finding parking. It would seem from a health service perspective that what appears to be the simple act of attending a health appointment in fact requires a great deal of effort, stress, organisation and work on many levels, as Māmā Toru described:

> I think for us it's even before getting to the appointments. That has to take into account when you've got other tamariki and then you're kind of like, okay if we have an appointment at 2 o clock, who's going to pick the girls up at 3 o clock? So it's all the pre-planning that has to go into effect or consideration… Who needs the day off? All that prepping. Is [pāpā] going to take him? Am I going to? Is mum going to come in? And what are the supports around, you know.

Parking barriers

Parking at Waikato Hospital a significant challenge across all whānau experiences, regardless of where the whānau lived both rurally and within Hamilton city. As a result, whānau factored in extra time into travel to search for an appropriate and available parking spot adding to the already lengthy appointment whānau experience. The two whānau with tamariki diagnosed with a syndrome found parking particularly challenging given the additional health needs of their tamariki. Whānau Rua have a particularly difficult time with every hospital visit as their tamaiti is so traumatised from previous hospital experiences.

> The parking is really, really hard, like our appointment will be nine thirty, we'll get there at nine o'clock and we'll spend half an hour trying to find a close park so our baby doesn't get wet, cause we can't park on the inside of the underneath because it's claustrophobic for our daughter.

Māmā Tahi shared a very similar experience:

> because [he] has been to the hospital so much and he starts crying when we start, when we go up the car park area so the sooner I can get a park, and get him out, and people might think I'm weird because I'm pushing a push chair and holding a kid, he's not in the push chair because this is how much he hates going to the hospital.

Unfortunately, tamariki who have disabilities but do not have mobility issues are not able to use the disability parking at the hospital. Whānau whose tamariki have a hearing loss or a syndrome that does not affect their mobility are not eligible to use the disability parking. These parking spots have easier undercover access to the hospital entrances. One whānau brings her mother so that they are able to use her disability-parking sticker for easier access to the service. Māmā Tahi suggested:

> I think it would be nice if they know the person doesn't actually qualify for a mobility park, but does have a disability that maybe they could do something like [give a mobility

> parking sticker] even just a temporary one, that they can use for the day or whatever.

Unfriendly and unsafe waiting area

Whānau shared that the Audiology Service waiting area was particularly unfriendly. They felt that it was not appropriate for whānau particularly those with young tamariki. This meant whānau needed to bring along "supplies" for the young tamariki to engage and entertain them whilst waiting to go into the appointment. Whānau Rua explained:

> We're going to take lunchbox, books, colouring in pens, you name it. We've got to take it with us. Tablet, so she can watch something. Māmā described the behaviour of their tamaiti that they had to prepare for:

> She runs… we got to keep her occupied or put her on the tablet so she doesn't see we're in the hospital and wheel her to Audiology as fast as possible and when we have to wait it makes it harder because she's trying to run, she's trying to get out of there.

Some reported that there were no whānau friendly areas for tamariki in the waiting area just rows of chairs for adults. Safety concerns for their tamariki were raised as the younger ones were often drawn to playing on the steep stairs close by. Having to take other siblings to appointments is sometimes necessary for whānau, but this added to the difficulties of keeping more than one child entertained while waiting or during the appointment.

> It's really hard to entertain a child, a young child up there (Māmā Tahi)

Whānau suggested that the waiting area needed addressing to be more child friendly to support a more positive experience with the service:

> {The waiting area needs] toys! Something to occupy the children. That should be a must, they got this one toy, the horse, that doesn't work, it used to work (Māmā Rua)

A safe and welcoming environment to arrive to, where whānau and tamariki feel comfortable particularly for those who have to travel a long distance, can have a major impact on future engagement with early intervention services.

Whānau appropriate appointments

Experiences expressed around the booking of appropriate appointment times varied between whānau. Some whānau had worked out how to manage appointment bookings that suited them. They found the booking system worked well and were confident to text and ring to make and rearrange suitable appointment times. For those who lived rurally it was noted by whānau that the service made efforts to plan appointments to accommodate their travel time. These whānau felt a sense of appreciation when the service was seen to be accommodating those who had to drive a significant distance. For others, the appointment arrived in the mail, without any consultation around appropriate times. These whānau reported feeling a lack of control to negotiate a more suitable appointment time as well as pressure to make it on the time offered. Māmā Tahi expressed the challenges of trying to negotiate appointments to suit her whānau:

> I try to ring up and say, hey, you've booked me in for an ear, nose and throat appointment on Tuesday, you've booked my son in for Audiology on the Wednesday, could maybe we do it on the same day so I'm only taking one day off… same floor, same area, same receptionist and I said, oh well I'll see you tomorrow for, for my sons audiology appointment, she's like, oh that was really silly you should've got it booked for the same day….tried…no one ever got back to me.

Duration of assessment appointment

Making it to the actual appointment is only half the battle. After finally making it to the hospital and entertaining tamariki while waiting, there is still more "work" to be done in the actual appointment itself. A diagnostic outpatient appointment for hearing loss can take up to one and a half hours (or more as some whānau discovered) and requires pēpi to be in a deep sleep. The reality of this assessment process can be challenging. Whānau Ono recalled travelling from their rural home as pēpi slept the whole way. This meant they needed subsequent appointments as the pēpi may did not settle or sleep through the entire appointment. This entire process in itself can be an anxious time for whānau trying to settle their new pēpi with the knowledge that other whānau are also booked and waiting for their appointments too.

Timeliness of information

Although the Audiology Service has outlined processes in place to provide information to whānau about early intervention (see Appendix 7) it was apparent that at times, whānau felt ill prepared for the different aspects of the screening, referral and diagnosis. A few of the whānau described occasions of not understanding processes and feeling ill prepared for the diagnostic assessment. Another whānau kōrero highlighted that it took some time before they understood why early intervention is important for their tamaiti. Māmā Ono recommended that other whānau needed to be given more information about the diagnosis assessment process.

> More info about the testing (would be good for whānau) so that the parents can be fully prepared. As I said before, I struggled with getting (pēpi) in a deep sleep after travelling for the appointment but the next time we came up with some solutions so it was good. The more people understand the easier it is.

