

**Growing up kāpo Māori: Whānau, identity,
cultural well-being and health / E tipu kāpo
Māori nei: Whānaungatanga,
Māramatanga, Māoritanga, Hauoratanga**



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2010**

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Dedication to Pura Parata

Hei tohu maumahara ki te mapihi pounamu, kua whetu rangitia,
Kua pau tōu hahana ki te whenua, engari, e tiaho kaha kē mai i te rangi,
Kua waiho nei ōu wawata, mā mātou e tutuki,
Nō reira, e Te Purapura o te Rangi, moe mai i tōu moenga roa!

This is dedicated to our sacred treasured pounamu, who is now amongst the stars,
Your glow is extinguished here on earth, but instead you shine brightly in the night sky,
You have left us your dreams, which we shall fulfil,
Therefore, sleep on Purapura o te rangi within the endless sleep!

Acknowledgements

The research team would like to acknowledge the Tumuaki of Ngāti Kāpo O Aotearoa Inc, who agreed to support and guide this project from its inception. We are grateful as well for the wise advice, direction, feedback and challenges that we have received from Ngāti Kāpo O Aotearoa Inc's Research Management Committee (Mr. Nigel Ngahiwi (Ngāti Maniapoto) (Chairperson), Mr. Pura Parata (Kai Tahu, Kāti Mamoe, Waitaha, Hawea), and Dr. Khyla Russell (Kai Tahu, Kāti Mamoe, Waitaha, Hawea and Rabuvai)).

We would like to acknowledge Mere Courtis for her manaaki, and for her deep knowledge about the kāpo Māori community that she has given to us. Thank you to Fiona Bradford and TK Onekawa, also from Ngāti Kāpo O Aotearoa Inc, who supported the research team in the successful completion of the project.

We acknowledge the membership of Ngāti Kāpo O Aotearoa Inc. for the support and encouragement that they have provided to the research team over the past three years.

Most importantly, we would like to thank all the participants in this project (the key informants and the case study participants) who have shared their stories and thoughts about growing up kāpo Māori. Without their considered and candid contributions, this project would not have had the depth or richness in documenting the experiences of kāpo Māori in Aotearoa.

We also would like to thank the Health Research Council, which has funded and provided support to this project.

Front cover artwork by Artists: Waka and Anaru Te Tai

Within the centre circle, framed by three koru, is a triangle that represents kāpo Māori and their whānau. The three koru that form the corners of the triangle represent the generations of kāpo Māori and their whānau who have passed away and now watch over the new generations of kāpo Māori and their whānau, linking each generation together. The threads that flow from the outer circle represent the knowledge that has been passed down through the generations of kāpo Māori and their whānau.

The colours used represent the heart (red), sky (blue) and sun (gold). The three circles represent the current generations of kāpo Māori and their whānau, with the patterns within each circle depicting future challenges that each generation will encounter, acknowledging that the future and one's pathway is difficult to determine.

As expressed by the artists: "The theme of the painting reflects that the future is uncertain but the experiences, knowledge and teachings handed down through the generations of kāpo Māori and their whānau give encouragement and confidence and although the future cannot be seen clearly there is a path to follow and it can still be great."

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Chapter One

Introduction

Before this project, there were no published studies about kāpo (blind) Māori in New Zealand, although there has been some general research about blind people and about Māori with a disability (Bevan Brown, 1989; Bevan Brown, 2003; Bevan Brown, 2006; Collins & Hickey, 2006; Higgins, 2001; Higgins, 2005; Higgins & Ballard, 2000; Phillips, 2005). This two-year project was funded by the Health Research Council and, like its title indicates, is about growing up kāpo Māori in New Zealand. In line with the Treaty of Waitangi, and, based on, or distinctly, kaupapa Māori, more specifically, the aim of this two-year project was to explore how the impairment of blindness affects Māori and how health and education services impact on the identity, cultural well-being and health of kāpo Māori and their whānau.

The seed for the study came from Hine's story, which was one of the Māori participants' stories from Dr. Nancy Higgins' 2001 doctoral thesis, *Blind people: A social constructivist analysis of New Zealand education policy and practice*. Dr. Higgins and a research colleague, Dr. Hazel Phillips, took this story to Ngāti Kāpo O Aotearoa (Ngāti Kāpo) for discussion because it was believed that the research about experiences such as Hine's was incomplete. Ngāti Kāpo fully understood Hine's story because it resonated with so many of their members' stories and thus Ngāti Kāpo became the initiators of this research. Tino rangatiratanga (self-determination) provided the framework in which the project developed. A partnership developed between Ngāti Kāpo and Dr. Higgins from the Donald Beasley Institute and Dr. Phillips from He Parekerekere of Victoria University to make certain that Māori cultural concepts, values and practices were safeguarded. This project was hosted by the Donald Beasley Institute under the leadership of the late Associate Professor Anne Bray and later, Dr. Brigit Mirfin-Vietch. The Donald Beasley Institute has a commitment to "identify critical issues affecting the lives of people with disabilities in New Zealand" (Donald Beasley Institute, 2010), and was well placed to be a host in that it had a history of research in disability, research expertise and research resources in place.

As a result of further discussions with Ngāti Kāpo, a three-way research partnership was established with the Donald Beasley Institute and He Parekerekere of Victoria University where Dr. Higgins and Dr. Phillips, respectively, were employed. Ngāti Kāpo held a governance role for the project through a Research Management Committee, which was a sub-committee of its Tuamaki or Executive, and this ensured that the project's and the researchers' accountability to Ngāti Kāpo was direct. It also enabled Ngāti Kāpo to fulfil their aspirations in terms of developing their own research capacity and capability (Ngāti Kāpo O Aotearoa, 2004). Mr. Nigel Ngahiwi (Ngāti Maniapoto) (chairperson), Mr. Pura Parata (Kai Tahu, Kāti Mamoe, Waitaha, Hawea), and Dr. Khyla Russell (Kai Tahu, Kāti Mamoe, Waitaha, Hawea and Rabuvai) were members of the research management committee. Also, the Royal New Zealand Foundation of the Blind (RNZFB) and Blind and Low Vision Education Network New Zealand (BLENNZ) supported this research in that they agreed to be localities in which data could be gathered as appropriate and participants recruited.

The research team for this project were Dr. Nancy Higgins (lead researcher) (Pākehā, American Greek), Dr. Hazel Phillips (senior Māori researcher) (Ngāti Mutunga), Mrs.

Christine Cowan (Ngāti Kāpo researcher) (Ngāti Kahungunu and Ngāti Porou), Ms. Kelly Tikao (emerging researcher) (Waitaha, Kāti Mamoe and Kai Tahu), and, later, Dr. Benita Wakefield (emerging researcher) (Ngāti Kahungunu and Kai Tahu). Thus, the research design and method reflected not only the location of the research within the kāpo Māori community but also drew together the particular strengths of all who were involved to provide a multi-disciplinary, multi-location, and pan-tribal approach to the research and a commitment to working together for a common end (Jeffrey, 2003). One of the aims of the project was to unlock the potential within whānau, hapū and iwi and, in particular, kāpo Māori so that they can live as Māori, actively participate as citizens of the world and enjoy good health and a high standard of living (Ngāti Kāpo O Aotearoa, 2005; HRC, 2004; Durie, 2001). The project privileged Māori ways of knowing, and by doing this retrieved spaces for Māori voices and perspectives in which Māori realities are legitimate so that social transformation may occur (Smith, 1999), not the transformation of Māori but the transformation of policies and services to Māori.

The Treaty of Waitangi both informed and underpinned this kaupapa Māori research project. For Māori, the Treaty is not only a blueprint for how Māori and Pākehā can live together, but it contains a set of rights guaranteed to Māori with regard to self-determination and sovereignty over lands, waterways, cultural, political and economic institutions (Article Two), and also with regard to equality in society (Article Three). Since 1840, it has been used as a leverage to resist, reclaim and redress historical Māori dispossession. To that end it has, and is, used to articulate Māori aspirations, reclamation and redress for historical and contemporary inequalities.

The different ways in which Māori and the Pākehā view the Treaty of Waitangi are underscored by a history of conflict. For example, there are different and conflicting versions, which have, not just different wordings for the Treaty, but also different intent and thus rationale for its signing, its legality and relevance, and last, but not least, the capacity of Māori to be a sovereign people. Given the different ways in which the Treaty has been read, interpreted and understood by Māori and Pākehā, the government and courts have grappled with understanding the Treaty. The mechanism through which this has been done in more recent times is through the development of a set of Treaty of Waitangi principles that first arose out of the court case *New Zealand Māori Council v Attorney General* in 1987. Since then, various court cases and Tribunal reports have consolidated the idea of Treaty principles. Thus, they have become the primary way in which the government and its agencies understand and express commitment to the Treaty of Waitangi. The four primary principles are: (1) protection and the Crown's duty to protect Māori lands, waters, possessions and self-determination; (2) partnership and the idea that the Treaty established a partnership between Māori and the Crown and the duty of the Crown to act in good faith; (3) participation in which Māori are guaranteed all the rights and privileges of citizenship; and (4) consultation in which the Crown has a duty to consult with Māori.

The basis of Māori criticism of the 'principles approach' to the Treaty of Waitangi is that they have arisen out of western legal deliberation. To that end, the principles are Pākehā understandings and interpretations of the Treaty that diminish Māori understandings and aspirations, and, in effect, reflect the continuation of historical and unequal relations of power. Notwithstanding this criticism, Māori continue to use the articles of the Treaty of Waitangi, as well as the principles, to advance their claims for redress and equality. In this project, the researchers and Ngāti Kāpo O Aotearoa Inc view the Treaty of Waitangi from a Māori world view. In doing so, the research team upheld the centrality of Te Tiriti o Waitangi

with respect to research methodology and analysis, effective partnership building with non-Māori, social equity and justice, and most importantly to Māori aspirations to be Māori and self-determining.

This final report presents how kāpo (blindness and visual impairment) affects Māori in New Zealand. Through ten case studies, or ten stories, of kāpo Māori and their whānau, it explores how health and education services impacted on their identity, cultural well-being and health. At the beginning of the project, a literature and policy review was completed about kāpo Māori to form the context for this study. An interim report and supplementary report have been previously produced which identified, in detail, the demographic and policy information that was relevant to kāpo Māori (Higgins, Phillips, Cowan & Tikao, 2008; Higgins, Phillips, Cowan & Tikao, 2008a). The next two chapters, Chapter Two and Chapter Three, summarises, synthesises and adds to the information from these two report, and these two chapters provide the context for this study.

Chapter Two presents the relevant research literature. The first part of this chapter documents information about kāpo Māori in the ancient world, which has been previously published in the *MAI Review* (Tikao, Higgins, Phillips, & Cowan, 2009). The next part of Chapter Two documents the current and relevant literature about marginalisation, indigenous people and disability, health and education services, human rights, and being Māori and kāpo in New Zealand. There was a dearth of research and literature about Māori and disability in general, and about kāpo Māori in particular. What has been written pointed to disconnections between mainstream policies and practices and Māori. Not only was there a lack of access to services, there was a lack of access to culturally appropriate services. Where research has investigated the needs and aspirations of Māori and indigenous peoples, gaps in access to services, culturally appropriate services and funding have been identified and appropriate frameworks proposed. Also, within the literature, being Māori and being disabled were seen not as discrete oppressions but rather as part of a world view in which difference was considered to be inferior.

The demographic information and policy information about kāpo Māori in New Zealand is presented in Chapter Three. In this chapter it is clear that across a range of well-being and quality of life domains, Māori continued to be over-represented in negative indices. There was a lack of knowledge within organisations that provide health and education services to kāpo Māori about the demographics of Māori with a vision impairment, and this has implications for diagnoses, ongoing treatments/therapies and access to services. Culturally appropriate policy enactment and providing easy access to services at the Royal New Zealand Foundation of the Blind and within the education system, while meeting Māori cultural and spiritual needs, remain a challenge. However, Ngāti Kāpo O Aotearoa has been able to fill a service gap by providing services ‘by kāpo Māori to kāpo Māori’ on a national basis. This service is also oriented towards fulfilling kāpo Māori education, health and cultural well-being and enabling tino rangatiratanga.

The next chapter, Chapter Four, presents our research paradigm and method. Stories, narrative, and case study methods are discussed, and our detailed research process is described. Initially, after our literature and policy review, forty-three participants, who were kāpo Māori since birth, who were kāpo Māori whānau members, and/or who worked with kāpo Māori and their whānau were interviewed for this research project about their experiences of, and thoughts about, being kāpo Māori. These were our key informant

interviews that helped us form an analysis framework to make sense of the data from our case studies, which occurred in the last stage of the project.

The ten stories within this report are from last stage of the project. They are the stories of ten kāpo Māori (Bruce, Ngaio, Hoani, Sara, Tommy, Elizabeth, Kahu, Kapua Kore, Marama, and Cathy) and their whānau (37 whānau members in total). These ten stories were developed from in-depth interviews and discussions about being kāpo Māori. The researchers also talked to them about their experiences when interacting with health and education services. The whānau's stories reflected a diverse range of experiences of growing up Māori and kāpo across the generations. While there were notable similarities of experiences between many of them, there were, at the same time, some stark differences.

Their stories are presented in five chapters and are told in a temporal and sequential manner. Storytelling is fundamental to making sense of our experiences, and life narratives can illuminate identities, the political and personal, and the participants' social lives. It is acknowledged though that the researchers in this project are the storytellers because they shaped the stories from the different perspectives of the different social actors and participants in the project. Each chapter tells the story of two kāpo Māori and their whānau who are of the same generation as identified by Ngāti Kāpo. Chapter Five tells the stories of two kaumātua (aged 65+) who grew up in the 1930s and 1940s. Their stories are about coping with being kāpo when there was little support available to them. Chapter Six is about Hoani and Sara from Ngāti Kāpo pakeke generation (aged 25-64), who grew up in the 1950s, 60s and 1970s, when the Foundation for the Blind was actively providing services. However, they resisted identifying as kāpo and instead remained firmly grounded in their identities which were connected to their whānau and community. Tommy's and Elizabeth's rangatahi (aged 15-24) stories are presented in Chapter Seven. They grew up in the 1980s, 1990s and early 2000s, and encountered inflexible health and education systems that as time went by become more rooted in individualised notions of 'special education' and became incongruent with, and distanced from, their cultural identity. In Chapter Eight, the taimaiti (aged 5-14) in this project, Kahu and Kapua Kore, encountered health and education services in their communities which were not able to adequately balance or provide for both their cultural and educational needs and rights. Chapter Nine presents the stories of the nohinohi generation (aged 0-4) in this project, Marama and Cathy. Their stories are difficulties in accessing health and education services in a timely and culturally appropriate manner, but more importantly are about whānau love, hope and aspirations for the future.

Chapter Ten presents the findings from these ten stories analysed through a thematic framework that was developed. These themes include (1) cultural location and dislocation, (2) cultural consonance and dissonance, (3) visibility and invisibility, and (4) transformation and change. The overarching context for these themes is the fact that all of the case study participants had firmly grounded identities as Māori, and were culturally located in whānau. The four themes are also fluid, and while the first three themes could be understood, perhaps, as opposites, the reality of each participant's story was that their experience of being kāpo Māori was much more complex and ever changing. For example, some participants were both visible and invisible to education and health services, and their experiences of being visible or invisible was either positive or negative, depending on the situation.

The first theme, cultural location and dislocation was about how the participants fit within their hapū, iwi, and communities, including the kāpo community. Most participants saw themselves as 'normal', that is, not being any different from anybody else, with many actively striving to lead 'normal' lives. However, moving away from home to go to school

because of being kāpo led to participants' dislocation from whānau, hapū and iwi, and te ao Māori. Those kāpo Māori who went to Parnell or in more recent times to Homai, were indoctrinated into another world that was based on difference and disability. However, remaining within whānau contexts and being schooled locally in their own community did not necessarily mean that kāpo Māori were culturally or educationally better off.

The second theme, cultural consonance and dissonance was about how education and health services fit with the experiences of being kāpo Māori. Meanings for dissonance for this study can be extrapolated from the field of music where dissonance is another word for discord or "an inharmonious combination of simultaneously sounded tones" (<http://www.thefreedictionary.com/discord>). Consonance can be thought of as harmony in the culture of service delivery and kāpo Māori. Across the participants' stories, the majority of health and education services experienced by kāpo Māori in this study were monocultural. Very few fulfilled kāpo Māori aspirations for services that were culturally relevant and appropriate. In education, some kāpo tamariki attended kōhanga reo and then went on to kura kaupapa before going on to Homai, Manurewa High or James Cook High Schools. Neither Homai or the high schools adequately acknowledged and supported these students' cultural identity as Māori. However, nor can it be assumed that kura kaupapa initiatives provided kāpo tamariki with an appropriate education in regards to being kāpo.

The third theme, visibility and invisibility, was about whether the participants were invisible or visible to others and to health and education services as kāpo, as Māori, and as kāpo Māori. Many of the participants have been invisible as kāpo to education and health services. Some wanted to be invisible because they saw it as enabling them 'to be normal'. Some participants were invisible as kāpo to their whānau, in one instance because other members of the whānau were more obviously kāpo and, in another, because whānau were not tuned into the issues that face kāpo Māori. Participants with multiple disabilities faced a different kind of invisibility because their vision impairment was often overlooked in the face of more obvious impairments. Also, many kāpo Māori in this study have been visible to health and education services. However, being visible did not necessarily mean having access to services that fulfilled their educational and health aspirations or improved their overall cultural well-being.

The last theme, transformation and change, was related to the ways in which the participants believed they could resist, transform, or change their circumstances to meet their desires and their aspirations to get on in the world. Many of the participants considered their futures in the context of being Māori who happened to be kāpo. This did not mean being invisible to services, rather it meant being able to access services and resources so that they could get on with living and being Māori. Many saw the whānau as the vehicle for transformation and change and thought that more should be done to support it. The struggles that kāpo Māori and their whānau faced have led to many of them taking on advocacy and leadership roles in their whānau and communities and in the Māori world in general.

This report concludes with a challenge for health and education services to better address the cultural well-being and the health of kāpo Māori and their whānau. At the heart of Māori aspirations is self-determination, whether as Māori or as kāpo Māori. The Treaty thus remains the most significant document and leverage for Māori to fulfil their aspirations, and if it is used alongside other rights based legislation and international conventions, a strong case can be made for the redress of historical inequalities that have existed, and continue to exist, for kāpo Māori.

Being Māori and kāpo had an impact on the participants' lives. They were marginalised but maintained strong and positive identities. They were active agents in shaping cohesion for themselves that enabled a way of seeing and understanding the world in positive and self-determining ways. They were thus highly resilient and resourceful in their everyday lives, and expressed their desire and rights to be self-determining, and being able to live life while being true to themselves. That is: 'to be Māori who happen to be kāpo'.

Chapter Two

The research literature

In this chapter, the research literature that is relevant to ‘growing up kāpo Māori’ is presented. The first part of this chapter discusses the literature that documents kāpo Māori in the ancient world up to about the 1840s and provides a historical and traditional context about being kāpo. The next part of this chapter documents current and relevant literature about marginalisation, indigenous people and disability, health and education services, human rights, and being Māori and kāpo in New Zealand.

Te ao tawhito (Māori in the Ancient World)

Kupu/Ingoa

A search of the literature was done around the general themes of: kāpotanga, disability, impairment and birth defects, which were documented in Māori communities in early Māori times. Finding the key words or the Māori words to best describe blindness was a challenge. Iwi have dialect differences, and thus there were a number of different words to describe the same thing (i.e. matapō and pohe). There can also be slight variations to a similar word (i.e. kāpō, kāpo).

Māori descriptions given for blindness indicated that Māori who had an impairment, ‘deformity’, or a bodily difference, often received a name that specifically described their difference (Best, 1924). Below are some of the words that came forward about blindness, as well as disability.

hauhaua – crippled (Beattie, 1990)
kāpo – blind (Ryan, 1990)
kāpotanga – blindness (Ryan, 1995)
kerepō – blind (Ryan, 1995)
matakerepō – blind (Ryan, 1990)
matapō – blind (Ryan, 1995)
matapōtanga – blindness (Ryan, 1995)
pohe – blind (Beattie, 1990)
pohe ka kanohi – blindness (Beattie, 1990)
pōrangī - mad, in a hurry (Ryan, 1990)
pura – blind (Beattie, 1990)
pura o te kanohi – blindness (Taylor, 1848)
tamaiti whakatoi – wayward child (Best, 1975)
toretore – inflammation of the eyes (Taylor, 1848)
wairangi – excited, wild monster, reckless (Ryan, 1990)

Ngāti Kāpo O Aotearoa adopted the term ‘kāpo’, which comes from Ngā Puhi dialect, and was brought to Ngāti Kāpo by Bill Rako. It was subsequently adapted by the kaumātua (respected elders) and kuia (respected older women) of Ngāti Kāpo after wide consultation with elders without, and with, sight, like Sir Kingi Ihaka. The word kāpo was used to

holistically identify the state of being for people who are vision impaired, blind, or deaf blind. Other terms that were considered by Ngāti Kāpo, which would identify the 'state of being blind' were 'matapō' (black) and 'pohe' (dim). Also, of importance is the fact that the meaning of 'kāpo' for Ngāti Kāpo is directly linked with the term, Ngāti and with the whakatauki (proverb) 'kā pō, kā pō, kā ao, kā awatea' (the forward journey from darkness into the light). This whakatauki is also used in whaikōrero (men's oratory) by most iwi. Further to this meaning, some have also indicated that the wairua (spirit) of a person may know before birth that their physical being will be kāpo but the onset of the physical impairment of blindness or vision impairment may occur some time after birth (Russell, 2007).

Ngā Rangi/Ten Heavens/Lore/Tapu

In order to understand the context in which some Māori perceived illness, impairment, or disability, some of the literature on Māori thinking about the ten heavens (also known as 12 heavens), and atua Māori/Māori gods was relevant to this review. In some of this literature, it was said that earth itself carried illnesses that were not found in any other realm of the taiao (environment). Teone Taare Tikao confirmed this. He was given tohunga training as a child, carried a vast amount of knowledge about mythology and history on the South Island and was interviewed by historian Herries Beatties in 1920. Tikao supported the premise of purity existing only in the heavens and illness only on earth. Tikao attributed the cold weather on earth as the main reason for illness amongst Māori. Tikao told Beatties, "There was no sickness in the heavens. There was no dew, rain, snow and frost up here. These things bring sickness on the earth." (Beatties, 1990, p. 39).

