You have to get into their world: Exploring parents' experiences of missed therapy appointments

Marcia Susan Underwood

A thesis submitted in fulfilment of the requirements for the degree of Master of Occupational Therapy, the Otago Polytechnic, 2018.

Abstract

This thesis explores the experience of families who have missed therapy appointments, focussing on identifying factors that either facilitate, or create barriers to, participation in these appointments. The study centres on four interviews with parents of children who are clients of a paediatric therapy team. This is the Child Health Centre team based in Whangarei, the only city in Northland, New Zealand’s northern-most province. The multi-disciplinary team is one service provided by the Northland District Health Board (DHB), which is the sole government-funded secondary health organisation in the region.

Previous research suggests that non-attendance is a widespread issue for health services and that the reasons clients miss appointments, are complex. The experiences of families keeping or missing paediatric therapy appointments has not been a big focus in the literature and little information has been located for this population compared with the literature for missed adult, medical or nursing appointments. In addition, the majority of the research is from international studies.

This study employs a qualitative descriptive methodology. Four themes were developed from the data: Connection, Empathy, Empowerment and the Therapist as the face of the organisation. Discussion around these themes highlights the necessity of effective therapeutic relationships with children and with their parents, as they collectively inhabit the role of client. The social context in which this engagement occurs incorporates both the health organisation’s, and the families’, values. Therapists awareness of these values is important. Occupational therapy theory and ethics can be used to guide therapists responses to the dilemma of missed appointments. Implications for practice include therapists contributing to the development of service policy and communication systems, which would place the family as central to service delivery. This involves the acquisition of skills in family-centred practice models such as Occupational

Performance Coaching. For paediatric therapists this may be challenging as it requires a transition away from expert models of practice.

When parenting a child who has been referred to the Child Health Centre, the experience of keeping or missing therapy appointments is part of this journey. Therapists play a critical role in supporting the parenting journey by creating a family-centred therapeutic environment to facilitate families' participation in therapy appointments.

Acknowledgements

I would like to acknowledge the tremendous support of Associate Professor Linda Robertson, who has been an invaluable guide through each new step of the thesis process. Linda, your patient dedication to my work was inspiring to me. Thank-you.

To the Masters programme team of the Otago Polytechnic and the other students within this programme - I want to express gratitude to you for sharing your expertise and experiences. I appreciated the on-line seminars as I transitioned into the role of researcher, geographically isolated from other occupational therapy researchers.

Carving out space to dedicate to writing was enabled by several generous people. I want to thank Jenny and Ella, and Jan, for letting me work in your peaceful, ocean-facing homes while you were away. I also want to thank Julie and Bohdan for proof-reading. I am hugely grateful to my clever IT geek husband - Kyle, you have supported me and my work in an absolute myriad of ways. Thank-you for believing in me. Also thanks to our children, who tolerated my disappearances and my pre-occupied moodiness, over the last many months. I am looking forward to being with you all much more, to getting back into your world.

Finally, I want to acknowledge Tui, who arrived, bringing boundless enthusiasm and joy, into our home around the same time as this thesis. Stepping into the role of dog owner, and preparing this thesis was a parallel process for me. I have used this experience as a metaphor in the form of a childrens' story to illustrate each chapter. I am so grateful for both of these growth opportunities.

Tui and mum at the beach: A story

Once upon a time the family had no pet. Leo, the old cat had died. All mum's friends and even aunty said, "Why not get a dog?"

"We must get a puppy before I grow up," said big brother.

"She will be fluffy and cute," said sister.

"We will help train her," said little brother.

"Must we get a dog?" asked dad.

"We must!" said mum. "A family needs a pet."

And that is how Tui the dog came to live with the family.

Show a people as one thing, as only one thing, over and over again, and that is what they become

~ Chimamanda Ngozi Adichie, 2018

Table of contents

List of Boxes

List of Figures

Glossary

This thesis uses Māori words throughout the text, as these words are in common usage in Northland, New Zealand. A glossary of definitions is provided to support the reader with any words that may be unfamiliar. The definitions are taken from modern and everyday Te Reo (Moorfield 2011).

ara	way, path
kai	to eat, or food
kaiawhina	helper
kanohi ki te kanohi	face to face
kaumātua	male elder
kaupapa	matter for discussion, proposal, plan
kaupapa Māori	a philosophical doctrine incorporating the knowledge, skills, values, attitudes of Māori society
kete	basket or kit
koha	a gift, an offering or contribution
kōrari	flax, Phormium tenax
kõrero	to tell, to talk or a narrative, a story, a conversation
Māori	indigenous person of Aotearoa/New Zealand
Pākehā	New Zealander of European descent
panui	public notice or poster, or to read to notify
tamariki	children
te ao Māori	Māori world-view
te reo	Māori language
tikanga	correct procedure, custom, meaning or practice
wero	challenge
whakawhanautanga	process of establishing relationships
whānau	extended family group
whenu	strand, lengthwise warp in weaving

Chapter 1: Introduction

This is a study of parents' experiences of missing a therapy appointment. In this introductory chapter I provide background for why I considered this to be an important topic and position myself in relation to the study. The organisational context for the study is introduced and is followed by the research aims and the question that emerged. An overview of the methodology used to explore the research question is given and the chapter concludes with an orientation to the whole thesis document.

1.1 Background

This thesis presents the perspectives of parents who have missed appointments with the therapy team within the Child Health Centre in Whangarei, and seeks to understand their stories. The missing of appointments is an issue for many health services, however, little is written about this issue within occupational therapy services (Green 1997), within New Zealand (Dayal, Puketapu, & Suafole Gush, 2013) and specifically in paediatric services (Cameron et al., 2014).

Taking up the personal challenge of a Masters thesis, I became aware of three whenu that would be woven into my project. The first whenu was accepting the opportunity to study at a post-graduate level. The second whenu pertains to collaboration. It was felt that this was a way of contributing to workplace conversations about an important and frustrating topic, and in doing so to critically analyse how therapists might be more collaborative in this one aspect of their practice. The third whenu was about empowerment by providing a means by which the voices of families raising children with health issues in Northland, could be heard. It was thought that in doing so, the research participants would provide a consumer perspective of the missed appointment experience, as the collective voice of this population was not yet captured in an in-depth study.

These three whenu are consistent with my personal values of exploring opportunities, encouraging collaboration and empowering oneself. Having been an occupational therapist since 1993, these professional values have, over time, become personal values. Originally practicing in mental health for a period of approximately 12 years, before branching into other adult settings, it was just three years ago that I took an opportunity to work in a paediatric therapist role. This involved self-reflection to identify which of my clinical skills were transferable to this new setting. One skill that I thought seemed central was the use of a therapeutic relationship in providing an effective practice. An examination of the therapeutic relationship as a driver in client outcomes comparing mental health and paediatric clinical settings (King 2016), resonated with my reflections. My observations appeared to fit with King's (2016) assertion that the paediatric literature hasn't fully explored the impact of therapeutic relationship. For example, the need for therapists to manage the whole therapy process rather than focussing on individual therapeutic techniques.

When embarking on the new occupation of research, I considered my personal background as relevant to my world-view, and approach to the research process. I have a strong interest in children and parenting, being (with my husband) in the midst of raising our three children. I have lived in Northland, New Zealand for the majority of my childhood and adulthood. While identifying my ethnicity as Pākeha New Zealander I also acknowledge my Māori ancestor Tiramate (Ngati Pou, Tainui) whose daughter to British settler Charles Marshall, Harriot, married Richard Buswell Underwood in 1873. They were the first in our family line of Underwoods in New Zealand. I value being a bi-cultural New Zealander having studied Te Reo, being a member of the Pā te Aroha kōrari weavers collective based in Whirinaki, Hokianga and actively pursuing Māori viewpoints through media such as Māori television, opinion pieces, film and books. It was therefore important to me, as I established myself in this new role, to follow bi-cultural research tikanga. Research is culturally safe for Māori when researchers commit to honouring the rights of their participants (Eggleton, Kearns, & Neuwelt, 2016). Personally and professionally, I recognise the value of, and strive to demonstrate, such authentic relationships. These background features establish my personal context for this study.

When initiating the thesis, a local organisational context around missed appointments was uncovered as I connected with a community of researchers. Conversations with clinicians who had undertaken, but not published, similar studies in their workplaces developed. For example, a report of a small study undertaken in the Child Health Centre was located on a storage shelf, and a compulsory workshop called 'Engaging Māori' offered at the Northland DHB heavily referenced work done to reduce missed appointments by the Child Development Team in Hawkes Bay. Then, when participating in the ethical approval process, I was made aware of studies in the outpatient departments of Whangarei Hospital. The key contact person for one of those projects had contact details for her counterpart in Canterbury who had also undertaken a similar study. In New Zealand the studies that have been carried out are localised within departments, and not published, so the work around this issue is fragmented. Obtaining anecdotal evidence provides valuable context that understanding missed appointments and taking steps to reduce the occurrence, concerns many health services. To provide an overview of this issue in New Zealand a summary of my personal communications with clinicians who had undertaken informal studies is presented. The literature review in Chapter Two presents a formal summary of the published national and international literature.

1.2 Whangarei example

In the Northland Child Health Centre the rate of missed appointments for the therapy team, ie. occupational therapy, physiotherapy, and speech language therapy, is 8% overall. Māori families comprise 45% of this data, and as just 32% of the population identify as Māori in Northland, then Māori are over-represented in this missed appointment data. A preliminary project seeking to understand the issue of missed paediatrician appointments at the Child Health Centre was carried out by a clinic nurse who conducted telephone interviews with families who had missed appointments. The method was a telephone interview seeking responses to a range of mostly closed questions (See appendix A) and five solutions were proposed. These were: the increased use of tele-health for families who lived some distance from the clinic, offering appointments at a range of times, utilising touch screens for client surveys, the intention to trial a whānau led booking system, and finally, including the reason for the appointment as well as the clinical speciality in appointment letters. In a recent discussion in this team, it was apparent that recommendations from this study have yet to be implemented to their full extent. Challenges associated with incorporating recommendations into practice are recognised in the literature (Clark, Park, & Burke, 2013).

The Northland DHB outpatient clinic undertook similar work focussing on reducing rates of missed appointments for children seeing ophthalmology specialists (B. McLean, personal communication, May 30, 2017). The project introduced Patient Centred Booking Processes which were then implemented across all paediatric outpatient clinic referrals in Whangarei, and included:

- a letter sent out inviting families to initiate contact to make an appointment at a suitable time
- the booking clerk introducing herself personally to the clients when she spoke with them
- the use of text and/or phone call reminders prior to appointments.

The project had introduced these strategies to all referred children rather than only those who had missed appointments previously. Outcomes were reported as improved staff and patient satisfaction, the team working closer together, and a reduction in the number of phone calls to reschedule and/or cancel appointments. However, a reduction in the rates of missed appointments was not an outcome noted. The importance of targeting initiatives to the populations who most require the intervention to avoid exacerbating disparities of access to healthcare, has been noted in the literature (Mills, Reid, & Vaithianathan, 2012).

A third study within the Northland DHB was undertaken by the medical outpatient team (C. Edmonds, personal communication, December 1, 2016). When this team reviewed the statistics on missed appointments, they learnt that the people who most frequently missed appointments lived closest to the clinic. The team concluded that as clients who lived in regional Northland towns had free, organisation-provided transport to get to Whangarei hospital for appointments, this advantaged them over people who lived in Whangarei where there was no free hospital transport. The issue was resolved when the medical outpatients clinic staff networked with kaiawhina from a non-governmental organisation, a kaupapa Māori health service, to provide transport for clients to appointments. However, this solution is based on the goodwill of kaiawhina staff outside the mainstream health organisation the appointment was with. This example begins to illustrate the different approaches of, and the relationship between, mainstream and kaupapa Māori health services. This could be viewed as the DHB absolving itself of the responsibility to ensure effective access systems are in place, instead relying on a smaller, non-governmental Māori organisation, which may not have been contracted or funded to provide the transportation. In this way, organisational values or world-view is seen as a contextual component for this study as it relates to how organisational power interacts around the client (Eggleton et al., 2016).

1.3 Hawkes Bay example

At the 'Engaging Māori' workshop the focus was bi-cultural practice for clinical and administrative staff, encouraging them to form authentic connections with Māori. It was recommended that, among other strategies, staff would relate to Māori as unique individuals and would interact with them accordingly. This was to avoid assumptions about whether people identify as Māori or not, as well as assumptions about how well-versed people might be in tikanga. The premise was that all staff have the capacity to develop communication styles for effective engagement with Māori and this would provide an improved service compared with staff relying on the organisation's few kaiawhina staff taking on the role of engaging Māori (H. Hurihanganui, personal communication, October 30, 2016). The discussion around engaging Māori in New Zealand provides necessary context for this study because, as with other indigenous populations across the world, Māori health outcomes are poor compared to non-indigenous populations (Hopkirk & Wilson, 2014).

The Hawkes Bay child development team recorded the missed appointment statistics as 25% for Māori whānau and 6 % for non-Māori families (R. Wills, personal communication, November 2, 2016). The team undertook a project to reduce the occurrence of missed appointments. The 25% missed appointments rate for Māori children reduced to 14% when phone call reminders were introduced. The booking team sought to further reduce this figure, and did so by looking at each referral individually and making decisions about what would work best for that whānau in terms of arranging appointments. Collecting social information about the referred child at point of referral enabled the team to personalise how to engage with each family. The population of children who consistently missed appointments was known to be small, as opposed to this being a community wide issue, and the team knew people would struggle to come if they were experiencing violence issues, mood issues, and had addictions. Additional reasons families may not attend and suggestions administrative staff made to empower families to attend, were listed in an email to the researcher (H. Martin, personal communication, November 1, 2016), (see appendix B). The team also recognised a change of language was required from 'did not attend' to 'was not brought' as this better captured the situation for the child who missed the appointment.

Strategies implemented were:

- booking staff spoke with referrers and public health nurses who already had a good relationship with the family about how best to approach them
- offering families the opportunity to choose a time and date most suitable for an appointment

- engaging families with Strengthening Families community programmes for family development
- staff evaluation of how the health organisation values are implemented
- having the team leader routinely audit client files to ensure staff are screening for social issues, ie. family violence, financial difficulty, mental health issues and addiction issues
- up-skilling the clinical team to collect this social information as part of their assessments with clients/families.

One strategy described as crucial to the project's success was emphasis on staff forming genuine connections as part of their administrative or clinical roles. Wills emphasised that "…relationship is the vehicle…" to achieving engagement. A second crucial strategy was a team process whereby staff established what the organisational values looked like when integrated into their team's practice. In particular administrative staff who contacted clients to arrange appointments, were recognised as having key responsibility to enact these values and principles. A systematic literature review on the missing of appointments reached the same conclusion, that engagement and social context are consistent influencers on attendance (Clark et al., 2012).

1.4 Canterbury example

Canterbury DHB Outpatients clinic sought to reduce their rates of missed appointments for children from an average of 8% (and higher than this for Māori) to 5% overall (N. Scott, personal communication, May 25, 2017). As was found in the Hawkes Bay example described earlier, there was a small but consistent number of families who missed appointments and also the term 'was not brought' was deemed a better fit than 'did not attend' for childrens' appointments. The service initiated a project aimed at reducing the rates of missed appointments for children and a second collaborative care project, for children with high and complex needs, ie. those children with three or more specialists involved. Both projects involved interviewing some of these families to learn how to better meet their needs. The team recognised the struggle for families of balancing family routine and dynamics with meeting staff expectations for keeping appointments. They were moved by one interviewee who described that although she hadn't had a holiday for many years, as her annual and sick leave was used for appointments and admissions for her child, she still seemed unable to meet the demands put on her time by the team. Sharing video footage of parents' interviews with clinical and administrative staff was said to be the most significant force for change, as this accessed staff empathy.

As a result of the project, changes made to the service included:

- each time this population was asked to come to an appointment they were also asked how they could be supported to attend
- explanations were given to ensure the families understood the value of the appointment
- one contact person from the health service was nominated for the client's school and parents' workplaces to liaise with.

Additional strategies undertaken by the service to specifically reduce missed appointment rates, among Māori and Pasifika families, included engaging a separate kaiawhina community service (as was done by the medical outpatients team in Whangarei) that could offer transport to appointments and, for Pasifika people, engaging advocates to help overcome language barriers. In this way the organisation took a cultural based health literacy approach to address the issue of non-attendance. This approach has been identified as being a particular challenge for health staff working with ethnic populations that are different to the mainstream ethnicity (Lambert et al., 2014).

1.5 Identifying the issue

These New Zealand examples illustrate that health services take seriously the missing of appointments; a finding that is echoed in the literature and will be reviewed in the literature review. Reasons for non-attendance are complex, and health services are concerned because not only do they result in service inefficiencies but they also are inequitable, as clients miss out on receiving the benefits of access to health professionals (Andrews, Morgan, Addy, & McNeish, 1990).

In referring to inequitable access, reference is also made to the 'inverse care law' which recognises that those people most in need of health services are also those most likely to be hard-to-reach (Rahman et al., 2014). All of the New Zealand examples present statistics that Māori have higher rates of missed appointments than non-Māori. The connection between missed appointments and poor health outcomes is not necessarily causative, however, it is known that the lack of access to services contributes to health inequalities for Māori (Robson & Harris, 2007). It is also clear that although clients' individual social context heavily influences their attendance, services are exploring how they might address these contextual factors. Service perspectives and client perspectives matter in this area, for example a systematic review of hard-to-reach families demonstrated the existence of a wide range of literature written from many aspects and questioned whether it was families who are hard to reach or services (Boag-Munroe & Evangelou, 2012). Therapists, who work in paediatrics, are recommended to transfer their focus from the individual child to include the social context surrounding that child, ie. to become family-centred (Dempsey & Keen, 2008). As occupational therapists have occupation as their unique professional focus and developing therapeutic relationships with their client, and their clients family, is fundamental to that (Fisher 2013), then it would follow that the profession is well-placed to seek to understand factors pertaining to keeping or missing appointments.

The Northland DHB policy is to discharge clients after they miss two offered appointments and there is no variation in the policy for specific services or client populations. At the Child Health Centre appointment letters do not advise what the implications of missing an appointment will be for the child. This is a standard approach to managing missed appointments, which has been criticised in paediatric practice as a childrens' rights issue (Arai, Stephenson, & Roberts, 2015). Being empowered to make choices – or conversely being a child and having choices made on one's behalf – about which occupations to participate in, is also described as an occupational rights issue (Rebeiro Gruhl 2009), and keeping or missing appointments could be seen in that light.

The projects described thus far have been initiated by nursing, medical, and administrative staff and no New Zealand based anecdotal or written evidence has emerged from therapy teams, in particular occupational therapists, exploring the missed appointment phenomenon. Occupational therapists are encouraged to undertake research into the missing of therapeutic appointments so that best practice around engaging those families who might be hard-to-reach can be established (Phoenix & Rosenbaum, 2015). In their own professional literature occupational therapists have been criticised for not taking sufficient interest in their client's social environment (Durocher, Rappolt, & Gibson, 2013). This may explain the limited literature on missed occupational therapy appointments (Green 1997), since as is becoming apparent, a study of this experience is a study of relationships, multi-agency connections and social context (Maharaj, Rahman, & Adamson, 2014).

Therefore it was considered that a study exploring this issue in paediatrics from an occupational therapy perspective would fill a gap in the profession's knowledge, but more importantly that such a study would fill a gap in health organisations' knowledge of how to address missed therapy appointments.

1.6 Identifying the purpose

As alluded to earlier, the aim of this research was to hear how parents describe the experience of missing a therapy appointment. The context for answering this question is the therapy team at the Child Health Centre in Whangarei, where no specific study in relation to attendance within the therapy team had previously been done. I became aware of an additional purpose for this research when reading the work of Hammell (2009) who has called for further client-centred research to contribute to a potential reconfiguring of traditional occupational categories, especially when those occupations indicate inter-dependence. Preliminary understandings of bi-cultural practice and of theories around occupational justice gained during the scoping stage of this study, resulted in excerpts from my early summary of literature being published in themed editions of the Occupational Therapy Insight magazine (Underwood 2017a, 2017b). These publications affirmed the projects value, timeliness and relevance for the profession.

On that basis, the purpose of this study was to answer the question:

What helps and what hinders families from participating in therapy appointments with the Child Health Centre in Northland?

The question refers to families rather than parents or caregivers as I did not want to pre-empt which family members perspective might be gathered, and I preferred to let the research design determine who might be recruited. The phrase '…participating in…' was used in favour of the more familiar term 'did not attend' or simply 'DNA' (Arai et al., 2015). This was because appointments with the therapy team are either a home visit or clinic based, and neither the term DNA nor the suggested 'was not brought' fitted with the home visit scenario. Also, as already mentioned, there was a need to establish the research within the contexts of occupational therapy and family-centred practice, where the concept of families participation or collaboration with therapists is highly valued (Graham, Boland, Ziviani, & Rodger, 2018; Hanna & Rodger, 2002).

1.7 Thesis organisation

To inform the research question, I conducted a review of the literature, which has been presented in Chapter Two. Literature on the phenomenon of missed appointments was the primary focus before also exploring literature pertaining to individual and organisational factors, as well as the ways that occupational therapists have sought to understand this issue.

The choice of methodology and methods was made to ensure a good fit with the research question. As this research explores the experience of an event or series of events, a qualitative methodology – qualitative description – was selected. A similar study into barriers and facilitators to mothers keeping neo-natal follow-up appointments also utilised the qualitative descriptive methodology (Ballantyne, Benzies, Rosenbaum, & Lodha, 2015). This choice of methodology was determined as consistent with my viewpoint of naturalistic enquiry. Chapter Three outlines the methodology as well as why and how the research was aligned to a Māori framework of ethical research, Te Ara Tika (Hudson 2010). Māori words have been used throughout the thesis as a component of bi-cultural writing and a glossary (see page xii) has been provided to assist with comprehension.

Chapter Four is an analysis of the research findings categorised into themes using qualitative content analysis (Sandelowski 2000). This captures the research participants' own language as they describe the range of factors involved with the decision to keep or to miss a therapy appointment. A discussion of these findings is presented in Chapter Five, where the researcher seeks to position the findings amongst the existing knowledge on this issue. Both the limitations of this study and the potential for further research are noted. Based on the findings of this study, recommendations and implications for occupational therapy practice at the Child Health Centre are suggested. Finally, Chapter Six concludes the thesis by synthesising the research project, and suggesting future directions.

Throughout this thesis the term 'parents' has been most frequently used rather than the terms 'care-givers', or 'family members', or 'whānau', or 'grand-parents raising grandchildren'. It was not my intention to exclude any people who may be in the important role of raising a child. I elected to use the term 'parents' due to the research participants all being parents and for consistency and flow through my work.

References and appendices are presented at the end of this thesis.

Everyone loved Tui, and Tui loved the family.
"Tui is the perfect puppy," said big brother.
"She is so fluffy and so cute," said sister.
"She sleeps on my bed," said little brother.
"She eats my socks," said dad. "And she runs away."
"Oh dear," said mum. "I will train her."
But mum had never trained a puppy before. How would she get Tui to come?

Chapter 2: Literature Review

A review of the literature was conducted to explore what is currently known on the topic of missed appointments in paediatric occupational therapy services. The search parameters extended to literature drawn from occupational therapy and other health professions; from international sources as well as New Zealand specific sources; and from a range of both adult and paediatric health care service settings. This breadth of search was undertaken for two reasons. First, New Zealand based, paediatric, occupational therapy literature alone did not provide a rich picture of missed appointments. Second, it was noted that issues described in the adult literature matched those described in paediatric literature, and this was the same when comparing issues from the international literature with New Zealand specific publications. Inpatient health services were excluded from search parameters due to the nature of these services not incorporating booked appointments. The focus was on community (eg. home visits, clinic settings away from a main service base) and outpatient (eg. clinic services offered on a hospital/clinic main site) health services. Research is drawn from physical health, mental health and paediatric services.

Literature was located using a range of search terms, such as 'non-attendance' with 'occupational therapy', with 'community services' and 'paediatrics'. A second phase of the literature search used terms that appeared as significant in the non-attendance literature, such as 'social context', 'hard-to-reach' and 'inequity of access'. Research was accessed electronically through the Otago Polytechnic Robertson library, which gave access to a range of data-bases, eg.CinAHL, Cochrane, PubMed, ProQuest and other libraries material. Google Scholar was also used as a search site. The time span for the literature gathered in this review is from 1990 to the present, with a noticeable trend of the majority of articles being published after 2002.

The literature reviewed has been arranged into five sections. The first section investigates the international commentary on missed appointments in adult health services. This is followed by a review of missed appointments in New Zealand adult health services, then how the issue has been researched in paediatric services. The fourth section collates the literature in relation to therapy settings, in particular, occupational therapy specific literature. This includes not only what occupational therapists have written about missed appointments but also how philosophically, occupational therapists might approach the issue. Finally, a summary of all the literature reviewed is provided, and this concludes by making a case for exploring the research question.

2.1 The International Conversation

Missed appointments at health service clinics are a concern internationally (Andrews et al., 1990; Green 1997; Simons, Pearson, & Dittu, 2015; Stathopulu, Ajetunmobi, & Selling, 2003). The rates of non-attendance across service types are described in the literature as varying from a low of 8% (Green 1997) to highs of 30% (Fitzpatrick & Remmer, 2011) and 40% (Lacy, Paulman, Reuter, & Lovejoy, 2004). An average non-attendance rate is around 12% (Cameron et al., 2014; Simons et al., 2015). However, when health services non-attendance rate is calculated for minority ethnic groups, then the rates are higher (Azerkan et al., 2015).

Language used to describe people who miss appointments includes a selection of terms, including 'hard-to-reach' (Phoenix & Rosenbaum, 2015), 'did not attend' or 'DNA' (Arai et al., 2015), 'No Show' (Abdus-Salaam & Davis, 2012; Arnold 2012; Lacy et al., 2004), and 'missed appointments' or 'MA' (Simons et al., 2015). Sometimes services are described as hard to reach or access, and this indicates that factors pertaining to service features as well as to individual client features, require consideration (Phoenix & Rosenbaum, 2015). Arai (2015) noted that a 'true' DNA referred to when reasons for missing an appointment related to the person and the term 'false' DNA was used to indicate a missed appointment pertaining to service factors.

A number of studies have examined the issue of non-attendance from the perspective of consumers (Azerkan et al., 2015; Ballantyne et al., 2015; Clark et al., 2013), as well as the perspective of the service. The perspective of health services is often further divided into the views of clinical staff, administrators and funders (Cameron et al., 2014; Dennison 2003; Fitzpatrick & Remmer, 2011; Simons et al., 2015). Cameron's (2014) study of clinical and administrative hospital staff and general practitioners found that all realised the impact of social factors on attendance and Cameron concluded that general practitioners are well-placed to strategise for families improved attendance at hospital clinics. Gathering information on the impact of missed appointments from both staff and consumer perspectives is valuable. Clinical staff can provide insights based on what they observe in practice and how this affects their practice (Arnold 2012; Cameron et al., 2014). While consumers can provide clinical staff and administrators with understandings about their reasoning when deciding to keep appointments or not (Azerkan et al., 2015). Simons cited Darzi (2015, p62) who recognised the value of this approach saying – "if quality is to be at the heart of everything we do, it must be understood from the perspective of patients". In this instance, improving the quality of service provision can occur when more is understood about what keeps people from attending appointments.

2.1.1 Individual factors

There are a wide range of services such as cardiac rehabilitation, dental outpatients, community nursing, and cervical screening, where research has been undertaken investigating barriers to keeping appointments. However, the factors contributing to missed appointments are similar across services, and can be divided into both personal and contextual factors (Andrews et al., 1990; Lacy et al., 2004; Mian, Eisenhower, & Carter, 2015). In a systematic review of influences on attendance at cardiac outpatient clinics, Clark et al., (2012) found that individual or personal factors are the main limitations to people attending cardiac outreach. Also, those people who miss appointments are more likely to do so due to social rather than health related factors, ie. they tend to be from deprived socio-economic backgrounds, to be single parents, to have a lack of transport options, and to have intellectual difficulty or mental health issues that impact on relationships (Clark et al., 2013; Stathopulu et al., 2003). Individual barriers to keeping appointments, ie. those pertaining to the clients perspective, are presented in box 1.

Box 1: Individual barriers to attendance

- remembering the appointment (Ballantyne et al., 2015; Simons et al., 2015)
- the appointment didn't seem to be required (Ballantyne et al., 2015)
- lack of awareness of appointment (Clark et al., 2013, 2012; Simons et al., 2015)
- client was too unwell to go out (Ballantyne et al., 2015; Simons et al., 2015)
- perception of and reaction to health condition, ie. lack of concern of impact of condition (Clark et al., 2013, 2012)

Client identity also plays a role (Clark et al., 2013, 2012). Clients may not view themselves as the sort of person who would benefit from attendance, and therefore decide not to attend (Clark et al., 2012). Conversely, Azerkan et al., (2015) found that people who missed appointments didn't see themselves as non-attenders just that "life got in the way" (p1). For some people engaging with health services can reinforce that their impairment is not a good thing, contributing to a negative self-identity (Kielhofner 2005).