At times, staff may not have known that whānau were unsure and feeling as if they did not have all the information they needed. In new and unfamiliar situations, whānau were less likely to feel comfortable to question or say that they did not know. Māmā Tahi explained:

> Even the first time I went to audiology for the first appointment, there was no real information given… it took me a while to realise… I flipped into that, I don’t want to question them, you know, they’re the ones that know everything

During this important phase of early life, when whānau may be experiencing many stressors as well as the burden of practical barriers, timely and accurate information sharing to prepare for and understand processes is critical.

Whānau perception of hearing loss as a disability

An important kōrero raised by some whānau was the perception that they did not recognise their tamaiti as having a hearing disability. Often tamariki with hearing difficulties were treated just like any other whānau member. Whānau Rua with pēpi living with a rare syndrome said they treated their tamaiti just like any other on the farm, sharing that other whānau with tamariki with the same syndrome think she is a miracle. In this way similarities with our pre contact Māori ancestors' can be drawn where tamariki with hearing difficulties are seamlessly incorporated into whānau and community life. When sharing their experience of their tama being diagnosed with a hearing loss, pāpā of Whānau Toru stated emphatically:

> …he can hear!

Māmā Whā did not recognise that her older tamaiti had hearing difficulties as she could interact and communicate with him well. She was not provided with any information during his newborn screening or follow up health appointments that identified a hearing issue. As she said:

> I was still like a new mum, I didn't really know anything, so I was thinking like that was his normal, 'cause he was talking but it was very mumbly talking but I could understand that.

It was not until she was at the Audiology Service for her younger pēpi that she realised her older tamaiti had not reached his hearing and speech milestones. Within their whānau unit, communication and understanding each other was not a cause for concern. This perception could influence whānau engagement and recognition of the need to attend Audiology Early Intervention Services, particularly when their tamaiti is doing well within the loving support of the wider whānau.

Whānau also spoke of the need to share the information and learnings from the Audiology Service about their child's hearing loss to other whānau members who questioned the diagnosis. Having other whānau challenging the diagnosis of and extent of tamariki hearing loss can influence whānau perceptions of the need for early intervention services. Māmā Toru said that it was not until the hearing advisor was able to explain to her why she needed to keep attending the audiology appointments that she was convinced to continue to attend the appointments.

> It was just so much easier because she came here. Her coming here, just probably encouraged us more to go up there. And she actually sat down and explained, this is what happens if you don't do this for T

It is important that the service recognises the complex nature a diagnosis of hearing loss for Māori whānau; to continue to share with them the long-term value of early intervention for their child's wellbeing in terms of interacting within the wider community and better health, academic and employment opportunities.

Whānau experiences of interactions

Hononga – Connecting with supportive staff

Throughout the kōrero, there were many reports of whānau engaging with caring and supportive staff. This ranged from reception staff to audiologists, to other support staff for their tamariki including hearing advisors and speech therapists. Māmā Tahi commented:

> Yeah, generally the like the ladies at reception are really nice, they honestly are really nice and helpful but it's just the waiting…

Other whānau made similar comments about feeling comfortable with staff:

> I honestly have no concerns about the staff 'cause they were very nice and they interact with the kids like nicely and that, I don't feel any bad vibes. (Whānau Toru)

> They have been really awesome to us. Its scary being told that your child has a hearing loss but they are there to help and support her and us. (Whānau Ono)

Some actions by staff were recognised as ‘getting it right’ in their engagement with whānau. For example, when asked what about the audiologist made her feel at ease, Māmā Toru replied:

> Yeah, just who are you? That simple thing. You know, I don’t know why, when or how she said that, but that’s something that we’re grateful for. Well the barriers go down aye. It’s getting to know your whānau instead of the time slot, and maybe that’s why we had that better hononga (connection) with (her) and why I request that, well if you’re here on that day they yep, we’ll come. But what’s going to happen if there’s no more [audiologist]?

She also added:

> I feel like at the start when like, she came into T’s care that I started requesting just to see her, because there was this automatic hononga that, I don’t know, she just did things a little different

Although claiming that this was only a simple act it highlights that it is only the little things that can make a difference to whānau engagement.

Some whānau also emphasised that staff members made themselves more accessible by sharing their mobile phone numbers to connect or request more information. Whānau appreciated this opportunity and highlighted when they were able to communicate with staff in this way, staff were viewed as more accessible and caring. Māmā Whā shared that in order to get what she needed for her tamariki she felt she needed to cultivate the relationship with the Audiology Service staff.

> Yeah 'cause I try to have good relationships because obviously I need stuff from them… so I do try to have good relationships so if I need something from them then I'd be able to ask and talk to them about it.

In this way, Māmā recognised that cultivating a good connection with health staff would facilitate her access to information that would ultimately be beneficial to her tamariki.

Culturally appropriate engaging

As identified in the literature, support for Māori ways of being is a significant enabler to whānau enjoying positive experiences of the health system (Graham & Masters-Awatere, 2020). Whānau Toru recommended culturally appropriate tools of early intervention as a way of engaging better with their tamaiti and whānau.

> Even the words that they're using, when their testing… the pronunciation… use familiar words like, whare, kai, karakia little things like that, because if the word is foreign or like what is [his] interests, man he loves the farm, anything to do with the farm. Say words like that and I bet you, you'll get a different response in his hearing test than what you would as opposed to car, oink.

Māmā Rua wanted to connect with more Māori staff in the Audiology Service to help her whānau to feel more comfortable:

> I prefer Māori because they actually explain, they don't use big words for us Māori, because I don't understand the medical big words that they use and a Māori would like try to explain to me.

Other whānau also noted that when staff asked how to pronounce their tamariki names correctly this made them feel more comfortable. Taking this time to get to know the tamaiti and whānau was acknowledged as important to better engagement with staff.

Whānau support

Whānau in the study emphasised the need for support at the appointments; someone in either their whānau or another caring support person; particularly for initial diagnosis. When they didn't have support people, this impacted on their own wellbeing. Ensuring someone was there to support no matter how it affected their work or other whānau commitments was essential for some. Māmā Toru explained the sense of loss she felt when her whānau weren't able to be with her for the diagnosis appointment.

> Because we come from such a supportive whānau and not having my pou next to me, to be like, not so much get over it, but be like - we've got you, and they weren't there…

Māmā Rua shared why she needed her partner at all health appointments to support her and her tamaiti despite the pressure that attending the appointments have on their paid farm work.

> Yeah, I think if he wasn't there (tāne) I'd just hide away in the corner. He's the straight up one.