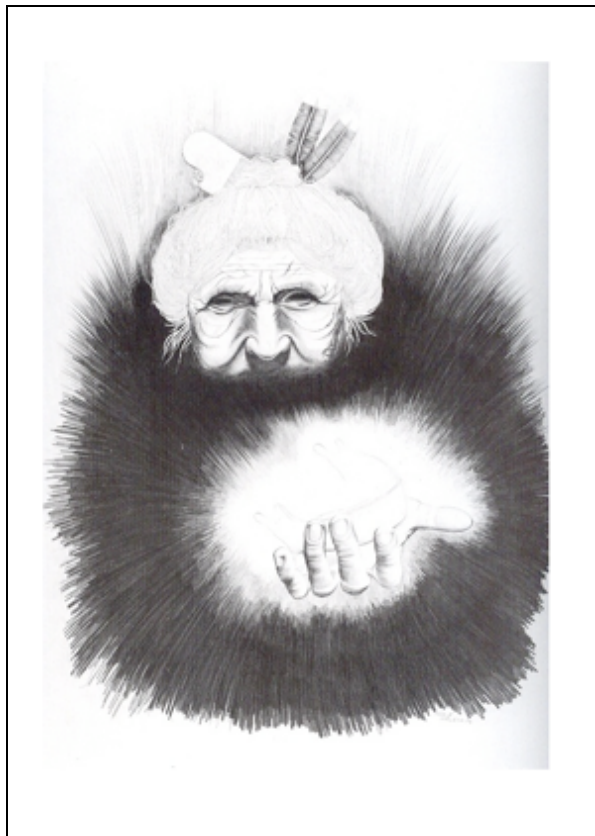
The ten heavens are often discussed when talking about Māori creation stories and about stories of a particular tipuna (ancestor) and their amazing feats which were undertaken to reach the heavens (Beattie, 1994; Best, 1982; Reed & Calman, 2004). Tikao told Beattie (1994) that the heavens extend beyond the stars and are suspended one from another. It was here in the levels of heaven that atua (gods) Māori dwelled, and these atua enforced Māori lore. If lore was broken, it was the atua that delivered the reprimand. The consequences for infringement of lore or tapu are discussed below under the tāngata Māori section. Also of importance is that Māori had a spirit for each part of the body, for the eyes, the spirit was Tongameha (Orbell, 1995).

In Māori ancient history kāpo atua (gods/goddesses) existed. Whilst their blindness was acknowledged in some of the readings (Reed & Calman, 2004; Best, 1982), no detail about their blindness was discussed. Questions about why these atua were blind or how they coped with their disability were not examined in any of the written literature. In some stories though, kāpo was not a disability but a tohu (sign) of greatness. Being kāpo was their source of power because they were not reliant on all of their senses and had high levels of ability, which were displayed in their use of the senses that they did possess.

Māui Tikitiki-a-Taranga, a well-known hero and trickster of Polynesian mythology had a blind grandmother, or grandfather, Murirangawhenua, who was also known as Matakerepo (cloudy vision) (Williams, 2008). Murirangawhenua gifted her jawbone to Māui so he could create a fishhook that would be used to fish up Te Ika a Māui (North Island), and thus show his ability to his sceptical brothers. Māui used karakia (prayer) and blood from his ihu (nose) to smear on the jawbone and lure the whenua (land) to his hook. Murirangawhenua was held

in high esteem for her/his knowledge and wisdom, and in te ao Māori these qualities reside in the jawbone. Hence, Māui knew that this was the tool that would make his mission successful (see Figure 1).

Figure 1: Robyn Kahukiwa's drawing *The Gift of Muriranga-whenua* (Oil on hardboard 118cm x 118cm) (Note: From P. Grace and R. Kahukiwa, 1984, *Wahine Toa - Women of Māori Myth* p.53. Reprinted with permission from the artist.)



Another whanaunga (relative) of Māui, Mahuika was the Goddess and Guardian of Fire, who was depicted and described as having no eyes:

Mahuika, the goddess, rose up before him, fire burning from every pore of her body, her hair a mass of flames, her arms outstretched, and with only black holes where her eyes once were. She sniffed the air. (Ministry of Education, 2008c, http://www.tki.org.nz/r/maori/nga_pakiwaitara/maui-mahuika/index_e.php)

The story that is told is that Māui, in order to obtain the secrets of making fire, tricked Mahuika into giving him all of her fire children, who were contained within the fingers of her hand. After Māui had tricked Mahuika for all but one of her fingernails of fire, she became very angry. Māui ran from Mahuika and she pursued him. Māui turned into a hawk so he could fly above the flames. However, his feathers were scorched and so he dived into the waters below him only to find that the water was boiling. He called on his tipuna (ancestor), Tāwhirimātea, to bring rain to drench the fires. This is what saved Māui. Mahuika, before being consumed by the torrential rain, threw her last fingernail of fire into the trees. Today,

kaikomako, māhoe, totara, patete and pukatea are now seen as guardian trees of fire (see Figure 2).

Figure 2: Robyn Kahukiwa's drawing, *Mahuika, Konui, Koroa, Manawa, Mapere and Toiti*. (Note: From P. Grace and R. Kahukiwa, 1984, *Wahine Toa - Women of Māori Myth*, p. 49. Reprinted with permission from the artist)



Another relation of Māui was Tāwhaki. He needed to travel the heavens to find his father, and there he met his grandmother, Whaitiri (full name, Whaitirimātakata – Crashing Thunder), who was blind. Whaitiri, after leaving her husband Kai-tangata to live with her sky parents, returned to the base of the sky's ascent and waited for the arrival of her grandson, Tāwhaki. Elsdon Best (1982, p 383) wrote that when Tāwhaki encountered Whaitiri, she was “quite blind” due to her eyes being scratched out by a “multitude of small birds” that passed Whaitiri each night. Best's description of this story told of Tāwhaki destroying the birds and consequently restoring Whaitiri's sight. Other versions tell how Tāwhaki performed karakia (prayer) over Whaitiri and made her see again. It was Whaitiri who knew, and told Tāwhaki, about which aka matua/rangi tuatangi (the main or parent vine) to climb to the heavens, and thus she gave Tāwhaki the correct knowledge to proceed to the heavens in search of his father (Mead & Grove, 2001).

Te Ao Māori (The Māori World)

The lives of Māori in te ao tawhito (the old world, from their arrival in New Zealand to the end of the 1800s) were harsh and short where life expectancy was between 40-50 years. Māori were nomadic, travelling to survive and often setting up temporary new kāinga (homes/villages). They moved towards the coast for kai moana (seafood) and returned inland to grow crops (Salmond, 1997) depending on the season and the availability of the resources. Best (1924) wrote that because Māori survived off the land and thus had a tough physical lifestyle, sight and hearing were two important senses that were needed to carry out the daily task of food gathering.

Jill Bevan Brown (1989) found that birth defects were viewed by some hapū as a punishment for the offence of breaking tapu by someone within the whānau, hapū or iwi, and that some Māori believed the same was true for people with an intellectual, physical, and sensory disability. Therefore, disability and impairment were “accepted with an air of fatalism” (p. 5). Mason Durie (1994) described tapu as:

secured by the sanction of the gods and reinforced by the endowment of mana. Tapu can be applied to people, places, animals, plants, events and social relationships ... transgression of tapu earned rebuke, ridicule and intense mental suffering – physical consequences were also expected, epidemics, bodily wasting, or even death.” (p. 9)

Durie wrote that tapu was essentially a safety measure in that it was intended to make Māori cautious and to warn of imminent danger should tapu be broken. For Māori, it offered a series of practical rules to protect communities. Without spiritual awareness, the individual was considered to be without well-being and much more prone to disability or misfortune (Durie, 1985). Elsdon Best’s writings in 1941 also supported this view. According to Best, sickness not only occurred as a result of a tapu infringement or incorrect processes according to lore, but it was also the sign of transgression and punishment of the gods.

Bevan-Brown (1989) stated that it could be said that traditional Māori society, whose economic level was often that of subsistence, would not be very tolerant of people with a disability who were considered dependent and who may not contribute socially or economically to the welfare of the iwi or hapū. Best (1924) wrote that people with an impairment amongst their hapū did not appear to receive a lot of sympathy from other whānau and hapū members. Perhaps a sense of shame was present for the individual and hapū. Also, fear of further misfortune may have caused Māori to remain silent about impairments. These issues may help to explain the dearth of information around blindness during this particular period.

Tāngata

In 1884, a traveller, Mr. Kerry Nicholls, wrote that he saw an albino Māori woman and described her as having “light flaxen hair, pink eyes and white complexion” (Robley, 1998:45). Makereti Papakura (1938) in her book entitled *The Old Time Māori*, said that albino Māori were mainly seen as atua (goddess or godlike) and were highly respected. She

noted that they were often blind and that this was an addition to their status not a subtraction. Albino Māori were called turehu or urekehu, and Makereti said, “these turehu children are supposed to be born of an ordinary Māori mother and a patupaiarehe (fairy) father” (Makereti, 1938, p. 123). Patupaiarehe were described as “supernatural children of the mist ... seen in the indistinct form ... they are fair, and are clothed in flimsy white like the web of the pūngāwerewere/spider” (Makereti, 1938, p.123). According to Elsdon Best (1982) fairy people were fair skinned and had light brown or red hair. Patupaiarehe, heketoro, turehu, urekehu, and korakorako are some of the Māori names for these people. Korakorako (also written as korako for short) was the name associated with albino Māori and were described as people who “could not see or look into the full blaze of the sun” (Best, 1982, p. 47). Best (1982) referred to a korako as a child with light, soft straight hair and blue eyes. Queenie Hyland (1997), in her book *Myths and Legends*, said that the korako people had white skin and pink eyes, which glowed in the dark.

Beatties (1990), in his book *Tikao Talks*, noted that Tikao witnessed blindness in the elderly because of the constant work that was done over fires, which could cause damage to the eyes. Also, of interest is the fact that illnesses increased when Māori moved from high hilltop forts to lower flat land dwellings. Houses were built on swamp-like land with spongy soil. Manning (2001) stated that these were heated with fires and were warm at night but were too moist during the day. This brought illness through poor ventilation and moist living conditions, and Beatties (1994) reported that the Murihiku Māori had eye problems because they sat in smoky dwellings over long periods of time. They seemed to have ophthalmia or inflammation (kukura) of the eyes. When they entered their later years the kukura (inflammation) would often progress to pohe (blindness) (Beatties, 1994).

Blindness may have also been caused by injuries that were sustained during tribal combat. For example, the Waikato chief, Horomona Maruhau, lost his eyesight in a conflict with Ngā Puhi. Horomona, who was called Maruhau initially, was referred to in the literature as Horomona Maruhau or Blind Horomona (Tucker, 1866). Horomona Maruhau met with missionaries, converted to Christianity, and became a native teacher. In 1866, Miss Tucker made a glowing reference to Horomona Maruhau in the report, *Southern Cross and Southern Crown*. She described him as a “consistent Christian” with a great memory, who was respected amongst his peers. Horomona could find his way alone to places within a three miles radius of his kāinga/whare (home), but beyond this distance he required a guide. Miss Tucker also said that “he was all light within, that the people of the world could not discern the light he possessed” (Tucker, 1866, p. 8). In 1849, Horomona Maruhau met Governor Grey, who was impressed at Horomona Maruhau’s attitude towards his blindness and in the writings about this occasion Miss Tucker wrote, “His blindness added a peculiar and calm dignity” (Tucker, 1866, p. 8) (see Figure 3).

Another chief in the 1820s, Hongi Hika, was documented to have had a blind wife, Turi-ke-tuha. Hongi Hika was a well-known Ngā Puhi chief, who was related to all the principal Ngā Puhi chiefs of his day. One interesting fact about Turi-ke-tuha was that she accompanied and advised Hongi Hika on all of his fighting campaigns. For example, in Smith’s 1901 article in the *Journal of the Polynesian Society*, a description was given of a tribal battle, Te Ika a Ranganui, between Ngā Puhi and Ngāti Whatua. Prominent Ngā Puhi chiefs led the taua (war party) and Hongi Hika was cited as one of them. In one particular part of the battle, Ngā Puhi looked like they were being defeated and it was Turi-ke-tuha, who called out to inspire Ngā Puhi. It was then that the Ngā Puhi taua fought harder and drove Ngāti Whatua back. In the battle, Hongi Hika and Turi-ke-tuha lost their son, Hare Hongi.

Figure 3: Drawing of George French Angas (1807 – 1889) *Horomona Maruhau* (aka *Blind Solomon*). (Note: From White, 1890, *The Ancient History of the Māori, His Mythology and Traditions: Tainui Vol VI*, p. 81. NB this reference came from this book off an online resource, which is also at this website address: nzetc.org/tm/scholarly/hy/tel-whi06Anci.html.)



Kelly (1938, p. 180) wrote that a chant was composed by an unknown Ngāti Whātua person about the battle of Te Ika a Ranganui and within this chant or kaioara, Turikatuku (aka Turi-ke-tuha) is mentioned;

Tarure ki te taha ko Turikatuku ko te wahine taki wairua
(Languishing listlessly to the side is Turikatuku, the spirit-challenging woman.)

It is interesting that Turi-ke-tuha was given this description by a composer from Ngāti Whātua, because it provides evidence that she was at Hongi's side in battles and was perceived by others as a gifted and knowledgeable woman to be feared.

The Māori population declined dramatically from the 1840s to 1890s and during this same time, Europeans began to increase in numbers and interact with Māori. In 1938, Makereti wrote:

There were few ailments before Europeans visited Aotearoa (New Zealand), but soon after Captain Cook came, the first epidemic swept over our land, and according to our traditions many thousands of men, women and children perished. It was called by the Māori Te Upoko o te rewharewha. Each vessel that visited us left an epidemic of some kind, which wiped out many children as well as grown up people. Though I could mention various epidemics, here I merely want to say that before Europeans came, there was comparatively little illness. (Makereti, 1938, p. 149)

Michael King (1991), in his book entitled *Māori - a photographic and social history*, talked about the changes to Māori living conditions during this period of colonisation. Typhoid and dysentery were present in epidemic proportions. Fertility rates also declined because Māori women suffered from general ill health and from the effects of syphilis, gonorrhoea and tuberculosis. King commented that in parts of the Waikato in the late 1850s over one third of married Māori women were found to be barren.

In conclusion, there is very little in the academic literature about Māori and disability and, more specifically, Māori and kāpotanga before the 1840s. Some information and knowledge is available in oral form, but has been rarely studied. The stories, waiata and memories that have been carried through whānau oral traditions can certainly provide enlightenment on kāpo Māori i te ao tawhito, and these need to be prioritised in the future. Also, it is important to note that the literature which talks about this period (before 1840) was written by non-Māori historians or missionaries who carried their own cultural bias. They would often write their own interpretation of what had been told to them by their informants, and thus placed a particular lens on their knowledge and writings. This will have an impact on how the reader sees and interprets the material. Linda Tuhiwai Smith (1999) has questioned the value of some of the research that has been compiled by early ethnographers, educational researchers and the occasional travellers' accounts of Māori society.

In conclusion, it appears that Māori in the ancient world who had a vision impairment were people with the power and status of deities. They were known for the talents that they possessed, not for what they didn't have. They also held great knowledge and shared that knowledge with others. As time has progressed, though, this notion appears to have changed.

Current literature relevant to kāpo Māori

Barriers, deficits, intersections, and diversity

According to New Zealand's *Disability Strategy*, disabled people have been disabled by a society that takes no account of their impairments (Minister for Disability Issues, 2001), and others have noted that society disables Māori by taking no account of their identity, their culture, or the meanings that they give to disability (Kingi & Bray, 2000; Phillips, 2005). Phillips (2005) noted that Māori have been disabled through assimilatory educational practices and deficit theorising that have marginalised Māori and excluded Māori from their own knowledge base, language, cultural values and practices. Jill Bevan-Brown (1994) pointed to the different ways in which Māori and Pākehā view disability. Like other researchers (Wilkie, 2000; Wilkie, Berryman, Himona, & Paul, 2001), she found that the predominant view held by those she interviewed was the notion that all people, irrespective of their abilities, were taonga and as such were valued members of their communities. Significantly, the participants in Bevan-Brown's Masters study did not know a Māori equivalent for the term intellectual disability (Bevan-Brown, 1989; Bevan-Brown, 1994). Māori concepts of disability today reflect an acceptance and valuing by the whānau of the person as they are, as opposed to the dominant perception of disability as a medical problem or tragedy (Bevan-Brown, 1989; Kingi & Bray, 2000). However, if just being Māori is considered disabling then being a disabled Māori takes on added meaning. On that basis it can be argued that perhaps Māori with an impairment, such as blindness, are doubly oppressed or disadvantaged (Higgins, 2001; Phillips, 2005). However, Phillips (2005) noted that being Māori and being disabled may not be discrete oppressions, but instead

“interconnected parts of a whole way of looking at the world in which difference is considered inferior and in which unequal relationships are demarcated” (p. 88).

When Soldatic and Fiske reviewed the wrongful detainment of lawful Australian migrants with an impairment (psychiatric, learning, and intellectual), they found that of the thirteen people who had been wrongfully detained, only one was ‘white’. They argued that the migrant’s ethnicity, or racial ‘otherness’ initially drew authorities’ attention to the migrant, and then the authorities’ resistance to understanding, and seeking evidence, about the migrant resulted in them stating that they had a ‘reasonable suspicion’ of unlawfulness. They then detained the migrant. Soldatic and Fiske stated that “racism (in the initial formation of suspicion) and disability discrimination (in the maintenance of suspicion and silencing of disabled voices) were critical aspects of all of these cases” (p. 293). They argued that the intersection of race and disability left people vulnerable to prejudice and human rights violations. Despite current legislation to the contrary, they noted that Australia’s dominant discourse and history have also left a legacy that encourages the State to exclude disabled and non-white people, who have been deemed to be undesirable immigrants. Disabled and non-white people are not in the ‘demos’ or the population of those who are accepted as full citizens with freedoms and rights.

Further to this, Petersen (2006) argued that an individual can be multiply ‘othered’ and that binaries of ‘white and black’, ‘abled and disabled, and ‘female and male’ are not sufficient to tell the nuanced stories of people with diverse and multiple identities. Also, identities can be fragmented, and in order to negotiate them the oppressed can become themselves the oppressor. She told the story of an African-American woman, Krissy, who was assigned the label, ‘learning disability’, within the American education system. Krissy described her educational life from different standpoints. For example, in the special education resource room, her life was boring and techno-rational, but when the opportunity arose, she ostracised an African-American boy within the resource room. Her life was ‘genderised’ in her maths class where the teachers attended mostly to the boys. She prioritised her race for her social relationships, in that she gave up a close and rewarding friendship with a white girl upon the encouragement of her African-American friends. Petersen used Collins’ group standpoint framework to make sense of Krissy’s story. This framework notes that a marginalised group’s oppressive experience should not be prioritised over another, and that it is more important to seek meaning about the interconnection and intersection of these oppressions through a discussion of the experiences of those with multiple identities.

Islam (2008) wrote that the social model of disability did not take into account socio-structural barriers and the multiple identities of disabled people. Islam noted that scholars now argue that ideas about oppression hierarchies should be abandoned, as well as notions that focus on unitary identities such as ‘disabled’, even though disabled people may share common material realities. Disabled people are of different ages, races, religions, sexual orientations, and classes, and each person does not “share one single reality”. Islam explored multiple aspects of difference and diversity in young Pakistani and Bangladeshi disabled people’s lives, and found that there was not a common disabled identity. His participants also maintained a hierarchy of impairment and differentiated themselves from others according to impairment subtypes. They also identified their ethnicity and religion differently in different contexts. For example, the participating South Asian girls wore their traditional headscarfs at home but not in public. Identity for these young people was a dynamic process and not fixed.

Ostrander (2008) stated that individuals who have multiple identities shape a cohesive identity by attending within the context of their particular socio-economic status to each of their multiple identities, and to the intersection and interaction of their identities. Ostrander qualitatively explored the identities of males of racial minorities (African-American or Latino) in the United States who had violently acquired a spinal cord injury. Their impairment caused them to renegotiate, because of their loss of complete independence, their notions of masculinity, but they were firmly grounded in their racial identity.

Diversity, visibility, inclusion and normality

Cruz (2007), when describing a diversity training programme for professionals in Victoria, Australia, argued that diversity and the complexity of the population was becoming a significant issue in the delivery of education services. She defined diversity as encapsulating 'difference' and 'identity', and noted that the literature has formally recognised identity categories of race, ethnicity, religion, gender, age, social class, sexual orientation and disability. However, she pointed out that scholars argue that identities go beyond fixed categories and are always contested, fluid, fragmentary, and that notions of diversity encapsulates identity and difference. Diversity looks at how identity is formed through the notions of 'self' and 'other' and is generated in and by the relationship between the self and 'the other'. Some theorists associate identity construction with rapid social change, dominant discourses, and images of normality (Hall (1996) and Roseneil & Seymour (1999) as cited in Cruz, 2007). Cruz wrote that four principles flow from assumptions about diversity:

First, 'diversity' is more than cultural or ethnic difference. Second, each of us embodies and represents difference. Third, 'identities' are multiple and include age, gender, race, ethnicity, culture, sexual orientation, disability and social class, and different histories and biographies. Fourth, diversity is valued in relation to complementarity rather than sameness, and that *one* can be different *and* equal.

Of further interest is Cruz's discussion about identity, visibility and bodies. She stated that visible aspects of bodies may signify certain identities (e.g. wrinkles and old age, some impairments). There are also social categories of identity that are additionally marked by bodily adornments (e.g. social class and jewellery), and that some identities are made invisible (e.g. mother, father, sexual orientation). Cruz also noted that some individuals may purposely visibly alter the bodies or add markers to have a more valued identity (e.g. women who dress as men), and that some identities may remain invisible in various ways (e.g. lesbians may not feel safe to 'come out' in some contexts). However, she pointed out that exploring levels of visibility and labels may help to challenge privilege, power, and marginalisation.