This links to the concept of internalised oppression, defined as when people who identify with a marginalised population, take on the mainstream attitudes of limitation about their own life (Reeve 2004). One form of internalised oppression known to limit participation is disablism and this is frequently under-recognised – especially in children whose able-bodied parents may without realising, transfer prejudices around disability (Reeve 2004). Although not referring directly to the missing of appointments in her work, Reeve (2004) noted that the impact of internalised oppression restricts participation in activity for people with disabilities as much as structural or environmental limitations do. Thus, client identity may be a factor in non-attendance.

Despite public healthcare systems being designed to meet the health needs of a whole population, there are a number of known systemic limitations. In 1971 John Tudor Hart first outlined the 'inverse care law' which states that those people most needing health care services are in fact those who miss out as they are hardest to reach (Rahman et al., 2014). Rahman et al., (2014) asserts that by understanding this link services can take steps to ensure clients have access to the appropriate health service. Wade & Stocks (2017) summarise this as: "Overall, these inequalities are hard to reverse because the advantaged groups who already have better outcomes, i.e. those who are urban, of higher SES (social economic status) and non-indigenous, have greater access to health care, adhere more to treatments, and are more likely to benefit from programs advocating healthy lifestyles … hence the disparity grows. This effect is commonly known as the 'inverse care law'." (Wade & Stocks, 2017, p332).

Concurring with the inverse care law a number of international studies show marginalised populations have poorer health outcomes compared to members of the mainstream society (Arnold 2012; Azerkan et al., 2015; Donnelly & McKellin, 2007). When attempting to reverse the impact of the inverse care law health organisations could focus on the concept of health literacy. This is defined as "the ability to obtain, process, and understand basic health information and services to make appropriate health decisions" (Lambert et al., 2014, p615). Although it is recognised that the ways limited health literacy contributes to poor health outcomes are complex, some organisations have developed diverse communication strategies targeted to address consumers with limited literacy (Schillinger 2007). An earlier literature review exploring desirable features of written health information, recommended that to facilitate clients' learning the material needs to be easily read and understood by the intended recipient (Griffin, McKenna, & Tooth, 2003). Lambert (2014) identifies that health professionals have a role in promoting clients' awareness of how health services can benefit them, ie. of understanding and promoting health literacy such as by ensuring communications are client-centred, yet many staff have a poor understanding that this is a role they can fulfil.

However, this individualised approach to improving health outcomes could be seen to value personal responsibility for addressing health needs, over considering the many additional societal factors. For example, writing about Vietnamese women in Canada accessing breast screening services, the authors note that the inter-relationships marginalised populations have in society can inhibit how they seek and engage with services for meeting their health care needs (Donnelly & McKellin, 2007). Arnold (2012), writing about rural indigenous North Americans as a marginalised population, agrees stating that the determinants of health are strongly related to socio-economic factors. She further asserts that because of this attending appointments doesn't necessarily improve health outcomes (Arnold 2012). In reviewing the literature on missed appointments, an analysis of social determinants of health is also therefore required. Services offering appointments for improved health outcomes of the people who attend, can benefit from understanding that improved health outcomes are largely determined by societal factors rather than individual factors.

2.1.2 Contextual factors

Literature about inequity of health outcomes links these with poverty (Hammell 2015; Roberts 2004). Poverty can be defined as "not simply a problem of inadequate financial resources, but comprises a matrix of social exclusion that includes limited access to education, employment, housing and transportation" (Hammell 2015, p15). Writing about social exclusion in Latin America, Roberts states that "inequality and vulnerability rather than poverty per se, are seen as the major challenges" (Roberts 2004, p2). Understanding the impact of these wider social factors is important to move the focus away from targeting the individual who missed their appointment as a form of victimblaming for their health disparities (Arnold 2012). Schillinger, (2007) agrees with this sentiment, acknowledging that addressing the impact of society on a person's ability to engage with health services may be viewed as outside clinicians realm of responsibility. Poverty is the factor that has the biggest impact on how people with disabilities are able to influence their participation with health services (Hammell 2015).

Nevertheless, it has been argued that services can take steps to minimise the rate of missed appointments, and that it is their responsibility to do so in order to address potential health outcome disparities for clients who miss appointments. Health services have an obligation to ensure that people know what the service can offer them (Donnelly & McKellin, 2007). Health service administrators rather than clinicians could be seen to have more of a role. The most frequent method for arranging an appointment with a client is for a health administrator to allocate a time, date and location and to advise the client of these in a written letter sent by post. This administrative process is complex and can break down for several reasons (Arnold 2012). For example, it places a high literacy demand on clients, relying on them being literate with relatively formal language (Schillinger 2007). The written appointment notification process also requires correct address details to be stored on file (Andrews et al., 1990). The process may involve the appointment being booked too far into the future and later overlooked or not required if poor health symptoms seem to have resolved (Andrews et al., 1990).

Administrators, in conjunction with clinicians, can also effect change at a policy level. An examination of the missed appointment policies of several services in the United Kingdom National Health Service, recommended publishing these on organisation web-sites, stating that consumers would benefit from increased awareness of the implications of missing an appointment, and health services would be advantaged by fewer missed appointments (Arai et al., 2015). Policies appear to have been developed with the assumption that society at large agrees with the organisation's perspective and yet this is debatable since the policycreators are typically located in an English-speaking (mainstream) context not representative of the communities impacted by those policies (Boag-Munroe & Evangelou, 2012).

Research identifies that many of the populations who miss appointments have differing world-views to those of the health service. There are several international studies that support this, eg. a study of community nursing in North American indigenous communities (Arnold 2012); a study of missed cervical smear appointments among Danish and Norwegian immigrant women in Sweden (Azerkan et al., 2015); and a study of dads not bringing their children to psychology appointments (Dennison 2003). Arnold (2012) iterates that when policies and attitudes embodied in clinical practice come from one particular world view, this perpetuates bias, such as institutional racism as maintained by processes of colonisation. An example from the North American nursing service was the organisation's policy of using a 'no show' stamp in clinical notes which inhibited clinicians and administrators from really understanding the reasons for, and the impact of, the missed appointment (Arnold 2012). There is a growing body of evidence that when services take measures such as diversifying their workforce, then improved outcomes result (Schillinger 2007), although it was not specified in that article if these improved outcomes include keeping appointments.

Differing world-views and institutionalised bias contribute to social or contextual barriers for missing appointments, ie. those factors at the interface between services and clients. As stated earlier, it was found that while individual factors had greater influence over attendance, there is a greater range of factors to consider in the category of contextual barriers to attendance. These barriers are listed in box 2.

Box 2: Contextual barriers to attendance

- misunderstanding the reason for the appointment (Andrews et al., 1990)
- previous negative experience of health services (Rossiter, Fowler, Hopwood, Lee, & Dunston, 2011)
- clients fear of what might be involved in the appointment (Dennison 2003; Lacy et al., 2004)
- clients feeling their time is not valued when required to wait in waiting rooms (Lacy et al., 2004)
- distrust and lack of understanding of booking system (Lacy et al., 2004)
- the logistics of getting there, including travel (Ballantyne et al., 2015)
- accessibility, eg. parking proximity to health service venue (Fitzpatrick & Remmer, 2011)
- location of appointment (Andrews et al., 1990)
- financial and work-related constraints (Clark et al., 2013, 2012)
- balance of perceived benefits of keeping appointment with costs to get there, eg. missed work, childcare for other children (Andrews et al., 1990; Fitzpatrick & Remmer, 2011)

In summary, the international literature on missed appointments highlights both individual and contextual factors for this widespread phenomenon. Strategies proposed to improve attendance rates are complex, taking into consideration not only individual client situations, but also service policy and practice as well as societal contributors to health disparities. It is appropriate that the issue of missed appointments has been researched from the perspective of consumers, clinicians and health service administrators as each group provides valuable insights into the experience. Ultimately, service developments need to recognise consumer choice to participate in therapy (Clark et al., 2013), and this requires staff to comprehend their clients various world-views. When organisations improve their health literacy, including advising consumers of policy regarding how the missing of appointments will impact them, then this contributes to reducing health disparities.

Having noted that the international literature identifies several influences that impact on attendance, this review will now focus on the New Zealand literature.

2.2 The New Zealand kōrero

In New Zealand the issue of missed appointments is widespread, although not widely published. This section discusses the limited New Zealand literature on missed appointments, and compares it to the international literature. Influences related to the patient or individual, as well as the clinic or organisation were found to be important for understanding the issue (Dayal et al., 2013; Loh, Jaye, & Dovey, 2015). The rates of missed appointments published in the New Zealand literature are lower than the 12% average for international health services. For example the Hutt Valley DHB calculated their overall missed appointment rate as 8%, with Māori rates being almost triple this figure (Dayal et al., 2013). Given the higher rate of missed appointments among Māori, this discussion also looks at the New Zealand literature on marginalised populations.

Hutt Valley DHB Outpatient clinics, as well as other lower North Island DHB's, aimed for a rate of 6% for all missed appointments as part of an 'equity indicators' target (Dayal et al., 2013). Māori and Pasifika health teams developed strategies specific to the populations served, adding specific steps into the standard booking system. These steps included a focus on obtaining the history of attendance for specific people the service was concerned about, supporting these people to attend, obtaining correct contact details and following up non-attendance. This resulted in a slight yet sustained improvement in attendance rates – Māori rates of missed appointments shifted from 16% to 13% (Dayal et al., 2013). Developing strategies that address unique client situations rather than seeking generalised solutions is an approach supported in the wider New Zealand context (Loh et al., 2015).

Another published study evaluated the experience of the audiology service in Northland DHB and demonstrates the challenges of implementing change. Here the service worked with a project team to evaluate how they could minimise missed appointments (Hetaraka & McLean, 2015). The team understood from service statistics that missed appointments were higher for Māori than non-Māori clients and to reduce all missed appointments they adopted the Patient Focussed Bookings (PFB) approach of offering client options around times and location of clinic. In her report, Hetaraka (2015) focuses on how the Model of Improvement's four steps of Plan-Do-Study-Act was introduced for administrative and clinical staff to implement changes to the booking system. The project intended to use the Transformational Patient Experience Model to measure benefits to clients, however at the end of the project, the audiology team were still in a phase of readiness to change. By contrast, the ear nose and throat (ENT) and general surgery outpatient clinics, benefitted from the audiology team's process as they adopted some of the recommended PFB changes (Hetaraka 2015).

These studies indicate that services are motivated to address the problem of missed appointments, however, the scope of changes that can be made is limited to focusing on clients as individuals and not taking into account their social context. Health funding models and the current economic paradigm pre-supposes that people will exercise their ability to make choices for the greatest advantage to themselves or their family (Mills et al., 2012). The extent to which they are able to do this is limited for families who are marginalised, as shown internationally and in New Zealand, as inequity of health outcomes are linked with poverty (Davies, Crothers, & Hanna, 2010; Nobilo 2014; Schillinger 2007).

2.2.1 Social context

Social context has come through from the international literature as a minor factor in keeping appointments when compared to individual client factors (Clark et al., 2012). However, in New Zealand the greater emphasis is on context (Dayal et al., 2013). Loh's (2015) study of people who missed appointments at a free GP service noted that people who access free services are likely to be experiencing socio-economic deprivation, and this population has been described as hard-to-reach, vulnerable, and marginalised. This population are known to feature health behaviours such as normalising poor health and having limited expectations of a good health outcome from engaging with clinicians (Loh et al., 2015). The outcomes of Loh et al.,'s (2015) study recommended addressing the mis-match in clinician values and expectations and consumer values and expectations, and the same conclusion was reached in a study exploring ways to engage vulnerable families in Australasia (Rossiter et al., 2011).

Links between the missing of appointments and marginalised or vulnerable populations are notable in the New Zealand literature as it is consistently found that the people who miss appointments are heard to reach. Also, as is evident in the international literature, indigenous peoples' rates of missed appointments are higher than non-indigenous populations (Arnold 2012; Dayal et al., 2013). Public health organisations in New Zealand provide free health services to all of New Zealand society, however, outcomes from those services are inequitable as Māori and other minority ethnicities are consistently over-represented in poor health outcomes compared with non-Māori (Nobilo 2014). Health disparities or inequities in access to, and outcomes from, health services for children are unjust, avoidable and result in a significant cost to New Zealand society (Mills et al., 2012). When children are raised in environments that are physically, emotionally and intellectually impoverished their ability to reach their potential is limited (Davies et al., 2010). Many New Zealand children struggle to manage the negative impact of disadvantage or of being different to the majority of children (Davies et al., 2010). It is a component of the role of paediatric occupational therapists to understand the links between childhood poverty and its impact on children's occupations (Leadley & Hocking, 2017).

2.2.2 Strategies for health equity

Strategies to address health inequities focusing on social context rather than the individual, have been shown to be effective. These include improved access to primary care, improved housing, reducing child poverty, and good early childhood education (Mills et al., 2012). Notably not all of these strategies would fall under a health service umbrella, as some would be considered housing, welfare and education responsibilities. Health service initiatives aimed at reducing health inequities are more successful when targeting deprived populations, as un-targeted initiatives have been found to also benefit less-deprived populations, where Māori are under-represented (Mills et al., 2012). Kaupapa Māori services view Māori and inequitable health outcomes as a central concern, (Mills et al., 2012) and are seeking to redress this imbalance through targeted initiatives as are isolated services within mainstream health organisations (Dayal et al., 2013).

Kaupapa Māori services have been developed by Māori tribal groups as alternative health services that are based on Māori principles and world-view. Mainstream health services have been established and maintained as organisations where power has been embedded within their infrastructure (Eggleton et al., 2016). In New Zealand health organisations, this power primarily comes from the world view of people who are descended from the colonisers (Eggleton et al., 2016). When the world-view of health practitioners fits with the world-view of indigenous or marginalised populations health improves for those populations (Hopkirk & Wilson, 2014). For example, it is known that often Māori clients value being seen as connected with the context of their extended family, the natural environment, and the historical and social realities of being Māori (Hopkirk & Wilson, 2014). To address this discrepancy in world-view, health professionals are recommended to become better informed around Māori culture to practice cultural safety (Lacey, Huria, Beckert, Gilles, & Pitama, 2011).

Cultural safety is one strategy for staff seeking authentic engagement with clients and their families, which provides for addressing power imbalances. In the introduction chapter, effective engagement with Māori was linked to reducing rates of missed appointments in Hawkes Bay DHB. When engagement is poor between medical clinicians and their clients, both report this as a negative outcome (Lacey et al., 2011). Rossiter (2011) noted that clinicians have the responsibility, skills and the power to impact how clients engage. One cultural safety strategy seeking to affirm Māori clients ability to engage in healthcare, is to work towards a match in values between services and Māori clients by adopting principles of Te Ao Māori (Rossiter, 2011). Lacey developed the 'hui consultation process' to provide a framework for medical students to promote engagement in their consultations. The four steps of the hui process are:

1. Mihi - an initial greeting, an introduction of the staff member and their role, an introduction of the purpose of the contact, and confirmation of whether the client identifies as Māori
2. Whakawhānaungatanga - making a connection by shared understanding of the value of land, whānau involvement and use of te reo, includes self-disclosure by staff about personal experience of these, often repeatedly returned to throughout contact
3. Kaupapa - focus on the purpose of the contact, which might be achieving specific communication or clinical outcomes
4. Poroporoaki - wrapping up the contact, having a clear end-point to the contact, identifying next steps, includes clarifying that the client has been understood, that health information has been understood and that next steps are explicit (Lacey et al., 2011).

There is potential for the hui process to be applied to all interactions between the health service and Māori clients, to enhance engagement at a service level by demonstrating shared world-view or values.

In summary, published New Zealand literature on the topic of missed appointments is a small body of work compared to the quantity of services seeking to understand and taking steps to address this issue. There is strong evidence that effective engagement is key. Māori are over-represented in the statistics for missed appointments as well as for poor health outcomes, although the link between these two facts has not been established. Literature describing poor health outcomes and disparities was included as these provide context for understanding the missed appointment experience as being not simply an individual health issue but largely a social issue. It has been suggested that consideration of power imbalance and world-view differences between mainstream services and Māori can be addressed by diversity of perspective in the workforce and by developing cultural safety.

Having focussed on the international and national literature regarding missed appointments, the literature review will now explore how paediatric services understand the missed appointment experience.

2.3 Paediatric Services

Authors of literature in the paediatric missed appointment space have recognised the need to consider the dynamics of the family and the therapy team. This is in addition to service features, such as referral information and individual factors, such as identity. These issues are explored in this section. The question of how families make their decision to keep an appointment is also considered.

The population of children who tend to consistently miss appointments is considered to be small, as opposed to being a widespread issue across the entire community (Simons et al., 2015). Children who miss an initial paediatrician appointment have a higher chance of missing consecutive appointments (Stathopulu et al., 2003). In a British community paediatric service those clients most likely not to attend are aged under 5 years old, known to child protection teams, have been waiting longer than 4 weeks for an initial appointment, and are from a deprived socio-economic area (Stathopulu et al., 2003).

2.3.1 Referral information

When services collect referral information, which gives insight into clients' social situations, this enables them to consider and create unique pathways for engaging with those clients (Dennison 2003; Simons et al., 2015). Discussion directly with clients/families allows therapists and administrators to understand what barriers to attendance exist and how these could be addressed (Simons et al., 2015). In addition, this gives an opportunity for establishing how concerned the family is regarding their child's health, as keeping appointments has been found to relate to how the parent interprets the child's need for assistance (Mian et al., 2015).

This and other relevant family factors are often not identified in referral information so are not able to be addressed. For example, information on who the primary caregiver is, how this person understands their own and their child's identity, both in relation to health factors and in general, would not be known. Yet, Ballantyne et al., (2015) found that perceived vulnerability of their child influenced mothers' decisions about attendance; while Dennison (2003) concluded that for fathers to attend appointments with their child was to challenge their male identity, which is stereotypically reluctant to disclose personal issues and ask for assistance. Not having awareness of the individual family structure, limits how services can target their approach to seeking an appointment with the identity of that person or whānau.

Instead services might focus on aspects they can address, such as restructuring clinics. Overall there is limited evidence that the match between service delivery and parent preferences, eg. time of day, has a significant impact on attendance (Mian et al., 2015). Simons (2015), who studied children's dental clinic attendance, also found that missed appointments were not related to receiving a reminder, the time of day, day of the week, what procedure was planned, or which clinician was to be seen. Heath (2013, p245) found that when care "fits into their lives" spatially, temporally, and emotionally families are more likely to bring children to appointments. These findings give weight to the argument that the most significant barriers are not related to the health system per se, but are personal to the client and their social situation. Conversely, it could be argued that if a service is aware of the existence of social inequities among children referred and does not take steps to address these, then the individual's social context that keeps them from attending appointments, in effect becomes a systemic or structural issue.

2.3.2 Policy

Understanding the range of barriers to keeping appointments for children assists the design of effective missed appointment policy. Arai et al., (2015) mapped 'did not attend' guidelines from paediatric services across the British national health service. Three main points from this work were that most guidelines were to discharge after two offered appointments had been missed; that guidelines were not designed for paediatric services; and that guidelines were not transparently displayed for families to make choices informed about the consequences of not attending. Arai et al., (2015) makes a further important point that balancing the unmet therapeutic needs of children and their right to therapy, with the need to support families, requires sensitivity and skill from the clinicians and service administrators. The practice of discharging after two missed appointments was seen as over-simplified as missing an appointment may or may not equate to risk for a child, so the recommendation was then made that services introduce distinctions within their policies for different scenarios. For example, if the health condition of the child is severe, if the missed appointment is considered to significantly impact the child's development, or if the child is vulnerable for social reasons then further efforts should be made to see that child. This approach requires services to understand the complex reasons people miss their appointments (Arai et al., 2015).

Information regarding how the appointment may benefit the child and their family contributes to decision-making about whether an appointment is worth investing in (Andrews et al., 1990). The status quo is to make phone calls or to address appointment letters and information about the therapy solely to the parents/caregivers. Contemporary studies of childhood increasingly view children as competent to make decisions about their own participation and engagement, as well as potentially having unique and differing perspectives from their parents (Gibson et al., 2009). In addition, in evaluating children's social and emotional responses to medical treatment it is recommended that asking children as young as five years old is more valid than asking for a parent report (Varni, Limbers, & Burwinkle, 2007). It appears there is a place for clients who are children to take on the role of informed health consumers and to be provided with adequate information that helps them anticipate the therapy appointment as beneficial. It has not been possible to locate research which explores children's perspectives on the topic of missed appointments.

2.3.3 Engagement

Engagement is promoted when the organisation's values, as demonstrated by staff practices, identify with clients values. Dennison (2003) gives a specific example of a service that wanted to increase the rates at which dad's attended therapy appointments with children. The service recognised the need to create a dad-friendly environment. They targeted dads who were the primary caregiver of children referred to the service, giving additional information to reduce uncertainty about what a healthcare appointment would typically involve. A second example is from Ballantyne et al., (2015) who proposed a family-centred care concept be implemented to facilitate increased attendance by mothers and their babies at ante-natal appointments. This was in response to recognising that the interaction between mothers interpretation of their child's need, and their context and resources, was a barrier to attending.

From the literature strategies outlined as effective for promoting engagement within paediatric services have been summarised, see box 3.

Box 3: Facilitators of engagement

- Identifying a single staff member who can work with families as they transition across service silos (Ballantyne et al., 2015)
- Paediatricians personally introducing occupational therapists to the client and family at the point where a referral and the potential to benefit from a referral is being proposed (Green 1997)
- Establishing the role of a trained health care worker who takes a counselling approach with families who miss bringing their children to appointments resulted in parents reviewing the initial decision to not attend and pursuing an appointment for their child (Andrews et al., 1990)
- Within adolescent mental health services the use of the 'Choice and Partnership Approach' (CAPA) model which after an initial interview invites the family to initiate a second interview at their pace (Robotham, James, & Cyhlarova, 2010)
- Utilising phone and text prompts (Schillinger 2007)
- Over-book clinics, offer clinics over extended hours (Simons et al., 2015)
- Reorganise the patient pathway (Simons et al., 2015)
- Reduce time between referral and appointment (Simons et al., 2015)
- Issue repeated reminders of upcoming appointment (Simons et al., 2015)
- Ensuring recommendations are understood by, and fit with, client and family (Lighter 2015)
- Review and improvement of access to services and social networks (Clark et al., 2013)

In summary, the paediatric literature continues to highlight the value of relationship between staff and clients as key to reducing missed appointments. The right balance of prioritising the child's health needs with relating effectively with the family is acknowledged as requiring a skilled approach. Services are best to focus on this engagement compared to making clinic or system changes, such as restructuring appointment times offered. Receiving more family information in referrals would also be beneficial.

The next focus of this literature review will be to locate the missed appointment work in an occupational therapy context. This refers to the environments in which occupational therapists work and how well professional philosophies fit with workplace priorities. Family therapy models are also reviewed.

2.4 Therapy theory

Literature that is specific to occupational therapy and missed appointments was limited. Studies from other allied health therapies exploring this issue have also been incorporated as it was found that there were shared values and philosophies. Rather than solely reviewing therapy literature on missed appointments, this section also explores the issue of missed appointments through an occupational therapy lens. Family therapy models suitable for paediatric practice have also been reviewed.

Several articles were located in the therapy literature exploring the issue of missed appointments in their services, covering various angles of the topic. Abdus-Salaam & Davis (2012) explored whether clustering children from the same family for dental appointments would increase attendance at the clinic, however, it had no effect. In a study exploring parents intentions to attend a group for pre-schoolers with anxiety, it was shown that putting in place enhanced recruitment strategies (summarised as matching parent preferences to specific service provided and personalising the engagement approach to potential participants), did not change attendance rates (Mian et al., 2015). This team were working in a so-called under-served community and this research indicates how challenging it is to engage this population as a means to reversing the inverse care law. A study exploring ways to reduce long waiting times, which is a known contributor to missed appointments, Robotham (2010) found that the adoption of the CAPA model enabled initial assessment appointments to occur in a timely manner. Although onwards referrals could be made from that initial contact, this did not lead to a reduction in wait-times for therapy being initiated, as there was then a bottle-neck for identified therapy services.

An occupational therapist studied missed appointments in a neuro-rehabilitation outpatient clinic in Bristol, United Kingdom (Green 1997). The project measured rates of attendance before and after the medical consultants introduced occupational therapists to clients while discussing the value of making the occupational therapy referral. The intervention was found to have no significant impact on attendance overall. However, it was interesting to note that one consultant who maintained the practice had significantly improved outcomes for occupational therapy attendance, while the second consultant neglected to engage completely with the research project (Green 1997).

Two studies in paediatric settings researched applying models of care for improved engagement within their settings. The first study, in a paediatric rehabilitation service in Canada, KidsAbility, resulted in the development of the Making Alternative Therapy Choices Happen (MATCH) evidence-based care pathway to engage effectively with hard-to-reach families, which were defined as those who had missed therapy appointments (Phoenix & Rosenbaum, 2015). MATCH is a three stage protocol that can be applied to various different paediatric therapy aims, eg. meeting a child at a childcare centre or reducing the frequency for therapist intervention (Phoenix & Rosenbaum, 2015). The stages are that the therapist identifies the child's need for the service, followed by creating a collaborative therapy plan, and concluding with collaboration to develop an action plan (Phoenix & Rosenbaum, 2015). The second study pertained to staff using the Family Partnership Model in child and family health organisations across New Zealand and Australia, and sought to explore it's effectiveness when services engage with vulnerable families (Rossiter et al., 2011). The model was found to be a good fit, and one conclusion was to emphasise the necessity for health professionals to advance from engaging with respect and empathy to developing specific knowledge and expertise with this population.

2.4.1 Family centred philosophy

Family centred philosophy, as the above mentioned models were drawn from, originates from empowerment and help-giving fields of knowledge (Dempsey & Keen, 2008). These authors define the four core beliefs as follows:

1. family rather than the health professional is seen as a constant in the child's life

2. family members, not the health professional, are best placed to determine what the needs of the child are

3. helping the child is often inseperable from helping the family, including understanding the families social circumstance and addressing family needs

4. emphasis is placed on family decision-making about services and enabling family control over therapy processes while respecting these choices (Dempsey & Keen,2008).

Family-centred paediatric practice has been gradually introduced since the 1970's. A review of this literature by Hanna & Rodger (2002) identifies four key variables for collaborative practice, which often looks different for different therapists and services. One variable is regarding the service's policy and models of practice. A second variable is how confident therapists are to connect with families as a move away from relying strongly on therapeutic techniques. Whether collaboration is for the whole therapy process or just one component, eg. goal-setting, is a third variable. The fourth variable is how comprehensively parents and therapists are viewed as equal partners with unique perspectives on their experience. More research is called for to understand how effective collaboration impacts health outcomes for children and families, as well as to hone in on the experiences of mums, dads and carers as separate populations (Hanna & Rodger, 2002). In other words, these authors encourage the move to a family-centred approach while acknowledging this is not a straightforward process but one that involves a change process requiring therapists to review their beliefs, attitudes and skills.

2.4.2 Occupational therapy

Occupational therapy literature as well as general paediatric models of practice have key beliefs that family needs and well-being are core components of therapy and that family-centred therapy results in desirable outcomes for the family as a whole (Dempsey & Keen, 2008). Families, whether of not they might be seen as vulnerable for social reasons, have much to gain by effective engagement at an early stage with their children, as it is known that when families work with health care providers incorporating a participatory approach then parents report increased sense of personal control and empowerment (Dempsey & Keen, 2008). Despite clinicians having a limited impact on societal issues there is a case for them to be pro-active in the area of working with these families, such as by challenging traditional health care models in favour of recognising the expertise of families and working in partnership with them (Rossiter et al., 2011). These authors imply that therapists have a role to play in ensuring referred children and their families keep appointments. In particular, acknowledging that families that are vulnerable have limited experience in, and are therefore less likely to, resolve logistical problems such as updating addresses and taking up the offer to phone and reschedule an appointment (Rossiter et al., 2011). The practice of services offering clients the responsibility to reschedule an inconvenient appointment may actually be a breakdown point.

Within health organisations occupational therapists as a profession are typically pro-active about empowering clients – both children and adults – to engage in health enhancing occupations (Rebeiro Gruhl 2009). The first steps of negotiating and then keeping an appointment are crucial for any further engagement to occur (Rebeiro Gruhl 2009). Typically for children, parents or caregivers make those negotiations and decisions to keep an appointment, on their child's behalf. Furthermore, in the current medical paradigm, parents are also expected to partner with the health professional, to be expert in their child's health and able to contribute to therapeutic direction (Valentine 2010). In child health settings it has been established that the occupational therapist's role is to work with referred families to facilitate effective engagement, empowering the parent to take ownership of the process as a therapy partner (King 2016). Writing about family and child health therapists Rossiter et al.,(2011, p382) clarifies that it is the clinicians role to "open up space for more agency for parents", which can confirm parents' sense of engagement with the health system. A contrasting view of this partnership is that parents find themselves in this role whether or not they feel equipped to carry it out, and whether or not they know and trust the clinicians they are in partnership with (Valentine 2010). It is assumed to be the parent's responsibility to keep informed, to make choices about their child's therapeutic intervention and to negotiate within the options that are offered by the therapist.