Māmā explained that she didn't feel comfortable or able to ask the questions that she needed to of the health professionals involved in the care of her tamaiti. Although their employer was not always supportive of the couple taking time off work, pāpā felt obligated to attend the appointments to help his whānau get the care they needed.

Māmā Tahi also recognised the need for additional support to advocate for the information and services whānau need.

> …sometimes it's hard for you to stand up for yourself.

A number of times whānau highlighted other people who provided much-needed support, guidance and advice including hearing advisors and speech therapists. Māmā Rima spoke of guidance from her hearing advisor:

> She was actually very helpful, because she came to one of my appointments, she was telling me things that I was entitled to, I was saying at the time [my toddler] was interested in baby's [hearing aids] and kept pulling them out, she was telling me that they can give you a teddy bear with fake hearing aids for my toddler to play with instead.

Other whānau also gave examples of support from hearing or speech advisors to not only understand their child's health needs but also to navigate the barriers of the health system:

> …because I struggle getting into contact with people from the hospital, because I don't want to ring, so I just go straight to her and she's like, your appointments on Thursday. Don't forget! (Whānau Rua)

> [she] explained everything to me and gave me tips or things I could do to help her [tamaiti] learn and understand speech better (Whānau Ono)

Facilitating whānau support is recommended throughout the health journey in recognition of the beneficial impacts on tamariki health and wellbeing.

Chapter 4: Discussion

The aim of this study was to understand the experiences of Māori whānau when accessing and engaging with the Audiology Early Intervention Service at Waikato DHB. To accomplish this, six whānau were interviewed about their experiences of processes and interactions when engaging with the service. In order to improve whānau access, the Waikato DHB Health System Plan emphasised the need for its services to listen to the voice and experiences of whānau (Waikato District Health Board, 2019). For this plan to enable transformative change for Māori equity, all staff need to take responsibility to act. As a Crown agent, the Waikato DHB has a Te Tiriti o Waitangi obligation to improve the health inequities experienced by Māori whānau (Waikato District Health Board, 2021). Good access to healthcare for tamariki and their whānau in the early years of life was highlighted in the literature as crucial to better health outcomes later in life. Similarly, for those with hearing difficulties, early access to audiology intervention was recognised as essential for maximising hauora gain for whānau. Understanding barriers to whānau accessing the service is an important part of determining what needs to change to improve access.

Experiences of systems and processes

Despite research showing that whānau lack appropriate access to healthcare and the drive for public health plans to address the inequities, system barriers are still ever-present. The location of the service within Waikato hospital for both rural and local whānau challenged whānau engagement with early intervention services. The separation of the health system response into siloed health services means that whānau with tamariki living with syndromes are required to attend different services at different times for their tamariki. This was a significant burden expressed by two māmā in this study with one whānau attending the same audiology service two day in a row for different whānau health issues. Another māmā could not attend appointments without the support of the pāpā to navigate the system as previous hospital experiences had left pēpi and māmā feeling anxious and traumatised.

All six whānau cited practical barriers that they had to navigate in order to attend appointments. For two of the Hamilton based whānau, appointments came in the mail without consultation about whether they were appropriate times. They found trying to contact the service via the one hospital phone number difficult to connect with. For all the whānau, coordinating the time to travel to Waikato hospital, finding appropriate parking and the challenges of making it to appointments with other priorities such as work and care of tamariki were also highlighted as barriers. However, the resilience of whānau shone through in their dedication to battle the systemic and practical barriers for the health and wellbeing of their tamariki. Across all the challenges, whānau shared strategies to access appointments despite considerable stress, effort and 'work required.' This included pre-planning of travel arrangements, arriving significantly early to find parking, organising whānau support, taking kai and bringing entertainment for tamariki.

Experiences of interactions

The challenges in engaging with the health system were explicit in the whānau kōrero. As well as these physical challenges, specific negative experiences of interactions were recalled. Four of the whānau revealed hidden experiences of māmāe (a heartfelt feeling of hurt and guilt) which they were unable to share with the staff in the service. Two of the māmā left the service holding back tears after they received the diagnosis about their tamaiti hearing loss. Whānau shared their emotional and physical challenges during this critical period of life associated with having a newborn pēpi and for some having tamariki with other health issues. Māma Tahi and Rua described the stress they had to encounter at each health appointment bringing their tamariki with a syndrome into the health service environment. Three of the whānau also felt ill prepared and lacked information about the diagnosis assessment, which contributed to a poorer experience with the health service.

There were however, many reports from all whānau of engaging with caring and supportive staff within the Audiology Service. This ranged from reception staff to audiologists, to other support staff for their tamariki including hearing advisors and speech therapists. Having a direct access to an audiologist via their mobile phone enabled whānau to feel more connected and informed. Positive experiences of engaging with staff encouraged further attendance at appointments for some whānau as they navigated engaging with the health service. A key focus of this discussion section, in line with a Kaupapa Māori approach, is finding solutions to the access barriers to ensure transformation for whānau.

Transformation: How the service can change to better meet the needs of Māori

The final research question of this study asked how the service can change to better meet the needs of Māori whānau as they access the Audiology Early Intervention Service. This called for a critical analysis of the experiences in order to identify areas where the service could change and focus action in order to meet the needs of Māori whānau as they access these services. Whānau also gave practical recommendations about what they felt would support further engagement. According to the findings of the report by Cram, "Māori access to health care is about the entry of Māori into health care, as well as their journey through health care" (Cram, 2014, p. 6). The whānau in this study have highlighted that the entry to and journey through our Waikato DHB health system can be better.

Manaaki-based Pathway

Māori academics recommend for whānau to flourish, we must address the factors that contribute to health inequities and ensure access to appropriate health services (Hodgetts et al., 2016; Kingi et al., 2014). For whānau, the first impressions of a service are crucial, thus the initial call of welcome or referral should ease them into using the service. On many occasions, the whānau in this study highlighted kind and caring interactions with staff within the Audiology Service. To overcome the hurdles that whānau encounter to accessing the early intervention services, a manaaki-based pathway that gently guides them through the systemic and practical barriers is proposed. Literature on whānau access to healthcare describes key facilitators to positive engagement which can determine a manaaki-based pathway. These include enabling Māori to experience positive communication with staff, ensuring whānau and other emotional support, providing practical assistance to address financial and logistical barriers as well as navigation through the health system (Cram, 2014; Stevenson et al.,2016; Graham & Masters-Awatere, 2020). This support is needed throughout the journey through the health system, from newborn screening, referral for diagnostic assessment through to regular appointment scheduling. To address the many barriers whānau experience to accessing services, it is essential the Audiology Service staff understand and practice the value of manaakitanga.