Invisibility or 'misrecognition', which Fraser (1995) described as being made invisible through dominant communicative, representational, and interpretive practices, can also impair a positive identity. It can prevent the full participation of individuals, and is disrespectful and oppressive (Fraser, 1995). Fraser (1995) argued that notions of difference and normality needed to be destabilised and transformed in ways that change everyone's notion of self. Through visibility in the arts, disabled people are challenging the representation of disabled people as 'other' (Kuppers, 2003, Swain & Cameron, 2002), and "inserting the sliver of difference into the safe spaces of 'normality'" (Kuppers, 2003, p. 6)

For example, Ferri (2008) documented a counter narrative to impairment as misfortune or loss in Lynn Manning's performance and poetry in *Weights*. Lynn Manning was an African-American man who was blinded through a shooting. His narrative spoke about being happy to be alive without grieving about his blindness. This shocked the professionals around him, who make no attempts to understand his perspective. He encountered a confused public as well who helped him when he didn't need help and who had preconceived notions of disability that have nothing to "do with what he (was) experiencing." (p. 502). In his performance and poetry, Manning illustrated how he was rarely seen as a black man and a blind man at the same time. Black men were seen as gang members, pimps, or basketball stars whereas blind men were seen as pitiful, burdens, or saintly. Manning was able to thus switch his identities with a "flick of his wrists". He wrote:

Quick-change artist extraordinaire,
I whip out my folded cane
And change from black man to blind man
With a flick of my wrist (Ferri, p. 503)

Manning could not occupy the space of both a blind and a black man because of the oppressive and contradictory images that existed about them. However, he did find intersections that blended his identities. For example, he recalled how he had 'natural rhythm' and thus had confidence that he would be able to figure out how to look cocky and cool when using his white cane. Through his performance art Manning brought to the fore his lived experiences and in the telling of these experiences refused to be limited to prescribed positions or identities.

On the other hand, Carpenter and Austin (2008) in Australia found that mothers of children with ADHD needed to overemphasise a prescribed 'deficit' identity for their child, and emphasise that their child was 'different' in order to fit into prescribed funding resource categories because educational support and 'special education' is determined within a deficit and medical model of disability. In addition, once the family has received support services, the mother and child encounter 'educational disablement' because of devaluing, exclusion and their invisibility in social interactions (Carpenter & Austin, 2008). Carpenter and Austin (2009) noted that those mothers and children who do not get recognised as needing support are also silenced, become invisible, and thus are excluded from the culture and social life of their schools.

In India, Singh and Ghai (2009) studied fourteen disabled children's lived experiences and their negotiation of identity and difference. They pointed out that the children considered being disabled as opposite to being 'normal'. Disability in the Hindu Indian context is understood as a retribution for past sins or karma; as part of God's will with consideration of other factors such as poverty; and signifies flaws. However, within Hindu mythology there are narratives that place disabled people as children of God with the ability to transcend the body to knowledge, and thus disabled people are able to overcome oppression. The children in Singh and Ghai's study thought that their impairment was God's will and a result of past sins, but they also considered themselves to be 'normal' and demonstrated this by drawing themselves without impairments, describing themselves as not different to normal children, negotiating meaning about disability by creating a hierarchy of impairment, and remaining invisible when possible. However, their narratives also challenged the dominant 'deficiency' discourse, because they identified that they were participating and achieving as other children in regular schools, and had the same aspirations for their lives. In their narratives, overall,

they minimised their differences and described ‘every day lives’, and they were able to claim space and power to disrupt notions of normality.

Petrou, Angelides, and Leigh (2009) in their deconstruction of ‘difference’ argued that difference will always be present in humans, society and in schools, and that usually differences are feared and dreaded. Feelings of superiority and inferiority exist in the meanings of difference. In schools, children are officially or unofficially marginalised because of their differences. Petrou et al. pointed out that children are officially marginalised when they are placed in an identifiable category, such as ‘special’, or when they are educated in separate settings away from their peers for even small lengths of time. They are unofficially marginalised when their social behaviours don’t fit, or are incompatible with, the dominant culture, such as when they speak another language. In order to cope with difference, some schools assimilate and homogenise their students and do not take into account difference. However, this tack reduces the school’s ability to learn and progress in a social environment where the presence of others helps to define the self and a consciousness of collective difference. It also does not enable creativity and new possibilities for the future. Petrou et al argued that inclusive education is a way to expand the margins of normal and difference. They stated that inclusive education is a

movement against all kinds of exclusion, including school exclusion, and reaction against the practice of political segregation and social inequality. The emphasis ... is on the needs and the rights of humans, including that of education, to be based on the acceptance of all differences and the support of each otherness. (Petrou et al, 2009, p. 446)

Given globalisation, the marketisation of education, and the presence of children of diverse cultures and with impairments, scholars have stated that the next big challenge for schools and professionals is to teach for diversity (Ainscow, 2008; Barton, 1997). In addition, Barton (1997) argued that educational contexts need to be identified and deeply understood as political, because when multiple discourses and power relationships within the system exist then it is important to understand who is allowed to speak, where, when, and with what type of authority. Also, it is important to understand and deconstruct the connections between policy and practice. Barton pointed out that ‘special’ education has drawn boundaries and maintained a culture of exclusion or ‘othering’. Also, certain types of schooling create more social divisions, and there are some schools that wish to ‘get rid’ of some types of students because they need to compete for students to their school for funding. In such a marketised system, disabled students are not an attractive way to market their school as a high achieving, high status, and highly desirable school for parents. Such exclusionary ideologies and practices are not rooted in social justice, democratic participation, or equity. Barton saw inclusion and an inclusive society as one which is based on a future where all forms of social oppression are removed.

Within New Zealand, the Ministry of Education (2009b) uses a definition of inclusion which is wide reaching and focuses on children attending their local school, participating in their culture, and reducing barriers. It defines inclusion as

about valuing all students and staff. It involves supporting all children and young people to participate in the cultures, curricula and communities of their local school. Barriers to learning and participation for all children, irrespective of their

ethnicity, culture, disability or any other factor, are actively reduced, so that children feel a sense of belonging and community in their educational context. (<http://www.minedu.govt.nz/NZEducation/EducationPolicies/SpecialEducation/ServicesAndFunding/TermsUsedInSpecialAndGeneralEducation.aspx>)

However, within New Zealand's education system itself, inclusive education is not emphasised, and there are contradictory and confusing discourses, rhetoric and policy statements in existence (Higgins, MacArthur, & Morton, 2008). For example, the Ministry stated that the aim of its '*Special Education Guidelines* (emphasis added) is "to achieve a world class inclusive education system that provides learning opportunities of equal quality to all children and school students" (Ministry of Education, 2009). However, a search of its website in December 2009, revealed that there were no inclusive education policies, nor any inclusion policies. In addition, there were 173 hits for the terms, 'special' education policy, and the aim of the Ministry's 'Special' Education Policy (Ministry of Education, 2009a) was not about attending local schools, reducing barriers, and a "world class inclusive education system" but about learning outcomes and school choice. Its policy statement said:

The aim of the Government's special education policy is to improve learning outcomes for all children and young people with special education needs at their local school, early childhood centre, *or wherever they are educated.* (emphasis added) (<http://www.minedu.govt.nz/NZEducation/EducationPolicies/SpecialEducation/PolicyAndStrategy/SpecialEducationPolicy.aspx>.)

Collaboration or Competition

Barton (1997) challenged researchers to explore, deconstruct, and further understand the societal discourse, context and societal systems that disabled people encounter in their lives, so that we can learn from our mistakes and the vision of an inclusive society can be realised. Adults in schools have also been challenged to advocate for inclusion, to encourage a collaborative culture, to use teaching and learning evidence, and to reflect about and beyond existing practice, because change cannot occur for all students unless adults' behaviours change (Ainscow, 2008; Nevin, Harris, & Correa, 2001).

In her review of the literature and research about collaborative relationships for disabled children from diverse cultures, Harry (2008) found that the main barriers to achieving a collaborative culture were deficit notions of families who were culturally and linguistically diverse. There were differences and misunderstandings about the meaning of disability, different views about the important goals for the children, and different views about the caregiver's role. Professionals in various research projects who exhibited ordinary human decency and commonsense successfully formed positive partnerships with families. However, Harry noted that both 'common sense' and 'human decency' could represent the ruling discourses, beliefs, and ideologies, and not allow for diversity. Professionals could thus be blind to their own cultural lens when working with families, and could be unconsciously limiting the progress of children from marginalised groups.

Further to this, Harry cited a number of studies that found that professionals and educators consistently made decisions based on racial stereotypes and generalisations. Also, the parent's marital status, socioeconomic level, and education levels influenced the

professionals' and educators' deficit view of the family and child. Harry thus called for preservice teacher and professional training programmes to be revised to include multicultural issues and history, personal values in regards to diversity, critical analysis about why disabled children of diverse culture are in 'special' education, practice in communication with families of diverse cultures, and placements in diverse socioeconomic and racial settings. Unfortunately, Trent, Kea, and Oh (2008) pointed out in their study of 'special' education teacher programmes that recommendations such as these have been made for the past twenty years and yet little progress has been made to implement them.

Like others (Ainscow, 2009; Barton, 1997; Davis, Watson, Corker, & Shakespeare, 2003; Oliver, 1988; Tomlinson, 1996) Connor and Ferri (2007) argued that present notions of 'special education' are deeply rooted in the deficit and medical model of disability and argued that such paradoxes within 'special' education services, which claim to be supporting inclusive education in mainstream schools, actually prevent inclusion. The 'special' education sector has been challenged about its growth and legitimacy, because usually being 'special' or 'disabled' means being marginalised, segregated and excluded at school. They noted that inclusion, while appearing to be a simple concept, remained contentious because it actually means that the 'special' education system needs to be dismantled, and the education system, as a whole, needs to be overhauled. Inclusion is based on the belief that each individual belongs and is valued. When parents choose a 'special' education placement for their child, according to Connor and Ferri, it is because they are not wanted at their regular schools, there is limited funding and supports for inclusion, and that it is a safe haven away from an unwelcoming and a merciless education system. They noted that within the 'special' education system, that certain groups are overrepresented, including boys and those of colour, of ethnic minorities, and of lower socio-economic groups. For example, in America, African-American children remain three times more likely to be labelled intellectually disabled, two times more likely to be labelled as emotionally disabled, and one and half times more likely to be labelled as learning disabled.

Also, of interest is that Connor and Ferri (2007) wrote that special education is seen as a way to remove students who disrupt the peace or status quo of the regular classroom or school. It is seen as a bureaucratic labyrinth that has low expectations of their students, and a place where students can fall through the cracks. They noted that choice for inclusion is not available because there are few schools that are actually fully inclusive and have sufficient access to competent professional support. Further to this, there are thus no two (let alone one) equally viable and compelling inclusive placement options from which to choose. Higgins, MacArthur and Morton (2008) noted that in New Zealand where placement choice is emphasised, this is a Hobson's choice. In New Zealand, education policy emphasises school choice because of its neo-liberal economic ideology that sees education as a private commodity (Higgins, MacArthur, & Morton, 2008; Morphis, 2009). Parents enter an educational market place where choice of schools (or products) is emphasised, and thus competition between schools for students is also emphasised. Morphis (2009) pointed out all children have a right to enrol in New Zealand's state schools. However, this had not prevented principals from denying access to schools by encouraging parents of disabled children to send their child elsewhere. Morphis stated that it cost more to educate a disabled child in regular schools, and so many schools in New Zealand may not wish to spend their scarce resources in this way and be inclusive.

Wylie (1999) wrote that New Zealand supported a quasi-voucher system of education in New Zealand because it funded schools based on their roll, because schools were self-governing,

and because zoning was not necessary for school enrolment schemes at the time. The government had become the purchaser of education as opposed to the provider, and there was a blurring between public and private schools. She noted that research has shown that quasi-voucher systems of schooling, which were based on school-autonomy and parent choice, consistently showed that they were ineffective in reducing the socio-economic disparities in regards to students' achievement and they actually reduced diversity in schools. Since then, New Zealand has tightened up its zoning regulations (LaRocque, 2005). However, in the recently released long-term fiscal strategy from Treasury in regards to education, it appears that there will be a strengthening of policies for school choice. It stated that there should be greater student mobility between education 'providers'. It also indicated that there needs to be more blurring between private and public schools, and said that one funding strategy for the future was

to reduce the quantity of publicly-funded education services – by shifting more of the cost of education services from the government to individual students and families ... (New Zealand Treasury, 2009).

On the other hand, researchers and scholars from every major university within New Zealand have called for educational policies and funding regimes that strengthen New Zealand's ability to provide services for diversity and inclusion (Ballard, 2004; Bevan-Brown, 2006; Higgins et al, 2008; Kearney & Kane, 2006; MacArthur Sharp, Kelly & Gaffney, 2007; Morton & Gordon, 2006; Wills, 2006). Disley (2009), the former Director of Group Special Education within the Ministry of Education believed that present funding mechanisms are fragmented and actually encourage the aggregation of students into special schools instead of supporting students in regular classrooms through itinerant educators with expertise. She noted that change would be required at every level of the education system so that every child can be valued and so that difference and diversity can be embraced.

Indigenous people and indigenous people with disabilities: Service access, success, and self-determination

Researchers have noted that the impact of multiple oppression on the lived experience of those from diverse cultures and with diverse abilities needs to be researched and recognised so that culturally competent services can be delivered and so that people who experience disablism and racism can have positive and inclusive educational and rehabilitation experiences. (Johnson & Morjaria-Keval, 2007; Miles, 2002; Simpson & Cameron, 2004). Hall and Bishop (2001) argued that cultural diversity alone poses a challenge for professionals because it raises questions about the ethical obligations that they have with regard to catering for cultural difference. The notion of cultural diversity, they continue, presents two major challenges for education professionals: the first in relation to understanding, addressing and developing the cultural identities of children, the second in acknowledging and understanding the impact their own cultural identities has on their students. Schools are a major site in which all children's perceptions about their ability and identity are developed, and to that end education professionals play a significant role in shaping the way their students see themselves and how and where they fit into the world. When students are consistently treated as less, whether because of their disability, culture or other reason, then their sense of identity is in danger of being negatively influenced and their ability to become self-determining individuals is threatened (Caran, 2008; Hall & Bishop,

2001). Hall and Bishop thus argued that to become autonomous and self-determining, a sense of authenticity – of being able to live life true to oneself – is necessary.

Berryman (2008), in her doctoral research, found that the research literature had told her that the research and educational agenda in New Zealand has continued to support colonial values that marginalise Māori knowledge, and thus has pathologised Māori, who are viewed as deficient. For example, she noted that the educational practice of focusing on individual needs that have been identified by outside experts “flies in the face” (p. 279) of Māori values of collaboration, collectivity, and accountability of the community. Māori value instead an educational focus on all people who are in the learning environment, and who can work together to address the problems that an individual is experiencing.

In Canada, Timpson’s (1995) literature review about child welfare services traced over time issues that have led towards an accelerated movement towards indigenous control over welfare services. She argued that child welfare indicators of Native Canadian children reflected generations of spiritual and cultural destruction that affected communities, and focus needed to move away from individuals and to relationships within communities. For example, the Water First Nation in Manitoba has a community-based treatment programme for sexual offenders that uses community healing circles when sentencing. Similarly, Pichette, Garrett, Kosciulek, and Rosenthal (1999) pointed out that American Indians see disability as primarily about relationships, and that all relationships involve sharing and giving to one another. A disability can thus be seen as occurring because of an individual’s or a family’s weak relationships within the tribal community.

In the Northwest Territories in Canada, Chisholm (1994) wrote about Canada’s history of aboriginal education of the Inuit Indians. Up until the 1960s, Inuit Indian children were expected to assimilate into the dominant European white culture through their placement in residential schools; to conform to institutional life; and to only speak English. When they returned home, they had lost their spirit and culture. Their separation from their community and family continued because their community had become a foreign place. Miller (1996), in his history discussion of residential schools for native children in Canada, described the psychological, physical and sexual abuse at these schools, and argued that the government was enacting education policies of forced assimilation and cultural genocide.

Chisholm (1994) wrote that assimilation is still at the heart of Canada’s formal regular school system where Inuit Indian children are immersed in English speaking schools and learn about a world view and a curriculum from the Euro-white Canadian middle class. Also, in isolated rural communities in the Canada’s North, boarding schools for secondary students are a reality, but these schools are still entrenched in the Euro-white culture. Chisholm argued that such schools needed to ensure that their students have consistent access to support, and to qualified aboriginal teachers and residential staff. She also pointed out that despite these difficulties, there have been some innovative improvements in the Northwest Territories in primary schools. Local communities have been given input into curriculum design and other relevant educational decisions through a 1982 policy, which required the teaching of the curriculum as well as the preservation of the northern aboriginal culture. The federal government in Canada has also adopted a devolution policy to politically empower the Northwest Territories at a local level, which supports and leads to aboriginal self-government. Chisholm concluded that the challenge for aboriginal people through self-determination is to effect change in a system that has brought misery to them, to preserve traditional knowledge, and to heal their cultural identity.

In America, providing health and rehabilitation services to American Indians on the reservations is a complicated multi-government department system, which includes the Bureau of Indian Affairs, Indian Health Service and various tribal and non-tribal agencies, and Americans with disabilities were reluctant to access services from the government agencies (Pichette, Berven, Menz, & La Fromboise, 1997). Pichette, Garrett, Kosiulek, and Rosenthal (1999) wrote that American Indian people resist talking to non-Indians about personal matters, and that healing and rehabilitation cannot be separated from American Indian's sacred narratives, spirit and culture. Also, American Indians may view what has gone awry as natural and not needing to be fixed or changed. They instead seek acceptance, solace, and understanding within their own cultural framework. However, some also seek healing and rehabilitation from the Western culture when they have a positive acceptance and understanding of both the American Indian and the mainstream Western culture.

However, Xuequin Ma, Coyle, Wares and Cornell (1999) have found that health and social services, in general, for American Indians are scarce, despite American Indians being over-represented in disability statistics and being a targeted group for services and funding. Somehow, policy does not turn into practice or funding, and many American Indians with disabilities are under-serviced or unserved. In Xuequin et al's survey of services in 15 states, administrative difficulties, lack of resources, and community awareness were identified as general barriers to service access. Other barriers to access included a lack of well-trained professionals, culturally competent professionals, physical and occupational therapists, and transportation (public and private).

In New Zealand, Māori have been documented to have difficulty accessing Health Services (Ellison-Loschmann & Pearce, 2006). Ellison-Loschmann and Pearce (2006) wrote that there have always been significant health disparities between Māori and non-Māori, and that, today, a significant proportion of the greater mortality rate for Māori comes from diseases for which health care services are available. They noted that referrals of Māori to specialist and surgical care are less likely than non-Māori, that Māori receive lower than expected hospital care than non-Māori, and that cost of services may be a factor. Other factors for the disparity included socio-economic factors, lifestyle factors, and discrimination. However, Ellison-Loschmann and Pearce noted that there have been self-determination initiatives that have been introduced in New Zealand, and that these are based on two beliefs. Firstly, Māori cultural processes need to be used in the delivery of health services, and, secondly, that provider organisations need to be controlled by Māori and be self-sufficient. Also, in parallel with the development of, and increase in, Māori service providers, there are other initiatives that may prove to be effective, such as the introduction of cultural awareness education, which focuses on social justice, racism, self-knowledge and understanding.

Similarly, in the education system, Kalyanpur, Harry and Skrtic (2000) argued that professionals in special education needed to be aware of the cultural assumptions within their field in order to work in a consultative, balanced and effective manner with families of different cultures. They noted that despite policies in America, professionals failed to include culturally diverse families in family centered practices, and pointed out that the values of equity, individual rights, and freedom of choice which underpin such policies may not fit with actual practice where the expert is in a hierarchical position above the family; where individual duties, and communal responsibility are central; and where there is limited freedom of choice because of socio-economic or other circumstances. For example, they noted that professionals did not understand a Hmong family's resistance to not have surgical

intervention on their son's clubfeet, which were seen as a sign of good luck that would help release the spirit of a warrior ancestor. Intervention would be seen to affect the spiritual well-being of the whole Hmong community. Professionals need to thus engage in critical pragmatism and reciprocity. Families and practitioners need to collaborate together in order to identify their different approaches and perspectives about decision-making, and the practitioner needs to examine the assumptions, meta-theories, and theories behind their practice and profession.

Māori with a disability and whānau

Researchers here in New Zealand have shown that health and education services that are delivered to disabled Māori, in either an appropriate or inappropriate manner, impact directly upon the health and identity of disabled Māori and their whānau (Bevan Brown, 1989; Collins & Hickey, 2006; Health Research Council, 2006). Cram, Smith, & Johnstone's (2003) qualitative study about how Māori talked about health argued that there is a challenge for Pākehā providers to remain mindful that they may think of health differently from their Māori clients, who may have a holistic approach to health that emphasises wairua. Wairua is translated as 'spirit' but is linked with Māori people's relationship to the environment and religious beliefs (Cram et al, 2003). Whānau was noted to be the basic support structure for health and well being, and marae based healthcare delivery was seen as positive. Also, good communication and rapport with health professionals were seen as vital so that, for example, whakamaa would not become a barrier to health care services. In their conclusion, Cram et al (2003) argued that the root cause of disrupted wairua, or health, is the colonisation process which separated Māori from their land, and that the burden for this should not only be on health care providers, but on government policy makers as a whole. However, a holistic outlook on health would require practitioners to also think about the individual's whānau and community circumstances that may be having an impact, e.g. poverty, industrialisation and non-land-based means of production.

The two health strategies that have specific relevance to this study and to kāpo Māori are the *He Korowai Oranga* and the *Disability Strategy*. In 2002 *He Korowai Oranga* (2002) the government's Māori Health Strategy was launched. According to the then Minister of Health, Annette King, and Associate Health Minister, Tariana Turia, it added Māori principles and objectives to the *NZ Health Strategy* and the *NZ Disability Strategy*. Moreover, *He Korowai Oranga* takes these documents further by providing more detail about how Māori health goals will be achieved. The focus and aim of the strategy is whānau ora, or family well-being, in which the whānau is recognised as being Māori society's foundation and a "principal source of strength, support, security and identity" (King, 2002, p. 1). Whānau is central to "the well-being of Māori individually and collectively" (King, 2002, p. 1).