It is known that for people with disabilities, socio-economic factors have a significant impact on being able to participate in occupations, and this has also been shown specifically related to the occupation of keeping an appointment. For example, people who are living in poverty have notably less ability to influence environmental factors and it is the environment that has an impact on how they can participate (Hammell 2015). People will engage in occupation as therapy when that occupation happens as in their regular routine, when it matches their own goals, and when it contributes pleasure, productivity or restoration to their experience (Fisher 2013). This connects with what was found in the missed appointment literature that people will keep appointments when they 'just fit in' (Heath 2013).

Another environmental aspect to consider is the political context. Occupational therapists are called on to contemplate the ways that the political and social arena are integral to how children and families can participate in any given occupations, including therapy (Rebeiro Gruhl 2009). For example, to understand which children might be eligible for funding of therapy resources is to understand there are politics in practice. In a New Zealand context, psychologists who work with vulnerable populations and gather awareness of the impacts of social factors, like poverty on their clients health, are encouraged to add weight to the media representation of the impacts of poverty (Davies et al., 2010). Occupational therapists could also take up this challenge to become political, either individually or as a professional body, and in doing so contribute to discussion in the public domain. One approach that could be undertaken in this domain is to raise awareness of how their social context impacts on participation in occupations for New Zealand children (Leadley & Hocking, 2017). This focus on occupation is unique to occupational therapists (Fisher 2013). When arguing for occupational therapists to explore the politics of health, Rebeiro Gruhl (2009) encourages therapists to boldly let it be known that participation in occupation is of core importance.

As described earlier, in both the international and the New Zealand literature review sections, understanding the client world-view or perspective is key to providing an improved health service, as well as to addressing health inequities. The client perspective may come from the client themselves, or someone in the "client constellation" (Fisher 2013, p7), ie. a parent or caregiver or childcare teacher. Occupational therapists place value on being client-centred, working with their client's definition of what meaningful occupations are to be addressed, within the therapeutic context (Fisher 2013). The Occupational Therapy Intervention Process Model guides occupational therapists to structure their clinical work around the central concept of occupation and the initial steps of this process are to develop therapeutic rapport, to work collaboratively with the client and to establish their performance context (Fisher 2013). By contrast, some evidence in the literature suggests that other branches of therapy, ie. physiotherapy and speech language therapy, may be in early stages of developing client-centred practice protocols. New Zealand physiotherapists are currently exploring ways to empower families through the provision of person and whānau-centred care and have created an initial discussion document around this (Darlow & Williams, 2018). A small study of speech language therapists, working in a paediatric setting, found that parents perspectives and values were only sporadically incorporated into therapy planning sessions (Hansen 2014). Client-centred practice and research from across therapy professions is valuable as it can capture clients and their families impressions of potential power imbalance in the therapeutic relationship, of service development initiatives or outcomes, and of level of involvement in decision-making (Rossiter et al., 2011). Occupational justice theory takes client-centredness further by acknowledging that people don't make individual choices to participate in isolation from the political environment (Rebeiro Gruhl 2009).

2.4.3 Occupational justice

Occupational justice is a theory founded on two core beliefs. First, that people have a need to participate in activities that are culturally valuable and health developing for them; and second, that when therapists facilitate their client's access to those occupations this contributes to client-centred and justice-oriented practice (Townsend & Wilcock, 2004). In other words it is an approach that promotes a good match between people's skills, inclinations and needs and their access to participate in activity for their overall health benefit (Durocher et al., 2013). Underlying principles of occupational justice include that people are able to participate as autonomous individuals within their own social context; that the occupations people participate in impact their health; and that when people have control over – and choice between – occupations, this results in empowerment (Townsend & Wilcock, 2004). Parents attending their child's therapy appointment are demonstrating these principles when they choose to keep or miss the appointment. Occupational therapists based in medical health services, which typically focus on provision of therapy to individuals, are not well situated to promote these principles which often relate to whole communities (Durocher et al., 2013; Hammell 2015). To do so, it is suggested a shift towards occupational therapists working in wider arenas than health, such as law or bio-ethics that focus on health policy development, would be required (Hammell 2015). This appears to contrast with Rossiter et al., (2011) who found that in paediatric settings where a family-centred model was practiced, clinicians could promote empowerment on an individual family basis, despite not operating on a policy-development or community wide level.

Occupational injustice occurs when peoples' rights to experience meaningful occupations are restricted (Durocher et al., 2013; Townsend & Wilcock, 2004). One category of occupational injustice is defined as occupational deprivation, ie. when over a prolonged period, factors outside of one's control result in an individual not being able to participate in occupations that are meaningful to them (Townsend & Wilcock 2004).

In other words, not participating in those occupations that would be expected to result in health development and social inclusion (Durocher et al., 2013). When a child's therapy is not deemed meaningful to participate in and they are not brought to their appointment, they are being deprived of access to engage in therapy. Rebeiro-Gruhl (2009, p23) states "Our task as occupational therapists is to ensure that our clients are not restricted, limited, denied, deprived, alienated or marginalised from engagement in occupation". However, occupational therapists in clinical roles have limited ability to address causative factors for this injustice. Writers on occupational injustice infer that by working in traditional health settings therapists have limited ability to prompt people to keep appointments, however, it is also acknowledged that "work is required to develop practice models to promote the use of occupational justice to address health disparities" (Durocher, Rappolt, & Gibson, 2013, p. 439). Reduced access to therapy appointments is one of those health disparities, and it may be that in paediatric settings where a family-centred approach is taken, therapists have more opportunity to explore reasons for ineffective engagement in therapy compared to therapists not utilising a family-centred approach. In a systematic mapping review of occupational justice literature, Gupta (2016) suggested that core strategies such as client-centred, occupation-based practice were important, and this was noted to be especially challenging for therapists in resource poor and bio-medical settings. These strategies provide a means for therapists to understand the individual's experiences of interacting with health systems and policies, which then provides a link between individual therapy provision and policy development for populations (Gupta 2016).

In summary, occupational therapy theory connects strongly at a fundamental level with exploring the issue of missing appointments in a way that other therapies might not, because it focuses on the meaning people place on participating, it accounts for client context and it elicits client-centred perspectives. The concepts of occupational justice and injustice allow further analysis of occupation, including the occupation of keeping a therapy appointment. In the therapy literature, links between hard to reach or vulnerable people and health disparities and missed appointments continue to be made. The central tenets of family-centred philosophy and models that have been developed from that, fit soundly within occupational therapy professional philosophy as both emphasise rapport building as a base. There is a need for more published research into missed appointments and occupational therapy.

In the next section, the literature review concludes by putting forward an argument for the relevance of the research question.

2.5 Summary

The issue of engaging hard-to-reach families is complex and solutions will therefore also be complex (Boag-Munroe & Evangelou, 2012). Recommendations to address the internationally concerning phenomenon of missed appointments, have been identified. As demonstrated in this literature review, the research gathered from many different health settings tells the same story. That is, while there are steps services can take to minimise the likelihood of clients non-attendance, ie. ensuring communication systems are known and readily accessible, negotiating appointment times, gathering relevant data at point of referral, and having key contact people, the primary contributing factor for non-attendance in paediatric therapy sessions is the quality of the relationship between the client and the therapist. This relationship is dynamic, incorporating the individual therapist, child and family world-views, expertise and experience within the context of a healthcare system, which itself inhabits a position in the wider social and political environment.

To summarise, this review of the literature draws together several ideas about missed appointments. Exploring this issue from many angles, in particular the experience of the client, is a valid approach as this enables a clear understanding of families explanations around the issue. The quality of the relationship that the health organisation and its staff have with their clients is significant to people keeping or missing appointments. One important question to ask is 'who is the client'? Commonly the referred child is seen as the client, however, the ways therapists engage with the child is necessarily through the family system. No formal data has been collected about how effective this relationship building is for families. The Northland DHB is a mainstream health organisation and therapists working at the Child Health Centre in Whangarei, as elsewhere in mainstream New Zealand health organisations, are mostly of non-Māori ethnicity. Therefore, when working with the Northland population, which was recorded as 32% Māori in the 2013 census (Stats NZ Tatauranga Aotearoa, 2013), staff require awareness of the impact of their world view for effective engagement.

Seeking to understand the clients' context and their world-view is essential to the quality of the interaction with the health organisation. Parents have an invested interest in promoting participation in therapy for their children and therapists have a formal training which enables them to provide therapy. Perspectives about what is important may differ. Increasing staff awareness of the world-view of parents cannot be accomplished without creating space for them to disclose their perspectives in their own words. As discussed earlier the value of working with kaiawhina and Pasifika support teams was highlighted to promote authentic engagement between health services and Māori and Pasifika clients.

There is very limited occupational therapy research published on the topic of missed appointments, and none has been located for child development teams in New Zealand. Taking a close look at the Whangarei situation provides opportunity to develop strategies that can be targeted directly to the local population, and will also have insights for other New Zealand services. This could involve rewriting policy for how to manage the missed appointments as currently the service's 'did not attend' policy guides clinicians to discharge after two missed appointments, giving little opportunity for obtaining the clients perspective. The therapy team the researcher is part of also consists of physiotherapists and speech language therapists. It has been suggested that of these three disciplines, occupational therapy theory with its focus on client-centredness and enabling meaningful participation in occupations, is well-situated to undertake a study of families motivations for keeping or missing appointments.

Keeping appointments with therapists is a component of the therapeutic journey for a child/client at the Child Health Centre in Whangarei. When an appointment is missed this limits therapy from occurring, therefore it is important to understand and address the reasons why appointments are missed. To capture the families experience of this phenomenon and to enable service development to minimise missed appointments and the resultant health disparities, this research question was developed:

What helps and what hinders families from participating in therapy appointments with the Child Health Centre in Northland?

Everyone had ideas for training Tui; aunty, mum's friends, the puppy preschool teacher and even gran. Mum listened to the advice and read the books. Use a whistle, use a clicker, use treats, use a long lead, don't give up. Mum felt confused.
One day mum took Tui to the beach. "Come, Tui!" Mum said.
But Tui was busy smelling fish-heads, seaweed, and long grass. She didn't listen to mum.
"I need a plan just for Tui and me," said mum. "I think we will use a big pocketful of puppy treats."

Chapter 3: Methodology

3.1 Introduction

This chapter describes the research design selected and used for this study. The chapter begins by outlining the intention of the research. It continues with explanations of the process for selecting the research methodology of qualitative descriptive, what this is and how it was implemented. For studies, such as this one, which seek to explore participants' perspectives of a service, qualitative descriptive methodology is often utilised in occupational therapy research (Stanley & Nayar, 2014). The chapter continues with an outline of ethical considerations using the Te Ara Tika framework, and positioning the researcher as an occupational therapist who is an emerging researcher. Following this background information the methods are described, including sampling, recruitment, data collection, and the data analysis process. Rigour or trustworthiness is demonstrated by aligning the research design with the intention of the research and more specifically with the research question.

The intention of this research was to better understand the missed therapy appointment experience from the client perspective. It was believed that this would help to shift clients from being seen in a passive role ie. as a DNA statistic, to an active role, ie. the appointment was missed by a person or family, in the conversation around how to address the problem of missed appointments at the Child Health Centre.

The central research question asks parents' whose children have missed appointments, what factors get in the way of keeping appointments. The research question also seeks to explore what factors would help parents keep therapy appointments.

3.1.1 Qualitative methodology

Initially, to answer the research questions, consideration was given to both quantitative and qualitative research design. Quantitative methodology assumes there is an objective reality that holds true and that once discovered will enable prediction of events (Kielhofner 2006). The outcome of a quantitative study would be to test hypotheses or theories and to describe how variables relate to each other. Use of a quantitative approach was discarded as this study sought to explore participants own explanations of the phenomenon of missing appointments rather than assuming there was a known truth about this already. Quantitative design was also seen as being too restrictive in terms of data analysis, with its focus on numbers and trends rather than participants own narrative. Using a qualitative approach would allow the participants an opportunity to explore the subject, taking it in relevant and personal directions.

Therefore a qualitative methodology was selected for this study as being a good fit with both the research questions and the researcher's world view. There are three assumptions that underpin a qualitative or naturalistic inquiry epistemology. The first assumption is that the research participants have developed, and can describe, their own realities, as opposed to there being a pre-existing, defined set of reasons why people miss or keep appointments. The second assumption is that by interviewing participants the researcher will be able to elicit their underlying thoughts. This acknowledges an influencing relationship between the researcher and the participant rather than them being independent of one another. The third assumption is around truth and states that generalisations are not possible as the context always provides relevance (Guba 1981). Given these assumptions as parameters, the researcher hoped to uncover a narrative that would provide insight into the specific study context.

3.1.2 Ethical framework

An important aspect of working with a qualitative methodology is to acknowledge the researchers' own assumptions as part of establishing researcher credibility.

This researcher has a world view which could be described as naturalistic inquiry, and as such is well-matched with qualitative research methodology. By undertaking this study the researcher is establishing personal researcher history as a clinician who also does research in her own workplace. In addition, the researcher, who is Pākehā, wanted to minimise the impact this might have on participants who may identify as Māori. This was important due to the researcher's belief in bi-culturalism as being integral to effective communication in Northland and, in particular, given the assumption that the researcher influences the material that is elicited during the interview. To ensure the researcher was positioned as undertaking an authentic bi-cultural research process, Hudson's (2010) framework, Te Ara Tika, was referred to.

Te Ara Tika provides a framework for standards of practice in relation to addressing Māori ethical issues and can be applied to all research methodologies. The first standard is Whakapapa, which focuses on why and how the research relationship is being formed and cultivated. The second standard is Tika, which looks at the research design being a good fit for the research question. The third standard is Manaakitanga, which is about taking care to ensure the dignity of all people involved in the research process. The fourth standard is Mana, which relates to acknowledging issues around justice and equity, power and authority within the research relationship (Hudson 2010). The standards can be met at either a minimum, good or best practice level and this researcher sought to meet the minimum standards with this first piece of research.

3.1.3 Qualitative descriptive

From the field of qualitative methodologies, a qualitative descriptive research design was selected for this study. Alternative qualitative methodologies of grounded theory (for studies exploring social processes) and phenomenology (to provide understanding of a lived experience) were considered (Stanley & Nayar, 2014). Qualitative descriptive methodology was preferred as it allows the researcher to gather and collate participants experiences of a service or event and maintains a spotlight on participants voices. It does this through semi-structured interviews, followed by coding participants words into themes and may include elevating key participant phrases to become titles of themes (Stanley & Nayar, 2014). In this study, the researcher selected a phrase from one interview to include in the title of the thesis. With this methodology the purpose of the themes is not to interpret the findings but to conceptualise meanings articulated by the participants and allow their words to describe the experiences in such a way that other people would also see the descriptions as accurate (Sandelowski 2000).

This research design, with its emphasis on participants describing their own realities through open-ended lines of questioning, was considered to align with the research question. The researcher sought to create space for the participants to explore their experience of missing appointments and considered that if the interview was formed around closed questions then the richness of data would be compromised. Qualitative descriptive design is often used when the researcher is asking what people think about an aspect of a service (Stanley & Nayar, 2014).

Qualitative descriptive methodology has been used in a similar study exploring barriers and facilitators to keeping appointments for mothers whose babies needed follow-up from a neo-natal service in Canada (Ballantyne et al., 2015). Here the researchers used an expanded methodology which included individual interviews with mothers as well as focus groups of staff. The methodology was seen as a strength as it enabled the researchers to gather multiple understandings of the issue. Ballantyne et al., (2015) applied thematic analysis to the data as it came in and continued data collection until analytical saturation occurred. It is noted that saturation is not a requirement of qualitative descriptive design and small sample groups are often sufficient to answer the research question (Stanley & Nayar, 2014).

In keeping with qualitative descriptive methodology, the interview question guide (See Appendix C) was loosely structured and simple so that participants could share what was relevant for them. The interview guide consisted of two main questions with sub-questions and several prompts underneath each. Open-ended questions were used to create an atmosphere that would empower participants to raise topics of value to themselves, and would give them space to relate personal and meaningful experiences. Having few open ended questions on the interview would also guide the interviewer to listen to, and extend on, the narratives raised by the participant.

The first main question was:
Thinking about a time when you missed an appointment, in your experience what factors made it *hard* to keep that appointment with the therapy team at child health?

The second main question was:
Thinking about a time when you missed an appointment, in your experience what factors would *help* you to keep appointments with the therapy team?

3.2 Methods

This section begins describing the sampling and recruitment methods used, as well as the ethical issues considered. The section continues with descriptions of the data collection process and the data analysis process.

3.2.1 Sampling

Purposive sampling was used to ensure a cross-section of perspectives could be gathered. Narrowing down of the sample, for example by using maximum variation sampling (Sandelowski 2000), was not considered beneficial for this exploratory study, but maybe appropriate for a follow-up study to gather a wider range of perspectives. A total of four interviews were conducted. The study aimed for a relatively small number of between four and six interviews as the researcher was not aware of how people who had missed appointments might feel about engaging with that same service for research purposes. The researcher had discussed this issue with other therapy team members at the Child Health Centre early in the research design phase. Team members' guidance was that when approached to share their experience to contribute to service development, a sufficient quantity of family members would be willing to contribute. It is noted that qualitative descriptive methodology doesn't specify that a representative sample is required, as it would be in a grounded theory or phenomenological methodology, due to data gathering and analysis not needing to result in social process exploration or developing new meanings (Stanley & Nayar, 2014).

Participants were selected based on one factor, that of having missed a child's appointment with the Child Health Centre therapy team. Variables such as socio-economic data were not gathered as this study was a simple exploration. It was found that all participants provided rich data for analysis, including insights into their socio-economic situation, as they spoke about their personal experience.

3.2.2 Recruitment

The aim was to recruit participants who had had an experience of missing their child's appointment with the therapy team at the Child Health Centre. The therapy team consists of occupational therapists, physiotherapists and speech language therapists. The Northland DHB statistician was approached and produced a list of children who had not been brought to booked appointments with the therapy team in the selected time period of January to December 2016. This period was chosen because a complete set of data could be obtained, it was recent enough to still be relevant, and it was known that the data would not include children who had missed an appointment with the researcher, as the researcher was not employed in the service at that time.

The researcher engaged a kaiawhina staff member to recruit research participants. This person, whose role within the Northland DHB is to develop relationships between the public health nursing service and so-called hard-to-reach clients, was approached via her manager to discuss the viability of her involvement in this study. This step had also been proposed by the Te

Poutokomanawa kaumatua during the locality ethics approval stage. He foresaw a role for kaiawhina because of his knowledge that potential participants would trust the role and speak to a non-clinician in a way they would not speak with a clinician or manager. This concept of engaging a kaiawhina fits with qualitative descriptive methodology which, while acknowledging the interviewer has an influence shaping the interview, also calls for the use of techniques that allow the participants to be comfortable. Such techniques allow the experience being discussed to be explored as naturalistically as possible (Sandelowski 2000).

The kaiawhina was given a list of 29 children, 16 Māori and 13 non-Māori who lived in Whangarei and who had missed therapy appointments. Statistics for children who missed appointments in Northland were also collated for possible use in recruitment. Inclusion criteria was that current residential details were known for the child, and that the child was not known to the researcher. The kaiawhina initially focussed on visiting the homes of children who had missed several appointments, however, expanded this to children who had just missed one appointment to meet recruitment target. All of the visits she made where she spoke with someone, resulted in that person agreeing to participate; the majority of visits she made resulted in no reply from knocking on the door. Telephone or written contact was not considered or used for recruitment as kanohi ki te kanohi techniques are important if recruitment of Māori is sought (Hudson 2010).

Potential participants were visited to ensure the child still lived at that address, to outline the research intention, and to obtain agreement to meet the researcher. The kaiawhina then forwarded those parents details to the researcher.

In a second stage of recruitment, following a period of no replies to cold-calling at homes, the researcher accompanied the kaiawhina while she visited potential participants so that appointments for interviews could be arranged immediately. One participant agreed to be interviewed during the introductory visit and there was no need to make a future appointment. One parent who initially agreed to participate, when approached to book a convenient interview time, declined to commit. The researcher, with kaiawhina agreement, telephoned that parent three times over a three week period to arrange an interview, however, this was unsuccessful. During the third phone call the potential participant hung up the phone mid-call giving the only indication that agreement had been withdrawn.

The four recruited participants had several factors in common; they all identified as Māori, they all lived in urban Whangarei, and they were all parents (as opposed to being grand-parents, step-parents or care-givers) of the child who missed the appointment. Also, they all chose to be interviewed in their own homes. Participants (names have been changed) are presented in Table 1.

Table 1: **Research Participants details**

Name	Age	Gender	Ethnicity
Darlene	37 - 46	female	Māori
Shana	27 - 36	female	Māori
Trent	27 - 36	male	Māori
Kiri	27 - 36	female	Māori

3.2.3 Data collection

The data collection process was informed by Te Ara Tika and bi-culturalism was highly valued. This was demonstrated by the researcher bringing a koha (in this case a bag of groceries), by removing her footwear at the door of peoples' homes, by establishing whakawhānaungatanga by asking people where they are from and by sharing the researcher's own connections to the area. In addition, the researcher collected only minimal, non-threatening demographic data, ie. age within a banded range and ethnicity (see table 1), as although it wasn't likely to be a strong feature of data analysis in this study, it may prove to be useful for future researchers.

The interviews were conducted in July and August 2017. The researcher, in the role of interviewer, arrived at each participant's home at the agreed time to conduct their interview. The first stage of the interview involved an explanation of the research, reading through the information sheet with participants and obtaining their consent. The consent forms were signed prior to each interview beginning. The information sheets were left with participants, and these included the researcher's contact details. It was explained to participants that the researcher would come back to them with their interview transcript to ensure that on reflection, the summary of the interview captured the intent of their comments. A digital recorder was used to record each interview, if consent was given for this to occur, and recording began after whakawhānaungatanga was established. Three of the interviews were approximately 60 minutes in duration, with the remaining interview being 30 minutes duration.

Shana included her partner, her child's father, in her interview and he contributed a few comments. Darlene had her children present in the room during her interview, and interacted with them intermittently throughout. During Kiri's interview she was home alone. For Trent's interview the kaiawhina was present caring for his children while he spoke with the researcher. At the introductory phase of Trent's interview he read the information and consent forms and discussed and understood the purpose of these with the researcher, however, he declined to sign a consent form and instead gave verbal consent for the interview to proceed and for the data to be used in this study. Trent also declined to have his interview recorded, so hand-written notes only were made, and the obtaining of direct quotes was limited.

The interviews were semi-structured based on the interview guide (see appendix C). Simple, open-ended questions were asked to initiate the kōrero and listed prompts as well as the comments from participants were used by the interviewer to shape the interviews. The intention was to let the person guide the conversation in a relevant direction for them, while ensuring information was gathered that would relate to providing an answer to the research question. During the interviews the researcher made brief, hand-written notes and immediately following the interviews added more detail to these, based on reflections and impressions of the interview process.

Interviews were transcribed by an external service, which guaranteed confidentiality. Next, the researcher listened to each interview while reading the transcriptions to make any necessary corrections, eg. spelling of names, clarifying mumbled responses, and spelling Māori words and colloquialisms.

Some unexpected data was collected that required consideration of how it would be utilised. For example, data that pertained to services that were not the focus of this study, eg. therapists from other geographical areas or services that participants had had appointments with, and also other clinical (non-therapy) staff from the Child Health Centre. In addition, most of the interviews focussed on missing appointments mid-way through the therapy process, rather than the initial visit. This unexpected data was able to be integrated into the results.

The research design excluded collecting socio-economic data as the interviews were structured in such a way that if socio-economic factors had an impact on keeping or missing appointments, this would be evident. Potential participants from across Northland were not approached, due to sufficient numbers of participants being recruited within Whangarei. In hindsight having no formal socio-economic data and no rural Northland participants did not inhibit data collection on limiting factors such as cost of transport and distance to travel, however, it is not known how extensive this focus may have become had these variables also been included in the sampling.

3.2.4 Ethics process: Te Ara Tika

Two ethics approvals were required for this study. Ethics approval was obtained by the Otago Polytechnic, the reference number is: 716 (See appendix D). In keeping with the Otago Polytechnic ethics committee process, a brief report of findings and conclusions will be forwarded as requested. Locality sign-off was also obtained from the Northland DHB, reference number: 2017 - 17 (See appendix E). A verbal request was made by the medical director of the DHB to have a summary of the findings and conclusions of this study, and this summary will be forwarded at completion of the thesis process.

Ethical considerations for participants and for the researcher were considered. Te Ara Tika provides a framework of four principles for meeting Māori ethical standards and this framework is used to discuss the study's ethical considerations (Hudson 2010).

The first principle of Whakapapa has consultation as a minimum standard. The intention of the consultation process was establishing researcher integrity and avoiding deception. Consultation occurred early in the research process when Te Poutokomanawa, the Māori health directorate staff within the Northland DHB, were involved with ensuring the information panui (See appendix F) was without jargon and included common usage Māori words. Consultation with kaitohutohu of the Otago Polytechnic was achieved when the research was presented for feedback on cultural safety considerations (See appendix G). The researcher informally consulted with the therapy team and team leader at the Child Health Centre regarding the intention, design and timing of the research.

The second principle of Tika has mainstream respect for the rights of participants and anonymity as a minimum standard. This involved reassuring participants that the research design would maintain their anonymity, ie. the participants were given pseudonyms and the name and gender of their child was anonymised. Participants understood the interview structure would enable them to raise points of relevance to them. This included reassurance that via anonymity and confidentiality agreements, accessing future therapy from the Child Health Centre therapy team would not be compromised. The rights of participants were respected and no coercion was involved. For example, when the kaiawhina met parents who agreed to be interviewed and said they would initiate contact with the researcher, then the researcher did not initiate arranging the interview. This resulted in two people who gave verbal agreement to participate in the study, not eventually being part of the study. As the kaiawhina had made that arrangement with those participants the researcher honoured that. Fitzpatrick et al., (2016) identifies the need when working with indigenous communities, to ensure consent is sought appropriately and rights are upheld.

The third principle of Manaakitanga has cultural sensitivity as a minimum standard to achieve. This involved ensuring confidentiality was maintained as per the consent agreement (See appendix H), ie. raw data was only seen by the transcriber and the research supervisor, and a small sub-set of anonymous data was shared with Masters programme peers during the coding process. Electronic data was stored in the researcher's computer with locked password access and written notes were stored in the researcher's home office filing system. Manaakitanga also meant providing participants with options to include support people in the interview, options about where to meet for the interview and the researcher respecting their home environment as home was the interview location.

The researcher became aware that ensuring cultural safety extended to careful responses during the interviews when participants referred to dissatisfaction with therapy colleagues. The need for this care was twofold. The therapist referred to may still be engaging with the parent and child and careful professionalism was required to avoid influencing that relationship. Also, the researcher was able to reflect on critiques about colleagues and their practice as seen through the eyes of the research participants. In this way the researcher had a responsibility to the confidentiality of the research in very real terms.

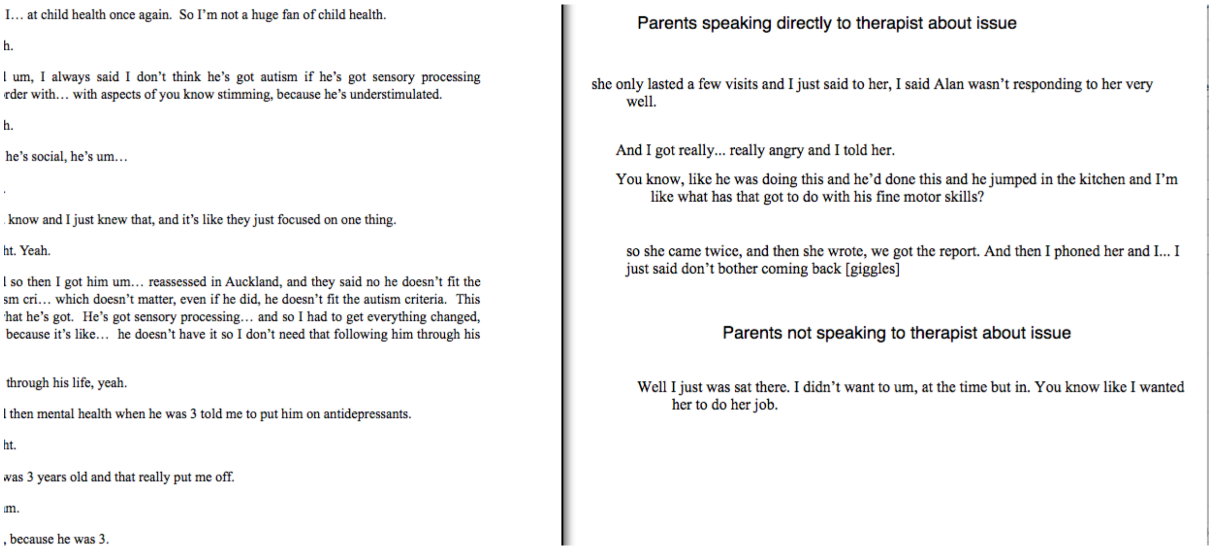
Principle four of Mana tangata has as a minimum standard that participants will be viewed as autonomous individuals. This involved user-friendly consent forms and research information panui that detailed potential risks. The researcher clarified that there were no right or wrong answers, and also that recordings could stop and participants could opt out at any time during the interview. One participant gave verbal, not written, consent to be interviewed and consented to the interview being recorded in written format but not audio-recorded. Another participant interrupted her interview when she was distracted by events outside. The recording was stopped mid-way and started again when she was ready to continue talking. In this way issues of power and trust in the research process were addressed.