> Manaaki is one of the cornerstones of our Māori worldview. It expresses the very essence of respectful caring and protection of others. Manaaki upholds generosity and providing hospitality… Manaaki is about the subtle and intuitive kindness in the touch of the hand, the hug, recognising each other's losses pain and triumphs. Manaaki is about the aroha of eye contact (Elder, 2020, p. 13).

Manaaki is an all-encompassing Māori framework to deliver responsive practices that better meets the needs of whānau. Bevan-Brown (1994), illuminated the inextricable link between Māori beliefs and values such as manaakitanga and perceptions of disability. Enabling Māori ways of being will ensure whānau remain engaged with health services instead of being alienated from them (Graham & Masters-Awatere, 2020). The following practical recommendations show a manaaki-based pathway for improving access to the Audiology Service, which if prioritised, can ease the burden of accessing early intervention appointments.

Accessible appointments for whānau

Ensuring accessible appointments for whānau, which can only be determined in consultation with whānau can help to address some of the systemic and practical barriers. The Whakarongo Mai report (New Zealand Review Team to Consider Hearing Impairment Among Maori People, 1989), recommended that Māori should have greater access to audiology services by providing more flexibility in referral procedures. The findings showed that some whānau who lived in Hamilton city were not given the option to determine a suitable appointment time. If the service only offers appointment options for those travelling from rural areas, this disadvantages those who live closer to the hospital and who may also face additional barriers. Although much research talks to the barriers of rurality to access healthcare it cannot be denied that rural whānau demonstrate their resilience and “making the most” of travelling to appointments by including health and wellbeing activities such as visits with whānau and shopping. Those whānau with tamariki with complex health issues requiring multiple clinic appointments need to be offered a coordinated approach to streamline their access to services.

Access to appropriate parking

Any solution that can reduce the additional stress on whānau of parking at the Waikato hospital is an important recommendation of this research. Gilmour et al., (2016) and Stevenson et al., (2016) highlighted whānau experiences of difficulties managing the practical considerations of attending hospital or clinic appointments. According to Cram (2014) addressing the logistical and financial barriers, such as parking, were the most effective interventions for improving Māori access to healthcare.

One of the whānau recommended Saturday appointments as an ideal option to ease access to the service due to more availability of parking spaces. After hours or weekend appointments ought to be considered and trialled. The two whānau with tamariki with other complex health issues emphasised the need for specific Waikato DHB disability parking conditions for tamariki with all disabilities to alleviate the extreme stress on whānau just to gain access to the hospital-based service. Targeted interventions for tāngata whaikaha particularly the most vulnerable tamariki need to be prioritised (King, 2019). Therefore the recommendation by whānau of disability parking for tamariki with non-mobility disabilities requires actioning as a practical solution to address access barriers for whānau with tamariki living with any form of disability.

Whānau friendly spaces

Whānau identified the need for not only whānau friendly spaces but also tamariki tailored spaces so that their tamariki can enjoy positive experiences within the Audiology service. In keeping with a Manaaki – based pathway approach, if their tamariki are happy and well supported then whānau are more comfortable and likely to access and remain connected to the service. Addressing the safety issues of the waiting area and access to the stairs for whānau with young tamariki needs to be a priority for the service. Further, the simple addition of toys for their tamariki was considered an easy, practical solution recommended by whānau. Alongside practical solutions, interacting with engaging staff is integral to improving whānau experiences.

Hononga - connection with whānau

Hononga is about making connections with whānau. Elder (2020) explains hononga as as essential element of whānau wellbeing.

> We are born to connect. Born social. Strengthening our bonds with others is a central part of our lives. And where these connections are tested or feel broken, we struggle to know what to do. We can feel lost and distant. (Elder, 2020, p. 118)

One of the key findings from Grahams & Masters Awatere's (2020) review of qualitative studies on Māori experiences with New Zealand's public health system was that whānau experienced a lack of relational connection (hononga) with staff. This study has shown that hononga with whānau is the solution to understanding their needs; their māmāe; their diverse experiences; their perceptions of their tamariki hearing loss or disability and how information is best shared and received by them. The findings of this study highlighted that even during periods of experiencing trauma and grief (māmāe) at the diagnosis, four of the māmā felt they had to keep themselves composed in order to make it through the appointment. If the staff had taken more time to connect and "check in" with the whānau, these experiences might not have been as distressing. Some actions by staff were recognised as "getting it right" in their engagement with whānau including pronouncing tamariki names correctly and providing a means of accessible communication by sharing mobile phone numbers.

Whānau in this study were diverse, there were single parents, small whānau units, extended whānau, rural whānau, working whānau and some were studying and caring for tamariki with other health issues. Whānau recognised when staff took the time to connect and understand their needs, they felt more comfortable to engage for further support when needed. As Māmā Toru illustrated, it was the connection they felt with an audiologist that convinced her whānau that they needed to continue attending early intervention appointments for the wellbeing of their tamaiti.

Provide multiple opportunities to share information

Three of the whānau described their lack of understanding about early intervention and its impact on the hearing health of their tamariki. It is critical for the service to recognise that whānau may be experiencing māmāe at that time and unable to ask the questions they may need to. Whānau responses demonstrated that receiving information about Audiology early intervention processes needs to be ongoing and via multiple methods. This must include pertinent information about managing appointments, processes, and the long-term impacts of early intervention on the health and wellbeing of tamariki. Despite having written information available for whānau (see Appendix 7) the kōrero from whānau showed that the way that information is delivered has a significant impact on their experiences, their future use of health services ultimately shaping health outcomes for their tamariki. One whānau described being unaware of the time needed for the diagnostic appointment and being unable to settle their pēpi. Others talked about bringing other whānau along so that they were able to understand information and processes between them.

Cram's report (2014) on improving Māori access to healthcare described health literacy as the health services' ability to provide culturally responsive information to Māori patients and their whānau. Further, to support whānau health literacy, information must be tailored to address specific healthcare barriers. It was stated that Māori whānau have diverse attitudes and beliefs about hearing and disability and this is reflected in the responses from whānau who participated in this study and their interactions with the wider whānau (Hickey & Wilson 2017). Informing and delivering health information about hearing loss to other whānau members was an important part of whānau experience. Consequently, sharing information to minimise delays is best delivered in many different ways to reflect the diversity of whānau.