Within this strategy, Māori and Crown aspirations and contributions articulate the roles and responsibilities of each partner. Importantly, in this structure Māori are encouraged to have more control over their health and well-being and then to determine their own aspirations and priorities. The Crown is charged with ensuring that there are no barriers to Māori control and aspirations. Three themes are identified that are woven throughout the strategy. Rangatiratanga acknowledges Māori control over Māori health and disability futures, at the same time as acknowledgement is given to the gains that have been made. There is also a focus on reducing health and disability disparities. Four pathways for action are then outlined. They include the development of whānau, hapū, iwi and Māori communities, Māori

participation, the creation of effective health and disability services and the importance of working across sectors to achieve whānau ora. One of the specific objectives of the strategy is increasing Māori provider capacity and capability to ensure that effective services are available to Māori.

The aim of the *Disability Strategy* is to eliminate the barriers that disabled people encounter as they try to reach their potential and fully participate in their community. This aim is also linked to the human rights of disabled people within the *Strategy*. There are fifteen objectives within the *Strategy* and each year, each government department is required to report on how it has progressed the *Strategy*. Its fifteen objectives include:

1. Encourage and educate for a non-disabling society
2. Ensure rights for disabled people
3. Provide the best education for disabled people
4. Provide opportunities in employment and economic development for disabled people
5. Foster leadership by disabled people
6. Foster an aware and responsive public service
7. Create long-term support systems centred on the individual
8. Support quality living in the community for disabled people
9. Support lifestyle choices, recreation and culture for disabled people
10. Collect and use relevant information about disabled people and disability issues
11. Promote participation of disabled Māori
12. Promote participation of disabled Pacific Peoples
13. Enable disabled children and youth to lead full and active lives
14. Promote participation of disabled women in order to improve their quality of life
15. Value families, whānau and people providing ongoing support (Minister of Disability Issues, 2001, p. 2)

According to the *Strategy*, achieving a vision of an inclusive society also involved “recognizing the principles of the Treaty of Waitangi.” (p. 1). However, the *Strategy* does not offer suggestions about how these principles can be enacted. In fact, the *Strategy*, itself, is relatively silent in regards to the needs of Māori with a disability, except for Objective #11, which is discussed below, and it is not stated how the other 14 objectives and actions are significant for Māori, if at all. For example, Objective 7 states that long-term support systems need to be centred on the individual, but Māori emphasise whānau and the collective in service delivery. A further analysis of each of the objectives may be necessary, and, in fact, some Māori with a disability have advocated for the development of a separate Māori Disability Strategy in accordance with the Treaty of Waitangi and as actually suggested by the present *Disability Strategy* on page v. However, such a strategy has not yet been developed, but such a development may be an appropriate way forward for Māori with a disability.

The only specific objective for Māori, Object #11 in the *Disability Strategy*, is described as promoting opportunities for Māori with a disability to participate in their communities, access disability services, and “receive an equitable level of resource that is delivered in a culturally appropriate way” (Minister of Disability Issues, 2001, p. 12). It is also acknowledged in the *Strategy* that 44% of Māori with a long-term impairment report an unmet need for assistance but only 29% of non-Māori report this. Given that the principles of the *Treaty of Waitangi* refer to partnership, protection, and participation, it is surprising that Objective 11 seems to focus only on participation. However, some of the proposed actions under Objective 11 imply

that the government will be encouraged to advocate for Māori self-determination by increasing the number of ‘by Māori for Māori’ services (Action 11. 2) and number of trained Māori professionals (Action 11.4) to “increase the advisory capacity of Māori” (p. 25). However, in regards to Māori forming a partnership in regards to decisions that are made about them or services for them within mainstream services, the *Strategy* only stated that these services will be “culturally appropriate” (p. 24). Action 11.3 of the *Disability Strategy* (Minister for Disability Issues, 2001) stated that government departments will work towards ensuring that “mainstream providers of disability services are accessible to and culturally appropriate for disabled Māori and their families” (p. 25) as part of meeting Objective 11 to promote the participation of disabled Māori in New Zealand.

In education, the Ministry of Education’s *Group Special Education (GSE) Māori Strategy* (Ministry of Education, 2008b) is underpinned by the *Disability Strategy* and the Treaty of Waitangi. It “provides a framework for delivering services to Māori in ways that are both culturally appropriate and empowering for Māori clients” (Ministry of Education, 2008b). Its vision is described below:

Kotahi te kohao o te ngira	There is but one eye of the needle
E kuhuna ai	Through which travels
Te miro mā	The white thread
Te miro pango	The black thread
Te miro whero	The red thread

Through this vision, GSE stated that it will take multiple pathways to achieve its goals. The strategy focuses on three achievement areas. Firstly, it stated that GSE staff and staff can be ‘upskilled’ in te reo Māori, tikanga, and appropriate practice. Secondly, a framework for responsiveness to Māori will be developed and implemented. Finally, it will ensure that outcomes “from its behaviour services are optimal.” GSE has only identified one step to achieve these aims and that is to hold a stocktake of its existing Māori programmes. It is hoped that this stocktake will highlight achievement areas that are being met and the gaps that need to be considered for the future. Thus, GSE seems to have only just begun its journey to develop staff and services that are responsive to Māori (Ministry of Education, 2008b).

Human rights and kāpo Māori

All New Zealanders have a set of basic human rights that include the right to be treated equally and the right to be treated with dignity. These rights are upheld within domestic legislation as well as by the instruments of international conventions and declarations. All people irrespective of their ethnicity, gender, disability or socio-economic status have the right to equal access to the goods of society such as education and health. As citizens of New Zealand, kāpo Māori should, without question, enjoy these same rights. More specifically, some of the rights legislation and documents that have relevance to this study include the *1990 Bill of Rights* and the *Human Rights Act 1993*. The *1990 Bill of Rights* contained a set of basic rights for all New Zealanders that affirms, protects and promotes human rights and freedoms (Ministry of Justice, 2004). It is the “mechanism by which the governments [of New Zealand] are made more accountable by being held to a set of standards” (Ministry of Justice, 2004). Thus all legislation must conform to the *Bill of Rights* and importantly non-

government bodies equally come under scrutiny with respect to their public functions in ensuring human rights and freedom from discrimination.

Within the *Bill of Rights*, the sections most relevant to this research and kāpo Māori are Sections 19 and 20. Section 19 stated that everyone has the right to freedom from discrimination, but that, more importantly, it also stated that measures taken to overcome social, cultural or economic disadvantage are not discriminatory under the law. One example of this is providing scholarships for Māori tertiary students. When Māori enrolment numbers reach parity with non-Māori, such a measure ceases to be lawful and therefore should be discontinued.

Section 20 of the *1990 Bill of Rights* stated that

Rights of Minorities: A person who belongs to an ethnic, religious, or linguistic minority in New Zealand shall not be denied the right, in community with other members of that minority, to enjoy the culture, to profess and practise the religion, or to use the language, of that minority. (Human Rights Commission, 2008).

According to the Ministry of Justice (2004) the rights of minority groups are distinct from and additional to all other rights held in common by all New Zealanders. However, the *Bill* did not define the term, 'minority'. In the absence of a definition, the United Nations' definition has been used. According to the *United Nations International Covenant on Civil and Political Rights*, a minority is:

... a group numerically inferior to the rest of the population of a state, in a non-dominant position, whose members ... possess ethnic, religious, or linguistic characteristics differing from those of the population, and show, if only implicitly, a sense of solidarity, directed towards preserving their culture, traditions, religion or language. (Article 27) (United Nations, 1976).

Similarly the notion of culture is not explored in the *1990 Bill of Rights*. Thus, the United Nations Human Rights Committee definition is used (Ministry of Justice, 2004). This definition acknowledges that culture manifests itself in many different ways and implies that it may be associated with land and its resources through traditions, especially when it comes to indigenous people. This has implications for Māori in that the state has an obligation to ensure the survival and continued development of culture, language and religion. The *1990 Bill of Rights* overlaps with the *Treaty of Waitangi*. Also, the contents of Article II in the *Treaty* and Section 20 (above) have common aspirations in that they both protect Māori culture, religious practices and language. The important point to remember here is that, according to Rishworth (2003), the *Treaty* has no legal teeth whereas the *1990 Bill of Rights* does.

The *Human Rights Act 1993* is made up of seven parts and contains a set of rights that protect people against discrimination in accordance with United Nations' conventions and covenants. It outlines a range of measures to protect people's rights and, where discrimination exists, measures to overcome them. In 2001, the Act was amended creating new commissioners, such as the Equal Opportunities Commissioner, while merging the Race Relations Office and the Human Rights Commission. Government, government agencies, non-government agencies or anyone who performs a public function are held accountable for the services they

provide within this Act. Within the *Human Rights Act*, while providing for the rights of Māori and disabled persons, the exemptions within it diminished those same rights when it comes to goods and services, employment, housing and, especially, education. It provided ‘an out’ for educational establishments or schools so that they do not need to enrol disabled students if a school cannot reasonably make accommodations for them. It said:

60: Further exceptions in relation to disability

(1) *Nothing in section 57 of this Act makes it unlawful to refuse admission to an educational establishment to a person whose disability is such that that person requires special services or facilities that in the circumstances cannot reasonably be made available (being services or facilities that are required to enable the person to participate in the educational programme of that establishment or to enable the person to derive substantial benefits from that programme).* (New Zealand Government, 1993, unpaginated)

McGurk (2009) noted that there has been a sharp increase in complaints to the Human Rights Commission on behalf of disabled students, and that these complaints fell into four categories, including:

- Schools not wanting to enrol children at all or only for limited hours;
- Children stood down, suspended or expelled because of disability or behaviour caused by disability;
- Lack of funding or lack of special assistance required to fully access the curriculum;
- Exclusion from participation in wider school activities such as school camps and other activities. (McGurk, 2009, p. 1-2)

These issues have resulted in a recent class complaint to the Human Rights Commission that has been filed by IHC under Part 1 A of the *Human Rights Act 1993*. The complaint focuses on the Ministry of Education’s responsibility to provide equal learning opportunities to disabled students when they are enrolled in regular schools. It states that the government is discriminating against disabled students as a whole and has breached Section 19 of the *1990 Bill of Rights*. Of equal concern is that the Act does not attend to discrimination with regard to access to, and outcomes of, health services, diagnosis and therapies (McGurk, 2009).

Internationally, the United Nations has, since its inception, developed a range of measures that promote, support, and legally enforce a complex web of human rights.

There are two types of UN documents: conventions and declarations. The intent of conventions, which are sometimes called treaties, is that they are legally binding documents for those countries that ratify them. Once a country has ratified a convention, they are required to write them into their own legislative framework, if that hasn’t been done already, and develop their own measures to fulfil the rights contained within the convention. They are then obligated to report back to the United Nations on their progress. The two most relevant conventions for kāpo Māori include the *Convention of the Rights of Persons with Disabilities*, the *Declaration of the Rights of Indigenous People*, and the *Convention on the Rights of the Child*. The *Convention on the Rights of Persons with Disabilities* and the *Convention on the Rights of the Child* have been ratified by the New Zealand Government, while the *Rights of Indigenous People* has not. Current indications suggest that there are major difficulties with a number of its clauses, which are stumbling blocks to ratification.

The *Convention on the Rights of Persons with Disabilities* is an international instrument to safeguard the rights of those with disabilities. Up until its development and ratification, there was no international treaty that addressed the concerns, issues and rights of disabled persons. The purpose of the *Convention* is to promote and protect the rights and fundamental freedoms, as well as the inherent dignity of all disabled people. It does this by articulating the rights of disabled persons and setting out measures for implementation. Overall, the *Convention* promotes the development of inclusive societies as well.

The key principles of the convention include:

- Respect for inherent dignity, autonomy and independence
 - Non-discrimination
 - Full and effective participation in society
 - Respect for difference, and acceptance of diversity and humanity
 - Equality of opportunity and outcomes
 - Access
 - Equality between men and women
 - Respect for evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.
- (United Nations, 2008, unpaginated)

These principles guide the substantive content and measures outlined in the *Convention on the Rights of Persons with Disabilities*. Within the context of this study, the relevant Articles include Article 23, which states that countries should ensure that disabled children have equal rights and that they shall not be separated from their parents. Where a child cannot be cared for by his or her parents, every effort shall be made to provide alternative care within the wider family and failing that within a family like setting in the community.

Also, in regard to education, Article 24 makes the case for an inclusive education for disabled children. Specifically disabled children should be able to access an “inclusive education system at all levels” (United Nations, 2008, Article 24.1). Accommodation of a student’s impairments should be made and the young person should receive appropriate support, when required, so that their education maximises their academic and social development, which is, in turn, consistent with the goal of full inclusion and participation. Appropriate modes of communication should be available to students to ensure their academic and social development. In particular, blind students should have access to “learning Braille, alternative script, augmentive and alternative modes, means and formats of communication and orientation and mobility skills, and facilitate peer support and mentoring” (United Nations, Article 24.3.a). Importantly, states should take appropriate measures to employ teachers who are qualified in Braille and other language modes. Moreover, measures should be made to train appropriate professionals to facilitate an inclusive and equal education.

As with education, the focus of the obligations of countries in regards to health within this *Convention* is about equality of access to health in order to enjoy a high standard of health without discrimination. Countries have an obligation as expressed in Article 25 to provide the same range, quality and standard of free or affordable health care and programmes. Where needed, health services specific to the impairment should be provided. These services should include early identification and intervention, and be thus designed to minimise and prevent further impairment. A critical element of the obligation is that such services should be within the communities where disabled persons live. Health professionals, therefore, need

appropriate and high quality training so that they can work to a high ethical standard in both private and public health provision. Article 26 outlines the specific habilitation and rehabilitation measures for independence, inclusion and participation in all aspects of life.

In regards to blindness and vision impairment, Thompson and Kaufman (2003) in the USA have pointed out that an early in-depth diagnosis can lead to appropriate medical treatment, vision aids or surgery, as well as the prevention of educational and developmental difficulties. They stated that in some developing countries between 9-58% of childhood blindness is preventable, but that socio-economic differences within countries can limit prevention and treatment. Gilbert & Foster (2001) noted that there is an urgency about treating childhood eye disease because some conditions, after the visual system has fully developed, cannot be treated. Also, worthy of note is that overseas studies have found that an ophthalmologic patient whose eye condition affects their field of vision (as in diabetes or stationary night blindness) are three times more likely not to be registered as vision impaired, and those whose impairment is potentially reversible are eight times more likely to not be registered as having a vision impairment. Researchers have found that white children with more educated mothers, and children and people in high-income families or with medical insurance were more likely to have a diagnosed eye and vision condition (Baker, Bazargan, Bazargan-Hejazi, & Caleroacuten, 2005; Ganz, Xuan, & Hunter, 2006).

Article 30 of the *Convention* addresses the right of disabled persons to have their cultural and linguistic identity recognised and supported. While acknowledging cultural identity as being important, the focus of this Article though is on 'high' arts and culture where disabled persons should be able to enjoy access to such things as films and theatre, television, cultural performances, museums, monuments and sites of national significance. There is also a focus on disabled persons' access and participation in recreational, leisure and sporting activities. Notwithstanding that access to high culture, recreational, leisure and sporting activities are important in terms of full participation in the social and 'cultural' life of a society, a primary concern for indigenous peoples is the maintenance of their cultural and linguistic traditions. The document does not attend to the rights of indigenous persons with disabilities and the particular sets of discriminations and marginalisation that they experience. Also, of note is that a key aspect of the *Convention* is its focus on disabled individuals. For indigenous people, including Māori, such a focus on the individual ignores collective aspirations, identity and values, and Hickey (2005) argued that the perspectives of indigenous people have not been adequately considered in its development.

In the making for the past 20-odd years, the *Declaration of the Rights of Indigenous People* was finally ratified in 2007. New Zealand, along with Canada, Australia and America, has not signed it. New Zealand led a challenge to the *Declaration* arguing that it was against New Zealand's national interests because it privileges Māori by giving them rights that other New Zealanders could not enjoy (Ministry of Foreign Affairs & Trade, 2008; World Indigenous Nations Higher Education Consortium, 2007). The *Declaration* represents the views of indigenous peoples from around the world, including Māori. Its preamble provides the context for the *Declaration* by affirming that indigenous peoples are equal to all others, that discrimination is "morally condemnable and unjust" (United Nations, 2007), and that indigenous peoples have the right to be free from discrimination of any kind. The document acknowledges the historic injustices faced by indigenous communities as a result of colonial processes and the dispossession that have prevented them from development in accordance with their own interests and wishes. The right of indigenous people to self-determination, local and internal self-government, citizenship, self-governance, cultural traditions,

education, belong, and to have their own knowledge, practices and institutions upheld are in the document. Thus, whilst the New Zealand Government has not ratified the *Declaration*, it remains an important document, alongside of the *Treaty of Waitangi* in expressing Māori aspirations for self-determination.

The *United Nation's Convention on the Rights of the Child* was first endorsed by the League of Nations in 1924. In 1946, an amended version was adopted by the United Nations. The *Convention for the Rights of the Child* brings together the rights of children that are contained in other United Nations conventions, including civil, social, cultural, political, economic rights and humanitarian law. In doing so, it gives voice to, and covers more extensively, children's rights, and provides "a set of principles that fundamentally shapes the way we view children" (UNICEF, 2008).

The *Convention on the Rights of the Child (UNCROC)* came into force in 1990. New Zealand ratified the treaty in 1993 and was the 131st country to do so. The Convention requires that member states act in the best interests of the child to protect and support their rights. A child is defined as anyone under the age of 18. There are 54 Articles in the Convention that set out the rights of children and young people and spell out the measures that member states are required to undertake to implement those rights. The Articles are commonly grouped into four sets of rights, including (1) survival, (2) development, (3) protection and (4) participation. There is also a set of guiding principles. The Articles that have specific relevance to this project include those that speak about the right of children to have a decent and full life, an education, social integration, cultural and spiritual development, their indigenous language, play, and to develop to their full potential.

UNCROC strongly promotes the idea of the child in need of protection, while the articles dealing with the rights of children to have a voice are weak. Of particular concern is Article 23, which has both a strong statement about the rights of disabled children and a much weaker statement about measures to ensure those rights 'where resources are available'. Further to this, Article 23, while promoting social integration, does not attend to how this might happen. It is unclear whether *UNCROC* promotes inclusion or segregated education as both are weakly discussed in the document. Finally, there is a tension between Article 23, which states that disabled children shall have care if resources are available, and Article 24 with its statement about rights of the child to have the highest standard of health and health care. Bray and Gates (2000) argued that a focus on the rights that are outlined for all children in the document instead of on Article 24, would more effectively improve the lives of disabled children.

UNCROC, as a whole, was the ethos for the 2002 *Draft Charter of the Rights of the Māori Child* that was developed by Te Kōmako, the Māori training and support unit within Early Childhood Development Ngā Kaitiuaunaki Kōhungahunga, which is a New Zealand crown agency for the development and promotion of high quality, accessible and culturally appropriate early childhood education. Within this charter, the Māori child has the right to whakamana, kotahitanga, whanaungatanaga, and ngā hononga, which are defined below:

Whakamana: The Māori child has the right to be and feel empowered as a valued and unique individual, and as an integral member of whānau, hapū, iwi and the society of Aotearoa overall.

Kotahitanga: The Māori child is a whole person and has the right to be treated in the wholeness of intellect, spirit, and being.

Whanaungatanga: The Māori child descends from a unique culture and history based on strong genealogical links and relationships, and has the right to be respected within the full context of those links and relationships.

Ngā Hononga: The Māori child exists within a society of extensive relationships, and has the right to know, contribute positively to, and benefit from those relationships.

(Early Childhood Development Ngā Kaituaunaki Kōhungahunga, 2002, p. 5).

Kāpo Māori and the Research Literature

In regards to the examination and exploration of the actual lived experiences of disabled Māori and the impact of their interactions with health and education services in New Zealand, there are only a few studies (Bevan & Brown, 1989; Collins & Hickey, 2006; Health Research Council, 2006). In their qualitative study, Kingi and Bray (2000) attempted to identify appropriate support and services to disabled Māori and their whānau but found that most of their participants were mistrustful and cynical of the health system, and that accessing services was difficult. They also found that the whānau was integral to the provision of health services, but some participants believed that the health and disability system relied too much on whānau.

Through whānau, hapū and iwi, scholars have noted that Māori identity is shaped and established (Moeke-Pickering, 1996; Phillips, 2005). Moeke-Pickering's (1996) literature review on Māori identity within whānau found that there are two primary reference points in conceptualising Māori identity. First is tribal structures and descent. Here whakapapa provides the framework for tribal structures (whānau, hapū and iwi) in which relationships are organised and maintained. Second, are cultural practices, such as language, customs, kinship obligations and traditions, in which shared understandings are constructed and maintained. It is within these 'nests of identity' as Macfarlane (1998) called them that many Māori argue that an understanding of the concept of whānau is central to understanding the individual and central in developing Māori educational and community capacity (Durie, 1997; Macfarlane, 2003; Wilkie et al, 2001).

Nikora, Karapu, Hickey, and Te Awekotuku (2004) in their research to develop a disability support service model for Māori with a disability recommended that the household unit be the core consideration and the "nested context of interest" with the whānau being situated within the household unit. Whānau were also intermediaries between the household and the community, which included medical services. For disability support services to be effective and successful, the household units needed to be understood in terms of the people within it, the type of disability that was present, the identity (cultural, disabled, religious, and socio-economic) of the people in the household, and the social relationships within the household.

In a study of the role of whānau in the lives of Māori with a physical impairment, Collins and Hickey (2006) noted that over time the notion of whānau has been widened from that of whānau with whakapapa links to include unrelated individuals who have ongoing

interactions, and groups of individuals who gather around a specific kaupapa. In their research, they found that participants used the term whānau in its widest sense. More importantly though, they found that the strength of their participants' identity and that of their whānau was the factor that underpinned the well being of the whānau as a whole. A disruption in the identity of a few of their participants caused obstacles to the well-being of their whānau. Collins and Hickey (2006) called for further research to fill a knowledge gap about cultural well-being and the health of disabled Māori and their whānau.