3.2.5 Data Analysis

Qualitative content analysis, a narrative-based and thematic approach to data analysis was used. Sandelowski (2000) proposes the use of qualitative content analysis to summarise participants' experiences, using their own words to develop themes, and allowing the theming process to be dynamic as the breadth of data is considered. In accordance with this approach interpretation of data was subtle. This allowed the quotes to be framed so their meaning was amplified and conclusions for service improvement could be hypothesised while avoiding transforming comments into something more sophisticated.

A combination of hand-written notes and on-screen information was utilised in the data analysis process and the process had five stages. In this way an audit-trail of evolving themes was created, contributing to the trustworthiness process. The five stages are outlined below.

Stage One:
Audio interviews were received back from the transcriber as Word documents via Dropbox. These were placed in Curio software (version 12, Zengobi Inc) and important quotes from each of the four interviews were taken from the transcripts and placed under headings (see Figure 3.1).



I… at child health once again. So I'm not a huge fan of child health.

h.

l um, I always said I don't think he's got autism if he's got sensory processing rder with… with aspects of you know stimming, because he's understimulated.

h.

he's social, he's um…

.

. know and I just knew that, and it's like they just focused on one thing.

ht. Yeah.

l so then I got him um… reassessed in Auckland, and they said no he doesn't fit the sm cri… which doesn't matter, even if he did, he doesn't fit the autism criteria. This hat he's got. He's got sensory processing… and so I had to get everything changed, because it's like… he doesn't have it so I don't need that following him through his

through his life, yeah.

l then mental health when he was 3 told me to put him on antidepressants.

ht.

was 3 years old and that really put me off.

ım.

, because he was 3.

Parents speaking directly to therapist about issue

she only lasted a few visits and I just said to her, I said Alan wasn't responding to her very well.

And I got really... really angry and I told her.

You know, like he was doing this and he'd done this and he jumped in the kitchen and I'm like what has that got to do with his fine motor skills?

so she came twice, and then she wrote, we got the report. And then I phoned her and I... I just said don't bother coming back [giggles]

Parents not speaking to therapist about issue

Well I just was sat there. I didn't want to um, at the time but in. You know like I wanted her to do her job.

Figure 3.1: Sample of highlighting quotes from transcript - Darlene

Stage Two:

The cross-checking process was initiated. One interview was coded by both the researcher and the research supervisor. A Skype conversation then took place in which the codings were compared. This helped to move raw data into relevant quotes and develop initial theme concepts. The researcher was able to refine or elevate the coded quotes from categories into more meaningful themes. This process involved adding new themes, while removing and modifying others, and resulted in five broad theme concepts emerging.

Stage Three:

Quotes were copied from individual interviews within Curio and placed in the first iteration of themes, which incorporated data drawn from all the interviews (see Figure 3.2).

Effective collaboration, effective engagement happens when: getting to know you/playfulness/fun/rapport/connection with child/ therapist attributes

▾ 1. I mean that's one of the main things about children isn't it that fun side of it

a. asking what (my child's) interests are, you know… finding out a bit about (my child) as a little boy, and so when they come around they can come around prepared. You know maybe they can bring something around that he likes and… then wow straight away you've got that connection there

b. I'd prefer visits at home yeah absolutely. Because he's in his own environment and he's comfortable.

c. home visits, sits round here

d. because the appointments are generally here anyway, like we get them to come to here…

e. because you have to get into their world you know instead of forcing them to try and come into our world. And then eventually you create a bond with them because they start to trust you

f. I would say that if therapists could um… find out about who they're actually working with, what they enjoy doing, you know whether it's watching the water run, anything, and centre that therapy around their interests…

g. They did say to me do you want another therapist and I was just like after… I had so many disappointing… I was just like no, look don't worry about it.

h. Yes, being very authentic. And I think children aren't stupid. They can pick up if someone doesn't really want to be there. If someone's not enjoying being with them. You know, if they're half there and half somewhere else, and you can see the therapist… it's almost like it was just a job and … when I play with (my child), I get down and I'm 100% involved with what they're doing. Nothing else around me exists you know, and we're laughing and I'm on their level. And (my child) knows that, but it's like they can't let go like just, actually just have fun.

i. that it's a bit more serious, I am determined and motivated and have promised to keep appointments because…yeah, it's my child and I need… to be consistent with taking care of his wellbeing

j. continue to get professional development and…keeping up to date with new diagnosis

k. I just think they, all round need to, be more understanding.

l. I think a few need to sort of be aware of their … reactions to things. And be, at least, act understanding

m. I know that you guys are real busy, huge client list but I've noticed with (my child) since he's been working with other therapists, having that one therapist and building rapport at the start…rather than diving straight into it.

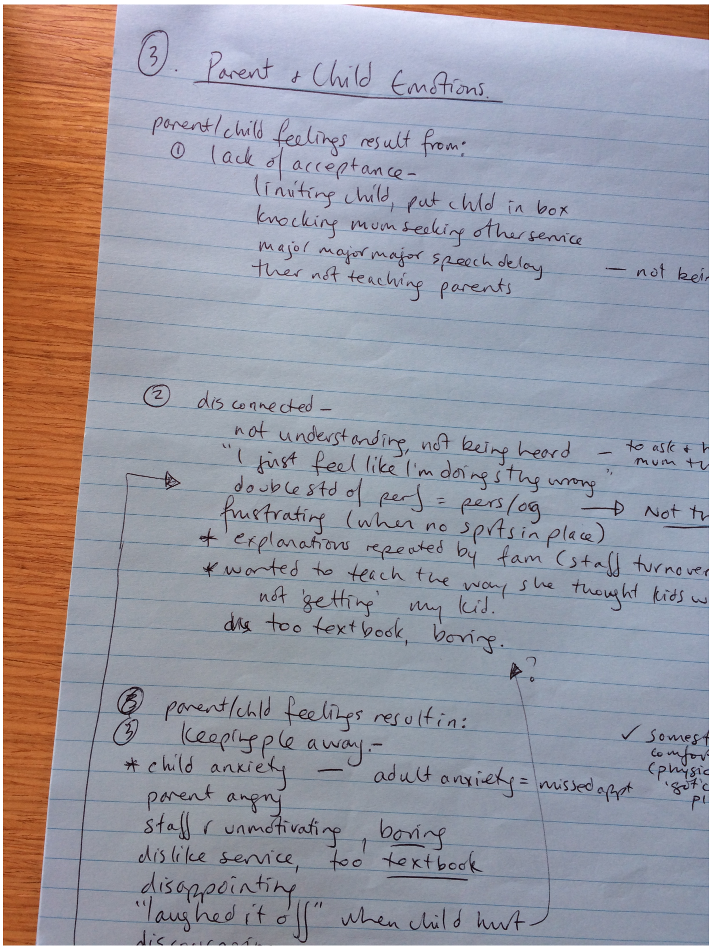
n. I would just like my child to be comfortable…

o. it's (keeping the appointment) about me. And I'm learning to, sort of like, dust the anxiety off for that moment for my child.

p. maybe they were young, I don't, I don't know

Figure 3.2 : Initial electronic coding

At this stage hand-written notes were also used to allow the researcher to have a more visual overview of concepts (see Figure 3.3).



③. Parent + Child Emotions.

parent/child feelings result from:
① lack of acceptance -
limiting child, put child in box
knocking mum seeking other service
major major major speech delay
ther not teaching parents — not bei

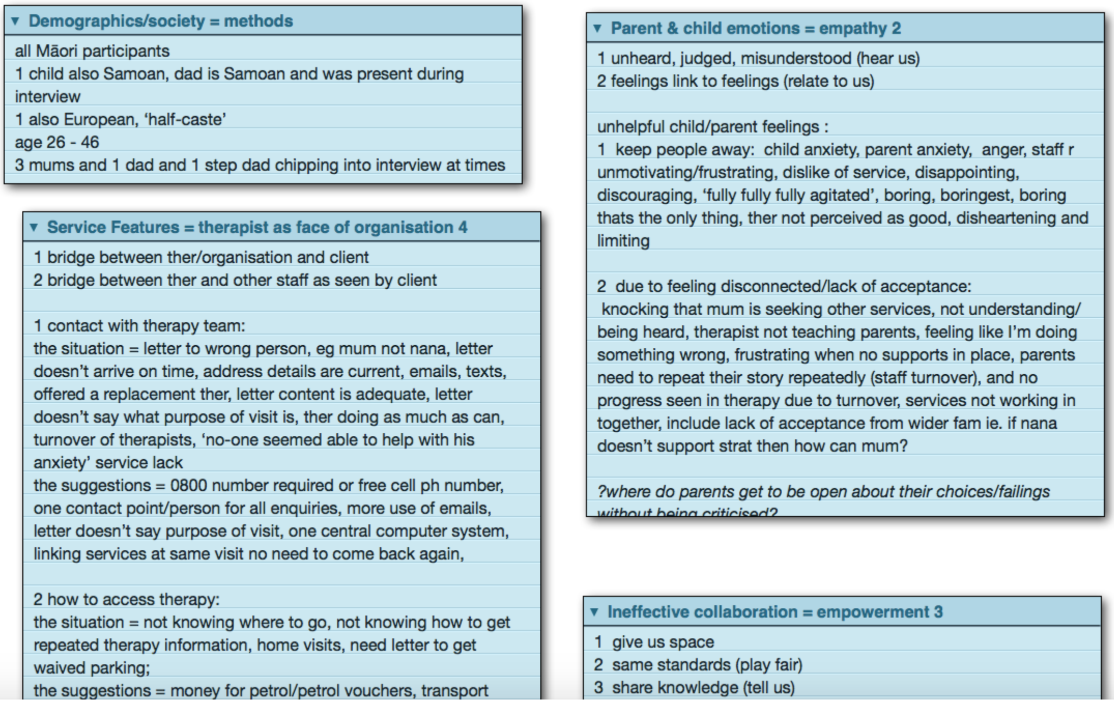
② dis connected -
not understanding, not being heard — to ask + h
"I just feel like I'm doing sthg wrong" mum tr
double std of perf = pers/og → Not tr
frustrating (when no sprts in place)
* explanations repeated by fam (staff turnover
* wanted to teach the way she thought kids w
not 'getting' my kid.
dis too textbook, boring.
?

③ parent/child feelings result in:
keeping ple away.-
* child anxiety — adult anxiety = missed appt
parent angry
staff r unmotivating, boring
dislike service, too textbook
disappointing
"laughed it off" when child hurt

✓ somest
comfor
(physic
'got'c
pl

Figure 3.3: Hand-written coding notes

As analysis progressed keywords and titles that captured the concepts of the quotes were derived. Components of interviews were shifted around and quotes that seemed to fit in multiple places were analysed for the best theme location. Initially five categories were created and upon further analysis these became a final four themes, with different titles altogether from the initial titles allocated. Between three and five themes is recognised as ideal for qualitative descriptive research (Stanley & Nayar, 2014). A theme around demographic features was removed, sub-themes were removed and some were later reinstated, and terms that were suitable for theme titles became apparent as the researcher reflected upon the data (see Figure 3.4).



Demographics/society = methods
all Māori participants
1 child also Samoan, dad is Samoan and was present during interview
1 also European, 'half-caste'
age 26 - 46
3 mums and 1 dad and 1 step dad chipping into interview at times

Service Features = therapist as face of organisation 4
1 bridge between ther/organisation and client
2 bridge between ther and other staff as seen by client

1 contact with therapy team:
the situation = letter to wrong person, eg mum not nana, letter doesn't arrive on time, address details are current, emails, texts, offered a replacement ther, letter content is adequate, letter doesn't say what purpose of visit is, ther doing as much as can, turnover of therapists, 'no-one seemed able to help with his anxiety' service lack
the suggestions = 0800 number required or free cell ph number, one contact point/person for all enquiries, more use of emails, letter doesn't say purpose of visit, one central computer system, linking services at same visit no need to come back again,

2 how to access therapy:
the situation = not knowing where to go, not knowing how to get repeated therapy information, home visits, need letter to get waived parking;
the suggestions = money for petrol/petrol vouchers, transport

Parent & child emotions = empathy 2
1 unheard, judged, misunderstood (hear us)
2 feelings link to feelings (relate to us)

unhelpful child/parent feelings :
1 keep people away: child anxiety, parent anxiety, anger, staff r unmotivating/frustrating, dislike of service, disappointing, discouraging, 'fully fully fully agitated', boring, boringest, boring thats the only thing, ther not perceived as good, disheartening and limiting

2 due to feeling disconnected/lack of acceptance:
knocking that mum is seeking other services, not understanding/ being heard, therapist not teaching parents, feeling like I'm doing something wrong, frustrating when no supports in place, parents need to repeat their story repeatedly (staff turnover), and no progress seen in therapy due to turnover, services not working in together, include lack of acceptance from wider fam ie. if nana doesn't support strat then how can mum?

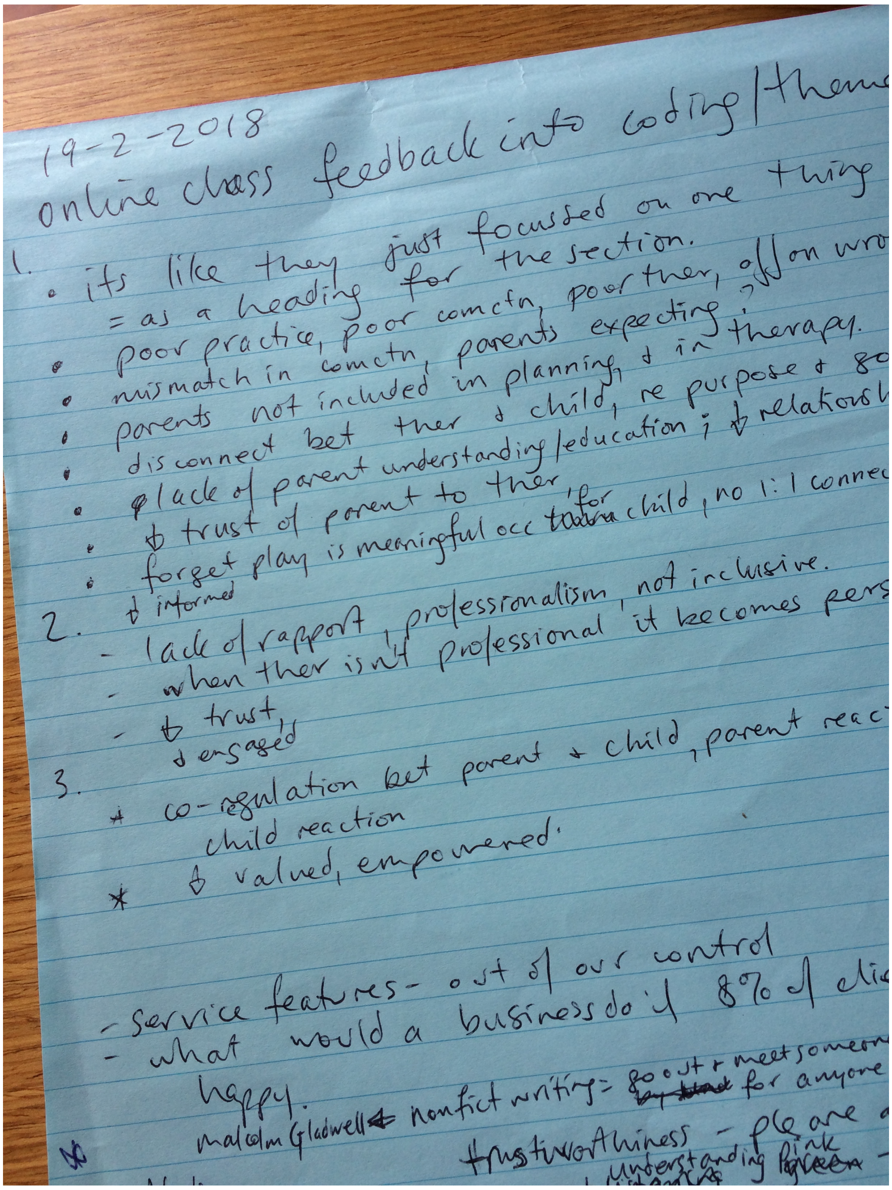
?where do parents get to be open about their choices/failings without being criticised?

Ineffective collaboration = empowerment 3
1 give us space
2 same standards (play fair)
3 share knowledge (tell us)

Figure 3.4: Developing themes

Stage Four:

The cross-checking process continued when an excerpt of quotes from across all interviews was presented to masters programme peers in an on-line class forum. Feedback helped to finalise theme concepts as well as contributing to the trustworthiness of this research (see Figure 3.5).



19-2-2018
online class feedback into coding/them

1. • its like they just focussed on one thing
= as a heading for the section.
poor practice, poor comctn, poor ther, off on wro
• mismatch in comctn, parents expecting?
• parents not included in planning, ↓ in therapy.
• disconnect bet ther & child, re purpose & go
• lack of parent understanding/education; ↓ relationsh
• ↓ trust of parent to ther,
• forget play is meaningful occ ~~taara~~ for child, no 1:1 connec
• ↓ informed

2. - lack of rapport, professionalism, not inclusive.
- when ther isn't professional it becomes pers
- ↓ trust,
↓ engaged

3. * co-regulation bet parent & child, parent reac
child reaction
↓ valued, empowered.
*

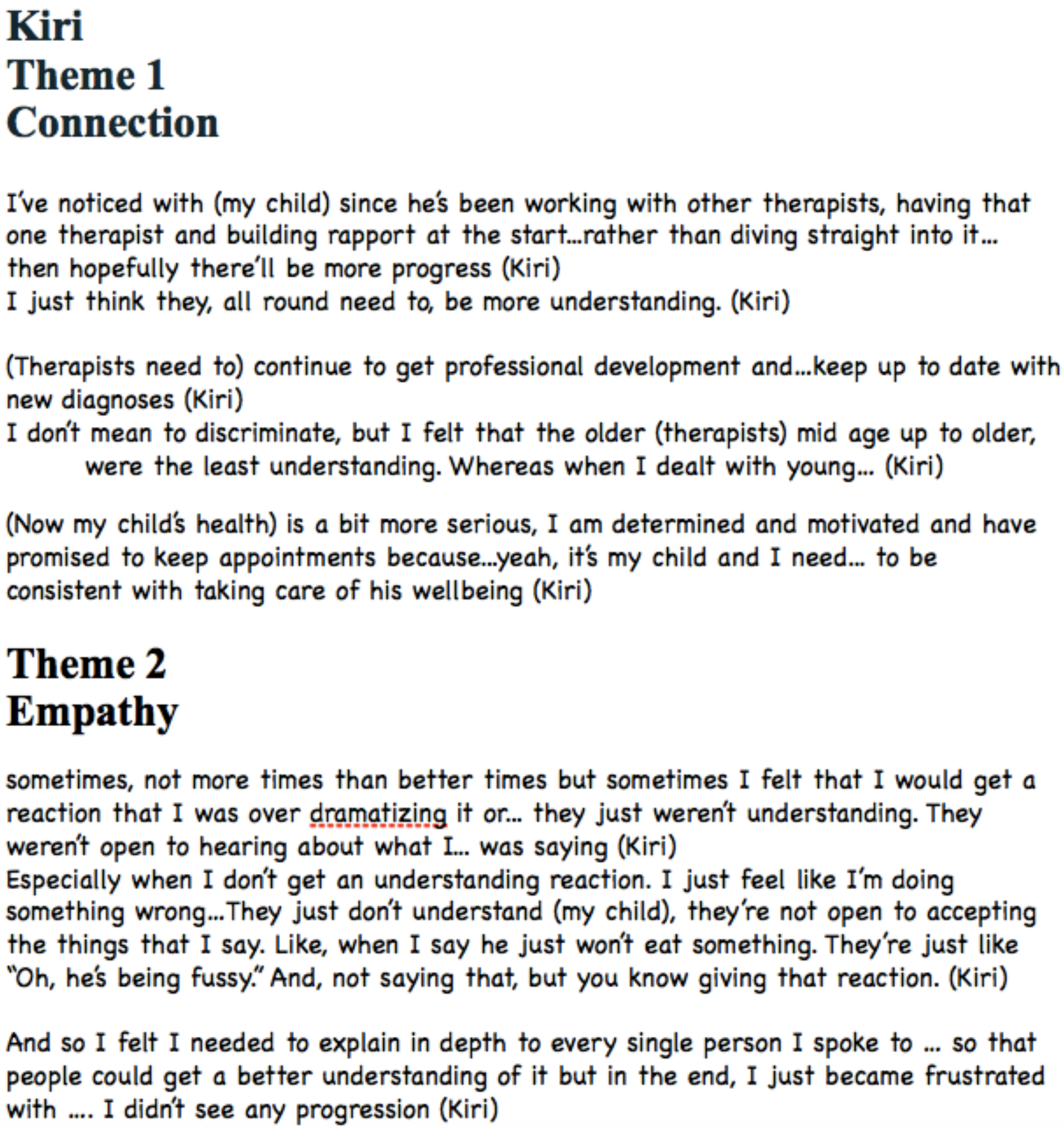
- service features - out of our control
- what would a business do if 8% of clie
happy.

Malcolm Gladwell ← nonfict writing = go out + meet someon ~~[illegible]~~ for anyone
trustworthiness - ple are a
understanding pink ~~green~~ -

Figure 3.5: Peer feedback

Stage Five:

Member checking was accomplished as a list of each participant's quotes in the relevant themes was prepared and taken back to participants to ensure the meaning from their interview had been accurately captured. An example of this is provided (see Figure 3.6) showing several quotes from Kiri's interview which contributed to the development of themes of Connection and Empathy.



Kiri
Theme 1
Connection

I've noticed with (my child) since he's been working with other therapists, having that one therapist and building rapport at the start...rather than diving straight into it... then hopefully there'll be more progress (Kiri)
I just think they, all round need to, be more understanding. (Kiri)

(Therapists need to) continue to get professional development and...keep up to date with new diagnoses (Kiri)
I don't mean to discriminate, but I felt that the older (therapists) mid age up to older, were the least understanding. Whereas when I dealt with young... (Kiri)

(Now my child's health) is a bit more serious, I am determined and motivated and have promised to keep appointments because...yeah, it's my child and I need... to be consistent with taking care of his wellbeing (Kiri)

Theme 2
Empathy

sometimes, not more times than better times but sometimes I felt that I would get a reaction that I was over dramatizing it or... they just weren't understanding. They weren't open to hearing about what I... was saying (Kiri)
Especially when I don't get an understanding reaction. I just feel like I'm doing something wrong...They just don't understand (my child), they're not open to accepting the things that I say. Like, when I say he just won't eat something. They're just like "Oh, he's being fussy." And, not saying that, but you know giving that reaction. (Kiri)

And so I felt I needed to explain in depth to every single person I spoke to ... so that people could get a better understanding of it but in the end, I just became frustrated with .... I didn't see any progression (Kiri)

Figure 3.6: Member checking sample - Kiri

3.2.6 Rigour

As the research aim was to capture participants perspectives, it was important to ensure their voice was heard throughout the process and was not obscured by researcher intentions or interpretations as this would invalidate the findings (Kielhofner 2006). Several steps were taken to ensure rigour or trustworthiness during this study. As Shenton (2004) has identified five key issues are: credibility, triangulation, transferability, dependability and confirmability.

Credibility, ensuring the study measures what it is intended to measure or, looking into how well-matched the findings are with the reality of the situation (Shenton 2004), can be accomplished in different ways. One strategy for addressing credibility involved the researcher clarifying that there would be no negative implications to accessing the service resulting from participating and that participants could opt to withdraw consent at any stage. This was seen to set the scene for honest and frank participant responses.

This study also employed investigator or researcher triangulation, which is a process of checking that other potential research informants contribute to the data analysis process (Shenton 2004). During the data analysis phase research supervision sessions were conducted regularly via Skype and between these meetings emails were exchanged about the process. This study utilised peer scrutiny, as the researcher discussed the analysis process with peers in the online forum and with a more experienced research peer who lived in the area. Finally, member checking was undertaken as presented in stage five above.

Transferability, the extent to which findings can be transferred to another similar situation, was limited because as with all qualitative studies context is crucial (Shenton 2004). However, by specifying the details of location, type and number of participants, data collection methods, and timeframe for data collection an element of transferability, for other therapists who might seek to reflect on the same issue, was enabled.

Dependability refers to how well the study could be duplicated (Shenton 2004). Comprehensive outlining of the methods used in this section gives opportunity for this, as other services may seek to explore peoples responses to their service. As captured in the literature review, there was no other research located that explored the experience of missing therapy appointments in child health centres across New Zealand.

Confirmability refers to limiting the impact of researcher preferences on the work (Shenton 2004). In this study triangulation, explanations of the researcher as an emerging bi-cultural researcher with potential weaknesses of inexperience, and the diagrammatic audit trail above were strategies used to attempt to limit investigator bias.

3.3 Summary

In concluding this chapter the researcher returns to the research question of 'what helps and what hinders people from keeping appointments at the Child Health Centre in Whangarei?' To give voice to those people typically not heard in the wider discussion around missed appointments and particularly who have not been comprehensively interviewed in relation to the Child Health therapy team in Northland before, a qualitative methodology was selected. More specifically, qualitative descriptive methodology was utilised in this study as well-suited to answer the research question. Te Ara Tika principles for addressing Māori ethical issues in the research have been adhered to, to initiate researcher authenticity in the emerging role as a researcher in Northland. The seeking of honest critique about the Child Health Centre required the researcher to ensure participant and researcher emotional safety. The methods used to ensure emotional safety were then described. The recruitment process used was through non-clinical DHB staff, ie. the kaiawhina team. Participants were interviewed about their experience of missing appointments with the therapy team. Data was collected, and reflected back to participants at a later date. The data was then studied to develop themes that captured the intent on the interviews. The next chapter presents these study findings organised into four themes.

Tui and mum always went to the beach early in the morning. Mum watched Tui all along the beach. When Tui finished running and sniffing and chasing the other dogs and rolling in stinky stuff, mum called her and gave her puppy treats. "Good girl Tui, good come!" said mum. Tui looked at mum and wagged her tail. She ran off to chase a seagull.
"Nearly there," said mum.

Chapter 4: Results

In this chapter the interview data has been presented in four themes that emerged from the analysis process. These themes reflect the dissatisfaction described by participants which contributes to lack of connection between themselves and the therapists. Participants also describe what they are looking for from therapists and the organisation. No participants described the missing of appointments as something that just happened. All participants outlined factors that kept them away, and what could be done to address these factors. Reasons pertained to the therapist as an individual, the quality of the connection with their child, as well as service features that are represented by the therapist. The four themes are: Connection, Empathy, Empowerment and Therapist as face of organisation. Extracts from interviews illustrate key findings of each theme.

Within the first theme of connection participants discuss how they would like to communicate with the therapist, and effective and ineffective instances are described. This includes being shown ways to contribute to the therapy process. Participants also spoke about their impressions of the therapists communications with their child and the impact of this relationship.

In the second theme of empathy two strands are identified. Empathic responses from therapists, or the lack thereof, are considered in terms of participants being heard and understood by therapists. These responses are also considered in light of compounding the emotional responses participants already experience from other sources.

The third theme, empowerment, captures three aspects of participants experience. These are that they didn't voice concerns observed at the time, that they saw a lack of transparency in the systems, and that opportunities for therapists to share their knowledge with parents were overlooked. As a result the child's therapeutic needs were not consistently the focus.

Finally, the fourth theme of therapists as face of organisation refers to therapists having a dual-identity, both as an individual as well as representing the organisation. In this latter identity the therapist is seen through service systems, such as communication strategies and inter-service cohesion.

4.1 Theme 1: Connection

The first theme is about the therapist as a person. It is about the connection that forms between the therapist and the child, as well as the child's parent. Connection emerged as an important theme early in the analysis process and it was frequently referred to by the participants. Being connected centred around the child being seen as an individual and the parent being included in the therapy process. These two aspects are explored separately.

The quality of rapport the therapist had with their child mattered to participants. They wanted their child to be viewed as unique by the therapist.

> *…every child is individual. You can't just have one set of rules for every single child that comes in…(Darlene)*

Darlene went on to provide a clear description of the process of rapport development.

> *asking what (my child's) interests are, you know... finding out a bit about (my child) … and so when they come around they can come around prepared. You know maybe they can bring something around that he likes and... then wow straight away you've got that connection there…because you have to get into their world you know instead of forcing them to try and come into our world… and then eventually you create a bond with them because they start to trust you (Darlene)*

It was explained by participants that rapport develops when the therapist meets the child at their level. Darlene spoke about how having a child-centred, fun and playful approach where each child is seen as an individual was a natural way to build connection.

> *Yes, being very authentic. And I think children aren't stupid. They can pick up if someone doesn't really want to be there. If someone's not enjoying being with them. You know, if they're half there and half somewhere else, and you can see the therapist... it's almost like it was just a job and … when I play with (my child), I get down and I'm 100% involved with what they're doing. Nothing else around me exists you know, and we're laughing and I'm on their level. And (my child) knows that, but it's like they (the therapists) can't let go like just, actually just have fun. (Darlene)*

Shana reiterated this perspective:

> *And it was actually our … therapist, she was awesome, I don't even know if she had any kids herself, but she had that kid friendly... I love kids, kind of … a thing. And it just worked. Like they worked together so well and the therapist only actually initially met (our child) the once. (Shana)*

Rapport was seen as a first step to therapy. Kiri observed that taking time initially to make a connection pays off over the long run and the process of doing this was interrupted by frequent turn-over of staff.