Supportive environments for whānau

Whānau in this study expressed their need for whānau support at crucial times of their early intervention experiences. They described the positive outcomes of support from other whānau members or other supportive staff including hearing and speech advisors. These results are supported by other studies on Māori access to health services. In order to improve whānau experiences, Kaupapa Māori researchers advise fostering positive communication between whānau and service providers (hononga) and creating welcoming and facilitating supportive whānau environments (Graham & Masters-Awatere, 2020; Stevenson et al., 2016). Although whānau support is not a new insight, there is still a disconnect with health services taking the responsibility to ensure that whānau have and are offered whānau support. Whānau need to be assisted to do so as an equity enhancing practice. This begins with referral and booking appointments to enable whānau support or an appropriate support provided through the health service.

A coordinated approach for those experiencing intersectionality

A significant insight that emerged from the kōrero was the added burden for whānau with tamariki who live with other health issues in addition to hearing loss. For some whānau, there was an intersectionality of multiple and diverse experiences including being single parents and caring for tamariki with additional health issues compounded with historical impacts of colonisation (Hickey & Wilson, 2017). Further, tamariki with hearing loss are more likely to have additional disabilities as many risk factors for hearing loss often include other disorders (Digby et al., 2020). The convergence of multiple forms of discrimination and disadvantage present as barriers to whānau engagement with health services (Crenshaw, 1989; Hickey & Wilson, 2017). Therefore, developing a streamlined process for prioritising these whānau within hearing services is a critical action. According to Becker (2018), Māori tamariki living rurally are more likely to have poorer health outcomes and with Māori having higher rates of disability (Hickey & Wilson 2017) facilitating access to services is a responsibility of the health service. King (2019), argues that health services have not done enough for tamariki Māori living with disabilities. Whānau-centred solutions across systems, practical and engagement barriers are needed to address compounding inequities of Māori whānau with tamariki with disabilities. This would include staff connecting with whānau to ensure an appropriate appointment time, aligned to any other health appointments, streamlined access to mobility parking and reduced waiting times. Prioritising whānau with co-ordinated approach is the pro-equity action which can reduce barriers to access (Cram 2014; Graham & Masters-Awatere, 2020; Stevenson et al., 2016).

Chapter 5: Concluding comments

Whānau journey through healthcare needs to radically improve. Despite research findings and health plans, little progress has been made to address the equity gap in access to health services for Māori whānau and Māori tamariki with lived experiences of disabilities. Good access to healthcare for tamariki and their whānau in the early years of life is crucial to better health outcomes later in life. For those with hearing difficulties, early access to audiology intervention is essential to maximise health outcomes for whānau. Māori are experiencing the public health system negatively with barriers including costs, travel, leave from work, childcare and staff attitudes and racism contributing to their disengagement from services. Positive health experiences are characterised by receiving practical assistance for financial and logistical barriers, whānau support, positive staff communication and navigation support through the health system. This study is particularly valuable for understanding whānau experiences of hearing services due to the scarcity of research in this area. The Audiology Early Intervention Service reviewed their data and found inequities in whānau access to the service. The staff requested support from a Māori researcher to engage with whānau about their experiences to understand what needs to change.

Six whānau from rural and urban Waikato were interviewed and shared rich narratives of engaging with the service. Whānau in this study have shone a light on their experiences of engaging with the Audiology Early Intervention Service and shown that there are areas across the system, processes and engagement with staff that can to be improved. Systems barriers including one hospital location for early intervention services and siloed health services that lacked culturally appropriate models of care contributed to creating burden to access. Practical barriers to accessing appointments were reported by whānau including appointment timing, travel and parking. Whānau described feeling stressed when they arrived at the hospital to an unwelcoming, unsafe waiting area. Hidden māmāe was a deep emotional response shared in response to the diagnosis of hearing loss. An acknowledgement of the context of their early life experiences was also highlighted including having a newborn or tamariki with other health issues. All whānau shared positive interactions with staff once access barriers were overcome. Whānau suggested what could have made their experience better including practical solutions; more accessible appointments, appropriate disability parking, more information on processes, and safe, whānau friendly spaces. They recommended support with Māori ways of being including testing in te reo, Māori models of care, better opportunities to hononga with staff, access to Māori staff and valuing the connection to Te Ao Māori.

After leaning into the kōrero and connecting to the whānau experience, a Manaaki-based pathway was proposed to acknowledge Māori ways of being, to ease whānau through the barriers and to combat the alienating experiences of engaging with the health system. In spite of claims to the contrary, whānau in this study demonstrated aroha for their tamariki and the desire to support their wellbeing by battling the systems, physical and staff engagement barriers they encountered along the way.

It is my expectation, in honouring the kōrero that action is taken to improve the audiology early intervention journey of whānau with tamariki with hearing loss so they receive the best opportunities for their future. Whānau in this study have gifted their experiences of accessing the service to make a difference for others and because of the partnership with the Audiology Service staff, this research has the potential to make a difference.

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Appendices

APPENDIX 1: INVITATION

My name is Cindy Dargaville, I whakapapa to Ngāti Maniapoto, Waikato Tainui and Te Rarawa. I live in Hauraki where I am raising my three tamariki. I work for Te Puna Oranga (Māori Health Service) at the Waikato District Health Board and study at the University of Waikato

AN INVITATION TO PARTICIPATE IN A RESEARCH STUDY KIA TIPU AI ĒNEI KĀKANO HEI RĀKAU NUI

Kia ora e te whānau

I have the privilege of leading a study about whānau who have a child who has hearing difficulties and their experiences of the Waikato District Health Board Audiology Early Intervention Service.

This study is looking at what can be improved in the service for tamariki with hearing difficulties and their whānau. The audiology service want to understand what they can do better for whānau and they have asked me to help. I will be asking the questions and writing up our kōrero.

You has been carefully selected to be interviewed because you are whānau of a child who has been identified as having hearing difficulties by the Newborn Screening Programme and been referred to the early intervention audiology services at Waikato Hospital.

It is important that we interview whānau who may have had issues with attending the early intervention service appointments so that we can learn how to do better.

It is your choice to take part or not, kei te pai.