Research has shown that culturally appropriate educational services foster emotional and psychological well-being, raise self-esteem, and facilitate learning. (Bevan-Brown, 2000). Gay (1994 cited in Bevan-Brown, 2003) explained that when students feel that services are alien to them or do not value who they are, then they will not be able to learn because of the stress and anxiety that accompanies their educational experience (Bevan-Brown, 2006). Macfarlane (1998, 2003, 2005) argued that the reason so many Māori fail in both mainstream and special education settings is because the links between culture and education are missing, in particular an understanding of Māori cultural practices and values.

In regards to blindness and vision impairment and self-esteem in blind children, Caran (2008) argued that it was directly related to having a positive identity. As a blind child, she took her sense of 'belongingness' to her social environment. However, she pointed out that such social experiences are not available to all blind children, and that some do not receive an education because it is thought that they cannot participate in society. Dodds (2008) and Nagel (2008) argued as well that feelings of competence and worthiness were precursors for positive self-esteem, and that access to a quality education was vital. Higgins (2001; 2004), as well as Nagel and Stobbs (2003), argued for an inclusive approach to the education for blind and vision impaired children in New Zealand where they can have a valued social place.

Also of relevance to this project is the 2004 *Circles of Light Project* in Canada that specifically explored the vision service needs of First Nations' People who were blind or vision impaired. The project's goals included the identification of (1) obstacles that prevented aboriginal people in Canada from accessing vision services, (2) service gaps, (3) the culturally specific experience of vision impairment, and (4) an appropriate service model to address the issues that were discovered. Using participatory action research with seven focus groups, which were made up of professionals and aboriginal people in Ontario, Alberta, and British Columbia, the project found that there was an urgent need to train and employ aboriginal professionals or those who possess adequate knowledge about first nation's values and culture. Also, of interest was that the project was not able to suggest a 'one size fits all' service model. However, there were overriding principles that were recommended from the project. These included culturally appropriate service delivery; individual and community control over service structure and delivery; stable and continuing long term funding; transport support; education and awareness programmes for sighted aboriginal people; and a focus on improving aboriginal people's access to vision services (Many Guns Traditional Consulting, Inc., 2004).

In New Zealand, Bevan-Brown (2000) reported on the interim results of a three-year research project evaluating New Zealand's Ministry of Education's Special Education 2000 policy. She found that Māori students were missing out on special education services and programmes because such services and programmes lacked cultural relevance and appropriateness (Massey University, 2001). She wrote that within education services there were:

- Negative and stereotypical attitudes towards Māori children, their parents and whānau;
- Low teacher expectations of Māori children;
- School personnel not recognising the importance of culture in the provision of programmes and services for Māori children;
- Principals believing culturally appropriate services need only be provided where there are a large number of Māori students; and
- School personnel blaming parents for their children's special needs. (Bevan-Brown, 2000).

In 2004, Bevan-Brown studied Māori perspectives of Autistic Spectrum-Disorders (ASD) by interviewing the whānau of nineteen children with ASD about helpful and unhelpful education services. She found that there were numerous barriers, which were experienced, and that improved culturally appropriate services would address some of these barriers. Later in 2006, Bevan-Brown noted that despite research in the area and the abundance of government guidelines and official documents about the rights of disabled Māori to receive a culturally appropriate and effective education, disabled Māori children and youth are still neglected, inadequately provided for, overlooked, and excluded (Bevan-Brown, 2006).

In regards to disabled Māori and their whānau, there is little research within New Zealand that specifically looks at their lived experiences and meaning of both disabled Māori and the experiences of health and/or education services of their whānau (Bevan Brown, 1989; Bevan Brown, 2003; Bevan Brown 2006; Higgins, 2001; Higgins, 2005; Higgins & Ballard, 2000; Phillips, 2005). However, as described above, there has been some research with the whānau of Māori with intellectual disabilities (Ballard, 1994; Bevan-Brown, 1989), physical disabilities (Collings & Hickey, 2006), and ASD (Bevan-Brown, 2004). Also, Smiler and McKee (2006) examined the negotiated identities of eight deaf Māori by exploring their education, membership in the Māori and deaf communities, their whānau relationships, their language, deaf community involvement, and aspirations. They found that deaf Māori had plural identities that were mediated through social interaction and specific social contexts. They noted that participants felt both connected and disconnected to the Māori world and to the deaf world. Within deaf education settings, which were usually Pākehā environments, they had limited opportunities to learn about Māori culture. Within mainstream educational settings, there were some opportunities but their communication needs were not taken into account. Similarly, the whānau of deaf Māori were not supported, and this resulted in poor communication, limited participation, and “an uncertain sense of Māori identity and cultural affiliation” (p. 6) for the participants. They learned about their culture, visually, but were excluded from oral information. The participants felt that there was a need to build their own unique cultural space because their Māori and deaf identities could not be separated. Some of their participants also felt that their capacity as Māori deaf to teach, support and express their culture as deaf Māori needed to be enhanced so that future generations of deaf Māori could have firmer identities.

For kāpo (blind and vision impaired) Māori, there are no such focused studies. Also, in general, the lived experiences of blind people in New Zealand has not been fully researched although there have been two history texts, one commissioned by the RNZFB (Catran & Hansen, 1992) and the other by the Association of Blind Citizens (Newbold, 1995). There have also been some notable studies that have examined the employment of blind people in New Zealand (Beatson, 1981; Newbold, 1987), a doctoral thesis about ageing and vision

impairment and life satisfaction (Good, 2005), and a Master's thesis which linked the identity of blind people to their common educational experiences in special residential schools (Small, 1998).

In regards to kāpo Māori, there are no specific studies, although there have been some publications from the initial findings of this research project (Higgins, Phillips, Cowan, & Tikao, 2009; Tikao, Higgins, Phillips, & Cowan, 2009). There are also some studies that include kāpo Māori participants or brief discussions about kāpo Māori (Gravitas Research and Strategy & Market Economics, 2006; Higgins, 2001; Tibble, 1992). An examination of a 2006 *Cost of Blindness* study (Gravitas Research and Strategy & Market Economics, 2006) indicated that kāpo Māori were not accessing health and education services. Previous to this, in 1992, Maaka Tibble, the National Advisory Officer for the RNZFB, won a Winston Churchill Fellowship to “explore and discuss with indigenous people in North America, the programmes they have for their people who have visual impairments” (Tibble, 1992, p. 2), and relate this information to the services that kāpo Māori received in New Zealand. Questionnaires ($n=49$), field notes, and document analysis were the data gathering methods for the study, which took place in the United States (i.e. New York, Arizona and New Mexico) and Canada (i.e. British Columbia, Yukon, North West Territories and Ontario). Tibble found that, as with kāpo Māori in New Zealand, native people with a vision impairment in North America were not accessing services; had been colonised; have migrated to cities and find it difficult to maintain their culture and language; and are positively advocating for self-government in every aspect of their lives. He recommended that a waiora approach to rehabilitation services be implemented that would include emotional, mental, physical and spiritual dimensions; that the RNZFB advance its bicultural policy and practices with Ngāti Kāpo; that iwi, runanga and Māori Congress allow for the full participation of kāpo Māori and other Māori with a disability; that the New Zealand Government support Ngāti Kāpo to lift awareness within Māori communities about the needs of kāpo Māori; and that the World Blind Union establish an international network of indigenous people with a vision impairment.

Of great significance to this project is Higgins' (2001) doctoral thesis. In her doctoral thesis, Higgins (2001) explored the meaning of blindness and the lived experiences of blind people in New Zealand. Participants in this study were ten blind people (aged 5-50) and five of their parents. These participants included two kāpo Māori participants, Hine (pseudonym), an adult who had attended a residential special school, and Davania (pseudonym), who attended the special school as a day student. Both Davania's parents were also participants in the study. Higgins found that blind people in New Zealand were constructed as different and 'othered'. Blind people were socially dislocated, and had to strive to achieve a social place in school and in New Zealand (Higgins, 1999; Higgins, 2001; Higgins, 2004; Higgins & Ballard, 1999; Higgins & Ballard, 1999a; Higgins & Ballard, 2000). This social dislocation and exclusion occurred because of the participants' encounters with health and education services, which took little account of their social place in their families or whānau, local schools, or local communities. They were rarely included at school, encountered prejudice in employment as adults, and some participants had difficulty finding friends and partners.

More specifically, the Māori participants in the study, Davania, Hine, and Davania's parents encountered ignorance, prejudice, as well as pity from health professionals, schools, and the community. Davania, as a kāpo Māori child who also had an intellectual disability, was not able to be included at her local school with her sibling because the school was not prepared and had little support to teach her. Also, Davania's educational experiences at the special

school were centred around her blindness, and little attention was given to te reo or Māori tikanga in class (Higgins, 2001).

Although Hine's whānau did not participate in this study, this whānau was identified as the most affected by the education and health services that Hine received (Higgins, 2001). Hine left her whānau at the age of two to go to the Foundation for the Blind's home for pre-schoolers where, after talking to a professional, her whānau thought that she would have more opportunities. Hine lost her whānau and her culture in a way similar to that of the indigenous people of North America and Australia who were taken to boarding schools (Bull, 1991; Kennedy, 1996; Miller, 1996; Urion, 1991). Hine stated that as a preschooler she did not actually remember her family and like Kennedy (1996) was traumatically re-introduced to them at age four. She said that she was different from her siblings, did not fit, had difficulty maintaining relationships, and was homeless. However, later as an adult, Hine found a place in Ngāti Kāpo, an organisation of kāpo Māori formed in response to the Foundation's limited awareness of Māori culture, with the goal that kāpo Māori would speak and advocate for themselves. Similar organisations of disabled people have developed in other countries in response to calls to change the status quo and to obtain full civil and human right (Asch & Fine, 1988; Barton, 1992; Driedger, 1989; Hahn, 1987; Oliver, 1990). Hine's story was the seed for this study because Higgins reported that she felt that she did not, and could not, do justice to Hine's story in her study because she was not Māori and her study was not a kaupapa Māori research project (Higgins, Phillips, Cowan, Wakefield & Tikao, 2009).

Conclusion

In this review, we found that there is a dearth of research and literature about Māori and disability in general, and about kāpo Māori in particular. What has been written points to disconnections between mainstream policies and practices and Māori. Not only was there a lack of access to services, there was a lack of access to culturally appropriate services despite a raft of policies that argue for inclusion and against discrimination. This goes on to have negative impacts on kāpo Māori identity, as being both kāpo and Māori. Where research has investigated the needs and aspirations of Māori and indigenous peoples, gaps in access to services, culturally appropriate services and funding have been identified and appropriate frameworks proposed. At the heart of these frameworks was the desire for self-determination.

The 'disconnects' and the dissonance that kāpo Māori experience on a daily basis arises out of a society that *is* disabling rather than out of their impairment. Also, being Māori and being disabled were seen not as discrete oppressions but rather as part of a world view in which difference was considered to be inferior. This poses a significant challenge to being Māori, let alone being kāpo Māori in contemporary New Zealand society, given the way in which Māori identity is rooted in whānau. On the one hand policies, programmes and services need to specifically recognise and be anchored in whānau and tikanga if they are to begin to meet kāpo Māori identity, health and education aspirations, and they need to embrace human rights, diversity, and inclusion as the underpinning fabric of New Zealand.

Chapter Three

The context:

Demographics of, and services to, kāpo Māori in New Zealand

Introduction

For this research, the research team explored the available information about kāpo Māori in regards to demographics and health and education services in New Zealand. The information that was gathered still, however, leaves questions about the number of kāpo Māori in New Zealand and their easy access to equitable health and education services. Statistics New Zealand figures about kāpo Māori indicated that few are accessing services. These services and the policies that underpin these services are also discussed in this chapter. Information about the Royal New Zealand Foundation of the Blind (RNZFB), the Blind and Low Vision Education Network New Zealand (BLENNZ), Ngāti Kāpo O Aotearoa, and other relevant service providers is presented.

New Zealand 2006 Census

According to Statistics New Zealand's 2006 Census the total population of New Zealand was 4,027,947. Of those 643,977 (16% of the total population) were of Māori descent, with 565,326 (14% of total population) identifying their ethnicity as Māori (see Figure 4) (Statistics New Zealand, 2006).

Figure 4: Ethnicity of New Zealanders, 2006 Census

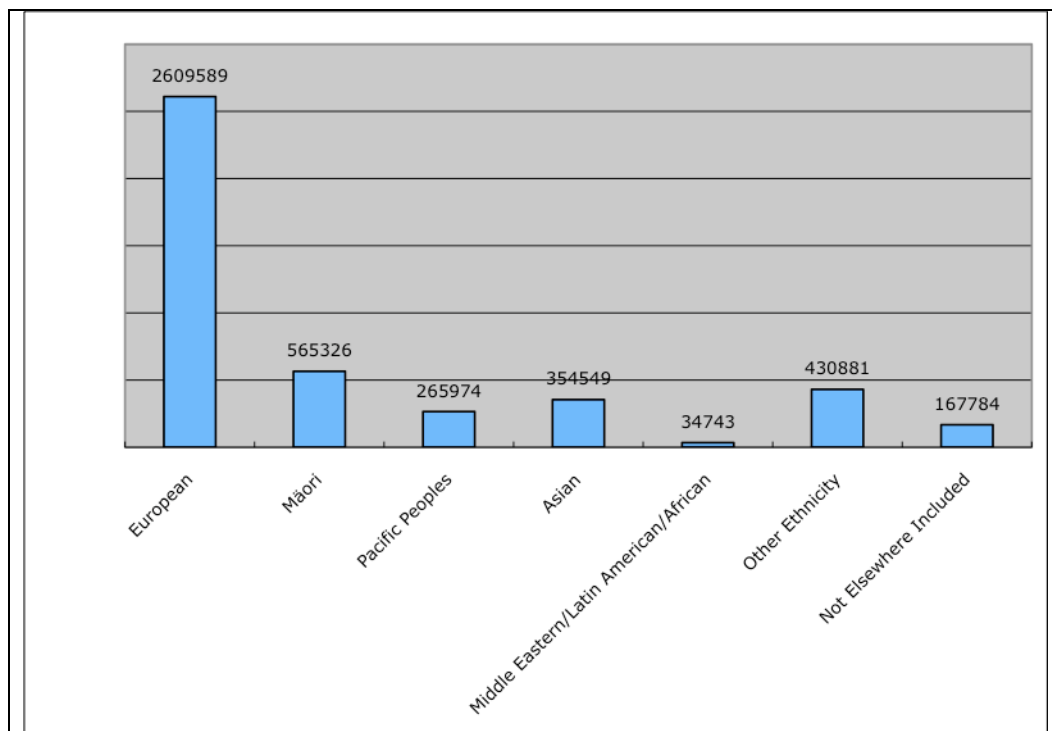


Figure 5: Percentage of Māori and non-Māori population in New Zealand by age, 2006 Census

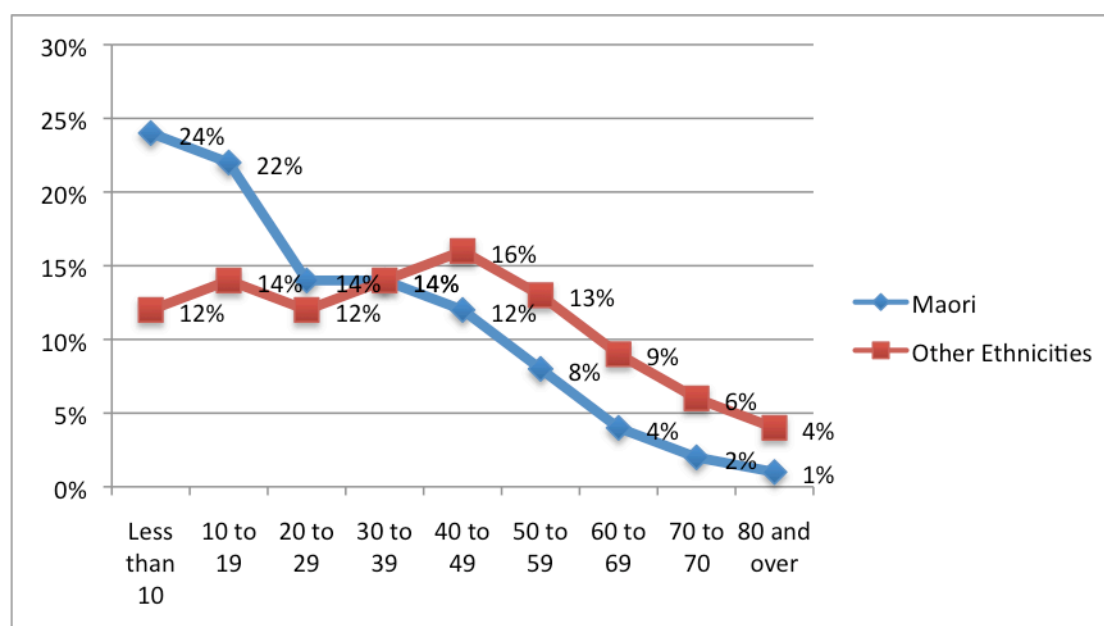


Table 1: Number of Māori and Non-Māori population by region, 2006 Census

Region	Total Population	% of Total Population	# non-Māori	% of Population in Region	# Māori	% of Region	% of Total Māori
Northland	148470	4%	104943	71%	43527	29%	8%
Auckland	1303068	32%	1165935	89%	137133	11%	24%
Waikato	382716	10%	306147	80%	76569	20%	14%
Bay of Plenty	257379	6%	189717	74%	67662	26%	12%
Gisborne	44499	1%	24738	56%	19761	44%	3%
Hawke's Bay	147783	4%	114225	77%	33558	23%	6%
Taranaki	104127	3%	88329	85%	15798	15%	3%
Manawatu-Wanganui	222423	6%	180138	81%	42285	19%	7%
Wellington	448956	11%	393522	88%	55434	12%	10%
Tasman	44625	1%	41562	93%	3063	7%	5%
Nelson	42891	1%	39276	92%	3615	8%	1%
Marlborough	42558	1%	38283	90%	4275	10%	1%
West Coast	31326	1%	28410	91%	2916	9%	1%
Canterbury	521832	13%	485163	93%	36669	7%	6%
Otago	193803	5%	181533	94%	12270	6%	2%
Southland	90876	2%	80454	89%	10422	11%	2%
Area Outside	618	0.02%	249	40%	369	60%	.1%
Total	4027947				565329		

Of interest to this research, is the fact that the age distribution of Māori was different to that of non-Māori, in that 46% of Māori were under the age of 20, whereas only 26% of non-Māori were under the age of 20 (see Figure 5). Also, only 7% of Māori were over the age of 60, whereas 19% of non-Māori were over the age of 60. An analysis of the percentage of Māori by gender from NZ 2006 Census data identifies that 48% of Māori were male and 52% of Māori were female. The general population gender proportion is 49% male and 51% female. According to Statistics New Zealand's 2006 Census, the number and percentage of Māori and non-Māori by region is shown in Table 1.

2007: The Social Report: Well-being and quality of life for Māori in New Zealand

The Ministry of Social Development's (MSD) *2007: The Social Report* monitors over time statistical indicators that provide measures of well-being and quality of life for New Zealanders in ten domains. These domains include Health, Knowledge and Skills, Paid Work, Economic Standard of Living, Civil and Political Rights, Cultural Identity, Leisure and Recreation, Physical Environment, Safety, and Social Connectedness.

This report also noted that in 2006 86% of Māori lived in the North Island, with 24% living in the Auckland region. Also, it pointed out that the median age for the New Zealand population was 36 years, while the median age of Māori was 23 years old. Te Reo Māori could be spoken by 4% of the New Zealand population, while 96% could speak English. The percentage of Māori speakers of Te Reo Māori in the Māori population was 23.7% (Ministry of Social Development, 2007).

According to MSD (2007), Within the Health domain, there are five indicators of well-being and quality of life, including health expectancy (age until which a person can be expected to live independently), life expectancy, suicide, cigarette smoking and obesity. Of note is the fact that Māori were the most disadvantaged in four of these five indicators. Within the first indicator of health expectancy Māori males were expected to reach the age of 58 (compared to 65.2 for non-Māori males) and Māori females were expected to reach the age of 59 (compared to 68.2 for non-Māori). Māori also were less likely to live as long as non-Māori. The *Social Report* indicated that the latest life expectancy figures for Māori (69 years) were also less than non-Māori (77.2 years). The suicide rate was higher for Māori with the average rate being 17.1 persons per 100,000 for Māori. This average rate for non-Māori was 12 persons. For the fourth indicator of health, Māori were identified as having the highest cigarette smoking rate (45.2%) compared to Pacific (37.4%), Asian (12.3%), and European or other ethnic groups (20.6%). The fifth indicator, obesity, identified Māori adults as being affected by obesity (28% of females and 29% of males), but Pacific people had higher rates (48% of females and 38% of males), and European/Other ethnicities had the lowest rate (20% of females and 18% of males) (Ministry of Social Development, 2007).

Within the knowledge and skill domain of well-being, there are four indicators including participation in early childhood education, school leavers' qualifications of NCEA Level 2 or above, participation in tertiary education, and adults' educational attainment level. Again, Māori did not have high levels in the four indicators of this domain. Within the first indicator, participation in early childhood education, Māori had the second to lowest participation rate of 89.9%. Pacific people had the lowest rate at 84.2%, and European people had the highest rate of 98%. Also, of interest is the fact that the lowest participation rate by region was in

Northland at 89%, where there is a high proportion of Māori. The proportion of school leavers with NCEA Level 2 was lowest for Māori at 36.2%, compared to the highest rate for Europeans at 65.4%. Of note, as well, was that lower school decile rates had lower rates of achievement for NCEA Level 2 (43% for decile 1-3; 57% for decile 4-7; and 74% for decile 8-10). In relation to the third indicator in the knowledge and skill domain, tertiary participation, Māori and Pacific students were less likely to be enrolled in degree level courses. However, over all age groups, they were most likely to participate in tertiary education at 18% compared to Asian (15%), European (13%) and Pacific (12%). Within the core tertiary age group (aged 18-24), though, European people had the highest rate (37%), compared to Asian (32%), Pacific (31%), and Māori (31%) people. In the third indicator, educational attainment, Māori and Pacific adults were less likely than European adults to have a tertiary qualification. In 2006, the proportion of the population with a tertiary qualification was 8.5% for Māori, in comparison to 18.9% for European adults (Ministry of Social Development, 2007).