> *I've noticed with (my child) since he's been working with other therapists, having that one therapist and building rapport at the start...rather than diving straight into it… then hopefully there'll be more progress (Kiri)*

Trent's suggestion of being allocated one key contact person within the health organisation was about his investment to develop an enduring relationship with one specific therapist rather than interacting with many. When asked for more detail about who might be in this role, his reply was:

> *anybody that's capable (Trent)*

Trent didn't expand on what being 'capable' looked like but he implied it was possible to recognise when a therapist had the necessary skills. The other three participants did articulate several therapist characteristics they believed contributed to genuine rapport. The quotes that follow describe some of these characteristics.

> *I just think they, all round need to, be more understanding (Kiri)*
> *If she was patient. She always loved to rush things (Shana)*
> *(Therapists need to) continue to get professional development and…keep up to date with new diagnoses (Kiri)*
> *I don't mean to discriminate, but I felt that the older (therapists) mid age up to older, were the least understanding. Whereas when I dealt with young… (Kiri)*
> *maybe they were (too) young, I don't know (Darlene)*

The second aspect was the connection between the parent and therapist. The participants were all willing and ready to work with the therapists for their child's benefit. In the quote below Shana captures how her perspective (and that of her partner) were not factored into the therapy approach. First, Shana observed that the way her child learnt might be different from how other children might learn, echoing comments included earlier about the child being seen as an individual. Second, Shana's day-to-day knowledge of her child wasn't acknowledged as valuable by being incorporated into therapy. Third, the noun 'water' that Shana taught her child wasn't used by the therapist and no explanation was given for this shift.

> *we had said to (the therapist) originally "hey we're with her 24/7, we know how she likes to learn and how she likes to do things. We've noticed that the way you're teaching her like this is too rigid for her. … it might be the way that you can, or you teach other kids, but we've noticed our daughter doesn't want to learn like that. She wants to learn music-wise you know, like singing songs*

> *or tapping instruments and that way the speech is still coming … gestures and those kind of things…we noticed we will go water, water, and we'd show her the water bottle. And then she started going oota, oota, but (the therapist) would say "drink", we didn't do that with her. So our way of getting her to understand was a lot of sign language (Shana)*

Parents looked for a shared understanding of the rationale for therapy. An example of a lack of shared rationale from Darlene was that insufficient explanation of the content of the session was offered.

> *she didn't actually explain anything to me. She sort of in a roundabout way like she said you know we'll do some drawing and maybe some cutting (Darlene)*

Shana shared another example of insufficient explanation which was in relation to the focus of therapy.

> *(Speech language therapists) main focus, and this is what I don't actually understand myself, is food and liquids (not speech). (Shana)*

Parents wanted to work with therapists in their child's therapy sessions. In the absence of negotiation parents could be unsure of how to contribute, which lead to Darlene getting involved 'spontaneously'. For instance, she found herself taking a hands-on role in the session.

> *I always had to be there with (my child) as well and I always had to be the one working with the therapist to get him to do things you know, and that shouldn't be like that. I shouldn't be there saying 'OK then, look', and explaining things. (Darlene)*

Darlene indicates that she was willing to take responsibility in the session. As further evidence of her commitment to therapy for her child, later in her interview Darlene disclosed she had been to the United States to pursue therapy for her child that fitted in with her values. Darlene felt that the local therapist was being 'too textbook'.

> *She would say OK nana stay there, (child) sit there. And it was almost so robotic you know… (Darlene)*

One further component of being connected was to establish trust. Darlene experienced difficulty trusting the therapist as demonstrated by her questions about the therapists' competence.

> *I didn't actually think they were good therapists…I think that half of them actually didn't know how to really relate to or motivate a child …I think they're in this little box. They've got their own set ideas on how to do things…And they don't branch out (Darlene)*

Two other participants spoke about the need to contribute towards the trusting relationship and that they prepared themselves to work together with the therapist. Acknowledging a previous trust issue, Shana described how a phone call could be an effective step towards connection, as a preference to written information.

> *I do have a trust issue where I don't know whether or not to trust... I find it quite hard to even... trust… phone conversations get me a little bit more eased kind of thing, …Just so that I'm not just going off black and white. (Shana)*

Finally, working together was about timing. The right time for the therapist may not have been the right time for the parent and the parent's ability to commit fluctuated. Kiri spoke about a recent insight which brought about a change in her attitude to working with the therapist for her child.

> *(Now my child's health) is a bit more serious, I am determined and motivated and have promised to keep appointments because...yeah, it's my child and I need... to be consistent with taking care of his wellbeing (Kiri)*

In summary, this theme of connection explored the value of establishing effective engagement between the therapist, the child and the parent. This involved the therapist entering into the world of the child and parent, understanding where they are at and valuing their contributions to the process.

4.2 Theme 2: Empathy

Valuing parents' contributions to the therapy process required therapists to hear, and give an empathic response to those contributions. During their interviews participants discussed their emotions related to the process of therapy for their child and to therapists' responses. This theme explores two components of empathy. First, that at times participants felt misunderstood, judged and unheard. Second that their responses were influenced by emotional responses from their children, from within themselves, and the wider community.

Being misunderstood was referred to by three participants. This was difficult for them to address with therapists and often resulted in parents feeling frustrated and unheard. Darlene encountered content during the sessions that didn't make sense to her. Her overall impression of therapists, and something that came up repeatedly during her interview, was that "they were boring, boring. That's the only thing". She went on to describe her unvoiced frustration when the therapist insisted that her child do something in therapy which the child was reluctant to do.

> *it was so frustrating and you're not going to get anywhere doing that (Darlene)*

When participants voiced their experience in therapy, attempting to be understood, they sometimes felt unheard. Kiri experienced this:

> *…sometimes I felt that I would get a reaction that I was over dramatising it or... they just weren't understanding. They weren't open to hearing about what I... was saying (Kiri)*

Shana also experienced this making an attempt to have her perspective understood, but feeling unheard.

> *… even when we tried to explain situations to do with (our child) playing with (the therapist) trying to read a book and get (my child) to understand and (my child) would just sit there and then go snap and shut the book you know, and it used to make (the therapist) very frustrated and I said "I know, we get this all the time, like but now do you understand?" … and she was just like "oh it's very frustrating" (Shana)*

Being misunderstood pertained to therapeutic priorities for two participants. This situation provoked Darlene to voice her frustrations with the therapist, and she was the only participant to describe doing so. She had received the therapy report, and reading it, realised that what she had thought was her child's priority area for therapy, had been misunderstood.

> *I got really, really angry…so I told her. You know, like he was doing this and he'd done this and he jumped in the kitchen and I'm like what has that got to do with his fine motor skills? (Darlene)*

The second participant who experienced frustration due to being misunderstood around therapeutic priorities was Shana. Her child was offered therapy appointments not long after she had moved into the area, at a time when Shana's priority was to establish support systems to enable her to participate.

> *So it was really frustrating because we had no supports up here. (Shana)*

As well as resulting in participants feeling frustrated and being misunderstood, parents felt judged by therapists. Kiri expressed this lack of being accepted, via therapists non-verbal communication cues.

> *Especially when I don't get an understanding reaction. I just feel like I'm doing something wrong…They just don't understand (my child), they're not open to accepting the things that I say. Like, when I say he just won't eat something. They're just like "Oh, he's being fussy." And, not saying that, but you know giving that reaction. (Kiri)*

In Darlene's experience judgement about her child's abilities and was discouraging.

> *I found that really disheartening (for the therapist to) say well he probably won't do this and he probably won't do that (Darlene)*

Feeling frustrated due to being misunderstood, judged and unheard was also influenced by responses from people other than the individual therapists, for example, other staff within the organisation. Trent and Kiri both identified the frustration of retelling their child's health background repeatedly to different staff.

> *And so I felt I needed to explain in depth to every single person I spoke to … so that people could get a better understanding of it but in the end, I just became frustrated with …. I didn't see any progression (Kiri)*

On occasions this was from people in the wider community, as outlined by Kiri.

> *I feel that a lot within the community as a whole. Not just the (therapists)… but also school teachers......everyone. Because everyone … part of that being unheard from the community... was my in-laws…and my own family (crying) (Kiri)*

Sometimes this frustration was from the parents own emotional state. In Kiri's situation, her mental health had an impact on her not keeping therapy appointments as the demands of the therapy session were too great.

> *a lot of the times I missed appointments or that my mum would go to my appointments with my (child) was...because I am in and out of depression and I get really bad anxiety (Kiri)*

Being aware of how their emotions impact on therapy was significant for parents. Kiri went on to speak about how she intended to move through her anxiety which was a barrier to therapy.

> *(keeping the appointment) is about me. And I'm learning to, sort of like, dust the anxiety off for that moment for my child. (Kiri)*

Shana was also aware that there were measures she took to reduce the emotional barrier to therapy.

> *'Cause sometimes like with her hospital appointments we actually spend about a week kind of... especially if it's quite a big procedure that's going to happen, we spend a … whole week prior, or a whole two weeks or three weeks prior to working ourselves up for it. (Shana)*

Finally, parents emotions towards therapy were influenced by their child's responses to the therapist. Shana talked about this.

> *they (therapist and child) didn't have a very good interaction… So we would get a bit agitated before an appointment with (the therapist) knowing… because we didn't even gel with her. (Shana)*

In summary, this theme of empathy explored participants' experiences of frustration which resulted from being misunderstood, judged and unheard by the therapists. Only one participant indicated that she directly addressed her feelings of frustration to the therapist. Participants feelings towards therapy were influenced by therapist responses and by emotional responses from others in their community. Participants were also influenced by their child's emotional responses to therapy.

4.3 Theme 3: Empowerment

The theme of empowerment emerged when considering why participants were not addressing their concerns during the therapy process. Three aspects of empowerment were highlighted in this theme: parents not voicing their concerns, parents observing a lack of transparency, and disempowerment for parents when therapists knowledge wasn't shared.

When parents were not empowered to voice their perspectives during therapy, their child's needs were not kept as the central focus of the therapy. Three of the four participants described occasions when they did not speak out about the content of therapy sessions. Darlene described a situation where she didn't give feedback during the session as she felt the right thing to do was to prioritise the therapist's work over her child's emotional well-being.

> *…always having these tasks set out and saying right first you've got to complete this one before... we're going to read this... (my child) hated reading, and I remember her saying no we have to read this book, we have to read this book, and (my child) just... ended up crying…Well I just was sat there. I didn't want to … butt in. You know like I wanted her to do her job (Darlene)*

Kiri, who had observed that her child's presence at the therapy sessions was counter-productive for him, felt that no space was created in the session for her to consider and contribute this observation.

> *every visit was the same. Like, there was no rapport built between my (child) and one (therapist) so that (my child) could gain...one's trust. And in the notes*

> *you could see that I would regularly say, "... shuts down when we have to talk about food"....He hated going to the appointments and I didn't see the need, him coming in the end.*

When asked about whether Kiri had raised the idea of seeing the therapist without her child, she replied:

> *No 'cos I've just, really had that realisation recently. (Kiri)*

Shana recounted an example of when a book being used in therapy did not relate to her child's life experience. Shana recognised at the time that the book's content would be unfamiliar to her child, however did not speak out about this in the therapy session.

> *But then when it comes to animals and things like that (in the book) ... because we struggled financially ... So we weren't going driving around and seeing cows and sheep and all those kind of pigs and... (Shana)*

When parents did contribute to the therapy process, this was sometimes an unsatisfactory experience. Two participants related examples of this. Kiri had collaborated in the therapy planning, however this collaboration did not extend to the phase of problem-solving and Kiri felt blamed for a negative outcome.

> *when I tell them that I tried the things that we both suggested or that we all came up with. And, it didn't work and they just tell me that I didn't try hard enough (Kiri)*

Similarly, Shana described when she had taken steps as asked of her by a therapist. She was then surprised by a change of plans from the organisation which left her feeling as though there was a lack of transparency.

> *And so we're feeling like... we've to be completely entirely honest, but they (the team from the organisation) can do what they want. And that's what … made me fully fully fully agitated. (Shana)*

Shana referred to feeling upset by the organisation doing "what they want" without having advised her and this was also Kiri's experience. When the organisation neglected to advise Kiri of staff turnover, she declined to keep appointments, also without advising the organisation.

> *I was consistent (attending appointments) at a point and then there was a point where… I had seen so many, every time we went it was a different (therapist)…and I had to relay the story…and in the end (it was easier not to go) (Kiri)*

Shana wanted to continue to provide her child with therapeutic play between appointments but was not given the necessary knowledge to do this.

> *…'cause (the therapist) would do a lot of … things where as soon as she went we didn't know how to do it, how she did it. So… Show me how to do this. Show me how to do that. Because I'm not... dumb or anything like that, but I didn't know her technique (Shana)*

In summary, the theme of empowerment explores how the parents were not enabled to contribute to the therapy process for their child. This resulted in parents either not giving their feedback or being blamed when feedback was given, experiencing a double standard of honesty and being restricted from gaining therapeutic knowledge. As a result, the child's needs were not upheld as a central focus to therapy.

4.4 Theme 4: Therapist as the face of the organisation

When a therapist engages with a client they are doing so as a function of their role as an employee in a health organisation. The therapist takes on a dual role identity; the identity of a health professional representing an organisation, as well as their own personal identity. As such the therapist is experienced, by parents, as the face of the organisation. This theme explores parents experience of interacting with the therapist as a representative of the organisation that provides a service to their children. It looks at how well the communication systems that exist between the organisation and the parent meet their needs, and reviews cohesion within the organisation.

One important communication strategy for three participants was the appointment letter. In particular, the timing of the appointment letter featured as a contributor to missing an appointment in two interviews. Trent described that waiting a long period of time between his child being referred and receiving an initial appointment letter, was an issue for him. This affect was compounded when the letter indicated another long wait before the appointment. There were many other parenting tasks he was managing from day to day, so the referral reason wasn't a high priority for him.

> *having to wait…appointment pending, (you) start to get lost…forget you have the appointment (Trent)*

For Shana the issue with the timing of appointment letters was that on occasion they arrived after the date of the appointment, thus resulting in a missed appointment.

> *(missing the appointment) is around them not sending the letters, and then they'll send a letter, say we'll have an appointment today and they'll send a letter tomorrow (Shana)*

In addition to the timing of appointment letters, the content of the letters featured, and was recognised as serving two key purposes; to advise of the appointment details and to have parking fees waived. From the organisations point of view this content was designed to convey important information about the visit, however information the client considered important was not always included. For example, the content of one appointment letter was noted by Kiri to be inadequate as she was not made aware about the purpose of the appointment.

> *I only just recently I got a letter from the paediatrician and that was the only letter that I had knowing exactly what I was going there for, what I needed to take. Whereas with the (therapists), I just got a letter saying that I had an appointment with them. I didn't know what we were going to discuss…(Kiri)*

Regarding the function of the appointment letter in having parking fees waived when the appointment was on the hospital site, Shana noted that:

> *when there's a hospital appointment we need the letter in order to... because normally see, we're struggling financially, so we don't have the petrol, as well as paying for parking. So we need the letter to verify when we go to the hospital (Shana)*

The usefulness of written documents was determined by how they could be accessed for future reference. With electronic communication such as texts, phone calls or emails, this was less likely to be an issue. This scenario was highlighted by Shana. She described how written communication on its own was not sufficient for keeping in touch with the therapist. When Shana was motivated to revisit the written plan for her child, she was unable to because it had been misplaced.

> *Our therapist, she did a plan …And she did send a copy for me, but this is another thing, Dad will move it to clean up... And it just disappeared. So I don't have a copy. (Shana)*

The organisation used electronic and telephone communications. However, Trent outlined some scenarios when electronic communication had failed him. He described the challenges of tele-communications as being:

- voicemail costs to access a message and therefore messages could be missed
- messages that were accessed may not give a return phone number for parents to call
- text messages were preferred as these can be accessed, although not always replied to
- only some hospital departments have an 0800 freephone number.

Trent gave an example of a solution that might make communications more reliable between the organisation and the client, ie. all departments could have an 0800 phone number.

For most effective communication, the organisation used a combination of written, telephone and electronic options. Kiri noted that while she had no particular issue with written letters, her preference was for electronic communication.

> *letters, I do get the letters. But yeah, to save paper, email…otherwise texts. (Kiri)*

For all these communication systems to work, contact details needed to be maintained when changes were made. Nevertheless, Kiri, who had made an effort to keep the organisation aware of her current contact details, still experienced frustrations with this. She said:

> *…letters were sent to my mum's house. And I had updated my address, my mum rang me to say that I had an appointment with the therapist, to remind me of it. And I just thought "Why didn't she (the therapist) ring me?" (Kiri)*

Kiri saw a solution which seemed straight-forward to her but which was not being implemented.

> *… the different computer systems and making sure that they're all updated. Which I don't understand. Like, how come...you guys don't have ... one central…(computer system)? (Kiri)*

An effective way to book an appointment could be to negotiate it at the end of the previous therapy session. Kiri suggested this would help her to meet employment responsibilities as well as parenting responsibilities. When appointments were allocated rather than negotiated, this interfered with her work and, while Kiri organised for a family member to take her child to the appointment, she saw that this was less valuable than if she had been able to attend.

> *It's quite hard because you know, if you leave that work it will just pile up. And, it's easier getting another family member to take (my child) but they're not so understanding of the situation. (Kiri)*

When asked about the location of therapy appointments all four participants valued home visits from their child's therapist. This was particularly true for Shana, who was new to the area and not familiar with the organisation lay-out. Trent also spoke about how factors such as having no petrol in the car because his finances were stretched and his child's physical health was fragile - "my child gets sores that break out on his skin" - limited his attendance at clinic appointments.

The cohesion between therapists and other staff of the organisation was noted to be an issue. Shana described a time when she initiated a more cohesive process because she saw the opportunity to minimise frequency of visits to the hospital. She did this because each visit was stressful for her child, and consequently for herself. While this wasn't specific to the therapy team it pertained to other services her child accessed within the same organisation.

> *The last hospital appointment we had at audiology, and … 'cause I wasn't happy with the outcome… But what was better is because I explained the situation of (my child's) global developmental delay…And then that's when they were quite concerned about the situation… that's when they went over to, or he rang ENT …Yeah so we did both of them on the same day. (Shana)*

This effective integration of visits occurred following agitation by a parent, rather than by organisational planning. Trent, made a suggestion to have one key contact person for all of the hospital services required by his child. He outlined four advantages of this:

> *keeping to a specific person who can take care of my (child's hospital related needs), that way you can always be in contact, can text my phone, knows the situation of my (child) and which people are needed (Trent)*

The same idea was suggested by Shana, who also recognised the value of having one key contact person. In particular she referred to the kaiawhina, who had been part of the recruitment process for this research, as being instrumental when making a link with the therapy team. The kaiawhina staff are part of the health organisation, but are not linked with the therapy team.

> *she (kaiawhina) was actually easy to talk to as well, it made it a lot easier, Yeah (kaiawhina) we've found really really handy. Really really good. (Shana)*

One final point is that when therapists are seen as the face of the organisation and in their professional role, their personal identity may be overlooked. This may have been a factor in Kiri's comment that she'd worked with an 'awesome' therapist but had 'forgot(ten) her name'. Darlene gave an example of this when she explained how unsatisfactory experiences with two therapists, deterred her from engaging with any further therapists.

> *They did say to me do you want another therapist and I was just like after… I had so many disappointing… I was just like no, look don't worry about it. (Darlene)*

In summary, this fourth theme explored the ways in which the therapist was seen by participants as the face of the health organisation. Parents expressed the challenge of using the organisation's communication systems that at times did not meet their needs, and of the demands of interacting with multiple staff and services within the organisation. They also made suggestions for changes to the interface with the organisation, ie. to increase service cohesion and service delivery. Participants felt those improvements would better meet their needs, and provide a streamlined service to their children.

One day mum said: "I have figured Tui out! She likes the puppy treats. She comes when I call her even when there is a nice smelly fish-head. And she doesn't say hello to strangers anymore."
"That's good," said big brother.
"She is still fluffy and cute," said sister.
"Show me," said little brother.
"She could still run away," said dad.
"Yes," sighed mum, and she took Tui to the beach again.

Chapter 5: Discussion

The research question this thesis sought to answer was 'what helps and what hinders families from participating in therapy appointments with the Child Health Centre in Northland?' Overwhelmingly participants in this study focused their interview responses on the quality of the therapeutic relationship. The consistency of this linkage between participation in therapy and therapeutic relationship provides rich data for answering the research question. Importantly, the wording of the research question being around 'participating in' rather than 'attending' set the tone for participants to comprehensively explore what keeping or missing appointments meant to them. Service features and intra-service cohesion also mattered to participants and it is argued that the way this is represented to families is through the therapist relationship. To answer the research question effectively, the researcher sought to understand how the therapeutic relationship can be firmly embedded in therapy practice.

In the results chapter the participant responses were themed as components of therapeutic relationship, ie. connection, empathy, empowerment and therapists as face of the organisation. Expansion and synthesis of the concepts contained within the themes has been used to form a discussion which addresses five main points. First the discussion will consider specific professional development for therapists around engaging families. The next section reflects on how the findings fit within the Northland DHB values and what these might look like when integrated into service delivery. This is followed by consideration of the demographic data, that is, ethnicity, gender and socio-economic status and the roles these factors play in relationship building. All participants in this study were Māori, only one of these four was a dad while the rest were mums, and three of the participants talked about financial stressors. As all the participants were parents, the word parents is used throughout the discussion. In the fourth section implications of the findings in relation to current and proposed occupational therapy theory will be discussed. Finally, limitations of this study are presented and further research proposed. In summary, this discussion chapter links the research findings to practice implications for service development in the therapy team of the Northland Child Health Centre.

5.1 Professional development for effective family engagement

Occupational therapy theory consistently places value on establishing an effective therapeutic relationship, based on client-centred interactions, between the therapist and the client (Fisher 2013). In paediatric clinical settings, the client is not simply one person, but is located in a client constellation of their family and/or caregivers. This study has shown that a poor relationship between the therapist and the child as well as the therapist and the family results in poor participation in therapy for the child. The findings of this study suggest that, for therapists working in paediatric settings, the development of strategies to engage a child and their family is essential. This discussion argues that there is merit in promoting family-centred practice models rather than an expert model in professional development for therapists.

The term 'expert model' is used to refer to working in an individual way with children, and it assumes the therapist has knowledge to contribute to therapy that places them in the role of an expert, and superior to the family and child (Davis & Meltzer, 2007). The expert model has a heavy emphasis on intervention techniques rather than therapeutic use of self in enabling therapy outcomes (King 2016). This model frequently results in significant parent disempowerment, dissatisfaction and reluctance to seek help for their child (Davis & Meltzer, 2007). Paediatric therapists might work from an expert model, with the best intentions, as a natural consequence of undertaking formal professional training, ie. they have not participated in training for family-centred models. Furthermore, some therapists and parents have expectations of therapists to somehow 'fix' the child when the therapist is viewed as expert. Therapists work in this way risk excluding parents from being active participants in therapy. More than one participant in the Child Health Centre study commented that interventions were used that the therapist was familiar with, but which the parents could not see as relating to the therapy goals. On reflection, when therapists lack training in family-centred models, they are likely to default to what is known, ie. an expert model that was presented to them in their undergraduate training, or their own eclectic models of working based on previous client work. It has been argued in the literature review, that when therapists practice in this solution-based way, then working in partnerships which emphasise families own understandings and contributions to the therapy process, are limited as therapists rely more heavily on their own knowledge and space is not opened up for collaboration.

In contrast to this is family-centred philosophy which guides therapists to be responsive to family needs and collaborative with families (Andrews, Griffiths, Harrison, & Stagnitti, 2013). Family-centred practice has over the last 30 years become a focus of occupational therapy in paediatric services, gradually taking over from individual child-centred practice (Andrews, Griffiths, Harrison, & Stagnitti, 2013). However, in a comparison of paediatric occupational therapy and mental health occupational therapy literature, King (2016) argues that in-depth communication skills, such as motivational interviewing and health coaching, necessary to develop collaborative partnership relationships to promote change, are "essential but neglected" elements of undergraduate training (King 2016, p11). Significantly, King (2016) found that the role of the therapist in effecting therapeutic change is minimally referred to in the paediatric literature, where change tends to be more linked with interventions rather than the therapists ability to facilitate conditions for therapeutic change. In the results of the Child Health Centre study, in Chapter Four, parents gave examples of how therapists inhibited their participation in therapy by not including them and by overlooking them as a resource for change with their children. It is important for therapists to develop the necessary skills to form effective, collaborative, therapeutic relationships with families. Family-centred models can provide the structure for this skill development. Three models developed around family-centred practice philosophy are discussed here: the Family Partnership model, Whānau Ora and Occupational Performance Coaching.

5.1.1 Family Partnership Model

The Family Partnership Model (FPM) was developed in the United Kingdom for staff in social support organisations, whose work is to support children and their families (Davis & Meltzer, 2007). A study of staff in New Zealand and Australia who were implementing the family partnership model, concluded that working in partnership relies on staff acknowledging and sharing power, and in so doing either enabling client/families feelings of competence in the partner role or denying them a true partner role (Rossiter et al., 2011). The FPM model offers training workshops emphasising the importance of staff developing comprehensive communication skills to enable them to construct conditions for forming effective partnerships with families:

> …partnership is not a relationship that can be assumed to develop quickly and naturally; it requires time, effort and skill. It also follows that an effective partnership may not be possible in all cases or at all times; it depends upon what the participants bring to the situation, and some may not want or be able to work with others in this way (Davis & Meltzer, 2007, p12).

Integrating skills developed for working within the FPM into the workplace could be limited where a shift in clinician attitude to practicing in a new way is also required, as this can be a more challenging change to facilitate.

5.1.2 Whānau Ora

Whānau Ora is a philosophy designed in New Zealand for working across government based services, including health, to accomplish whānau well-being (Te Puni Kōkiri 2016). The model, which is based on Māori values of collectivity does this by focusing holistically on families as well as individuals needs within those whānau. Key features include to build trusting relationships, being focused on whānau aspirations and whānau self-management (Te Puni Kōkiri 2016), features that are arguably shared with the FPM. The first phase of implementation of this government lead initiative was for services to transform from siloed services to 'provider collectives' and the second phase involves commissioning agencies in developing an understanding of how non health and social services can also work with the Whānau Ora philosophy (Te Puni Kōkiri 2015). Also similarly to FPM, to effectively implement Whānau Ora, staff training in strategies to empower whānau to increase capability around their health self-management is required (Taranaki District Health Board 2015). In contrast to FPM the content of such training is not provided under the Whānau Ora framework and organisations employing this model would need to look to other services utilising the Whānau Ora approach for training or develop their own training package.

In a study reviewing collectives of service providers implementing phase one of the approach, an example of a successful outcome was presented from Te Hau A Otangarei, in Whangarei, where the Whānau Ora staff (Kaimahi) established tikanga for conflict resolution hui resulting in improved whānau well-being (Te Puni Kōkiri 2015). It is not clear to the researcher how paediatric occupational therapy practice in the Northland DHB might transition into a Whānau Ora collective or adopt the philosophy.

5.1.3 Occupational Performance Coaching

The Occupational Performance Coaching (OPC) model was developed by Dr Fiona Graham in 2009 specifically for therapists (occupational therapists, physiotherapists and speech language therapists) who work in child development teams, such as the Child Health Centre in Northland (Graham et al., 2018). OPC is strengths-based, centred on empowering parents through collaborative practice and supports the move away from expert models of service provision (Graham et al., 2018). Similar to the FPM, OPC has provision for training staff to up-skill around empathic enquiry, motivational interviewing and goal-setting. A study of paediatric therapists using OPC sought to understand how this was integrated into practice, and found that using the model of OPC lead to, among other outcomes, “listening better” (Graham et al., 2018, p. p4). One particular strength of OPC is to advance occupational therapy theoretical understandings around client-centredness by offering a way for paediatric therapists to develop the additional skills to be client-centred in their setting, ie. with the child and their family.

5.1.4 Family-centred models and family perspectives

The models presented here have in common an acknowledgement of the effort required by therapists to shift their approach to work by adopting a new model and by developing the necessary skills for authentic partnership relationships with families. The Child Health Centre research participants clearly identified the benefits of closer working relationships in which they felt able to contribute in the interests of their child and where the therapy sessions were relevant and fun. A poster detailing parents' priorities for parent-professional relationships in Australia (Heyworth 2017) strongly echoes this sentiment. The poster articulates points for staff, eg. being family-centric, empowering the child and family, and relating directly with the child to have fun sessions. The poster also contains points for families eg. the importance of self-education, and embracing and sharing one's own experience and expertise (Heyworth 2017).

Of these three models, the OPC stands out for its applicability to the therapy team at the Child Health Centre because it brings together family-centred and occupational therapy principles. OPC would provide a scaffold for therapists to move away from expert models of practice, and in addition it fits with the results of this study.