Brief Details:

What: Interviews of whānau for a research study

Where: At home or somewhere close where whānau choose

Time needed: About an hour

A koha for participation will be provided

Your information is private and your contact details are confidential.
I will only contact you if you agree to participate.
Please text or email me on ph. 0274400638 cynthia.dargaville@waikatodhb.health.nz and I will contact you with more information.

More detailed information is available in the information sheet attached.

Ngā mihi nui for taking time to read this invitation.
Cindy Dargaville

APPENDIX 2: PARTICIPANT INFORMATION SHEET WHĀNAU

Kia tipu ai ēnei kākano hei rākau nui: May these tender seedlings grow into mighty trees

A research study to enhance the early intervention experiences of whānau with tamariki living with hearing loss

HE TONO – AN INVITATION TO PARTICIPATE IN A RESEARCH STUDY

You are invited to take part in this research because you are whānau of a child who has been identified as having hearing difficulties by the Newborn Screening Programme and have had a referral to the early intervention audiology services at Waikato Hospital.

This study is looking at what can be improved in the service for tamariki with hearing difficulties and their whānau.

It is your choice to take part or not.

If you don't want to take part, you don't have to give a reason and you and your child will receive the same care. If you do want to take part now, but change your mind later, you can pull out of this research at any time. If you choose to pull out of this research, we will use the information that has already been collected but we will not collect any more information from you or your whānau.

This Participant Information Sheet will help you decide if you'd like to take part.
It tells you:

- why we are doing the research (or the study)
- what taking part would involve
- what the benefits and risks to you might be
- what will happen after the study ends

You do not have to decide today whether you want to take part or not. Before you decide you may want to talk about the study with other people, such as whānau, friends, or healthcare providers. Feel free to do this.

If you agree to take part, you will be asked to sign the Consent Form on the last page of this document.

You will be given a copy of the Participant Information Sheet and Consent Form to keep.

Please make sure you have read and understood all the pages. We can also answer any questions you may have.

HE AHA TE KAUPAPA - WHAT IS THE PURPOSE OF THE STUDY?

The aim of this study is to find out what are the experiences of Māori whānau and their tamariki (identified as having hearing difficulties) to accessing the audiology early intervention service at the Waikato District Health Board. We know that at times this can be difficult for a number of reasons and we would like to understand this more.
We hope this study will help the audiology service provide better support for Māori whānau in the future. This study will help us look at better ways to improve the health system for Māori whānau and tamariki.
If you agree to take part in this study you will be interviewed by a Māori researcher.

ĀKU MAHI -WHAT WILL MY PARTICIPATION IN THE STUDY INVOLVE?

The researcher will explain the study to you and ask for your consent to take part.

Questions

The researcher will ask you a series of questions about your experiences with the Waikato DHB audiology early intervention services. You will be asked about your experiences of the processes and interactions with the audiology early intervention service and what could be improved for whānau.

It should take about 45 minutes to ask all the questions. These questions will be asked somewhere private either in your home or at an agreed location.

A kaitiaki/ whānau support person will also be available if you would like.

You do not have to answer any questions that you find too sensitive, or that make you uncomfortable, and you can stop answering questions at any time. You can answer the questions in English or te reo Māori.

Information from records

We will **not** be collecting any personal health information about you or you tamariki from the Waikato District Health Board.

NGĀ HUA ME NGĀ TUPATOTANGA- WHAT ARE THE POSSIBLE BENEFITS AND RISKS OF THIS STUDY?

Taking part in this study may take some time to answer all the questions. You do not have to answer any questions if they make you feel too uncomfortable. We will try to make sure that the questions are being asked at a time, and in a place, that works for you and you can stop at any time.

You will still receive the same care from the hospital, your doctor and other health services. Your child's and your own usual medical care will not be affected in any way by participating in the study, or by declining to participate or withdrawing from the study at any time.

You may not directly benefit from the study. However, new findings from this study will help the people who provide and deliver health services find out how to better support whānau with tamariki with hearing difficulties.

The information that you share with us will be treated with respect, privacy, protection and care.

MA WAI E UTU -WHO PAYS FOR THE STUDY?

This study is funded by a research grant provided by the Eisdell Moore Centre for Hearing and Balance Research, University of Auckland.

A koha will be provided to each whānau group who participates in the study to acknowledge their contribution to the research.

ME HE MEA NGĀ HARA - WHAT IF SOMETHING GOES WRONG?

If you were injured in this study, which is very unlikely, you would be eligible to apply for compensation from ACC just as you would be if you were injured in an accident at work or at home. This does not mean that your claim will automatically be accepted. You will have to lodge a claim with ACC, which may take some time to assess. If your claim is accepted, you will receive funding to assist in your recovery.

If you have private health or life insurance, you may wish to check with your insurer that taking part in this study won't affect your cover.

HAUMARU - HOW WILL MY INFORMATION BE KEPT CONFIDENTIAL?

The information you provide will be only accessible to members of the research team. The study files and all other information that you provide will remain strictly confidential, unless there is an immediate risk of serious harm to yourselves or others. No material that could personally identify you will be used in any reports on this study. When the study ends, your records will be stored for at least 10 years in a secure place at the Waikato District Health Board. All computer records will be password protected. All future use of the information collected will be strictly controlled in accordance with the Privacy Act.

The study findings will be published, but there will be no identifying information included, so there is no way that anybody could identify you from what is reported.

TIKA TŪĀPAPA - WHAT ARE YOUR RIGHTS?

Your participation is voluntary.
If you decide to take part by participating in this interview, you will be given a consent form to read and sign if you want to participate.
If you have any questions or concerns regarding your rights as a participant in this study, you may wish to contact an independent Health and Disability Advocate. This is a free service provided under the Health and Disability Commissioner Act:

Free phone:	0800 555 050
Free fax:	0800 2787 7678 (0800 2 SUPPORT)
Email:	advocacy@hdc.org.nz

For Māori health support, please contact:
Te Puna Oranga (Waikato DHB Māori Health Unit), Hockin Building Ph: (07) 834 3628

This research project has been approved by the Human Research Ethics Committee of the School of Psychology. Any questions about the ethical conduct of this research may be sent to the Secretary of the Committee, email ethics@waikato.ac.nz, postal address, School of Psychology, Faculty of Arts and Social Sciences, Te Kura Kete Aronui, University of Waikato, Te Whare Wananga o Waikato, Private Bag 3105, Hamilton 3240. Reference number

HE AHA TE HUARAHI WHAI MURI - WHAT HAPPENS AFTER THE STUDY OR IF I CHANGE MY MIND?