In the well-being and quality of life domain of paid work, Māori had the highest unemployment rate in 2006 at 7.9%, compared to that of 2.7% for European adults. In 2006, the median hourly wage, \$15.15, for Māori salary earners was \$2.59 less than that of Europeans' \$17.74. Māori also had the most workplace injury claims rate per 1,000 FTE at 182, in comparison with Europeans at 119 per 1,000 FTE. Employed Māori had the lowest rate of work-life balance satisfaction at 71%, and second to lowest satisfaction rate (68%) for their leisure time. However, in other key indicators Māori, behind Europeans, had the second highest participation rate (72%) in physical activity, and were the most likely (97%) to participate in at least one cultural activity (Ministry of Social Development, 2007).

Despite the negative results for Māori in these domains, Māori seemed to be relatively neutral in the domain of Social Connectedness. Māori (73%) were more likely to host a meal for friends or family once a month, compared to Europeans (66%). Europeans (77%) were more likely than Māori (72%) to say that people could be trusted. Asian (68%) and Pacific people (67%) were the least likely to indicate that people could be trusted. Māori (18%) were second to Europeans (16%) in having a low proportion of people who experienced feelings of loneliness. However, on a negative note, the difference between Māori secondary students (55%) and European students (65%), reporting that they spent enough time with one or both of their parents, was statistically significant (Ministry of Social Development, 2007).

It is interesting to note that MSD (2007) reported that a Human Rights Commission survey indicated that only 51% of respondents felt that Māori were subject to a great deal or some discrimination, even though Māori seem to be at a disadvantage in most areas of well being and quality of life. Also, of note, is that only 51% of respondents in the survey indicated that disabled people were subject to discrimination. The percentage of respondents, who indicated that Asians were subject to a great deal or some discrimination was 72%, recent immigrants (70%), refugees (63%), people on welfare (63%), people who were overweight (59%), gays and lesbians (57%), Pacific peoples (54%), older people (44%), women (38%), and men (30%) (Ministry of Social Development, 2007).

Health and Disability Demographics and Issues for Māori

In 2006, the Statistics New Zealand's Household Disability Survey had a sample size of 40,665 people. From this survey, estimates were done to determine the number of type of disability by age, ethnicity and gender across New Zealand. Accordingly, in 2006, there were 629,200 disabled people, or 16% of the general population in New Zealand. Of these, 95,700 were Māori, which equals 2.4% of the general population (see Figure 6) and 14.9% of all Māori in New Zealand (Statistics New Zealand, 2006).

Figure 6: Number of disabled people by ethnicity (Total = 629,200), Statistics New Zealand, 2006

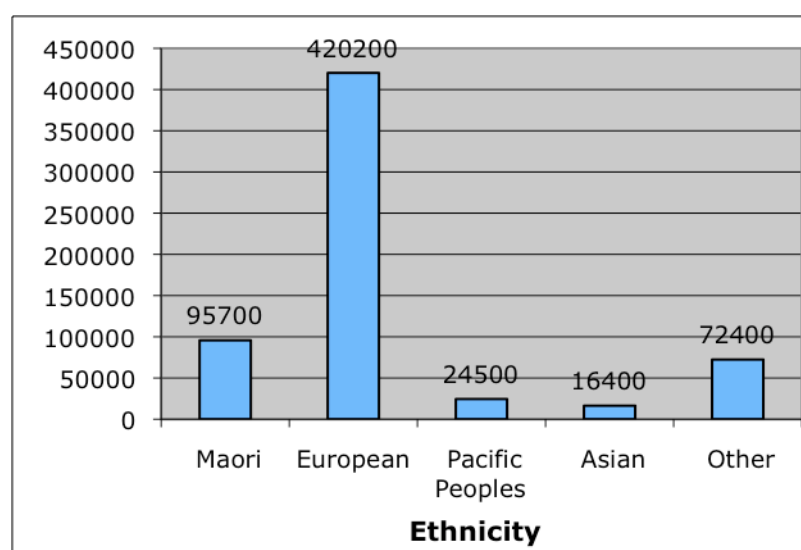


Figure 7 depicts the number of disabled people, according to age and ethnicity. These numbers equate to 29% of disabled Māori were under the age of 15, while 12% of disabled non-Māori were under the age of 15. Eleven percent of disabled Māori were over the age of 65, compared to 34% of disabled non-Māori over the age of 65, 60% of disabled Māori are between the age of 15 and 64, whereas 54% of disabled non-Māori were in this age group.

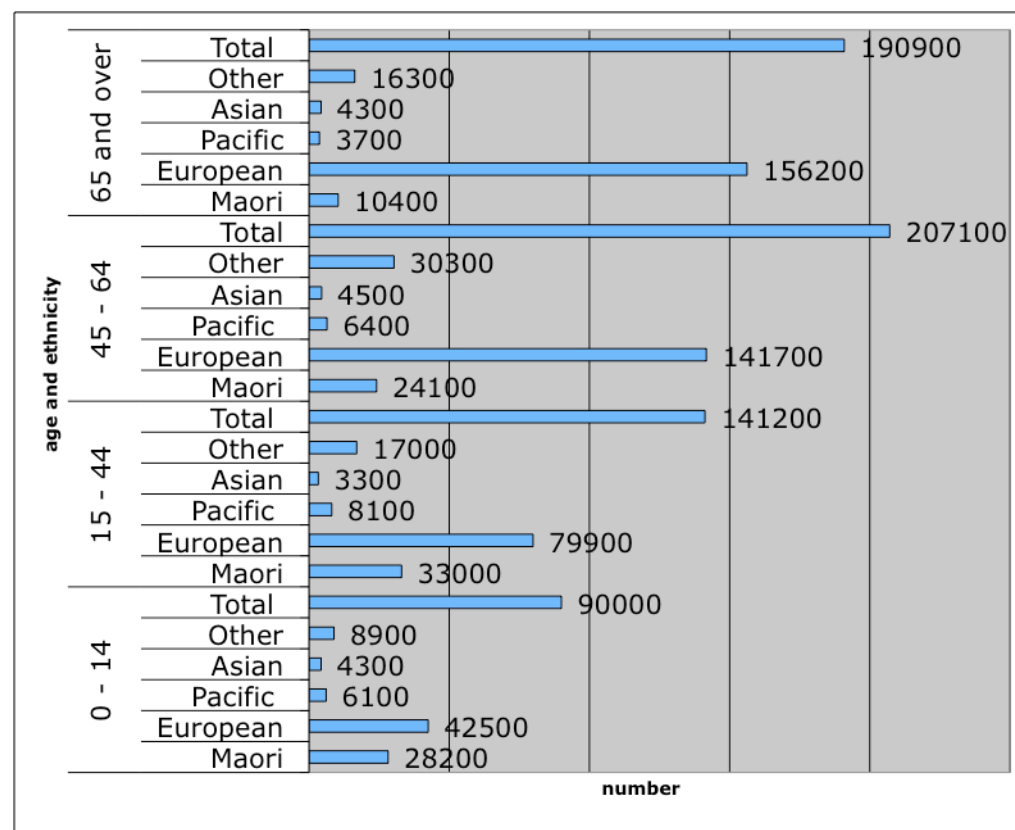
Diabetes

Of relevance to kāpo Māori and this study is the fact that Māori have a high rate of diabetes, which can result in diabetic retinopathy. According to the Ministry of Health, the prevalence of diabetes across the population of New Zealand is currently estimated at around 4%. The prevalence of diabetes in Māori and Pacific populations is around three times higher than among other New Zealanders (Ministry of Health, 2008). Using Census 2006 information those with diabetes, who identified as Māori, would then be approximately 67,839 persons. The Ministry of Health estimated that in 2006 there were 78,380 Māori over the age of 30 with a diagnosis of diabetes (Ministry of Health, 2007).

The Mayo Clinic in the United States estimates that 45% of people with diabetes have some type of retinopathy (Mayo Clinic, 2008), and personal correspondence from Dr. Carolyn Hope, the ophthalmologist at the South Auckland Diabetes Clinic, indicated that 30% of people with diabetes have retinopathy. If these percentages are applied with 2006 Census

based calculations for the number of Māori across the country with diabetic retinopathy, then the estimated number of Māori with diabetes would range from approximately 20,136 people to 27,136 people. Using the Ministry of Health's 2006 estimates of Māori with diabetes over the age of 30, this would equal between 23,514 to 35,271 Māori adults with diabetic retinopathy. The risk factors for individuals that may contribute to diabetic retinopathy include poor control of blood sugar levels, high blood pressure, high cholesterol, pregnancy, smoking, and in America being black or Hispanic. Being of Māori or Pacific Island descent in New Zealand would also be a risk factor. Also, of note is that the longer an individual has diabetes, then there is a greater risk of developing diabetic retinopathy (Mayo Clinic, 2008).

Figure 7: Number of disabled people by age and ethnicity, Statistics New Zealand, 2006



How many kāpo Māori are there in New Zealand:

Definitions, meanings and statistics?

While this query seems straightforward, we have found in this project that there was no simple answer to this question. Publically available census data did not tell us how many kāpo Māori there were in New Zealand and thus we commissioned further information from the 2006 Household Disability Survey from Statistics New Zealand. This information is presented below. However, it should be noted that within the Household Disability Survey, respondents 'self-identify' as having a seeing impairment, and thus this information may not be completely accurate.

Most ophthalmologists in New Zealand use the World Health Organisation definitions of vision impairment or the Royal New Zealand Foundation of the Blind's membership criteria to identify those with a vision impairment. The World Health Organisation is presently considering adopting the definitions and categories of low vision and blindness as outlined in Table 2. Their present definition was developed in 1972 and did not consider that the major cause of blindness and vision impairment in the world is uncorrected refractive errors and that within the 1972 definitions some people could be classified as being in the low vision category as well as in the blindness category.

Table 2: World Health Organization's proposed change to the definitions of blindness (from the World Health Organization, 2008, p. 5)

Presenting distance visual acuity		
Category	Worse than:	Equal to or better than:
Mild or no visual impairment 0		6/16 3/10 (0.3) 20/70
Moderate visual impairment 1	6/18 3/10 (0.3) 20/70	6/60 1/10 (0.3) 20/200
Severe visual impairment 2	6/60 1/10 (0.3) 20/200	3/60 1/20 (0.05) 20/400
Blindness 3	3/60 1/20 (0.05) 20/400	1/60 1/50 (0.02) 5/300 (20/1200)
Blindness 4	1/60 1/50 (0.02) 5/300 (20/1200)	Light perception
Blindness 5	No light perception	
9	Undetermined or unspecified	

The Royal New Zealand Foundation of the Blind defined blind people as those who are eligible for membership at the RNZFB and thus eligible for their specialised services. The criteria for membership are based on medical information that documents the applicant's visual acuity and fields of vision. Their definition of a member is:

a person who, in the opinion of a registered Optometrist or Ophthalmologist, has visual acuity not exceeding 6/24 in the better eye with correcting lenses or serious limitations in the field of vision generally not greater than 20 degrees in the widest diameter. (Royal New Zealand Foundation of the Blind, 2003, p. 10)

There are also other definitions of vision impairment, which are in use by service providers, including The Blind and Low Vision Education Network of New Zealand (BLENNZ) which provides education services on behalf of the Ministry of Education. BLENNZ has a more open definition of vision impairment and blindness, which fits with BLENNZ's focus on the promotion of educational opportunities, and provision of education and specialised services and support for blind and low vision learners, their whānau and professionals. Vision

impairment is defined as “vision that cannot be improved to normal levels with glasses or surgery” (Vision Education Agency, 2003, p. 1). Students with a vision impairment, who are eligible for BLENNZ’s educational roll, are defined as those students who have a:

- Visual acuity of 6/18 or less after the provision of the best possible glasses or lenses (this is approximately 30 percent of normal vision); or
- Visual field so restricted that it affects the ability to function in an education setting; or
- Progressive loss of vision, which may affect the ability to function in an education setting. (p. 1)

Recently, in New Zealand, the J.R. McKenzie Trust studied the prevalence and characteristics of childhood vision impairment, of vision screening policy and practice, and of the information that is available to families and whānau of children. They described their use of the term, vision impairment, as:

Traditionally, ‘vision impairment’, as been used to describe a person whose vision cannot be corrected to ‘normal’ level. In this document, we have used the definition of ‘vision impairment’, which includes children whose eyesight can be fully corrected through the use of glasses. (J.R. McKenzie Trust, 2008, p. 8)

In addition to these varying definitions in use within New Zealand, there are Māori cultural and social meanings ascribed to the terms, vision impairment and blindness, and more specifically to the word, kāpo. Ngāti Kāpo uses the term, kāpo to indicate those who are visually impaired, blind, or deaf/blind. The word kāpo was brought to Ngāti Kāpo by Bill Rako, comes from Ngā Puhi dialect, and was subsequently adapted by the kaumātua and kuia of Ngāti Kāpo after wide consultation with elders without and with sight, who were native speakers of te reo Māori, like Sir Kingi Ihaka, in order to holistically identify the ‘state of being’ for people who are vision impaired, blind, or deaf blind. Other terms that were considered by Ngāti Kāpo, which would identify the ‘state of being’, were ‘matapō’ (black) and ‘pohe’ (dim).

Also, of importance for Ngāti Kāpo was the fact that the meaning of ‘kāpo’ needs to be directly linked with the term, Ngāti (iwi). The whakatauki (proverb), ‘Kā pō, kā ao, kā awatea’ (the forward journey from darkness into the light), is also linked to Ngāti Kāpo’s use of the term, and is a whakatauki used in whaikōrero (men’s oratory) by all iwi. Further to this, some have also indicated that the wairua (spirit) of a person may know before birth that their physical being will be kāpo despite the onset of the physical impairment of blindness or vision impairment occurring some time after birth (Russell, 2007).

In regards to the specific membership criteria of Ngāti Kāpo for their kāpo members, Ngāti Kāpo’s 2005 *Constitution* stated that its individual members would be:

12.2.1.1 Any person, who on account of loss of sight are certified blind or partially blind within the definition of blindness recommended by the World Council for the Welfare of the Blind as a world standard may apply to become an Individual Member of the Society (Ngāti Kāpo, 2005, p. 10)

However, The World Council for the Welfare of the Blind (now called the World Blind Union) does not define blindness or partial sight. Its *Constitution* stated:

The term ‘blindness’ includes both blindness and partial sight and ‘blind’ includes persons who are blind or partially sighted. National Members shall be entitled by this Constitution to use their own national definition of blindness. (World Blind Union, 2004, unpaginated)

In New Zealand, there is no agreed national definition of blind or partial sightedness. Therefore, in practice, Ngāti Kāpo relies on kāpo Māori themselves to self identify as kāpo Māori.

Statistics about the number of people with a vision impairment or blindness, however defined, is not kept at a national government level, but some public information is available through Statistics New Zealand (2001), the RNZFB, BLENNZ, and Ngāti Kāpo. The 2001 Statistics New Zealand Disability Survey indicated that there were 81,500 adults who were blind or had limited sight, which could not be corrected by glasses or contact lenses, with 21% of these adults having an unmet health need in regards to their impairment. Approximately 7,800 of these adults were completely blind, and the rest had some limited vision (Statistics New Zealand, 2001). Of the blind and vision-impaired population, in total, it was estimated by Statistics New Zealand in 2001 that 75% were NZ European (61,125); 15% were Māori (12,225); and 10% were from ‘other’ ethnicities (8,150) (Gravitas Research and Strategy & Market Economics, 2006; Statistics New Zealand, 2001).

2006 Household Disability Survey of Seeing Impairment

In the 2006 Statistics New Zealand’s Household Disability Survey, respondents were asked if they had a seeing impairment, which was defined for adults as “difficulty seeing or cannot see ordinary newsprint and/or the face of someone from across a room, even when wearing corrective lenses”, and for children as “children who are blind or have difficulty with seeing that is not corrected by glasses or contact lenses.” (Statistics New Zealand, 2008). From this survey, with a sample of 40,665 people¹, statistics have been generated to estimate the number of people with a vision impairment within the entire New Zealand population for this project.

Statistics New Zealand (2008) estimated that since 2001 there has been a slight increase in the numbers of people with a vision impairment. In total, there were 83,200 people with a vision impairment or 2.1% of New Zealand’s total population in 2006. The proportion of Māori, who have a vision impairment, was estimated to be 2.2% of the Māori population. Of the total number of people with a vision impairment in New Zealand, 57,700 (69%) were European, 12,300 (15%) were Māori, 3600 (4%) were Pacific people, and 9700 (12%) were Asian/Other (see Table 3) (Statistics New Zealand, 2008).

¹ This includes an oversample of Māori and Pacific people to improve estimates for these groups.

Table 3: Total number of people with a vision impairment by ethnicity in New Zealand, Statistics New Zealand Disability Survey 2006

Ethnicity	Vision Impairment	Total population
European	57,600	2,436,600
Māori	12,300	559,200
Pacific Peoples	3,600	224,600
Asian/Other	9,700	768,100
Total (including those not elsewhere included)	83,200	3,988,600

The geographic profile of people with a vision impairment was about evenly spread between the five District Health Board Regions, and ranged from 18,500 people with a vision impairment in the Northern District Health Boards to 17,000 people in the Midlands District Health Boards. The Midland District Health Board, which includes the Bay of Plenty, Lakes, Tairāwhiti, Taranaki, and Waikato District Health Boards, had the greatest percentage (36%) of Māori with a vision impairment in its region, and the Southern District Health Board had the lowest percentage (8%) (see Table 4) (Statistics New Zealand, 2008).

Perhaps because of the aging population, and the tendency for women to live longer than men, in total there were more females (42,200) (59%) with a vision impairment than males (28,900) (41%) across all of the ethnicities (see Figure 10). Also, perhaps because of the general age profile for Europeans, and the fact that, according to the 2006 census, 46% of Māori were under the age of 20, whereas only 26% of non-Māori were under the age of 20 (see Figure 8), 29% of all children with a vision impairment under the age of 14 were Māori (see Table 5) (Statistics New Zealand, 2008).

Table 4: People with a vision impairment in private households by DHB Region and ethnicity, Statistics New Zealand Disability Survey 2006

DHB Region	European	Māori (% of Māori with a vision impairment)	Pacific Peoples	Asian/Other	Total (incl Not Elsewhere Included)
Northern DHBs	9,600	3,300 (27%)	2,500	3,100	18,500
Midland DHBs	10,000	4,300 (36%)	..S	2,400	17,000
Central DHBs	12,400	3,500 (29%)	..S	1,700	18,300
Southern DHBs	14,200	1,000 (8%)	..S	1,700	17,200
New Zealand	46,300	12,100 (100%)	3,600	9,000	71,000

Notes

Estimates are rounded to the nearest hundred. Owing to rounding, components may not sum to totals.

Suppression (..S) is applied where sampling error is too high for practical purposes.

Figure 8: Sex of people with a vision impairment by ethnicity in private households, Statistics New Zealand Disability Survey 2006

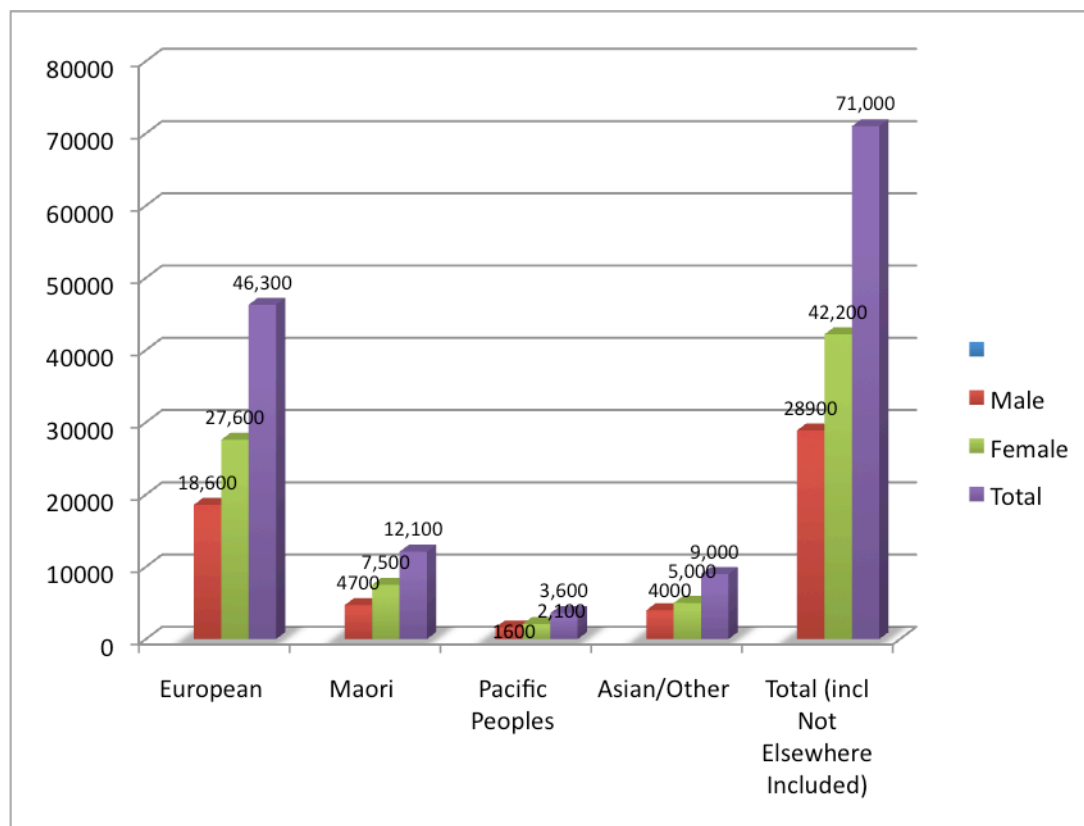


Table 5: Age group of people with a vision impairment by ethnicity in private households, Statistics New Zealand Disability Survey 2006

Age Group	# European (% of total by age group)	# Māori (% of total by age group)	# Pacific Peoples (% of total by age group)	# Asian/Other (% of total by age group)	Total # (incl Not Elsewhere Included)
0-14 Years	5,700 (50%)	3,300 (29%)	..S	1,600 (14%)	11,400
15-24 Years	1,000 (43%)	..S	..S	..S	2,300
25-44 Years	4,800 (51%)	3,000 (32%)	..S	..S	9,500
45-64 Years	13,300 (63%)	3,600 (17%)	1,200 (6%)	3,000 (14%)	21,000
65-74 Years	4,400 (61%)	..S	..S	1,700 (24%)	7,200
65 Years and Over	17,100 (87%)	..S	..S	1,600 (8%)	19,600
Total	46,300	12,100	3,600	9,000	71,000

Notes

Estimates are rounded to the nearest hundred. Owing to rounding, components may not sum to totals. Suppression (..S) is applied where sampling error is too high for practical purposes

Within the 2006 Disability Survey, respondents were also asked about the level of support needs that they had because of their vision impairment by Statistics New Zealand. Statistics New Zealand estimated that of the 83,200 people with a vision impairment, 13,400 people

(0.3% of general population), including 2,100 Māori (0.4% of general Māori population), had high support needs in that they needed daily assistance with tasks such as bathing or preparing meals. 47,400 people (1.2% of the general population), including 7,400 Māori (1.3% of general Māori population), were estimated to have medium support needs in that they used, or had an unmet need for, some type of assistive device, aid or equipment. (see Table 6) Thus, in total 60,800 (1.5% of the general population), including 9,500 Māori (1.7% of the Māori population) have a vision impairment that may require health, rehabilitation, and/or education services. However, as of February 2008, in total, there were only 12,224 individuals who were registered with the Royal New Zealand Foundation of the Blind, including 725 Māori (see section below).