5.2 Implementing the organisation values

The discussion began by providing a case for therapists to undergo additional training so they could develop effective partnerships with their clients, ie. the child and their family. Next, the discussion will position findings from the theme of ‘therapists as the face of the organisation’ in relation to the values of that organisation. As employees it is their responsibility to demonstrate these values, which indicate that in the pursuit of quality client experiences, a focus on relationships is invaluable. To answer the question of what helps and what hinders participation in therapy, it is important to reflect on the Northland DHB values so that therapists can ensure that these are then acted upon. In demonstrating the organisation values, therapists are enabling the organisation to address it's role in the keeping or missing of appointments.

The vision, mission and values of the Northland DHB are displayed around the campus and can also be found on their web-site: www.northlanddhb.org.nz. The vision is: A Healthier Northland. The mission is: to work together with Northlanders in partnership under the Treaty of Waitangi to improve population health and reduce inequities; to improve patient experience; and to live within its means. There are five values outlined to guide the organisation towards achieving its mission, and these will each be discussed in relation to the research findings. This discussion demonstrates the ways the Northland DHB intentions and the research participants experiences, interact around the therapist's role.

5.2.1 People First - *taangata i te tuatahi* - people are central to all that we do.

The Child Health Centre employs the Northland DHB wide DNA policy which is to discharge clients after two missed appointments. This is a standard approach (Andrews et al., 1990), but is being challenged in some paediatric services (Powell & Appleton, 2012). The phrase 'was not brought' (WNB) was proposed by researchers in the child protection field in the United Kingdom as a better descriptor for the scenario of children missing appointments as being a child's rights issue (Powell & Appleton, 2012). It was considered that introducing this term for children would invite clinicians to look beyond a missed appointment, into the bigger context of the child's well-being and safety, and in doing so would promote a more child-centred practice (Powell & Appleton, 2012).

Powell & Appleton (2012) identify several questions to raise when a child is not brought to a health appointment and these seek to explore the child's needs, their overall health, well-being and vulnerability and the potential impacts of having missed the appointment. Replacement of the standard DNA policy with active management of missed appointments is also supported by a study undertaken to tackle health inequities in the United Kingdom (Maharaj et al., 2014). It was found that this enabled staff to focus on meeting the needs of children who might otherwise be lost to follow-up and whose health issues might not be addressed (Maharaj et al., 2014).

The shift from DNA to WNB runs parallel to another shift, which is to view the service as being 'hard to reach' rather than the client and family as being 'hard to reach' (Boag-Munroe & Evangelou, 2012; Phoenix & Rosenbaum, 2015; Te Puni Kōkiri 2015). The Child Health Centre findings outlined in Chapter Four add weight to this impression as parents described many barriers to attendance that related to service features. This type of shift in organisational thinking and policy is challenging yet has been demonstrated to be successful in increasing attendance and addressing inequity in a paediatric service (Maharaj et al., 2014).

Re-conceptualising in these ways gives an example of how the organisation can fulfil the value of people, ie. children, being central to the work at the Child Health Centre. More specifically this would involve introducing the terminology of WNB, rewriting the policy around missed appointments to include provision for the impact of that on the child's health, and reflection on how the service might be hard to reach for families.

5.2.2 Respect - *whakaute (tuku mana)* - we treat others as we would like to be treated

Parents in general want their children to thrive, to reach their potential and not to simply avoid negative health outcomes (Moore, Bethell, Murphey, Martin, & Beltz, 2017). As was captured in the results chapter, parents in the Child Health Centre study were no exception to this, and wanted their children to be treated as individuals who like to play and have fun, without limits being placed on what the child might accomplish. Enacting the organisational value of treating others as they would like to be treated would conjure an image of children being facilitated to participate and flourish. When therapists have limited expectations for a child's participation as was found in the Child Health Centre study this is an element of a deficit thinking. Paediatric health services in New Zealand have been described as accepting deficit culture as the norm, in particular through the language used to describe children living with disability (Callander 2018). When talking with families in the context of preparing a photo essay of children with special needs, termed "super-power babies", Callander (2018, p1) was often told by families that they had never before used positive words to describe their child. In the New Zealand education system the prevailing deficit model was found to limit achievement by groups of students, eg. Māori or those from diverse populations (Bishop & Berryman, 2010). This was because teachers focused on deficits, tended to look to blame rather than be solution-based, and sought to abrogate responsibility for poor achievement outcomes (Bishop & Berryman, 2010).

A Good Start in Life is a collaborative, multi-sector project undertaken in New Zealand using a co-design methodology to identify options that would improve service delivery for families raising a child with a disability (Goodwin et al., 2018). Many of the findings of this process related to parents experiences and one was that "almost without exception parents were proud of their children and said they brought them joy" (Goodwin et al., 2018, p20). A definition for flourishing and a method for monitoring this concept has been developed in the United States by researchers in both the child/adolescent mental health and the child/maternal mental health services (Moore et al., 2017). The definition centres on eight measurable constructs of value, with the first four being most important. These are the child's ability to self-regulate emotions and stressors, their attachment or co-regulation with a significant adult, curiosity as seen through cognitive, behavioural and emotional engagement in learning, and communication (both receptive and expressive) (Moore et al., 2017). The authors argue that this is necessary so that policy and programmes that focus on children flourishing, can be developed and monitored for their effectiveness (Goodwin et al., 2017).

These researchers suggest that there is an argument for moving away from deficit language, and they provide evidence that parents would like their children accepted and encouraged as unique individuals. One final consideration for enacting this Northland DHB value is that rather than treating people as we might want to be treated, it is better to enquire into ways that would be acceptable to the person (Pitama et al., 2007). The research participants, as well as the literature, gives a clear indication that parents' preference is to surround their children with empowering and respectful language.

5.2.3 Caring - *manaaki* - we nurture those around us, and we treat all with dignity and compassion

Participants in the Child Health Centre study referred to feeling unheard, misunderstood, judged, and even blamed for poor outcomes of therapy. They also described occasions when their children were crying during therapy sessions. These factors demonstrate a lack of care and nurturing by therapists that negatively impacted on parents keeping appointments. As families bringing children to therapy are likely to face multiple challenges as they seek to keep appointments (Phoenix & Rosenbaum, 2015), these negative attitudes create an additional barrier.

To enact this value of demonstrating caring, therapists would benefit from understanding how their attitudes can inhibit clients' participation as much as the limitations in physical environments can. Impairment, either in children or adults, can be considered value-neutral until it encounters social attitudes, especially those of non-acceptance (Kielhofner 2005; Reeve 2004). This places therapists in a challenging situation because therapy typically focusses on problem-solving issues of individual disability, and this in itself can send a message of non-acceptance (Kielhofner 2005). One study found that occupational therapists had significantly higher positive attitudes towards people with disabilities when compared to physiotherapists and nurses working in rehabilitation settings (White & Olson, 1998). Nevertheless, as revealed in the Child Health Centre findings, when families do encounter uncaring therapist attitudes these have a compounding effect as parents are sensitive to community feedback already.

There remains a need for increased awareness of how occupational therapists can demonstrate caring attitudes when engaging families. It is debatable at what level occupational therapists ought to be involved in resolving attitudinal limitations, ie. as individual therapists, as a service or as a professional body (Kielhofner 2005). However, as the Northland DHB stipulates caring as a value then individual therapists have a responsibility to attend to the impact of their attitude on a child's engagement. Therapists might do this by actively listening and taking on an advocacy role for the children they work with (Durocher et al., 2013).

5.2.4 Communication - *whakawhitiwhiti korero* - we communicate openly, safely and with respect to promote clear understanding

Enacting this Northland DHB value of effective communication has in part been discussed earlier in the chapter when it was recommended that therapists participate in OPC training with its focus on developing sound therapeutic communication skills. This skill development would address the Child Health Centre participants' concerns regarding wanting to interact with therapists as people, who were not too 'boring' or 'textbook' in their interactions.

Another process for achieving this is drawn from the early childhood education literature and involves the concept of relational agency. This is defined as a complex skill set that enables staff to develop "knowledge of how to know who" services need to focus on engaging (Boag-Munroe & Evangelou, 2012, p29). Interestingly, responsive, reciprocal and empowering relationships between staff and families, was enhanced when staff introduced themselves to families via an information sheet containing a photo and brief written biography (Clarkin-Phillips & Carr, 2009). A simple strategy like this would provide therapists with a system for personal disclosure which would help them be viewed as people and not simply therapists.

As identified in the Child Health Centre study, another aspect of communication is the method used, eg. the use of written or electronic communications. Electronic messaging from health organisations to clients is becoming a mainstream practice for reminders about upcoming appointments. A Cochrane review of this concluded that for reducing DNA rates electronic reminders were more beneficial than a letter or than no reminders, and were cheaper than reminder phone calls (Gurol-Urganci, de Jongh, Vodopivec-Jamsek, Atun, & Car, 2013). The review also noted that there were no studies exploring the subtleties of electronic messaging on clients or linking these electronic reminders to health outcomes for clients (Gurol-Urganci et al., 2013). Parents in the Child Health Centre study referred to preferring electronic communication about upcoming appointments as it enabled a two-way conversation, whereas letters did not, particularly if the letter had been misplaced.

Another aspect of communication is using principles of health literacy, such as ensuring people understand the interventions for their health condition as well as the roles of staff and services involved. The participants in the Child Health Centre commented that appointment letters do not typically indicate the purpose of appointment; there were also concerns that a report was written about intervention goals that were different to what the parent thought were being addressed; and parents were confused about the choice of interventions to meet therapy goals. Health professionals frequently have a low awareness of the impact of health literacy and their role in addressing it (Lambert et al., 2014). These researchers suggest employing techniques such as client-centred communication, confirming that the family understand what is being conveyed, as well as creating a therapeutic environment of empowering people to voice their concerns (Lambert et al., 2014). These are all ways that therapists might enact the organisational value of 'open and safe communication' to promote understanding.

5.2.5 Excellence - *taumata teitei (hiranga)* - our attitude of excellence inspires success, competence, confidence and innovation

When participants commented that therapy didn't seem to be benefitting their child, or that disappointing experiences with some therapists put them off meeting other therapists, this demonstrated a lack of trust in the quality of the service being provided. This experience of less than excellence was also apparent when participants observed a lack of service cohesion. Wrapping up their comprehensive review of the literature on hard to reach families, Boag-Munroe & Evangelou (2012, p235) state "one message above all others stands out: services need to build relationships of trust with families and with each other".

Ensuring service provision is at an excellence level would require staff to feel supported in their work. The Child Health Centre study results captured participants' awareness that staff face resourcing issues, such as an impression that staff were rushed and that computer programmes do not sync to each other. Studies from the United States of America, the United Kingdom and across Europe record that the majority of healthcare workers lack joy and meaning in their work, and that this is in a large part due to business models encroaching into the healthcare arena and requiring staff to focus on efficiency rather than on the necessary complex therapeutic relationships (Sikka et al., 2015). When there is a lack of support from their employer, staff may experience 'citizenship fatigue' a term coined by Bolino (as cited in Cannon 2008) which is used to describe staff frustrations, the feeling of being undervalued, disconnected from the workplace and not inclined to contribute to the organisational values.

With that in mind, inspiring an attitude of excellence could be enacted by a review of the organisation mission from which these values flow. The Northland DHB's mission appears to be closely developed around Berwick's Triple Aim which articulates three goals: to improve the peoples experience of care, to improve population health, and to maintain financial targets (Sikka et al., 2015). Sikka (2015) proposed a Quadruple Aim which could be adopted by adding a fourth goal to these three: to improve the clinical and administrative experience of providing care. This fourth aim is argued as being essential to enacting the first standard three aims, as without it staff engagement, teamwork and respect for colleagues is far from excellent (Sikka et al., 2015). Leaders are recognised as having influence over effecting staff engagement in their workplace (Cannon 2008).

In summary, undertaking a process of evaluating what the health organisation's values might look like in action can guide therapists practice. This process has been initiated in this discussion. It has been argued that findings of this study fit with the literature that staff employed by health organisations, have a role to play in creating conditions more conducive to families keeping their appointments. However the degree to which staff are enabled to enact the workplace values may be restricted by pressured health workplace culture. The Child Health Centre is currently developing a team vision, mission and value statement. This is a timely opportunity to consider how structures such as policy, communication systems, language around disability, and the introduction of a mission statement around staff satisfaction at work, could be instrumental for reducing WNB rates.

5.3 Socio-cultural context

The social context has been shown in the literature review in Chapter Two to have a significant impact on the way in which people engage with healthcare services. In the Child Health Centre study three elements of context (age, gender and ethnicity) were gathered from participants at the outset of each interview and this information has been summarised in the methodology in Chapter Three. This demographic data was not referred to again during the interviews by the participants or the interviewer. Collecting this data was consistent with the qualitative descriptive methodology which is concerned with identifying the "who" as well as the "what" of experiences (Sandelowski 2000, p338). The following discussion will reflect on two aspects of the demographic information: Māori ethnicity and gender. Socio-economic status will also be discussed as it featured in all of the interviews.

The concept of intersectionality states that features such as ethnicity, gender and socio-economic status are inseparable when considering mechanisms of marginalisation or disparities of values (Gerlach 2015). However, as New Zealand is a bi-cultural country, where the impact of colonisation is seen to contribute to poor Māori health outcomes for their children (Mills et al., 2012), it is necessary to discuss ethnicity as a standalone factor. In seeking to understand health disparities either by colonisation or by intersectionality, therapists could benefit from comprehending how power dynamics play out in health services and communities, both historically as well as currently, as this will be likely to enable them to reduce the impact of these dynamics (Eggleton et al., 2016; Gerlach 2015; Hopkirk & Wilson, 2014). One strategy for therapists is "to integrate a critical perspective of health and health equity in our theorising and practices" (Gerlach 2015, p247). As Gerlach contends, when therapists do not challenge the status quo they are further contributing to sustaining health inequities (Gerlach 2015).

5.3.1 Māori ethnicity

This is a mainstream study of parents who missed appointments with the therapy team, in which all the participants were Māori. Given that Māori were over-represented in the Child Health Centre missed appointments statistics used for recruitment, as described in the methodology in Chapter Three, this was not unexpected. However, if this study had intentions to focus singularly on Māori perspectives, then a different methodology, such as was used by Hopkirk and Wilson (2014) would have been employed. These researchers utilised Smith's (as cited in Hopkirk & Wilson, 2014) seven principles of Māori research to enable them to collate, analyse and protect knowledge from a Māori perspective.

Using a non-Māori methodology is likely to have overlooked valuable data by not enquiring into participants experiences of engaging with the therapy team as Māori parents. To learn about the values and beliefs of Māori participants, requires a series of questions, not just one, about ethnic identity as not all Māori share the same world-view (Pitama et al., 2007). This kind of overlooking and silence around Māori perspectives can be seen as non-Māori therapists having a privileged position where it is possible to ignore issues that are tangible for Māori (Emery-Whittington & Te Maro, 2018). In a study seeking to understand how cultural perspectives are incorporated by occupational therapists in therapy, it was found that non-Māori research participants did not mention points raised as important by Māori participants, such as emphasising positive outcomes for the whole family rather than provision of service to one individual family member (Hopkirk & Wilson, 2014).

Gaining such deep knowledge about client context is a labour intensive process for therapists (Gerlach 2015). Yet when Māori perspectives are assumed, or shared but not integrated into research outcomes, this amounts to a continuation of the colonisation process of devaluing indigenous knowledge (Hopkirk & Wilson, 2014). In this way research involving Māori does not always benefit Māori, a concept acknowledged to be challenging for many New Zealand researchers (Brewer, Harwood, McCann, Crengle, & Worrall, 2014). For the Child Health Centre study, it is argued that the use of the qualitative descriptive methodology is appropriate as it enabled participants own words to tell their stories by not requiring researcher interpretation at the data analysis stage (Sandelowski 2000). The data has been regarded as inherently valuable, being parents' personal content and assumptions, and no attempt has been made to elicit further meanings from their words. Even without utilising a Māori methodology (other than Te Ara Tika guidelines for Māori ethics (Hudson 2010)), the findings emphasised connection and empathy within the therapeutic relationship, as well as a focus on relationship building with the whole family, which is consistent with existing literature analysing Māori perspectives (Hopkirk & Wilson, 2014; Pitama et al., 2007).

In summary, considerations for researching Māori as a non-Māori researcher have been discussed. Neglecting to focus on the experience of Māori participants as Māori is recognised in the literature as an issue for non-Māori researchers. Non-Māori therapists can move towards placing value on te ao Māori when they invest time in establishing research relationships with Māori participants, by respecting knowledge shared and by taking responsibility for understanding factors which contribute to health outcome disparities.

5.3.2 Gender

Just one interview was conducted solely with a dad. A second dad was present during a mum's interview, but as he took such a minor role no quotes from him were able to be included in the results chapter. It is important to discuss that more participants were mums than dads as this reflects parent involvement in health appointments for their children even though the role of father's is known to have a significant impact on child development (Dennison 2003). Some services have been criticised for being gender-blind with no specific ways to engage fathers (Boag-Munroe & Evangelou, 2012). Among paediatric health services literature there is little evidence of challenge to the tradition of neglecting the father's role (Dennison 2003). In their systemic literature review, Boag-Munroe & Evangelou (2012) identify that services for children could promote dads' active engagement with their childs' health services by creating referral systems and policies that specifically address this. Without consciously targeting strategies to increase dads involvement assumptions about the roles of family members are made which may be inaccurate and as pointed out by Dennison (2003), this is an area that requires further analysis in relation to fathers' identity, masculinity and parenting role.

Conversely, it could be assumed that more mums were interviewed as they were in the lead parenting role. In addition, these mums identify as Māori, who as detailed above, would often hold a world-view different to that of the health professional and would therefore be described as vulnerable. Health professionals have observed that vulnerable women can feel as though their sense of inadequacy is exacerbated by health professional responses and are known to avoid health professionals (Rossiter et al., 2011). The Child Health Centre findings appear to indicate a low level of assertiveness from the participants in their reluctance to point out to therapists events that concerned them during therapy, as well as hesitancy when critiquing the staff or service. This is linked to the concept of health literacy which incorporates the ability to verbalise matters of importance during therapy sessions. Māori women are known, as a group, to have a very low health literacy rate of 75%, where the New Zealand adult average is also low at 56% (Lambert et al., 2014). These statistics, add strength to the results and indicate there is a role for clinicians to empower female family members to find their voice, to confidently explain their child's situation and what might be best for them.

When the health care system employs staff to do tasks that traditionally were carried out by mums, ie. a lactation consultant or a behaviour support/parenting specialist, this can have the undesired affect of undermining innate female knowledge and confidence, placing value instead on knowledge gained through participation in formal training programmes and in this way medicalising childhood development (Ryan & Runswick–Cole, 2008). Clinicians are recommended to develop effective client-centred communication skills, eg. providing space for parents to raise concerns which would then be addressed, albeit while acknowledging there are organisational resourcing factors that would hamper these efforts, such as time restraints (Lambert et al., 2014). When health professional skills in family-partnership models are enhanced, this is shown to reduce mums' sense of alienation from services (Rossiter et al., 2011). Further, in their literature review of the position of mothers raising children with disability, Ryan & Runswick-Cole (2008, p1) concluded that mothers experience disablism in relation to their disabled child in a socio-political environment of "oppressive mothering ideologies" from which it is challenging to parent without letting the disability of the child dominate other aspects of family life.

To engage parents effectively with the therapy process there are different issues for therapists to consider for mums, and for dads. Health services, and the therapists within these, with their understandings of the valuable roles that dads play in their child's development, are encouraged to create opportunities for them to participate in therapy and to recognise the importance of their role in their child's development. Whereas for mums the issue is for therapists to think critically about health literacy, in particular increased assertiveness with health professionals. Up-skilling therapists in family-centred models combined with introducing policies and protocols, such as allowing time for developing effective relationships, and collecting information about parenting roles on referral, would move towards that end.

5.3.3 Socio-economic status

Demographic data about the participants socio-economic situation was not formally collected but featured in the interviews as a factor for keeping or missing appointments. Comments indicating how socio-economic factors impacted include irrelevance of story-books used in therapy due to these being disconnected from the child's limited experience; parents needing to work and not being able to take time off for appointments; and financial limitations related to the cost of petrol, car-parking and accessing electronic messages. As an outlier, one participant referred to accessing treatment for her child overseas, indicating a higher socio-economic status. These findings showed that limited financial means decreased childrens' experiences and parents' choices while more available finances resulted in extended therapy choices and experiences.

Occupational therapists are encouraged to be aware of how limited resources can effect their clients ability to engage in occupation (Davies et al., 2010; Powell & Appleton, 2012). Combined with reduced health literacy, as was discussed earlier, these limitations require consideration by therapists to ensure the family's unique social context is factored into the therapy process. This is evidence consistent with socio-economic status being a very significant determinant for child health outcomes (Maharaj et al., 2014). Data from 2012 states that 27% of children in New Zealand are growing up in poverty with higher rates among Māori and young children than among non-Māori and older children (Davies et al., 2010; Nobilo 2014). Occupational therapists by definition have tertiary qualifications and this places them in a high socio-economic grouping within society (Andrews et al., 2013). Parents on low incomes and therapists have been found to differ greatly in the ways they describe children's health issues and therapy expectations, so it is recommended that therapists clarify their role with parents early in the therapy process (Andrews et al., 2013). Parents in the Child Health Centre study had the same expectations as parents in Andrews et al., (2013) study. These were that connections with therapists for the sharing of ideas, for the receipt of timely information and for developing strategies of how to support their children. When therapists are aware of the impact of poverty on their clients they are encouraged to be proactive in sharing these impacts with policy-makers to affect community change, ie. the ways in which people living in poverty are included (Davies et al., 2010).

After exploring the literature on ethnicity, gender and socio-economic status it is evident that therapists need to comprehensively understand their clients social context because it plays a significant role in health outcomes. More than simply having awareness of this, therapists are called to comprehend how they might be maintaining health care inequities. There is risk involved with that, as voicing and seeking to address observed impacts of socio-economic factors in their work could be at odds with their organisation's values, creating the need for demonstrating 'moral courage' based on their personal integrity (Cannon 2008). While the cost of addressing inequities might be thought of as high, there is also a cost to the community associated with not taking steps to address these (Mills et al., 2012).

5.4 Occupational Therapy Theory

As discussed above occupational therapists have a role in addressing health inequities that arise from social context. Considerations such as family therapy practice models and therapists responsibility for demonstrating the health organisations’ values have been discussed. Ethnicity, gender and socio-economic status have also been examined and it has been concluded that therapists have a responsibility to understand the social factors that contribute to families keeping or missing appointments. Taking one step further than that, the final sections of the discussion focus on how occupational therapy theory, and an ethical approach, can be used to guide therapists as they position therapy participation in relation to the occupation of parenting.

For occupational therapists the concept of occupational justice has been used to alert the profession to wider issues than simply working with a client. The literature review in Chapter Two introduced the theory of occupational justice with its accompanying concept on occupational injustice. It was thought that this would enable therapists to focus their practice on social factors and not simply individual factors, although it was acknowledged that this would be difficult while working in medical model-based services (Durocher et al., 2013). However, this theory has been challenged because the language of occupational justice and injustice is confusing, and the concepts privilege middle-class, Western and female values at the expense of integrating a critical look at social determinants of health (Gerlach 2015; Hammell 2009). Also, the profession has in practice moved away from its theoretical origins that included socio-political perspectives of well-being as therapists are employed in medical, individual focused, healthcare systems (Hammell 2008). Specifically, the categories of self-care, productivity and leisure have been challenged as excluding marginalised populations who might find these categories irrelevant and not distinct (Gerlach 2015). The occupation of keeping an appointment, for example, would not obviously fit into one of these three categories, for the parent or the child. This study has found that parents view keeping or missing an appointment much more in terms of a relationship with a therapist and health service than as a stand-alone task.

Furthermore, the keeping of appointments could also be seen as a component of parents' vision to create a better life for their children. Thematic analysis reflected that parents wanted their children to participate in therapy and they wanted to contribute too. Thus enabling one's child to reach their potential would appear to be a key parenting motivation. When therapists share this vision, and work from a family-centred approach which identifies the families' unique world-view and social context, then the grounding on which therapy can proceed is strong. This would require therapists to transition from using procedural reasoning, based on clinical problem-solving, to interactive reasoning, based on connection, knowing and empathy (Fleming 1991). Making this transition would enable therapists to help parents assist their child to be more meaningfully occupied into the future as the focus shifts to exploring parents concerns and from there looking at the longer term outcomes for how their child will be able to engage in occupations. Fleming (1991) refers to a process by which therapists use procedural reasoning for planning and carrying out treatment, and when therapists engage interactive reasoning they are in a position to conduct therapy.

This conversation about participating in children's therapy appointments has become a discussion of the universal human experiences of relationships and engagement in parenting. A new direction for occupational theory which emphasises well-being and relationships has been explored. This links participation to intrinsic human needs, such as meaning and purpose, choice and control, and a positive sense of self-worth, with an overall focus on well-being rather than ill-health or disability (Hammell 2009). In making these links, it moves beyond the traditional self-care, productivity, and leisure categories and is based on critical thinking about how populations in the international literature, in particular marginalised populations, have been excluded from contributing to definitions of occupation. As described by Hammell (2009) this population often value inter-dependence rather than independence. Using Hammell's work as a guide, an alternative occupational structure with the following four categories has been proposed in the literature: occupations that are restorative; occupations that foster belonging, connecting and contributing; occupations that require active engagement in doing; and occupations that reflect life continuity and hope for the future (Hammell 2009). The second category resounds with the Child Health Centre study in that the participants highly emphasised connecting and contributing, termed here as inter-dependence, ie. they sought being valued by the therapists and being valuable to the therapists not only for with their child's benefit but also because this contributed to their own well-being.

Opportunities exist for studies to contribute to the suggested occupation categorisation re-framing. In a mapping review seeking to understand the story thus far of occupational justice in the profession, Gupta (2016) cited only three articles focussing on paediatric occupational therapy practice. The participants in this study have shared experiences that could contribute to this story. Given that the participants in this study were Māori, mostly female, and raising children with disabilities, and given there is a need for more evidence to develop the suggested occupational categories, then it is appropriate to allow their perspectives to affirm Hammells (2009, p112) enquiry into: "What might occupational therapy's theories of occupation and well-being look like if they were not informed solely by the perspectives of middle-class, minority-world theorists, but rather by those of other cultural groups and ill and disabled people?" To this list could be added children and the parents raising them.

This question is answered by parents describing that their own well-being is in part dependent on their child's meaningful therapeutic relationship with therapists. Keeping an appointment meant more to the parents than simply having their child participate in therapy. It also validated them in the role of parent and as a person, when they were engaged despite their socio-cultural differences with the therapist and when the therapist developed effective relationships with the child and themselves. The proposed category of 'occupations that foster belonging, connecting and contributing', is a good way of analysing the parent perspectives of keeping appointments as a component of parenting. Therapists would benefit from moving away from traditional individual constructs of occupation to consider earlier theoretical underpinnings of socio-political context on well-being. This would allow them to view participation in therapy appointments in the same ways that parents view them, that is, as an indication of the strength of the therapeutic relationship. When therapists can appreciate the world view of their client, that is the parent and the child, they are positioned to push through socio-political barriers which contribute to inequitable health outcomes, and support the parents to be the parents they want to be.

5.5 Ethics

While making sense of the world through occupational therapy theory as outlined above, occupational therapists are also guided by their professional Code of Ethics. The New Zealand occupational therapy board code of ethics states therapists are to use the code as a guide for ethical reasoning as they endeavour to exemplify professional values (Occupational Therapy Board of New Zealand 2015).

An example of applying ethical reasoning to the missing of appointments is provided by Phoenix et al., (2014), who suggests when this occurs occupational therapists face an ethical dilemma, ie. to spend time following up a child who missed an appointment or to spend time planning or providing therapy with a child who is present. The concept of autonomy reminds therapists to respect clients' decisions and culture as well as focusing on the needs of the client (Occupational Therapy Board of New Zealand 2015; Phoenix et al., 2014). When services discharge a client after two missed appointments without understanding the context for the missed appointment, this is over-riding the client's decision-making autonomy and the therapist is missing an opportunity to better align therapy with the clients' needs (Phoenix et al., 2014). In addition, Phoenix et al.,

(2014) writes that the concept of beneficence pertains to ensuring everything possible is done for the client, in this case, offering support to address the family's barriers to keeping the appointment. Non-maleficence, or the possible causing of harm, also requires therapists to understand the reasons for the missed appointments, ie. keeping an appointment may cause harm by negatively impacting parents employment, alternatively, missing an appointment may cause harm by not treating performance limitations that have implications for later in life (Phoenix et al., 2014). Finally Phoenix et al., (2014) discusses the concept of fairness and asks how services can be fair to all children and their families when often the reason for discharge after missed appointments is more about the service resourcing issues than the child's health status. The New Zealand code of ethics, states therapists "shall advocate for occupational justice for clients" and alert managers to resourcing issues as they endeavour to provide fair and equitable services (Occupational Therapy Board of New Zealand 2015, p6). For many therapists this may be creating a paradox where in their own workplaces they feel caught up in a demeaning workplace culture that marginalises them over medical and nursing staff, and as they are not experiencing occupational justice for themselves they will be challenged to promote this for their client group (Hammell 2008).