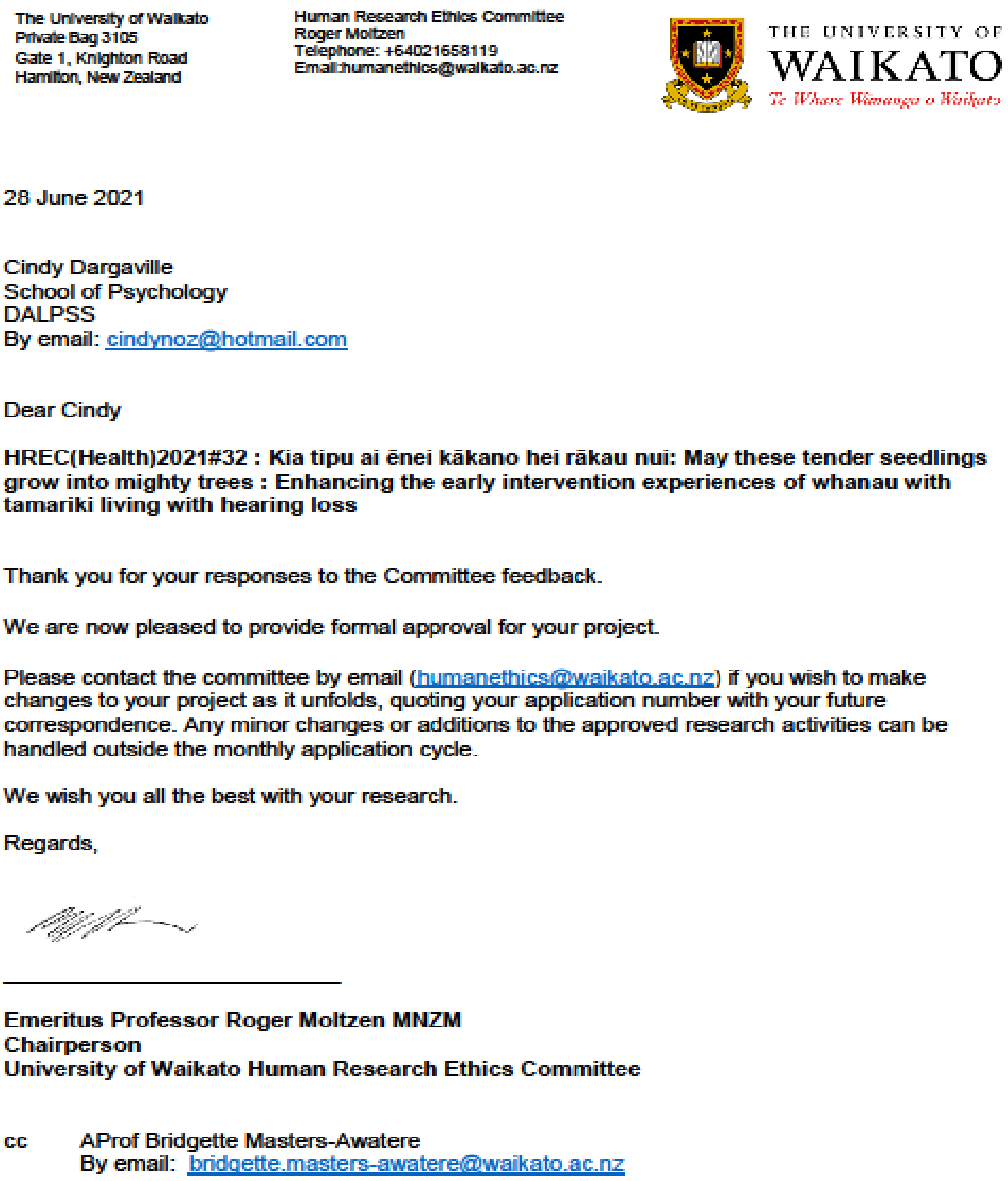
If you take choose to take part in this study, you can choose not to answer any of the questions, and you can also change your mind and stop at any time. If you want to completely pull out of the study, you can do so at any time by contacting me via my contact details below. You are also very welcome to ask any other question about the study by contacting us at the email address below.

WHO DO I CONTACT FOR MORE INFORMATION OR IF I HAVE CONCERNS

Cindy Dargaville (Lead Investigator)
Te Puna Oranga, Hockin L1, Waikato District Health Board
Email: cynthia.dargaville@waikatodhb.health.nz
Phone: 839 8899, 0274400638
Supervisor
Dr Bridgette Masters Awatere
University of Waikato Email: bridgette.masters-awatere@waikato.ac.nz

Thank you for reading about this study, please keep this information if you wish to participate in the study

APPENDIX 3: HUMAN RESEARCH ETHICS COMMITTEE APPROVAL



The University of Waikato
Private Bag 3105
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Hamilton, New Zealand

Human Research Ethics Committee
Roger Moltzen
Telephone: +64021658119
Email:humanethics@waikato.ac.nz

THE UNIVERSITY OF
WAIKATO
Te Whare Wānanga o Waikato

28 June 2021

Cindy Dargaville
School of Psychology
DALPSS
By email: cindynoz@hotmail.com

Dear Cindy

HREC(Health)2021#32 : Kia tipu ai ēnei kākano hei rākau nui: May these tender seedlings grow into mighty trees : Enhancing the early intervention experiences of whanau with tamariki living with hearing loss

Thank you for your responses to the Committee feedback.

We are now pleased to provide formal approval for your project.

Please contact the committee by email (humanethics@waikato.ac.nz) if you wish to make changes to your project as it unfolds, quoting your application number with your future correspondence. Any minor changes or additions to the approved research activities can be handled outside the monthly application cycle.

We wish you all the best with your research.

Regards,

Emeritus Professor Roger Moltzen MNZM
Chairperson
University of Waikato Human Research Ethics Committee

cc APProf Bridgette Masters-Awatere
By email: bridgette.masters-awatere@waikato.ac.nz

APPENDIX 4: CONSENT FORM

Please let us know if you consent to the following

I have read, or have had read to me in my first language, and I understand the Participant Information Sheet.			
I have been given enough time to consider whether or not to participate in this study.			
I am satisfied with the answers I have been given regarding the study and I have a copy of this consent form and information sheet.			
I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time without this affecting my or my child's health care.			
If I decide to withdraw from the study, I agree that the information collected about me up to the point when I withdraw may continue to be processed.			
I understand that my involvement in this study is confidential and that no material, which could identify me personally, will be used in any reports on this study.			
I know who to contact if I have any questions about the study in general.			
I understand my responsibilities as a study participant.			
I wish to receive a summary of the results from the study.	Yes ☐	No ☐	

Declaration by participant:

I consent to take part in this study.