Table 6: Level of support by ethnicity for people with a vision impairment in private households

Support	European	Māori	Pacific Peoples	Asian/Other	Total (Not Elsewhere Included)
Low support needs	5,800	2,700	..S	1,100	10,200
Medium support needs	31,000	7,400	2,100	6,900	47,400
High support needs	9,400	2,100	..S	..S	13,400
Total	46,300	12,100	3,600	9,000	71,000

The Royal New Zealand Foundation of the Blind (RNZFB)

The Royal New Zealand Foundation of the Blind (RNZFB) is the largest non-government agency provider of specialist services to people who are blind or have a vision impairment in New Zealand. The RNZFB, as it is today, evolved from the special school and institution for ‘the blind’, which was temporarily established in 1891, and then permanently established in 1909 as the Jubilee Institute (Higgins, 2001). It was later named the Institute for the Blind, the Foundation for the Blind, the Royal New Zealand Foundation for the Blind, and now the Royal New Zealand Foundation of the Blind. The Jubilee Institute was a total institution where individuals lived away from society, were educated, worked, and then retired. In 1955 an Act of Parliament, the only one of its kind in New Zealand, established the Institute for the Blind as a charitable organisation that was to educate a certain group of people (e.g. blind people). One of its purposes was:

to provide for the care, relief, education and training of blind persons, the amelioration of their condition, and the maintenance and promotion of their general welfare. (New Zealand Government, 1979, p. 4)

However, the Institute has been constantly challenged by blind people, themselves, through the Dominion Association for the Blind, now called the Association of Blind Citizens, New Zealand (ABC (NZ)), which was formed in the 1940s as a result of stopwork meetings by

workers at the Institute who were concerned about their working conditions. In 1964, the special school at Parnell moved to its own grounds in Manurewa and eventually became Homai College. In 1979, the Association won representation on the Institute's Board of Trustees and changed the name of the Institute to the Foundation for the Blind. In 2001, Homai became a state school under the Ministry of Education, and later became part of the Blind and Low Vision Education Network New Zealand (BLENNZ) (described below). The Foundation for the Blind's adult workshops at the Parnell site closed in the late 1980s and in the early 1990s its adult hostels and homes closed (Catran & Hansen, 1992; Higgins, 2001). Over time, the Parnell site has been renovated and now holds the RNZFB's National and Auckland offices, and associated shops and facilities.

In 2002, *The Royal New Zealand Foundation of the Blind Act 2002* superseded the other Acts that had formed the RNZFB, previously. It established the Royal New Zealand Foundation of the Blind as an organisation and gave it the option in the future to become an Incorporated Society. The Act outlined the RNZFB rules, and gave the voting rights for adapting these rules and for electing its Board to registered blind people, aged 16 and over and to one parent of each blind person under the age of 16.

Of note to this study is Objective 10 (o.), which recognises, in particular, the principles of the Treaty of Waitangi and their application to RNZFB's governance and services. However, to date there has not been a Māori representative on the RNZFB's Board of Directors. The Board can have up to eleven persons, eight of whom are elected by registered members, one of whom is elected by associate members, and two of whom can be co-opted under rule 7.12 of the RNZFB's *Constitution* (RNZFB, 2003).

There are no references to Māori, specifically, or kāpo Māori in the RNZFB's *Constitution*, but there is a Board policy statement about tangata whenua (which is left undefined) in section 6.7.2.2. of the *Constitution* that seems to relate to service delivery and cultural regard for tangata whenua. The two clauses in this section stated:

6.7.2.2.1 In relation to Members who are Tangata Whenua, to recognise, respect and have reasonable regard for any cultural or spiritual values, needs or interests that are unique to the Tangata Whenua.

6.7.2.2.2 To require Foundation management to institute, maintain and comply with appropriate general systems and procedures to ensure that, in the provision of services to blind or vision impaired Tangata Whenua, the Foundation and its staff recognise, respect and have reasonable regard for any cultural or spiritual values, needs or interests that are unique to, the Tangata Whenua. (Royal New Zealand Foundation of the Blind (RNZFB, 2003, p. 23)

From this section of the *Constitution* a Te Tangata Whenua Cultural Policy (section 3.17) has been developed for the *Board of Trustee's Policy Manual* (Royal New Zealand Foundation of the Blind, 2007a). It stated that there needed to be a special and meaningful relationship with Te Tangata Whenua o Aotearoa within RNZFB's governance policies. Also, in recognition of the "special cultural and spiritual values, needs and interests that are unique to kāpo Māori" (p. 51), the Board outlined that it will:

1. Promote the principles of Te Tiriti o Waitangi (the Treaty of Waitangi), specifically partnership, participation and proactive protection of the interests of kāpo Māori and their whānau.
2. Uphold the principles of Tino Rangatiratanga (self-determination) of kāpo Māori and their whānau in respect of the types of Foundation services designed to meet their needs and the manner in which all services are delivered.
3. Ensure that kāpo Māori and their whānau are consulted in all areas that affect or have potential impact upon them.
4. Develop and implement appropriate governance training relative to Te Tangata Whenua, encompassing Te Tiriti o Waitangi, Māori customs, beliefs, principles and practices.
5. Ensure that implementation, monitoring and updating of the policy are conducted in consultation with kāpo Māori and their whānau. (p. 51)

As of February 2008, there were 12,224 individuals registered as members at the Royal New Zealand Foundation of the Blind. 11,499 (94%) of these members were non-Māori, and 725 (6%) were Māori. Given that Māori make up 16% of the general population and 15% of the population of those with an impairment, it appears that Māori are not using RNZFB services as much as they should be. Also, of note is the fact that the total number of RNZFB members was significantly less than the estimated number of people with vision impairments from Statistics New Zealand in 2006 and the estimated number of non-Māori or Māori people with Diabetic Retinopathy.

In regards to the age profile of non-Māori and Māori members at the RNZFB, 93% of non-Māori members were over the age of 20 at the RNZFB, with 70% of non-Māori members being over the age of 60. 78% of Māori RNZFB members are over the age of 20, with only 29% being over the age of 60. (see Figure 16) These figures are somewhat consistent with the age profile of the general population. Within the general population, 19% of non-Māori and 7% of Māori were over the age of 60.

The age of RNZFB members is a factor in regards to what services members may be interested in receiving (e.g. Children's Services, Vocational Services, Library Services e.g. talking books, etc.). A further analysis of 2008 RNZFB membership data showed that 68% of non-Māori members at the RNZFB were over the age of 65, and that 23% of Māori members were over the age of 65 (see Table 7). According to Statistics New Zealand, in 2006, 34% of disabled non-Māori were over the age of 65, and 11% of Māori were over the age of 65 (see Figure 9). Thus, the proportion of non-Māori over the age of 65 was three times greater than the proportion of Māori over the age of 65, and this proportion was similar to that of those non-Māori and Māori members who used RNZFB services. However, as stated above, the total percentage of Māori members using RNZFB services was low.

Figure 9: Percentage of non-Māori and Māori RNZFB members by ten-year age group, RNZFB 2008

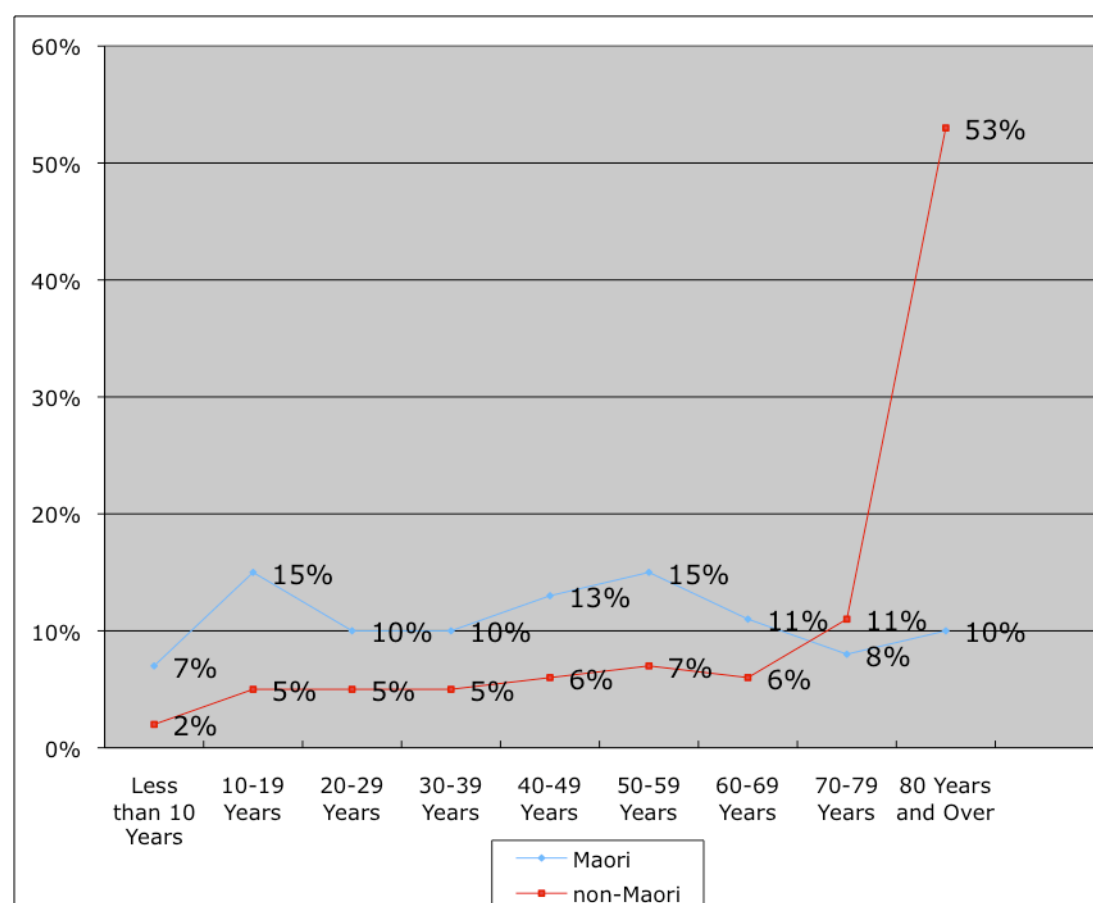


Table 7: Number and percentage of total non-Māori and Māori RNZFB 2008 members by census disability age group

Age	0-4yrs	% *	5-14yrs	%*	15-24yrs	%*	25-64yrs	%*	65+years	%*
Total #	78	1%	531	4%	659	5%	3003	25%	7953	65%
Māori	13	2%	89	12%	98	14%	356	49%	169	23%
Non-Māori	65	1%	442	4%	561	5%	2647	23%	7784	68%

*= % of total Māori Members, or % of total non-Māori Members

In keeping with the demographics of the older majority of RNZFB non-Māori members, 62% of non-Māori RNZFB members were female, while, according to available RNZFB 2008 figures, there was a more equal proportion of Māori females (51%) and Māori males (49%).

The demographic profile of visual diagnosis for non-Māori members differed from that of Māori members. More non-Māori members (35%) had macular degeneration, compared to Māori members (6%) who had macular degeneration. Of note is the fact that 42% of Māori members had no visual diagnosis on RNZFB's database, while only 19% of non-Māori were in this position. When there was a diagnosis on the database, the most frequent diagnosis for

Māori was retinitis pigmentosa (8%). Interestingly, as well, was the fact that diabetic retinopathy was only present in 4% of the RNZFB Māori membership and was twice the proportion of the non-Māori membership with diabetes, which was 2%. (see Table 8) Thus, it would seem that the high numbers of Māori who have diabetic retinopathy, as estimated in the section on diabetes above, are not utilising RNZFB services, and it also suggests that Māori have higher rates of diabetic retinopathy.

Table 8: Top eight visual diagnoses for non-Māori and Māori RNZFB members

	Total # RNZFB Members	Non-Māori	Māori	Total % of Members	% of Non-Māori	% of Māori
Macular Degeneration	4042	4001	41	33%	35%	6%
No Diagnosis	2514	2212	302	21%	19%	42%
Maculopathy	816	811	5	7%	7%	1%
Glaucoma	652	639	13	5%	6%	2%
Retinitis Pigmentosa	507	450	57	4%	4%	8%
Cataract	332	300	32	3%	3%	4%
Optic Atrophy	321	285	36	3%	2%	5%
Diabetic Retinopathy	313	281	32	3%	2%	4%

Usually, individuals register with the RNZFB to receive services from them. Services include Library Services; Technology, Employment and Awareness Services; Children's Services (described below); Mana Kāpo Services (described below); Pacific Services; Deaf Blind Services; Guide Dog Services; and Adult Rehabilitation Services, which include Communication Skills Instruction, Independent Travel Instruction, Counselling Services, Adaptive Daily Living Instruction, and Recreation Services. Library and Adult Rehabilitation Services are the most utilised (Royal New Zealand Foundation of the Blind, 2007).

According to the RNZFB's most recent annual report, 60 awareness and prevention programmes were delivered to Māori and Pacific people as part of its objective to "operate culturally relevant programmes for Māori, Pacific Island and other ethnic populations." (Royal New Zealand Foundation of the Blind, 2007, p. 23). No figures were given on the number of Māori members who received individual or whānau services. It was noted that referrals to Rehabilitation Services, or Adaptive Living services, was not in proportion to the number of Māori members. However, it noted that Mana Kāpo staff were working to promote Foundation services and to educate whānau, hapū, and iwi. The RNZFB also indicated that it had a more positive referral rate for Adaptive Living Services from Pacific members. When services were provided, the RNZFB ascertained that they were culturally appropriate through general satisfaction surveys and verbal feedback from members. The RNZFB also trialled different service delivery approaches, and, more specifically trialled group sessions in South Auckland, which the RNZFB reported worked well for its Māori and Pacific members (Royal New Zealand Foundation of the Blind, 2007).

Also, in regards to more effectively communicating to Māori communities, the Public Relations service at the RNZFB stated that progress had been made because of the quantity and quality of media coverage during the past two annual appeals, Māori media contacted the RNZFB for stories outside the appeals. The Annual Report noted that it felt that its key activity to improve the accessibility of its governance and voting process for Māori and Pacific members was mostly achieved because links to Māori and Pacific members were being strengthened through dedicated services, such as Mana Kāpo for Māori members. The report stated that Mana Kāpo services ensure that “Māori people receive support in a way that is appropriate to their cultural values, and aim “to raise awareness of blindness and blindness prevention within the Māori community by running blindness awareness and prevention programmes in schools and on marae. In 2007, there were eight Aronga, or Mana Kāpo staff, in Aotearoa, who were based in Auckland, Hamilton, Rotorua, Gisborne, Palmerston North and Christchurch.

The RNZFB’s current operational policies, like the Board Policy, recognises the Treaty of Waitangi and tino rangatiratanga. It accepts the principles of partnership, participation and protection of taonga (things of value). (Royal New Zealand Foundation of the Blind, 2008a, Policy #25, p. 1). It is here in this policy’s principles that Māori are recognised as tangata whenua. Its other principles outline that it will develop direct partnerships with Māori; that throughout the RNZFB, it will promote an acceptance and understanding of the Treaty of Waitangi; that it has a commitment to address the needs of Māori; that services will be culturally appropriate; and it will recognise Māori perspective in the provision of services. The operations that will occur to achieve these principles include training of staff (although this training is not mentioned in the Induction Policy, which requires training specific to vision impairment, like sighted guide skills.); the provision of information and services in te reo Māori; the collection of data in regard to Māori for targeted services; the consultation with Māori as service recipients; the adaptation of employment practices to improve employment opportunities, specifically, for kāpo Māori and for Māori at the RNZFB (although the Equal Employment Opportunities Policy, Volunteers Policy, and Selection and Recruitment Policy does not mention this); and the development, promotion and evaluation of culturally appropriate services to Māori (Royal New Zealand Foundation of the Blind, 2008a).

The RNZFB began dedicated services to Māori members in 1990 with the establishment of its national Māori Services, which had four whānau workers and one ethnic worker. In 1997, Māori Services became Te Kupenga Hou, and then this service was restructured in 2001 and Mana Kāpo Services began at the same time as the RNZFB’s Pacific Island Services. In addition, to its awareness and prevention work, Mana Kāpo services supports whānau to access RNZFB services, and promotes RNZFB services. It also has a strategic goal to “collaborate with Ngāti Kāpo on joint initiatives with key groups that provide services to kāpo Māori and their whānau” (Royal New Zealand Foundation of the Blind, 2008). The key drivers of Mana Kāpo were to provide service for whānau of all ages, increase RNZFB’s Māori membership, reduce the isolation of Māori members, and work collaboratively with Māori health and disability providers (Royal New Zealand Foundation of the Blind, 2008).

According to the RNZFB’s position description for Mana Kāpo staff, their main purpose was to “ensure that Māori members receive support from the RNZFB in a way that is appropriate to their cultural values”. They work with other RNZFB staff to assess and coordinate services for Māori members to ensure services are culturally appropriate. They also work to raise

awareness of blindness within the Māori community, Māori Hauora, Māori organisations, employers, schools and training establishments. However, with only eight staff and 725 members, the researchers question whether the wide brief that is given to these staff in their position description and in RNZFB policies may be an issue to consider.

Also, of note in RNZFB statistics was that a number of RNZFB members had additional impairments that need to be considered in service delivery. In regards to the proportion of non-Māori RNZFB members and Māori members, who had other impairments as of June, 2008, the RNZFB's database indicated that there is relatively little difference between these two groups. 88% of non-Māori and 86% of Māori have no other stated impairment. However, about twice the proportion of non-Māori members to Māori members were hard of hearing. This may again be due to the age profile of the non-Māori RNZFB membership. Interestingly, three times the proportion of Māori members to non-Māori members had another impairment that was identified as 'other', and no further information was available about their impairment through the RNZFB's database (See Table 9).

Another statistic that seems to fit with RNZFB's older age profile was the fact that Māori members on average join the RNZFB at an earlier age (age 44.1), and thus also had a longer length of membership (13.8 years) than non-Māori members (10.1) (see Table 10).

Table 9: Other disabilities for 2008 RNZFB non-Māori and Māori members

Disability Type	Non-Māori	% of non-Māori Members	Māori	% Māori Members
None stated	10086	88%	621	86%
Hard of hearing	856	7%	29	4%
Deaf blind	376	3%	25	3%
Other (See Notes)	80	1%	22	3%
Intellectual	68	1%	9	1%
Physical	56	1%	7	1%
Multiple (See Notes)	40	1%	6	1%
Multiple - Excluding Deaf blind (See Notes)	15	1%	4	1%
Psychological	7	1%	2	1%

Table 10: Age of membership and length of RNZFB membership for non-Māori and Māori

	Non-Māori	Māori
Average Length of Membership	10.1	13.8
Average Age at Joining	59.1	30.3
Average Membership Age	69.2	44.1
Median Length of Membership	6.2	9.7
Median Age at Joining	73.9	26
Median Membership Age	80.5	44.6

Also, of interest to service provision and access to services for Māori was the geographic spread of the RNZFB Māori membership. It varied from the geographic spread of the general Māori population in New Zealand (see Table 1 and Table 11) in that the proportion of Māori members in each RNZFB region was lower than the proportion of Māori in the general population in each of the regions.

Table 11: Number of Māori members in RNZFB's regions

Region	Total Number	% Total Members	# Non-Māori	% of membership in Region	# Māori	% membership in the Region	% of Māori members in total	General Comparable % of General Māori Population
Auckland	3583	29%	3339	93%	244	7%	34%	32%
Wellington	3256	27%	3049	94%	207	6%	28%	20%
Waikato	1881	15%	1741	93%	140	7%	19%	26%
Christchurch	2065	17%	2016	98%	49	2%	7%	14%
Dunedin	1224	10%	1196	98%	28	2%	4%	2%
Hawkes Bay & Gisborne	194	2%	140	72%	54	28%	7%	9%

Māori population) where approximately 20% of Māori lived. The Waikato region had 19% of the Māori membership, and this included the Bay of Plenty (12%) and the Waikato (14%) where approximately 26% of Māori lived. The Christchurch Region had 7% of the RNZFB Māori membership, and this included the Tasman (5% of general Māori population), Nelson (1%), Marlborough (1%) and West Coast (1%) districts. However, the proportion in each RNZFB region of the total Māori RNZFB members was in keeping with the percentage of Māori in the region, when the outlying areas around the main centres were taken into account. However, there were some areas where the proportion was smaller. The proportion was slightly higher in the Auckland region where 34% of the total RNZFB Māori membership lived. This figure included Northland, which has 8% of the general Māori population and Auckland, which has 24% of the general Māori population and thus where approximately 32% of Māori lived. Of the total RNZFB Māori membership, 28% lived in the Wellington region, which included Taranaki (3% of general Māori population), Manawatu-Wanganui (7% of general Māori population), and Wellington (10% of general Māori population), Marlborough (1% of general Māori population), West Coast (1% of general Māori population) and Canterbury (6% of general Māori population) where approximately a total of 14% Māori lived. Dunedin had 4% of the RNZFB Māori membership, and this included Otago (2% of general Māori population) and Southland (2% of general Māori population) where a total of 4% of Māori lived. The Hawkes Bay and Gisborne had 7% of the Māori membership, where approximately a total of 9% of Māori lived.