Discussion on such dilemmas is encouraged in workplaces as this assists therapists to reduce ethical stress, which results when therapists grapple independently with these issues, or when issues are not recognised as being ethical (Cannon 2008). The research design of the Child Health Centre study didn't explore therapists perspectives of missed appointments, therefore this discussion looked to the literature to provide that perspective. What was found there was that therapists are caught in a challenging position of opposing priorities. That is, resource constraints and organisation policies on the one hand, and ethical codes, organisation values and professional theories on the other. This can feel like an unsupported position. A key point for therapists is to contribute to ethical discussions and professional debates across work setting divides, and even to inhabit the occupation of being an occupational therapist outside of workplace limits.

5.6 Limitations

The researcher has identified limitations, and these related to who was interviewed. The research was designed to gather families' experiences and in doing so excluded children's and staff perspectives. Also, while the design aimed for between four and six interviews, just four interviews were conducted. The impact of these limitations and what they might mean for future research has been considered.

One critique is that the methodology focused on parents perspectives and the children who had missed appointments were not interviewed. Interviewing children with disabilities for their perspective on engaging with health care services has been described as fundamental (Watson 2012). Recently New Zealand occupational therapists have been promoting the idea that enquiring into how children describe their engagement in occupations is important, in particular around children living in poverty (Leadley & Hocking, 2017). A comment from one participant in the Child Health Centre study about resolving to keep appointments now that her child's health issue had become serious, captures how seeking therapy is an issue about the rights of a child that children are not in a position to address (Arai et al., 2015). Just as it has been advocated that those people who identify as Māori would benefit from defining what constitutes important questions to research through a kaupapa Māori research approach (Brewer et al., 2014), so it is suggested that a new approach providing children with platforms to be involved in research direction and priorities is needed (Watson 2012). Enabling marginalised populations, such as Māori and children, to speak for themselves is an emerging paradigm shift in healthcare research (Gibson et al., 2009). As this research question was concerned with the factors that contribute to families keeping or missing appointments rather than the experience of engaging in therapy, it was deemed valid to interview only adults, because it is an adult responsibility to be available for a pre-booked child and children don't have responsibility for this.

A similar critique of this study is that therapists or administrative staff perspectives of the missed appointment experience were not sought. In one study of missed outpatient paediatric appointments that solely interviewed staff, the conclusion recommended moving forward by discussing with families their motivations to attend (Cameron et al., 2014). The Child Health Centre researcher wanted to create a forum to give voice to parents, as this had not been explored through a qualitative research project before. In addition to that, it was believed that at the conclusion of this study, results would be shared with staff so their perspectives on missed appointments could be factored into taking steps to resolving the issue. A further study, could utilise the Rashomon effect, which is recommended when seeking to capture various perspectives of the one phenomenon, ie. child, family, therapist, health service administrator perspectives on a missed appointment (Sandelowski 2000).

By limiting the data gathering to parents' perspectives, a further critique of this study is that the results are skewed towards parents' placing blame for missing therapy appointments on features of the therapists and/or the health service, rather than on themselves. One example of this is that when the date for an appointment was too close to when the family had moved into the area, with no family nearby and social supports not yet established, the family missed the appointment. They also questioned why a therapy appointment would be organised when no offer of social support had been initiated. Feeling trapped, isolated and powerless (as that participant seemed to be describing) has been named as feeling shame in a study of womens' shame experiences, and a consequence of that shame is confusion, judgement, and blaming behaviours (Brown, 2006). The most effective response to shame is empathy, especially when this comes from outside oneself (Brown 2006). The Child Health Centre results indicate parents want closer, empathic relationships with therapists as people, not simply as staff. Participants proffered personal perspectives in their interviews, and as has been discussed placed themselves in a vulnerable position. Acknowledgement of being vulnerable enables women to develop resilience to shame, which in turn would result in less blaming as they move to owning their circumstances (Brown 2006). The rich personal data gathered in this study provides therapists at the Child Health Centre with evidence of what it looks like when they have not developed the empathic collaborative relationships, that parents are seeking.

The fact that just four interviews were conducted could be seen as a further limitation of this study. It was considered at the outset that people who had missed appointments may not be motivated to discuss this experience with a researcher from the same service. The recruitment process included a kaiawhina repeatedly visiting the 29 homes of children identified as meeting criteria for this study, and from all of the homes where the door was answered, with three exceptions, someone then participated in the study. Data gathered is largely about the missing of consecutive appointments. It has been demonstrated in this discussion that results from the four interviews concur with the literature on missed appointments and participation (Andrews et al., 1990; Green 1997; Phoenix & Rosenbaum, 2015). Fitzpatrick & Remmer (2011) exploring attendance at a cancer wellness centre found that people who registered and then didn't attend were more likely to identify barriers with logistics, compared to people who registered and attended intermittently who were more likely to identify poor emotional engagement as a barrier to attendance. The researcher surmises that those homes where there was no answer at the door, might house families who miss initial appointments and a study designed to focus solely on those people would require a different research approach.

5.7 Recommendations

To best answer the question of what factors help parents keep therapy appointments, is to explore the quality of the therapeutic relationship. When parents feel validated and engaged in the therapeutic relationship then they will bring their children to therapy. Several implications for practice based on this are recommended.

5.7.1 Professional development for effective family engagement

It has been suggested that the client is not only the referred child but also the child's family, or at least the main caregiver or parent. As a child is not able to participate in therapy without adult support, then the therapeutic relationship must be established with the key adult as much as with the child. This is not the same as being client-centred with a single client because of the existence of the dynamic between the child and their family. Therapists working in the Child Health Centre require professional development in a family-partnership model to enable their practice to transition from being client-centred, to being family-centred. The OPC is recommended as this has been developed for therapists working in child development roles and it is supported by a training programme for therapists. The OPC guides therapists to facilitate families through in-depth communication skills including active listening and acknowledgment of shared power to develop their own specified goals and create their own strategies of intervention (Graham et al., 2018). Services investing in professional development for therapists in this model could also be seen to be addressing the universal issue of missed appointments.

5.7.2 Health organisation values

The health organisation vision, mission and values statements were examined so that therapists practice could be linked to demonstrating these values. The Child Health Centre study found that what parents were seeking from therapists fitted within what the values stipulate. The six values were considered as equally important and indicated that the Northland DHB seeks to connect effectively with the people it serves. One criticism of the mission is that at present staff well-being is not explicitly prioritised and this may have negative implications for how staff demonstrate the values in their practice. A second outcome of not prioritising staff well-being is that when staff feel unsupported teamwork diminishes. The Child Health Centre team leadership are currently exploring the development of the teams own separate vision, mission and values statements. It is recommended that an aim of appreciating therapists, as well as the nursing, medical and administrative team members, be integrated at an early stage of this process. Without this intention the team will likely struggle to unite around enacting either their own team, or the organisation's values.

5.7.3 Ethnicity

Considering all four participants in the study identified as Māori, the researcher took care to ensure their words, as indigenous New Zealanders, would speak for themselves. Principles of Māori research were not part of the research design, and the impact that being Māori might have on interacting with therapists (or the researcher) was not explored during the interviews. Nevertheless the research findings supported the findings of other kaupapa aligned studies with Māori participants. That is, there was a strong emphasis on being connected, inclusive and validated as unique. A recommendation from this ethnicity discussion is for therapists to take steps to consistently factor into their practice,Māori clients world-view, by taking time to establish whakawhānaungatanga at the outset of the therapeutic relationship. A strategy such as The Hui Process could be used to achieve this. Shared world-view has been shown to improve the relationship and to diminish power differentials between therapists from mainstream health organisations and Māori clients, which flows onto improved health outcomes.

5.7.4 Gender

The discussion reflected on the majority of research participants being female and that this probably results from their role as lead parent in the family. Both parents are known to affect child development and referral information doesn't establish who in each family is in the key caregiver roles. Unless otherwise stated by parents, assumptions are made by therapists about parenting roles in the family, and these probably lean towards traditional roles. There is no clear expectation or system of facilitating inclusion of parents not attending with the child at therapy appointments, ie. those at work or living in a different home than the child. It is recommended that therapists and health services work to challenge gender roles in child development by encouraging and enquiring into the parenting roles of mums and of dads. One suggestion is to include family consumer representatives, ie. a family member of a child who would be eligible for referral to the team, onto therapy teams as this would prompt therapists to consistently promote parent engagement (Gibson et al., 2009). Information about family dynamics could be collated on referral documentation as well as during the initial interview. Family-centred therapy practice would promote the standardisation of this information gathering.

5.7.5 Socio-economic context

When considering context, socio-economic situation was discussed as this was a feature in the interview findings. By definition therapists with their tertiary qualifications will be seen as being from a higher socio-economic situation than many of their clients, and research has shown that these different situations do equate to different expectations of therapy. Therapists are recommended to clarify their role and the families expectations at the outset of the therapeutic process. Therapists are also recommended to consider their clients socio-economic status when selecting therapy materials, such as therapeutic books and toys, so there is a match with the client's world experience. It is acknowledged that changes in therapy approach can be very challenging for therapists, and to assist with change, implementation of a knowledge broker model incorporating a change champion in the workplace has been suggested (Phoenix & Rosenbaum, 2015).

5.7.6 Occupational therapy philosophy and ethics

The traditional categorisation of occupations as being self-care, productivity and leisure are being challenged as they have been found to marginalise sectors of the community (Gerlach 2015). The occupation of parenting, one task of which is keeping a child's therapy appointment, has been presented as an example of an occupation that doesn't readily fit this framework. These categories have been established largely by therapists and theorists themselves, rather than being evidence based on a cross-section of community populations. A different categorisation based around principles for clients well-being has been proposed and with its emphasis on engagement this theory is a good match for the Child Health Centre study findings. Alongside consideration of therapists ethical responsibilities of client autonomy and fairness, occupational therapy theory provides a solid philosophical standpoint for therapists to legitimately seek to understand the reasons appointments are missed. It is recommended that therapists create opportunities for considering ethical dilemmas within their practice. This could be done at team meetings by sharing challenging cases, through regular and robust discussion of professional articles, and by inviting someone who has expertise in exploring ethical dilemmas to facilitate new understandings. It is also recommended that therapists stay current with debate in the literature around professional theories.

To summarise, this discussion has presented the findings alongside the literature and found that answering the question of what helps and what hinders participation in therapy considered from different aspects, ie. therapist practice, the organisation, the client social context, and philosophically, identifies one solution, ie. the establishment of sound therapeutic relationships. The next chapter, which provides a conclusion to the entire study, draws together all the whenu or strands to a final endpoint.

Tui loved being at the beach. She liked to run and sniff and chase, but she liked getting treats from mum even more. Tui also loved the family and the family loved her, just as everyone said they would. Mum was happy too. One day aunty came to the beach with Tui and mum.
"Good," she said, "Tui is learning to come because she knows you have a treat and you did not give up."
Mum felt proud of Tui and remembered all the beautiful sunrises and beach walks they had shared.

Chapter 6: Conclusion

The aim of this thesis was to understand how families describe the experience of missing therapy appointments. In this conclusion chapter, I will comment on how this original aim was achieved, as well as synthesising the learnings from the study to identify implications for future practice and research.

Although the missing of appointments is an issue for services in New Zealand as it is internationally, no published studies were located in which occupational therapists explored the issue in New Zealand. It is very important for occupational therapists to understand this phenomena as their response with the child and their family may be the difference between that family engaging or not engaging with the service.

The literature review on the topic of missed appointments highlighted that the client's context was an integral component for consideration and, due to the significant role of social context, health service outcomes differ among populations. Occupational therapy literature about occupational justice was referred to because when families miss their child's appointments this impacts on that child's rights. The challenge for families to balance their child's health priority with family needs was also described. It was revealed that universal missed appointment policies guide clinicians to discharge children who have missed two appointments, irrespective of the reasons for this.

The results gathered during the participant interviews strongly pointed to the quality of the therapeutic relationship as having a significant impact on parents' decisions to keep appointments, with a second, minor focus on the health service systems. Parents provided clear explanations of what effective engagement for them and their children looked and felt like which, contained a consistent message about therapists understanding, empathising with and empowering them.

The discussion moved from a micro-level to a macro-level by exploring an occupational therapy practice model, reviewing health service values, considering social context, family role and ethnicity, and by looking to occupational therapy theorists and the ethics of responses to missed therapy appointments. Having linked the findings of this study with the literature, I am now in a position to create new meanings from this study. Conclusions and implications are presented from the perspectives of the three primary players within the paediatric therapeutic relationship scenario: the child, the family and the therapist.

6.1 Children

I feel the curtains have been drawn open allowing a glimpse into families experiences of missed appointments and this has shown how far from centre-stage children are in the systems and policies ostensibly designed for them. The opportunity exists to place children at the centre of the Child Health Centre missed appointment policy. Making this change is an important ethical response for children who are vulnerable members of the community, as they depend on adults to make informed decisions for them. Children can be unintentionally caught up in a cross-fire of world-view differences between therapists (as the organisation) and their parents or families. Revision of the current widespread missed appointment or DNA policy to one that incorporates the child's context, ie. the reasons for, and implications to the child of each missed appointment, is vital.

Reframing the issue as WNB initiates this shift in perspective, however, more is required to ensure that therapist and organisation responses to missed appointments centre on the child's best interests. Seeking authentic connection with the child and their family would be an initial implication for therapists. This would then move to understanding the child's social context and the family's world-view. Finally, the child and their family would develop awareness of how engaging in therapy might add value to themselves as the therapist would be in a position to relate potential to benefit from therapy with the family priorities.

In the absence of policy holding the child's needs as central to the missed appointment response, therapists make individual decisions based on their own ethical reflections of whether to discharge a child after two missed appointments or not. The decision to follow-up the missed appointments also depends on competing work demands for therapists time. Policy that places children, their rights to access therapy, and the context in which they are growing up, at its centre creates an opportunity to reduce inequity of access to the service.

6.2 Families

In addition to being child-centred, being family-centred is also relevant. The parents in my study have presented a wero to therapists, that is a challenge of collaboration. There is an expectation that families will be included in all stages of the therapy process based on their recognition that no one party is responsible for the missing of appointments. What families are asking for is safe spaces for sharing ideas of how best to support their child, irrespective of having differing social context and world-view to the therapists. In presenting this wero, parents remind Child Health Centre therapists that being client-centred is being family-centred. Occupational therapists are not family therapists yet work with families, and understanding how the child fits within their family is important. My study indicates a gap in therapeutic skill about how to work alongside all families, in particular, those families who have significant needs and who have different world-views from therapists. Collaborating with parents or family members, involves understanding each unique family dynamic, and this understanding would begin with gathering additional social information either at referral or initial interview stage. It might continue with advocating for mums to become more assertive on behalf of their children, and themselves, when participating in therapy. It might also continue with advocating for dads to take an active role in the therapy process as a component of parenting their child.

The OPC model enables therapists to develop clinical skills in family-centred practice. This model prompts therapists to collaborate with families throughout the therapeutic process, including when issues, eg. missed appointments, might occur in that process. This locates therapists in a sound position from which to work alongside families and to contribute to individual child and family development. Therapists additional clinical skills, knowledge, and expertise pertaining to specific therapeutic strategies are more meaningful when they fit with unique family goals and context. Adopting OPC across the Child Health Centre therapy team, which consists of occupational, physiotherapy and speech language therapists would likely have the additional benefit of unifying the multi-disciplinary team as they would be working from a single approach.

One further consideration of the implications for families is that parents have their own narrative around ability and disability. Holding hope for the child's future, what the child contributes and the ways the child connects with their family, are unique to each family. Therapists who have developed trusting relationships with families have a role to play with those families which may be challenged to envisage their child's potential. Therapists who accept the wero to collaborate with parents in this way can help facilitate them to find new meanings around parenting their child and supporting them to create hopeful images of their child's future.

6.3 Therapists

Health equity and empowerment are viewed by occupational therapy theorists as elements of well-being. The profession is encouraged to be concerned with enhancing the well-being of communities, as a founding occupational therapy principle. This focus on family well-being dovetails with what parents in my study indicated they would prefer. When therapists take a family-centred approach, this enables them to enhance the well-being of those families they do connect with. However, a consequence of occupational therapy positions being typically located within services developed on the medical model, is that referrals are made for individual children. This focus on the individual as a consequence of the medical model structure, means that therapists roles are not resourced or well placed to promote well-being at a community level. As a result, therapists are familiar with the frustration that accompanies having their roles limited by a non-occupational therapy framework and not having their potential contributions to the service recognised.

Furthermore, when therapists roles are consistent with their professional values their own well-being is enhanced. Strategies of reflecting on ethical issues, and sharing clinical case-studies, professional concepts and theories in their workplaces empower therapists. Sharing ideas in this way can be a vulnerable process requiring courage, and this process would benefit from being supported by the organisation as it seeks effective team-work for optimal performance.

In the same way, parents are empowered when space is created for them to share ideas, concepts, and reflections on the ethical issues of parenting. Similarly, this is a courageous process that therapists can support by recognising the vulnerable position parents are in. Creating this space and empowering parents requires therapists to come out from being cloaked in their professional qualification and to be comfortably aware of their own identity as humans in the workplace. In particular, therapists might be expected to empathise with the frustration expressed by families of not being heard, of being limited from contributing to the therapy process, and of not having their world-view validated. Therapists and parents are connected by the occupation of supporting the referred child. Therapists awareness of empowering themselves by developing skills that fit with overarching professional theories for a satisfying occupational experience, is a parallel process with empowering parents to develop skills for a satisfying performance in the occupation of parenting.

By engaging in therapy appointments, therapists and families are in an interdependent relationship which involves connecting and contributing to each others well-being based on mutual understanding and empathy. It is a therapist role to open up space for this to occur. This concept of contributing to each other's well-being and sense of belonging by participation in a shared occupation, adds to the discussion of new occupational categories.

6.4 Further research directions

This study provides the groundwork for a consecutive study that explores therapists' experiences of missed appointments enabling the profession to make a unique contribution to this topic. Conducting a study across a range of paediatric services where occupational therapists are employed, could create a united approach to this ubiquitous issue. This would fill a research gap both in occupational therapy literature as well as among New Zealand paediatric services.

Another research approach that could be taken is move into kaupapa Māori aligned research methodology. In my study all the participants identified as Māori, and as such the data proffers the groundwork for more in-depth research into Māori narratives of missed appointments. Partnership with Māori for exploring whether this is a valid research direction for Māori researchers would be an essential first step.

Parents have articulated their experience of missing therapy appointments. Key findings of this study were the benefits of a family-oriented perspective in which the child is positioned as central, as well as for therapists to acknowledge their role in creating empathic relationships with the child and family. The parents I interviewed permitted me to get into their world for a moment in time. This enabled me to let their words converse with the literature in the discussion, Chapter Five. My take-home message to the reader is that social context is integral to understanding what it means to participate in therapy appointments. Parents and their children are seeking empathic relationships with therapists and when therapists are enabled within the health service to establish meaningful connections with the families, then well-being for families and therapists is enhanced.

Personal reflection of thesis process

This thesis unexpectedly propelled me into a realm of new potential. Undertaking post-graduate study helped me reflect on what I brought to a different clinical setting - paediatrics. Then, when stepping into the role of researcher, I once more reflected on what I had to offer. I was challenged by putting myself 'out there' in the health organisation and I wasn't sure how I could stay true to myself in my research.

Now, drawing to the close of the thesis process, I feel that my values have been affirmed by the stories I was entrusted with, by my participants. For me, undertaking the thesis showed how relevant it is to connect practice and theory with system structures and with gut instinct. I can whole-heartedly say this thesis is my creation (albeit guided by some very wise people), that it reflects my world-view, and this is my offering to my profession.

Finally mum said: "I used puppy treats, I did not give up and now I have trained Tui to come at the beach."
"She doesn't come for me," said big brother, "unless it is a game."
"She doesn't come for me," said sister, "unless it is for a hug."
"She doesn't come for me," said little brother, "unless she is on the lead."
"Well," said dad, "she might come on the beach, but what about in the orchard?"
Tui looked at mum with her head on the side. Mum looked at Tui. She looked at her curious eyes and wagging tail.
"I think we will like the orchard!" said Tui.
"Yes, there are lots of treats in the orchard," thought mum.

References

Abdus-Salaam, H., and Davis, L. B., (2012). Impact of batch appointments on no-show rates: A public vs private clinic perspective. *Health Systems, 1*(1), p. 36-45. doi:10.1057/hs.2012.4

Andrews, F., Griffiths, N., Harrison, L., and Stagnitti, K., (2013). Expectations of parents on low incomes and therapists who work with parents on low incomes of the first therapy session. *Australian Occupational Therapy Journal, 60*(6), p. 436-44. doi:10.1111/1440-1630.12044

Andrews, R., Morgan, J. D., Addy, D. P., and McNeish, A. S., (1990). Understanding non-attendance in outpatient paediatric clinics. *Archives of Disease in Childhood, 65*(2), p. 192-195. doi:10.1136/adc.65.2.192

Arai, L., Stephenson, T., and Roberts, H., (2015). The unseen child and safeguarding: Did not attend guidelines in the NHS. *Archives of Disease in Childhood*, archdischild-2014.

Arnold, O. F., (2012). Reconsidering the ‘no show' stamp: Increasing cultural safety by making peace with a colonial legacy. *The Northern Review, 36*(Fall), p. 77 - 96.

Azerkan, F., Widmark, C., Sparén, P., Weiderpass, E., Tillgren, P., and Faxelid, E., (2015). When life got in the way: How Danish and Norwegian immigrant women in Sweden reason about cervical screening and why they postpone attendance. *PloS One, 10*(7), e0107624.

Ballantyne, M., Benzies, K., Rosenbaum, P., and Lodha, A., (2015). Mothers' and health care providers' perspectives of the barriers and facilitators to attendance at Canadian neonatal follow-up programs. *Child: Care, Health and Development, 41*(5), p. 722-33. doi:10.1111/cch.12202

Bishop, R., and Berryman, M., (2010). Te kotahitanga: Culturally responsive professional development for teachers. *Teacher Development*, *14*(2), p. 173 - 187.

Boag-Munroe, G., and Evangelou, M., (2012). From hard to reach to how to reach: A systematic review of the literature on hard-to-reach families. *Research Papers in Education*, *27*(2), p. 209-239. doi: 10.1080/02671522.2010.509515

Brewer, K. M., Harwood, M. L., McCann, C. M., Crengle, S. M., and Worrall, L. E., (2014). The use of interpretive description within kaupapa Māori research. *Qualitative Health Research*, *24*(9), p. 1287-97. doi: 10.1177/1049732314546002

Brown, B., (2006). Shame resilience theory: A grounded theory study on women and shame. *Families in Society*, *87*(1), p. 43-52.

Callander, R., (2018). Evie. *Journal of Paediatrics and Child Health*, *54*(2), p. 203-205. doi:10.1111/jpc.13840

Cameron, E., Heath, G., Redwood, S., Greenfield, S., Cummins, C., Kelly, D., and Pattison, H., (2014). Health care professionals' views of paediatric outpatient non-attendance: Implications for general practice. *Family Practice*, *31*(1), p. 111-7. doi:10.1093/fampra/cmt063

Cannon, E. P., (2008). Promoting moral reasoning and multicultural competence during internship. *Journal of Moral Education*, *37*(4), p. 503-518. doi: 10.1080/03057240802399384

Clark, A. M., King-Shier, K. M., Spaling, M. A., Duncan, A. S., Stone, J. A., Jaglal, S. B., . . . Angus, J. E., (2013). Factors influencing participation in cardiac rehabilitation programmes after referral and initial attendance: Qualitative systematic review and meta-synthesis. *Clinical Rehabilitation*, *27*(10), p. 948-59. doi:10.1177/0269215513481046

Clark, A. M., King-Shier, K. M., Thompson, D. R., Spaling, M. A., Duncan, A. S., Stone, J. A., . . . Angus, J. E., (2012). A qualitative systematic review of influences on attendance at cardiac rehabilitation programs after referral. *American Heart Journal, 164*(6), p. 835-45. e2. doi:10.1016/j.ahj. 2012.08.020

Clark, F., Park, D. J., and Burke, J. P. (2013). Dissemination: Bringing translational research to completion. *The American Journal of Occupational Therapy*, *67*(2), p. 185-93. doi:10.5014/ajot.2013.006148

Clarkin-Phillips, J., and Carr, M., (2009). *Strengthening responsive and reciprocal relationships in a whānau tangata centre: A summary*. Wellington. Teaching and Learning Research Initiative.

Darlow, B., and Williams, A., (2018). *Person and whānau centred care; model for consultation*. Wellington. Physiotherapy New Zealand.

Davies, E., Crothers, C., and Hanna, K., (2010). Preventing child poverty: Barriers and solutions. *New Zealand Journal of Psychology*, *39*(2), p. 20-31.

Davis, H., and Meltzer, L., (2007). Working with parents in partnership. *Working in partnership through early support: Distance learning text*. London. Department for Education and Skills (DFES).

Dayal, S., Puketapu, K., and Suafole Gush, T., (2013). 99% attendance: Reducing Māori and Pacific did not attends at Hutt Valley DHB clinics. [Web page] Retrieved from http://koawatea.co.nz/99-attendance-reducing-did-not-attends-at-hutt-valley-dhb-clinics/.

Dempsey, I., and Keen, D., (2008). A review of processes and outcomes in family-centered services for children with a disability. *Topics in Early Childhood Special Education*, *28*(1), p. 42-52. doi:10.1177/0271121408316699

Dennison, E. L., (2003). *Father's engagement with child clinical psychologists: A grounded theory study of client and provider perspective.* (Published doctoral thesis). University of Leeds, Leeds, United Kingdom.

Donnelly, T. T., and McKellin, W., (2007). Keeping healthy! Whose responsibility is it anyway? Vietnamese Canadian women and their healthcare providers perspectives. *Nursing Inquiry*, *14*(1), p. 2-12.

Durocher, E., Rappolt, S., and Gibson, B. E., (2013). Occupational justice: Future directions. *Journal of Occupational Science, 21*(4), p. 431-442. doi: 10.1080/14427591.2013.775693

Eggleton, K., Kearns, R., and Neuwelt, P., (2016). Being patient, being vulnerable: Exploring experiences of general practice waiting rooms through elicited drawings. *Social & Cultural Geography*, p. 1-23. doi: 10.1080/14649365.2016.1228114

Emery-Whittington, I., and Te Maro, B., (2018). Decolonising occupation: Causing social change to help our ancestors rest and our descendants thrive. *New Zealand Journal of Occupational Therapy*, *65*(1).

Fisher, A. G., (2013). Occupation-centred, occupation-based, occupation-focused: Same, same or different? *Scandinavian Journal of Occupational Therapy*, *20*(3), p. 162-73. doi:10.3109/11038128.2012.754492

Fitzpatrick, E. F., Martiniuk, A. L., D'Antoine, H., Oscar, J., Carter, M., and Elliott, E. J., (2016). Seeking consent for research with indigenous communities: A systematic review. *BMC Medical Ethics*, *17*(1), 65. doi:10.1186/s12910-016-0139-8

Fitzpatrick, T. R., and Remmer, J., (2011). Needs, expectations and attendance among participants of a cancer wellness centre in Montreal, Quebec. *Journal of Cancer Survivorship : Research and Practice*, *5*(3), p. 235-46. doi:10.1007/s11764-011-0176-8

Fleming, M. H., (1991). The therapist with the three-track mind. *The American Journal of Occupational Therapy*, *45*(11), p. 1007 - 1014.

Gerlach, A. J., (2015). Sharpening our critical edge: Occupational therapy in the context of marginalised populations. *Canadian Journal of Occupational Therapy*, *82*(4), p. 245-53. doi:10.1177/0008417415571730

Gibson, B. E., Darrah, J., Cameron, D., Hashemi, G., Kingsnorth, S., Lepage, C., . . . Menna-Dack, D., (2009). Revisiting therapy assumptions in children's rehabilitation: Clinical and research implications. *Disability and Rehabilitation*, *31*(17), p. 1446-53. doi:10.1080/09638280802621390

Goodwin, E., Scott, S., Carpinter, A., Geerkens, M., Murray, S., and Wilson, J. (2018). *A good start for children with disabilities - co-designing with parents*. Wellington: Connect & Co.

Graham, F., Boland, P., Ziviani, J., and Rodger, S. (2018). Occupational therapists' and physiotherapists' perceptions of implementing occupational performance coaching. *Disability and Rehabilitation*, *40*(12), p. 1386-1392. doi: 10.1080/09638288.2017.1295474

Green, A., (1997). An audit of occupational therapy outpatient attendance. *The British Journal of Occupational Therapy*, *60*(9), p. 384-388.

Griffin, J., McKenna, K., & Tooth, L., (2003). Written health education materials: Making them more effective. *Australian Occupational Therapy Journal*, *50*(3), p. 170-177.

Guba, G., (1981). Criteria for assessing the trustworthiness of naturalistic inquiries. *Educational Communication and Technology*, *29*(2), p. 75-91.

Gupta, J., (2016). Mapping the evolving ideas of occupational justice: A critical analysis. *OTJR: Occupation, Participation and Health*, *36*(4), p. 179 - 194. doi: 10.1177/1539449216672171

Gurol-Urganci, I., de Jongh, T., Vodopivec-Jamsek, V., Atun, R., and Car, J., (2013). Mobile phone messaging reminders for attendance at healthcare appointments. *The Cochrane Database of Systematic Reviews*, (12), CD007458. doi:10.1002/14651858.CD007458.pub3

Hammell, K. W., (2008). Reflections on...Well-being and occupational rights. *Canadian Journal of Occupational Therapy*, *75*(1), p. 61-4. doi:10.2182/cjot. 07.007

Hammell, K. W., (2009). Self-care, productivity, and leisure, or dimensions of occupational experience? Rethinking occupational 'categories'. *Canadian Journal of Occupational Therapy*, *76*(2), p. 107 - 114.