Child's name:

Participant's name *(caregiver/parent)*:

Signature: Date:

Declaration by member of research team:

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

I believe that the participant understands the study and has given informed consent to participate.

Researchers name:

Signature: Date:

APPENDIX 5: QUESTIONS FOR WHĀNAU INTERVIEW

The purpose of this interview is to understand how Māori whānau access and engage with the Audiology Early Intervention service at Waikato District Health Board. This study is looking at what can be improved in the service for tamariki with hearing difficulties and their whānau.

Introduction

Mihi and acknowledgement of whānau time to participate in the interview.

Introductions and whakawhānaungatanga

Identify the purpose of the project and the interview including:

The purpose of the interview is to gain a broader understanding of how Māori whānau currently access the early intervention audiology service

Identify what will be done with their information and steps to ensure confidentiality.

Their rights in the interview

- Refuse to answer any questions
- Leave the interview at anytime
- How their data will be used

Ask if they have any questions before starting the interview.

Confirm their consent and work through the consent form.

Request follow up contact if needed for further information or to send summary of interview.

Questions

1. What was your experience of engaging with the Audiology early intervention services for your child?
    - What was your experience of hearing that your baby had hearing difficulties,
    - What was your experience of the staff,
    - What was your experience of the hospital or outpatients environment,
    - What was your experience of the appointment process,
    - What were some of the issues or barriers that prevented you from attending the early intervention appointments
2. What can be changed to improve the service for whānau?
    - What additional supports do you think whānau need to continue to get help for their tamariki with hearing difficulties?
3. Is there anything else you would like to add?

APPENDIX 6: CONFIDENTIALITY AGREEMENT TRANSCRIBER

For someone transcribing data e.g. audiotapes of interviews

Project title:

Project Supervisor:

Researcher:

○ I understand that all the material I will be asked to transcribe is confidential.

○ I understand that the contents of the recordings can only be discussed with the researcher.

○ I will not keep any copies of the transcripts nor allow third parties access to them.

Transcriber's signature: ……………………………………………………………………………………………………

Transcriber's name: ……………………………………………………………………………………………………

Transcriber's Contact Details (if appropriate):

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……………………………………………………………………………….

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……………………………………………………………………………….

Date:

Project Supervisor Contact Details (if appropriate):

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Approved by the Waikato University Ethics Committee on 28.06.21 on which the final approval was granted reference number HREC(Health)2021#32

Note: The Transcriber should retain a copy of this form

CONFIDENTIALITY AGREEMENT WHĀNAU SUPPORT

For a whānau support worker (kaitiaki)

Project title:

Project Supervisor:

Researcher:

- I understand that the interview meetings I will be asked to participate in are confidential.
- I understand that the content of the interview meetings can only be discussed with the researcher.

Whānau support signature: ……………………………………………………………………………………………………

Whānau support name: ………………………………………………………………………………………………………

Contact Details (if appropriate):

……………………………………………………………………………….

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……………………………………………………………………………….

Date:

Project Supervisor's Contact Details (if appropriate):

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……………………………………………………………………………….

……………………………………………………………………………….

Note: The signee should retain a copy of this form.

Approved by the Waikato University Ethics Committee on 28.06.21 on which the final approval was granted reference number *HREC(Health)2021#32*

APPENDIX 7: EARLY INTERVENTION JOURNEY AT WAIKATO DHB AUDIOLOGY SERVICE

The journey a whānau might take through the entirety of the Early Intervention Service would often look like the following:

Step 1) Screening - before one month of age:

- The whānau is approached by a new born hearing screener either at the birth centre/hospital or via phone if a home birth and/or already discharged, to see if they would like a hearing screen for their pēpi
- The screen is conducted either at the birth centre/hospital or at a visiting outpatient clinic
- If the baby refers the hearing screen in either one or both ears over two screening events the baby is referred to the audiology department for a diagnostic assessment.

Step 2) Diagnosis – before three months of age:

- The booking clerk contacts whānau to arrange a clinic appointment to come in with pēpi. The whānau are spoken to on the phone about what the appointment will involve, and that pēpi needs to be asleep for the appointment
- They are asked to arrive at the appointment with pēpi tired and hungry as this is helpful for pēpi to be put to sleep for the assessment
- An appointment letter is sent out with a link to a video so that whānau can see what will happen at the appointments
- Sometimes more than one appointment is necessary if pēpi does not sleep or only sleeps briefly during the 1.5 hours put aside for the clinic appointment
- If a hearing loss is identified, the audiologist will go through the results with the whānau, including the familiar sounds audiogram, which details the hearing results of pēpi. They are also given the "Getting Started" brochure for more information, which is also available in te reo.
- At this appointment the audiologist will usually seek informed consent from the whānau for referral to the following:

  -Advisor on Deaf Children (who provides support through Ministry of Education)

  -Ear Nose and Throat department for specialist medical opinion as to the causes (etiology) of the hearing loss

- The Audiologist will discuss technology – hearing aids or if the loss is severe-profound cochlear implant and time frames that would be acceptable to the family about when/if to introduce this.

Step 3) Habilitation/Early Intervention

- The goal of habilitation is to help people with disabilities maintain, acquire, or improve their functional abilities in daily life. Typically, habilitation appointments are available from diagnosis until adulthood. Early intervention is habilitation offered in the early years up to 5 years old.

During the First year

- The first early intervention appointment is usually hearing aid fitting
- Following the fitting appointment, the service will see pēpi approximately every 6-8 weeks during the first year to:
    - Take ear impressions as babies ears grow very fast
    - Start testing hearing from 6 months of age using a special type of test called Visual Reinforcement Audiometry.
    - Fine tune hearing aids as more information about pēpi hearing is gathered and to compensate for changes in size of the ear canal as they grow.

During the 2nd and 3rd years, appointments are offered between two and four times a year with the appointment will essentially consist of the same activities as above. At some point, hearing testing transitions to using play audiometry where tamariki respond to sounds using age appropriate games.

(WDHB Audiology Service, email communication, Oct 2021).