Hammell, K. W., (2015). If human health is impacted by occupational opportunities (and it is), what are we doing about poverty? *Occupational Therapy Now*, *17*(5), p. 14-15.

Hanna, K., and Rodger, S., (2002). Towards family-centred practice in paediatric occupational therapy: A review of the literature on parent-therapist collaboration. *Australian Occupational Therapy Journal*, *49*, p. 14 - 24.

Hansen, D., (2014). Parent perspectives in paediatric SLT's evidence-based practice. *Revista De Logopedia, Foniatria Y Audiologia*, *37*(4), p. 155 - 163.

Heath, G. L., (2013). *The experience of paediatric care closer to home: A place and space perspective.* (Published doctoral thesis). University of Birmingham, Birmingham, United Kingdom

Hetaraka, R. M., and McLean, E., (2015). *Positive patient outcomes: Can we do it? Yes we can!* [Nursing review of 'did not attend' issues and resolutions in the Whangarei area, Northland DHB].

Heyworth, M. D., (2017). *Plumtree Now and Next Alumni Conference: Parent professional relationship statement.* [Pamphlet] Australia.

Hopkirk, J., and Wilson, L. H., (2014). A call to wellness - whitiwhitia i te ora: Exploring Māori and occupational therapy perspectives on health. *Occupational Therapy International*, *21*(4), p. 156-65. doi:10.1002/oti.1373

Hudson, M., (2010). *Te ara tika: Guidelines for Māori research ethics: A framework for researchers and ethics committee members.* Auckland, Health Research Council of New Zealand.

Kielhofner, G., (2005). Rethinking disability and what to do about it: Disability studies and its' implications for occupational therapy. *American Journal of Occupational Therapy*, *59*(5), p. 487 - 496.

Kielhofner, G., (2006). *Research in occupational therapy - methods of inquiry for enhancing practice.* Philedelphia: FA Davis.

King, G., (2016). The role of the therapist in therapeutic change: How knowledge from mental health can inform paediatric rehabilitation. *Physical & Occupational Therapy in Pediatrics*, p. 1-18. doi: 10.1080/01942638.2016.1185508

Lacey, C., Huria, T., Beckert, L., Gilles, M., and Pitama, S., (2011). The hui process: A framework to enhance the doctor-patient relationship with Māori. *NZMJ*, *124*(1347).

Lacy, N. L., Paulman, A., Reuter, M. D., and Lovejoy, B., (2004). Why we don't come: Patient perceptions on no-shows. *Annals of Family Medicine*, *2*(6), p. 541-5. doi:10.1370/afm.123

Lambert, M., Luke, J., Downey, B., Crengle, S., Kelaher, M., Reid, S., and Smylie, J. (2014). Health literacy: Health professionals' understandings and their perceptions of barriers that indigenous patients encounter. *BMC Health Services Research*, *14*, 614. doi:10.1186/s12913-014-0614-1

Leadley, S., and Hocking, C., (2017). An occupational perspective of childhood poverty. *New Zealand Journal of Occupational Therapy, 64* (1), p. 23-31

Lighter, D. E., (2015). Patient engagement: Changing paediatric practice to improve patient care. *International Journal of Pediatrics and Adolescent Medicine, 2*(3-4), p. 107-111. doi:10.1016/j.ijpam.2015.08.001

Loh, L., Jaye, C., and Dovey, S., (2015). Why do patients attend Dunedins free clinic? An audit of general practice activity using the ICPC-2 classification system. *NZMJ, 128*(1410), p. 40-49.

Maharaj, V., Rahman, F., and Adamson, L., (2014). Tackling child health inequalities due to deprivation: Using health equity audit to improve and monitor access to a community paediatric service. *Child: Care, Health and Development, 40*(2), p. 223-30. doi:10.1111/cch.12011

Mian, N. D., Eisenhower, A. S., and Carter, A. S., (2015). Targeted prevention of childhood anxiety: Engaging parents in an underserved community. *American Journal of Community Psychology, 55*(1-2), p. 58-69. doi:10.1007/s10464-014-9696-5

Mills, C., Reid, P., and Vaithianathan, R., (2012). The cost of child health inequalities in Aotearoa New Zealand: A preliminary scoping study. *BMC Public Health, 12*(1), 384.

Moore, K. A., Bethell, C. D., Murphey, D., Martin, M. C., and Beltz, M., (2017). Flourishing from the start: What is it and how can it be measured? *Child Trends, 2017-16.*

Moorfield, J. C., (2011). *Te aka : Māori-English, English-Māori dictionary.* Auckland: Pearson.

Nobilo, H., (2014). The experience of poverty for infants and young children. *Brainwave Trust Newsletter, 21*(Summer).

Occupational Therapy Board of New Zealand., (2015). *Code of ethics for occupational therapists*. Wellington.

Phoenix, M., and Rosenbaum, P., (2015). Development and implementation of a paediatric rehabilitation care path for hard-to-reach families: A case report. *Child: Care, Health and Development, 41*(3), p. 494-9. doi:10.1111/cch.12194

Phoenix, M., Fishcer, L., Walsh, K., and Missiuna, C., (2014). Promoting a reflexive ethical approach when families miss their child's occupational therapy appointments. *Occupational Therapy Now, 20*(1), p. 11-13.

Pitama, S., Robertson, P., Cram, F., Gillies, M., Huria, T., and Dallas-Katoa, W., (2007). Meihana model: A clinical assessment framework. *New Zealand Journal of Psychology*, *36*(3), 118.

Powell, C., and Appleton, J. V., (2012). Children and young people's missed health care appointments: Reconceptualising 'did not attend' to 'was not brought' - a review of the evidence for practice. *Journal of Research in Nursing*, *17*(2), p. 181 - 192.

Rahman, F. R., Maharaj, V., Yates, R., Beeley, C., Moore, I., Rose, A., and Counsell, A., (2014). Addressing the inverse care law: The role of community paediatric services. *Perspectives in Public Health, 134* (2). doi:DOI: 10.1177/17579139135160D8ow9n

Rebeiro Gruhl, K. L., (2009). The politics of practice: Strategies to secure our occupational claim and to address occupational injustice. *New Zealand Journal of Occupational Therapy*, *56*(1), 19-26.

Reeve, D., (2004). Psycho-emotional dimensions of disability and the social model. In *Implementing the social model of disability: Theory and research* (pp. 83 - 100). Leeds: The Disability Press.

Roberts, B. R., (2004). From marginality to social exclusion: From laissez faire to pervasive engagement. *Latin American Research Review*, *39*(1), p. 195-197. doi:10.1353/lar.2004.0017

Robotham, D., James, K., and Cyhlarova, E., (2010). Managing demand and capacity within child and adolescent mental health services: An evaluation of the choice and partnership approach. *Mental Health Review Journal*, *15*(3), p. 22-30. doi:10.5042/mhrj.2010.0656

Robson, B., and Harris, R., (2007). *Hauora: Māori standards of health IV. A study of the years 2000-2005*. Wellington: Te Ropu Rangahau Hauora a Eru Pomare.

Rossiter, C., Fowler, C., Hopwood, N., Lee, A., and Dunston, R., (2011). Working in partnership with vulnerable families: The experience of child and family health practitioners. *Australian Journal of Primary Health*, *17*(4), p. 378-83. doi:10.1071/PY11056

Ryan, S., and Runswick–Cole, K., (2008). Repositioning mothers: Mothers, disabled children and disability studies. *Disability & Society*, *23*(3), p. 199-210. doi:10.1080/09687590801953937

Sandelowski, M., (2000). Focus on research methods-whatever happened to qualitative description? *Research in Nursing and Health*, *23*(4), p. 334-340.

Schillinger, D., (2007). Literacy and health communication: Reversing the inverse care law. *The American Journal of Bioethics*, *7*(11), p. 15-18.

Shenton, A. K., (2004). Strategies for ensuring trustworthiness in qualitative research projects. *Education for Information*, *22*(2), p. 63-75. doi:10.3233/EFI-2004-22201

Sikka, R., Morath, J. M., and Leape, L., (2015). The quadruple aim: Care, health, cost and meaning in work. *BMJ Quality & Safety*, *24*(10), p. 608-10. doi:10.1136/bmjqs-2015-004160

Simons, D., Pearson, N., and Dittu, A., (2015). Why are vulnerable children not brought to their dental appointments? *British Dental Journal, 219*(2), p. 61-5. doi:10.1038/sj.bdj.2015.556

Stanley, W., and Nayar, W., (2014). Methodological rigour: Ensuring quality in occupational therapy qualitative research. *New Zealand Journal of Occupational Therapy*, *61*(1), p. 6 - 12.

Stathopulu, E., Ajetunmobi, S., and Selling, D., (2003). Non-attendance in community paediatric clinics in Dartford, Gravesham and Swanley primary health care trust. *Quality in Primary Care*, *11*(2), p. 163-165.

Stats NZ Tatauranga Aotearoa, (2013, October 15). *2013 Census QuickStats About Culture and Identity*. Retrieved from http://archive.stats.govt.nz/Census/2013-census/profile-and-summary-reports/quickstats-culture-identity/maori.aspx.

Taranaki District Health Board, (2015). *Pae ora framework and TDHB position statements*. New Plymouth.

Te Puni Kōkiri, (2015). *Understanding whānau-centred approaches: Analysis of phase one whānau ora research and monitoring results*. Wellington.

Te Puni Kōkiri, (2016). *The whānau ora outcomes framework: Empowering whānau into the future*. Wellington.

Townsend, E., and Wilcock, A. A., (2004). Occupational justice and client-centred practice: A dialogue in progress. *Canadian Journal of Occupational Therapy*, *71*(2), p. 75 - 87.

Underwood, M., (2017a). Missing therapy appointments - an occupational injustice? *OT Insight, 38*(6).

Underwood, M., (2017b). Understanding bicultural needs for better health outcomes. *OT Insight*, *38*(5).

Valentine, K., (2010). A consideration of medicalisation: Choice, engagement and other responsibilities of parents of children with autism spectrum disorder. *Social Science & Medicine (1982)*, *71*(5), p. 950-7. doi:10.1016/j.socscimed.2010.06.010

Varni, J. W., Limbers, C. A., and Burwinkle, T. M., (2007). How young can children reliably and validly self-report their health-related quality of life?: An analysis of 8,591 children across age subgroups with the PedsQL 4.0 generic core scales. *Health and Quality of Life Outcomes*, *5*, 1. doi: 10.1186/1477-7525-5-1

Wade, V., and Stocks, N., (2017). The use of telehealth to reduce inequalities in cardiovascular outcomes in Australia and New Zealand: A critical review. *Heart, Lung & Circulation*, *26*(4), p. 331-337. doi:10.1016/j.hlc.2016.10.013

Watson, N., (2012). Theorising the lives of disabled children: How can disability theory help? *Children & Society*, *26*(3), p. 192-202. doi:10.1111/j.1099-0860.2012.00432.x

White, M. J., and Olson, R. S., (1998). Attitudes toward people with disabilities: A comparison of rehabilitation nurses, occupational therapists, and physical therapists. *Rehabilitation Nursing*, *23*(3), p. 126 - 131.

Appendix A: Previous CHC questionnaire

Did you receive an appointment letter or appointment card?

Was this your first appointment or a follow up ?

Was it clear to you why the referral was made?

Did you feel that this appointment was needed?

Did you receive a reminder phone call or text?

Were you given enough notice for the appointment?

Was the appointment time convenient to you?

What time would have suited you better?

Would you have come if the appointment time was after hours or at the weekend?

Was travel an issue for you?

What could have helped with this?

Is there anything we could have done to make it easier for you to get to your appointment?

Appendix B: Strategies from Hawkes Bay Child Development team

What I have discovered in the texting and ringing of family regarding attending clinics. I understand you will be talking to Northland at some stage this week and thought some of the things I have discovered may be helpful to them.

Reason why they may not attend –

- No money for petrol for the transport
- No money for transport
- All overwhelming
- Embarrassed, did not understand the appointment card. Reading not great
- Nanny knows what to do, she has had a large family so I don't need to come
- The doctor may think I have not done my job as the parent
- Kids take the mail out of the letterbox and throw it away. Didn't get the appointment card (Padlock?)
- Child frightened to come and refuses to get in the car
- Can't get time of work. Boss said no, I might lose my job
- I can't read or write, I might have to fill in forms
- My child's so much better now, I don't think we need to come
- Times of appointments were no good so we didn't come.
- We've moved and thought you would know.

I do make a lot of suggestions like:

- Can we get you picked up by the Health nurses?
- Shall we book you again for another time?
- Bring Nanny with you she might like to talk to the doctor
- The doctor is here to help not chastise you
- We will help you with forms in a private place
- Why don't you come just this once and if you don't ever need to come again that will be great?

- Bring some support with you, you're welcome to do so, we want you to feel comfortable

There are lots more that I sometime come up with on the spur of the moment. Just thought this might be useful. The work one - getting time off - is a big one, I understand there is legislation against this happening, but then it might rock the boat.

Appendix C: Interview Question Guide

Demographic data:

- age range: 16 - 26, 27 - 36, 37 - 46, over 46.
- ethnicity: NZ European, NZ Maori, other - please state

1 Thinking about a time when you missed an appointment, in your experience what factors made it *hard* to keep that appointment with the therapy team at child health?

What would be the most challenging issue/s to overcome?

What would be the least challenging issue/s?

Prompts - if required may include these topics, eg. Tell me about the impact of:

- Organisation - eg. of travel, time, work/family responsibilities
- Understanding - eg. knowing why the appointment is booked, what is required
- Emotions - eg. from family or your child, or from staff at previous appointments

2 Thinking about a time when you missed an appointment, in your experience what factors would *help* you to keep appointments with the therapy team?

What factors would make the biggest difference for you?

What factors would make the least difference for you?

Prompts - if required may include these ideas, eg. What about this idea, what do you think of:

- Practical ideas, eg. transport offered, home visits, negotiating time of visit, help with forms

- Relationship ideas, eg. whānau meet therapist, kaiawhina or nurse involved,
- Awareness ideas, eg. knowing about more about appointment and about the therapist

Appendix D: Otago Polytechnic Ethical Approval

24 May 2017

Marica Underwood
174 Marsden Point Road
Ruakaka
Northland 0116

Dear Marica

Re: Application for Ethics Consent
Reference Number: 716
Application Title: *What helps and what hinders families from participating in therapy appointments with the Child Health Centre in Northland?*

Thank you for your application for ethics approval for this project.

The review panel has considered your revised application including responses to questions and issues raised. We are pleased to inform you that we are satisfied with the revisions made and confirm ethical approval for the project.

Many thanks for your careful responses to our recommendations.

We wish you well with your work and remind you that at the conclusion of your research you should send a brief report with findings and/or conclusions to the Ethics Committee. All correspondence regarding this application should include the reference number assigned to it.

Regards

Richard Humphrey
Chair
Ethics Committee
Otago Polytechnic

Otago Polytechnic
Forth Street
Private Bag 1910
Dunedin 9058

Freephone 0800 762 786
Phone +64 3 477 3014

Email: info@op.ac.nz

Appendix E: Northland DHB Ethical Approval

NORTHLAND DISTRICT HEALTH BOARD
Te Poari Hauora Ā Rohe O Te Tai Tokerau

22 June 2017

To Whom it May Concern

Re: What helps and what hinders families from participating in therapy appointments with the Child Health Centre in Northland, Locality Assessment 2017-17

This letter is to confirm the Kaunihera Kaumatua have expressed approval through the Locality Assessment process for the above study.

This study was approved on 22 June 2017 under Reference No. 2017-17.

Yours faithfully

Te Ihi Tito
Kaunihera Kaumatua

34287

Phone: (09) 430 4101 - Fax: (09) 470 0001 - DHB Office, Tohorā House, Hospital Road, Private Bag 9742, Whangarei 0148, New Zealand
www.northlanddhb.org.nz

A Healthier Northland
He Hauora Mo Te Tai Tokerau

NORTHLAND DISTRICT HEALTH BOARD

Locality Assessment No. 2017-17

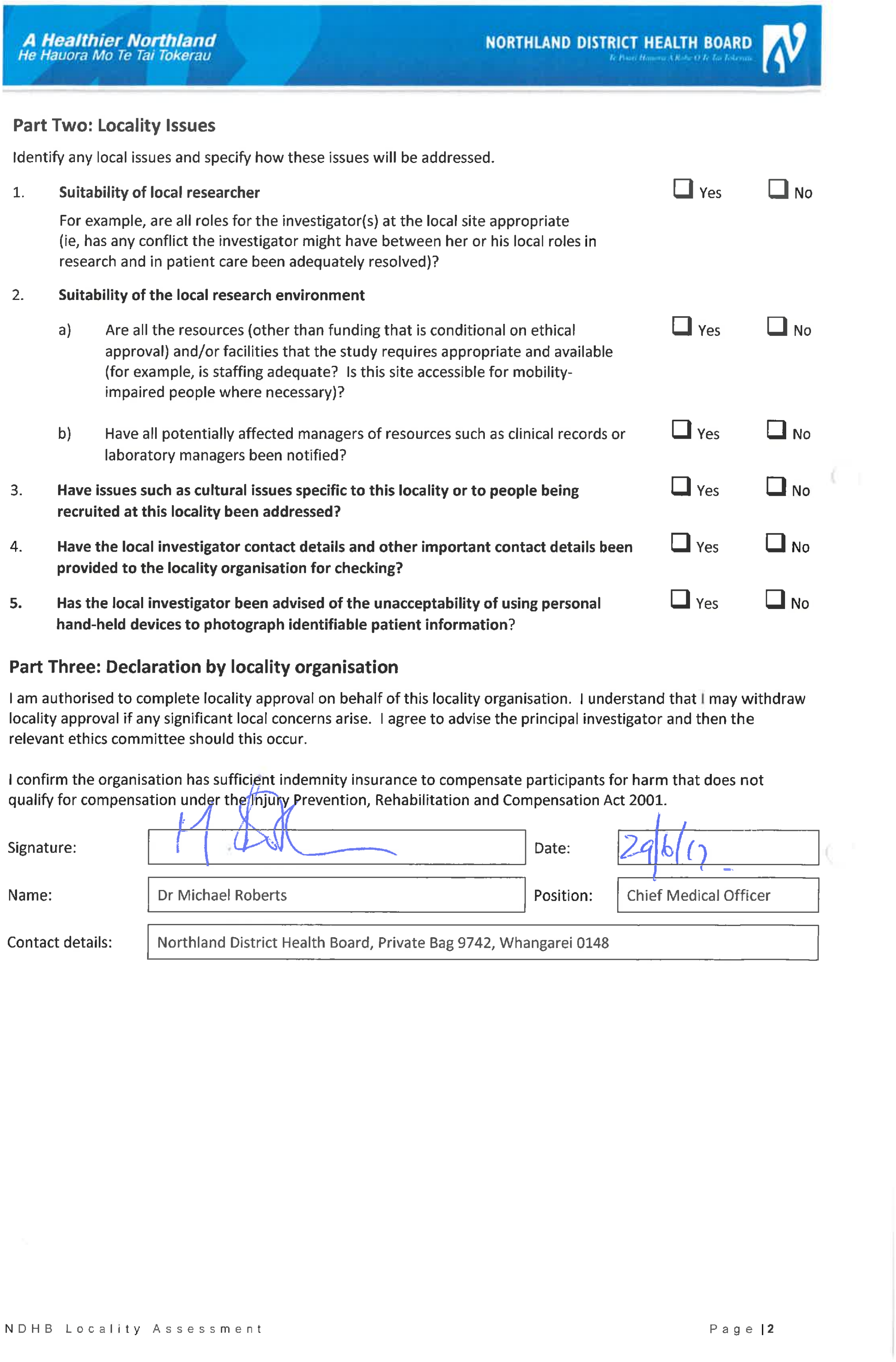
Locality Assessment Sign Off

All research conducted in the Northland DHB must be conducted with the knowledge of the Northland DHB, and must meet all the requirements of the Health & Disability Ethics Committees (HDECs), though not all research will require HDEC review.

A locality assessment must be undertaken to review all research conducted at Northland District Health Board. Locality Assessments will consider resource implications, suitability of the local researcher and research environment, and cultural issues.

Part One: General

Full project title:	What helps and what hinders families from participating in therapy appointments with the Child Health Centre in Northland?
Short project title:	What helps and what hinders families from participating in therapy appointments with the Child Health Centre in Northland?
Locality to be assessed:	Northland
Brief outline of study:	Therapy staff at the Child Health Centre (CHC) in Whangarei work within a family-centred model, which is based on building an effective relationship with children and family/tamariki and whanau. When this relationship is not achieved, therapy potential is limited. The appointments to which families do not bring their children are a source of frustration for staff as well as concern, as clinicians are not able to build the effective relationship with whanau that will result in the referred child participating in and benefitting from therapy. The therapy team, including the team leader, at CHC support this exploration into the experience of families who miss appointments. They are motivated to gain insight into factors that contribute to or inhibit effective engagement, with the outcome of providing an improved service to children in Northland. The researcher will interview between 4 and 6 whanau participants who have missed appointments to capture their experience using an interview format within a qualitative descriptive methodology. The research is part of a Masters thesis in Occupational Therapy from Otago Polytechnic
Principal investigator (for this locality):	Marcia Underwood, Occupational Therapist
Contact details:	Email : marcia@wonderwood.co.nz or Marcia.underwood@northlanddhb.org.nz Mob : 021 272 2526 (work) Cell : 027 335 3824
Other local investigators (list all at this site):	N/A
Contact details:	



A Healthier Northland
He Hauora Mo Te Tai Tokerau

NORTHLAND DISTRICT HEALTH BOARD

Part Two: Locality Issues

Identify any local issues and specify how these issues will be addressed.

1. **Suitability of local researcher** ☐ Yes ☐ No
   For example, are all roles for the investigator(s) at the local site appropriate (ie, has any conflict the investigator might have between her or his local roles in research and in patient care been adequately resolved)?
2. **Suitability of the local research environment**
   a) Are all the resources (other than funding that is conditional on ethical approval) and/or facilities that the study requires appropriate and available (for example, is staffing adequate? Is this site accessible for mobility-impaired people where necessary)? ☐ Yes ☐ No
   b) Have all potentially affected managers of resources such as clinical records or laboratory managers been notified? ☐ Yes ☐ No
3. **Have issues such as cultural issues specific to this locality or to people being recruited at this locality been addressed?** ☐ Yes ☐ No
4. **Have the local investigator contact details and other important contact details been provided to the locality organisation for checking?** ☐ Yes ☐ No
5. **Has the local investigator been advised of the unacceptability of using personal hand-held devices to photograph identifiable patient information**? ☐ Yes ☐ No

Part Three: Declaration by locality organisation

I am authorised to complete locality approval on behalf of this locality organisation. I understand that I may withdraw locality approval if any significant local concerns arise. I agree to advise the principal investigator and then the relevant ethics committee should this occur.

I confirm the organisation has sufficient indemnity insurance to compensate participants for harm that does not qualify for compensation under the Injury Prevention, Rehabilitation and Compensation Act 2001.

Signature:		Date:	29/6/17
Name:	Dr Michael Roberts	Position:	Chief Medical Officer
Contact details:	Northland District Health Board, Private Bag 9742, Whangarei 0148		

Appendix F: Participant Information Panui

Tena koutou katoa

I am Marcia Underwood, an occupational therapist from the Child Health Centre in Whangarei. Thank-you for your time. This research is to help with my Masters qualification. Please feel free to ask questions at any time.

OTAGO
POLYTECHNIC
Te Kura Matatini ki Otago

My project asks:

What helps you keep appointments with the therapy team at the child health centre? What makes keeping appointments hard?

This is really all about:

When you have an appointment with health staff for your tamariki, I would like to talk with you about keeping those appointments.

So I would like to:

Ask whānau - like you - to tell your story about a time when you missed an appointment. I realise this might not be an easy conversation to have. The reason for this focus is to try and understand what it is like when that happens.

How you can help is:

I am looking to kōrero with about 6 people or whānau, so that could be you with your whānau or you by yourself, your choice. I want to learn something about walking in your shoes.

What I ask of you is:

To meet with me at a place and time that suits you - I will bring the cup of tea! This will be for about 1 hour. Then talking to me again once I have summarised all the points that have been shared, into themes, to make sure that I have captured what you meant. This will be about 30 minutes.

You might be worried about privacy. To protect your privacy I will:

- With your permission record the kōrero and when this is typed up it will be anonymous, as a code name will be used so that your personal details are not shared.
- Always use a code name in my written work as well as when I talk to my supervisor about my work.
- Keep my work on a password protected laptop.

Finally, if you would like to participate in the research - kei te pai!
And if you change your mind that is also no problem at all, no questions asked.
Do you have *any questions for me? I'm listening!*

Marcia Underwood	Linda Robertson
Student of Masters Programme	Otago Polytechnic Supervisor
Occupational Therapy School	Can be contacted for comment of complaint on:
Otago Polytechnic	email: linda.robertson@op.ac.nz
ph: 027 335 3824	ph: 03 470 4339

Appendix G: Kaitohutohu Consideration

Application:

Will the research involve Māori?

Yes. The ways in which Māori will be involved are:

1. I have been working in with the Te Pou Tokomanawa (Māori Health Directorate) team within the Northland DHB, which is the organisation I work for and where the research will take place. The team have offered to be involved with feedback on my survey questions and my information for participants. We have also discussed the research implications, other areas within the DHB which have undertaken similar projects, as well as how the Kaiawhina team could be involved.
2. Māori in the role of Kaiawhina within Northland DHB are able to participate as the people who approach potential participants in the study. This is in acknowledgement of the communication and networking skills this team have. It is envisaged the researcher will sit with the Kaiawhina as they make introductory phone call to participants so that the phone cal can move into an interview if this is indicated as a preference by the participant. Alternatively the researcher and Kaiawhina will arrange to meet the participants for the interview at a later date and in a place of their choosing.
3. Participants will come from across Northland and it is therefore likely that a proportion will be Māori. It is not know yet what that proportion will be. Participants will be invited to arrange an interview and this will be recorded and transcribed. Once data has been collected and analysed into themes, then I will go back to the participants and check that I have captured the intention of their responses, as well as share the themes and conclusions that are starting to form.

Is the research being conducted by Māori?

No. I do not identify as Māori and my organisation is not a Māori health service, being a general DHB Child Health Centre team.

Are the results likely to be of specific interest or relevance to Māori?

Yes. Given the inequities that exist across Aotearoa/New Zealand between Māori and non-Māori in accessing health services as well as in health outcomes, an exploration into factors influencing attendance at the Child Health Centre and suggested strategies to overcome obstacles to attendance from the participants and the literature will be relevant and interesting to Māori. I believe my research gives a small number of the population, who could well be Māori - the participants at this stage are not identified, an opportunity to voice their stories and experience. Currently in my workplace, the story of the appointments that are missed is almost invariably heard from the clinical staff and administrators perspective; to hear it from the perspective of whānau who missed appointments is relevant.

Could the research potentially benefit Māori?

Yes. Themes identified and conclusions reached in this research will be fed back to Child Health Centre team leaders for service development. If, as is expected due to Northland being home of the largest Iwi (Ngapuhi), Māori participate in this research and identify solutions to obstacles to attending appointments, this data will benefit current and future Māori whanau and tamariki who are involved with the Child Health Centre in Northland.

Response:

Kia ora Marcia,
This response is more than adequate and we are appreciative of the effort taken.
We support your research and this part of the ethics application.
Good luck and go well.
Naku noa
Richard Kerr-Bell
On behalf of the office of the Kaitohutohu
richardkb@op.ac.nz

Appendix H: Participant Consent Form

This project is to look at these questions:

What helps you to keep appointments with the therapy team at the child health centre? What makes keeping appointments hard?
Thank-you for agreeing to be part of this research, I really appreciate it.

Here is what you are agreeing to:

- I have read the information pānui about this project and I understand what it is about. All my questions have been answered to my satisfaction.
- I understand that I am able to request more information at any time.
- I am participating in this project on a voluntary basis.
- I am free to withdraw at any time without giving reasons and without any disadvantage to myself or my tamariki who might need contact with the child health centre in the future. I know that no identifying details will be used.
- I understand that I do not need to answer all of the questions and can also ask for the recording to be turned off at any time.
- The interview will be recorded (audio not video) and will be deleted at the end of this project. The written notes from the recordings which are important to the summary will be stored securely for seven years then these will be destroyed.
- The researcher will bring a koha in the form of snacks and a hot drink to share, and there will be no payment for participation.
- The information gathered during the interview will be used for the researchers thesis, in an anonymous format. I look forward to seeing a summary of the research.
- The learning will also be shared with the team at child health centre when discussing ways to improve service delivery. An article for publication in an academic journal may also be prepared.

I agree to take part in this project under the conditions set out in the Information Sheet.

……………………………………………………………………………. *(name of participant)*

……………………………………………………………………………. *(signature of participant)*

.... *(date)*

………………………………………………………………………………… *(signature of researcher)*

This project has been reviewed and approved by the Otago Polytechnic Research Ethics Committee