Ngāti Kāpo O Aotearoa Inc

Ngāti Kāpo O Aotearoa's inaugural hui was held in 1981 in Auckland, and soon after developed seven rōpū (support group). In 1991, it was registered as an incorporated society and by 1995 had eleven rōpū. Its sole funder up until 1996 was the Royal New Zealand Foundation for the Blind, which suspended funding from 1996 to 2003. During this period some funding was obtained from Te Puni Kōkiri to develop a three-year plan. In 2001, Ngāti Kāpo also took time "to heal and rebuild" the society (Ngāti Kāpo, 2008), which had encountered some difficulties from 1996-1999, including the RNZFB severing funding, employment action against the society, and a faction of the membership claiming the name and governance of the organisation. The last difficulty resulted in a high court hearing to resolve the issue. By 2001, the rōpū network had expanded to thirteen, and a business brand was adopted. In 2003, formal links with the RNZFB were re-established, while Ngāti Kāpo regional field services were disestablished. However, by 2004 a three-year strategic plan was developed to become self-sustaining and to be a core service provider. In 2005, it reviewed its Constitution, and in 2006, the regional field service was re-established, and the Ministry of Health provided some funding and recognised Ngāti Kāpo as the first and only Māori consumer driven service provider for disabled people. In 2007, Ngāti Kāpo had seventeen rōpū, four staff, offices in Hastings and Christchurch, and an accessible website for its members and the public. It also became a research partner for this research project, and established a Research Management Committee to advise the research team.

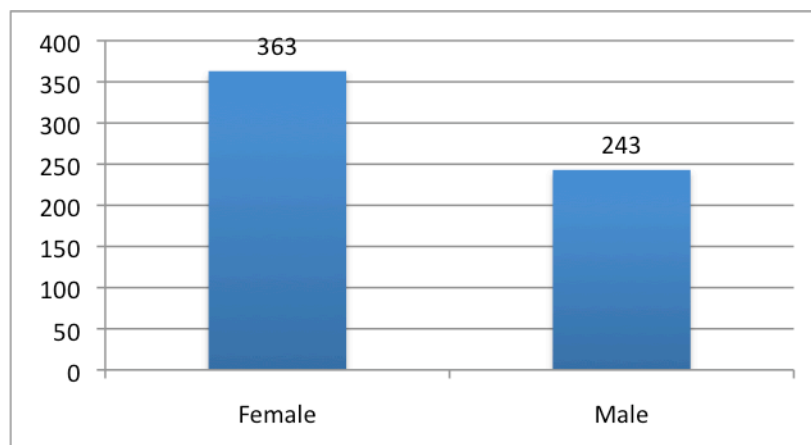
As of June 2008, Ngāti Kāpo had, in total, 786 individual (kāpo and whānau members), associate, honorary, and organisational members. Of these there were 606 individuals, 582 (94%) identified as kāpo. Of the 606 individual members, the majority (63%), like the RNZFB Māori membership (49%), are in the 25 to 64 age band (see Table 12). However, the proportion of members in this age band is larger for Ngāti Kāpo than for the RNZFB. Similar to the RNZFB, though, a large percentage is under the age of 24. Ngāti Kāpo has 27% of its members under the age of 24, and the RNZFB has 28% under this age. Of interest, is that Ngāti Kāpo older membership group, or its kaumātua, only make up 10% of its membership, while the RNZFB has 23% of its membership in this age group. Thus, Ngāti Kāpo seems to attract younger people to its organisation.

In regards to gender, in the general Māori population, 52% are female and 48% are male (Statistics New Zealand, 2006). Ngāti Kāpo membership, though, is 60% female and 40% male (see Figure 10). This gender balance is similar to that of the RNZFB's non-Māori membership gender balance, which is 62% female and which, it is proposed above, may be due to the older non-Māori age group (68% over the age of 65) at the RNZFB. However, Ngāti Kāpo does not attract an older age group, and thus, it seems that Ngāti Kāpo attracts more females, in general, to its organisation.

Table 12: Percentage of total non-Māori and percentage of total Māori RNZFB 2008 members by 2006 census age group

Ngāti Kāpo Age Name	Age Group	# of NK Members	% of NK Members	% of RNZFB Māori Members
Nohi Nohi	0 to 4 yrs	5	1%	2%
Tamati	5 to 14 yrs	38	6%	12%
Rangatahi	15 to 24 yrs	120	20%	14%
Pakeke	25 to 64 yrs	381	63%	49%
Kaumātua	65+	62	10%	23%

Figure 10: Number of Ngāti Kāpo members by sex



In regards to its geographic spread, Ngāti Kāpo has a similar proportion of members to the RNZFB's proportion in Auckland (NK=34%, RNZFB=32%) and Wellington (NK=28%, RNZFB=28%). However, it has a higher proportion to the RNZFB in Christchurch (NK=11%, RNZFB=7%) and Gisborne/Hastings (NK=16%, RNZFB=7%) where it also has its offices. Ngāti Kāpo has lower proportion of members than the RNZFB in the Waikato (NK=10%, RNZFB=19%) and Otago/Southland (NK=1%, RNZFB=4%) (see Table 13).

Table 13: Number and % of Ngāti Kāpo members in Ngāti Kāpo regions and generally comparable RNZFB's regions

Ngāti Kāpo Region	General Comparable RNZFB Region	# of NK Members	% of NK Members	Approx % of RNZFB Māori Members	Approx % of Māori General Population
Te Tai Tokerau	Auckland	202	33%	34%	32%
Te Tai Hauauru	Wellington	167	27%	28%	20%
Te Puku o Te Ika	Waikato/Rotorua	61	10%	19%	26%
Te Tai Tonga	Christchurch	71	11%	7%	14%
	Otago/Southland	7	1%	4%	2%
Te Tai Rawhiti	Gisborne, Hastings	98	16%	7%	9%
TOTAL		606			

Ngāti Kāpo was established to:

1. Uphold ngā Tino Rangatiratanga of Tangata (kāpo Māori and their whānau).
2. Provide, or enable the provision of support, training or services, which are of economic, social and cultural benefit.
3. Advocate for resources and services to meet the needs of Tangata.
4. Promote awareness of the needs of Tangata amongst Iwi and Tauīwi
5. Link with other Tangata Whenua and people of Te Moananui-a-kiwa. (Ngāti Kāpo O Aotearoa, 2005, p. 1)

Ngāti Kāpo's *Constitution* ensures that kāpo Māori maintain dominance at the governance level in that its Tumuaki (Board of Directors), which is made up of five persons, are elected by members at its biennial hui. Also, three of the five positions must be held by kāpo persons, including the Tumuaki Tua Tahī (president) and the Tumuaki Tua Rua (Vice President) positions. The Tumuaki meet at least four times a year and endeavour to make decisions by consensus, not by majority vote. Currently, financial members of Ngāti Kāpo pay an annual membership fee of \$20. However, the Constitution allows for non-financial members, who are not able to vote at the biennial hui (Ngāti Kāpo O Aotearoa, 2005).

Ngāti Kāpo vision is that:

Ngāti Kāpo O Aotearoa Inc. is globally recognised, valued and supported by all stakeholders as the core element in promoting and facilitating the aspirations of Ngāti Kāpo members in accordance with the society's "Key Statements". (Ngāti Kāpo O Aotearoa, 2008, p. 10)

The mission of Ngāti Kāpo is to:

- Improve the quality of life for kāpo Māori and their whānau;
- Advocate for kāpo Māori and their whānau observing the principles of whanaungatanga; (and)

- Provide peer support as an integral part of whānau development, which in turn, provides opportunity for the member to reach their potential.

In the most recent *Strategic Plan 2008-2012*, Ngāti Kāpo listed the underlying values of the organisation as accountability, compassion, confidence and trust, cooperation, integrity and respect, professionalism, and reliability, security, and privacy of information. Ngāti Kāpo services include the provision of advocacy services for the individual and wider community of Ngāti Kāpo; training and information about kāpo and kāpo Māori; public education and awareness services; and advice and support. It has an Operations Manager, who manages the day to day activities and supervises staff; a National Administrator, who maintains the Hastings office, disseminates information within the organisation, and provides administrative support; and two Regional Kaiwhakahaere, who coordinate the organisation at a regional level, provide support to individual members and rōpū to link with their community, liaise with local government and non-government stakeholders, and initiate and organise relevant hui. Over the next four years, The strategic goals of Ngāti Kāpo focus on developing the organisation, improving its communication, identifying the needs of its members, building relationships (both internally and externally), developing a twenty year plan, enhancing the organisations capabilities, and initiating new services and initiatives. In summary, Ngāti Kāpo is a significant organisation for supporting the identity and cultural well-being of kāpo Māori and their whānau. It is run by kāpo Māori, and is building its organisational reputation and services. It has few staff, but continues to grow, and is taking strategic steps to identify its future focus and services through tino rangatiratanga and kaupapa Māori.

Tamaki Ngāti Kāpo and Vision Pacific

There are two smaller organisations that have a different focus than Ngāti Kāpo, but which also provide support and advocacy services for kāpo Māori, as well as for people of Pacific Island descent. The first organisation is Vision Pacific (formerly called Akamarama Advocacy), whose secretary is in Auckland, but which also has an active group in Otago. There is little written or publicly available information about Akamarama but anecdotal information indicates that its founders were once part of Ngāti Kāpo, who left because they wished to focus on including other kāpo people from the Pacific Islands in the organisation. The second group that has a local focus is Tamaki Ngāti Kāpo. Again, little public information is available about this organisation. Anecdotal information indicates that some members in Ngāti Kāpo formed Tamaki Ngāti Kāpo in order to receive local community funding to provide advocacy and support services to kāpo Māori and those of Pacific Island descent in the Auckland area. It has one employee, who provides its services and coordinates the organisation.

District Health Board Services

There are 21 District Health Boards (DHBs) providing services across Aotearoa, New Zealand. The majority of these are in the North Island, which reflects New Zealand's demographic profile. District Health Boards put into effect current health and disability policies and in doing so plan for, provide and fund a range of services, which include those to

the disability sector and to Māori. As such they operate under the Public Health and Disability Act 2000, give recognition to the principles of the Treaty of Waitangi and are guided by the following four strategies:

- NZ Health Strategy
- NZ Disability Strategy
- Primary Health Care Strategy
- He Korowai Oranga (Māori Health Strategy)

Whilst they are all governed by the above strategies, how they put them into effect is up to each of the DHBs. This is not surprising because of the different health contexts of the regions. As a consequence there is variation in the provision of services to Māori and people with disabilities. Some have put together Māori and disability health plans, some have established specifically Māori and or Disability committees, many have incorporated Māori concepts and tikanga and use te reo Māori in their documents, while some have memorandum of understandings with their local iwi. All DHBs fund health Māori and disability service providers. For example, the Northland DHB in 2008 funded seven Māori organisations to provide 22 contracts in the Northland region for Māori. Similarly they funded 13 disability support organisations to deliver 19 programmes for people with disabilities. (Northland District Health Board, 2008) It is unknown how many of these are crossovers, that is Māori organisations providing disability services and vice versa.

Māori Health Services

There are well over 44 specifically Māori health providers² around New Zealand, contracted to their local DHB, who are working in and with local Māori communities. Most of these are in the North Island. Some of these are iwi and hapū based; others are urban based. All provide a kaupapa Māori – by and for Māori – service to address the issues of their local Māori communities and to fulfil their aspirations. All uphold Te Tiriti o Waitangi. But at the same time, however, they are, as primary health organisations, also accountable to their DHB for the funding they receive. In turn the DHBs are guided by government health policies, which include a number of specifically Māori ones (see section above). Te Kete Hauora (Māori Health Directorate)³ has been established to provide policy advice that relates specifically to Māori health and disability (Ministry of Health, 2008a).

Many of the Māori health providers are hapū and iwi based who uphold specific iwi mātauranga and tikanga in providing their services. Currently there is only one specific Māori disability provider, which provides services to over 45 year olds. However, many of the organisations incorporate disability services in their provision and, in doing so, may cater for kāpo Māori.

² As of September 2008 there were 44 providers listed on the MoH Māori Providers webpage. However this did not include information on the Canterbury, Wairarapa and Waitemata regions, nor does it necessarily present all the Māori providers in a given region. An example of this is the Northland DHB, which funds seven Māori organisations, but only four are registered on the Māori providers MOH web page.

³ See Te Kete Hauora's webpage -

<http://www.Māorihealth.govt.nz/moh.nsf/menuma/Māori+Health+Directorate>

Given that Māori health providers operate within kaupapa Māori frames their services are holistic and include both health and social services. For example, Te Kupenga Hauora – Ahuriri in Napier provides a range of health, social and disability services that includes Aukati Kai Paipa (Smoking Cessation), Breast and Cervical Screening Support, Dental Health/School-based Nursing, Family Start, Healthy Lifestyle Coaching, Kaupapa Māori Mental Health, Kia Piki o te Ora (All Age Suicide Prevention and Health Promotion), Outreach Immunisation, Social Workers in Schools, Tamariki Ora/Well Child, Vision and Hearing, Whānau Ora (Ministry of Health, 2008a).

Currently little is known about Māori health providers. A project on the socio-political impact of policies on providers in the South Island has been completed. This project found that kaupapa Māori services struggle within the mainstream funding and accountability environment given their differing philosophical and political orientations and as a consequence their ability to deliver appropriate services is compromised (Wakefield & Kahu, 2008). What this project also found was that despite the challenges the providers were committed to the work that they did. Two projects (by MDRC and Te Kete Hauora)⁴ are currently underway which are investigating Māori disability services. The researchers in this project anticipate that their findings will contribute to the dearth of literature in this associated sector on Māori disability.

There are also informal networks and organisations that support Māori with disabilities, including kāpo. For example the Aotearoa Māori Carers Network is one such organisation that has been established to support whānau caring for tangata with disabilities.

Education Services

The history of services for children with a vision impairment has been extensively documented in Higgins (2001), Nagel and Stobbs (2003), and on BLENNZ's website (www.inclusive.org.nz/blennz/home). Specific educational services to children began in 1891 with the establishment of the Jubilee Institute for the Blind in Parnell, which has developed into the Royal New Zealand Foundation of the Blind (RNZFB). The Jubilee Institute housed and educated twenty children. Most children with a vision impairment boarded and attended the special school at Parnell up until the 1960s. In 1964, the Department of Education bestowed upon the Foundation for the Blind twenty-eight acres of vacant land in Manurewa for the purpose of the education of blind children. A special school, Homai College, was built there in 1965, and, today, the Homai Campus of the Blind and Low Vision Education Network New Zealand (BLENNZ), an Early Childhood Centre for children with a vision impairment, and the RNZFB occupy this land.

Since 1956, parents of children with a vision impairment and professionals have been advocating for a unified system of educational services to New Zealand children with a vision impairment, instead of the individually governed special school (Homai) and itinerant vision services. In 2005, staff at Homai National School for the Blind and Vision Impaired came together with the itinerant Resource Teachers Vision and Support Staff in Visual and Sensory Resource Centres within regular schools around the country to form BLENNZ. Also,

⁴ See the MDRC website - http://www.mdrc.co.nz/index.php?cPath=449_450_452 - and Te Kete Hauora's website - <http://www.Māorihealth.govt.nz/moh.nsf/pagesma/544>

the Early Childhood Centre became a stand-alone entity that is governed by the Homai Early Childhood Centre Education Trust. BLENNZ is funded by the Ministry of Education to provide specialist services to children with a vision impairment throughout New Zealand, and it emphasises inclusive education (Nagel & Stobbs, 2003). Eligible children with a vision impairment also may receive services from the Ministry of Education's Group Special Education and the Royal New Zealand Foundation of the Blind (Blind and Low Vision Network New Zealand, 2008b).

Currently, New Zealand children who have a vision impairment are identified by either medical or educational services. In its report about policy and practice for children with mild and moderate vision impairment, the J.R. McKenzie Trust (2008) was not able to estimate the number of children with a vision impairment in New Zealand. The report noted that there were wide disparities in the statistics about children with a vision impairment. They pointed out that there is no requirement for eye professionals to report new diagnoses of children with vision impairment as is done for children with a hearing impairment, and there is no national database for children with a vision impairment, although some figures are available for children who are eligible for services from BLENNZ, the RNZFB, and Ngāti Kāpo.

Statistics New Zealand data about kāpo children

In 2001, Statistics New Zealand estimated that there were 13,200 children (less than 15 years), who were blind or had limited vision that could not be corrected (Gravitas Research and Strategy & Market Economics, 2006; Statistics New Zealand, 2001). Of these children, 2300 (17%) were diagnosed by an eye specialist as being blind. Interestingly, however, BLENNZ only had approximately 1300 children (less than 22 years) on its roll in 2001 (Higgins, 2001). In 2006, the number of children with a vision impairment, according to Statistics New Zealand, under the age of 15 was estimated to be 11,400, including 3300 kāpo Māori children. A total of 13,300 New Zealanders under the age of 25 was estimated to have a vision impairment, but the sample size was too small within Statistics New Zealand's Disability Survey to estimate the number of kāpo Māori under the age of 25 (see Table 14) (Statistics New Zealand, 2008).

Table 14: Number of kāpo Māori under the age of 24 by ethnicity, 2006 Disability Survey

Age Group	# European (% of total by age group)	# Māori (% of total by age group)	# Pacific Peoples (% of total by age group)	# Asian/Other (% of total by age group)	Total # (incl Not Elsewhere Included)
0-14 Years	5,700 (50%)	3,300 (29%)	..S	1,600 (14%)	11,400
15-24 Years	1000 (43%)	..S	..S	..S	2,300
Total	6700				13, 700

Note: Suppression (..S) is applied where sampling error is too high for practical purposes.

Blind and Low Vision Education Network NZ (BLENNZ)

The Blind and Low Vision Education Network (BLENNZ) is a Special Residential School and a national network of Resource Teachers of Vision. BLENNZ's vision is to have equity through access and open doors so all may learn. It has four missions:

1. Provide a quality education for blind and low vision learners irrespective of where they live or which school or early childhood centre they attend
2. Provide and facilitate ways in which education opportunities for these learners can be maximised
3. Ensure specialised programmes and services required by these learners, particularly the Expanded Core Curriculum, are readily accessible
4. Support learners, their families and whānau, and all involved professionals to achieve educational outcomes for students that are equivalent to, or better than those expected of their peers (BLENNZ, 2008a, p. 4)

It is governed like other schools by a Board of Trustees. Previous to its establishment, educational services to blind and low vision children were essentially provided through Homai National School for the Blind and Vision Impaired, and itinerant Visual Resource Teachers, who were attached to schools. However, in January, 2005, Homai staff and Vision Teachers (now called Resource Teachers Vision (RTVs), along with their Resource support staff, came together to form BLENNZ. In 2005, Nagel (2005) estimated that BLENNZ's roll included 17% of totally blind learners, 81% of low vision learners, 2% of deaf blind learners, and 36% of learners with additional impairments. In 2007, BLENNZ had 1404 children on its roll (J.R. McKenzie Trust, 2008). More specific demographic data has been collected from its 2006 roll for this report, and then it provided educational services to 1323 learners on its roll (see Table 15), which is a figure substantially less than Statistics New Zealand's estimates of children with a vision impairment.

Table 15: 2006 total number, and number of learners, in BLENNZ's school and early childhood rolls

BLENNZ Roll 2006	Totals	Early Childhood	School Aged
# Learners	1323	226	1098
% of Roll	100	17%	83%

BLENNZ's organisation is currently led by a principal and is made up of four main service strands that include Assessment and Teaching Services, School and Residential Services, Learning Support Services and Administration Services. Educational Services in the first strand, Assessment and Teaching Services, are provided to children in regular schools through RTVs, who are attached to twelve Visual Resource Centres, and the Specialist National Assessment and Teaching Service at Homai National Campus. The second BLENNZ service strand, School and Residential Services, includes the Homai Campus School, the satellite class at James Cook High School, and residential facilities. The third service strand, Teaching and Learning Support Services, includes the following services: Intensive short term courses in the Expanded Core Curriculum, Professional Development,

Research and Development, Planning and Future Forecasting, Technology Innovation, Inter-Agency Links, Publications, Library/Information/Resources, and Tertiary and ESVI links and support. Finally, BLENNZ's last service strand is their Administration Services, and includes secretarial, finance, human resources, property, catering, resourcing and contract and administration services (Blind and Low Vision Education Network New Zealand, 2008).

According to BLENNZ's *Charter*, BLENNZ's services support the intent and principles of government strategies, goals and priorities for education, the aim for an inclusive society and the removal of barriers as in the New Zealand Disability Strategy, and the "principles of best practice in Blindness Education" (Blind and Low Vision Education Network New Zealand, 2008a, p. 5). In 2006, about 66% of children on its school aged roll attended regular schools, 13% attended a special unit in a regular school, and 20% attended a special school. The number of children in 2006 enrolled at Homai National Campus was 8% (n=108) of its roll (Vision Education Agency, 2007).

Through its *Charter*, BLENNZ recognised its obligations under the Treaty of Waitangi to provide a safe and welcoming environment for Māori students. To do this, BLENNZ stated that it will ensure that one member of its Board of Trustees will identify as tangata whenua; that it will encourage and support the group, Te Whānau o Homai; will develop a positive relationship with Ngāti Kāpo and other kāpo Māori organisations; will provide appropriate support to Māori learners in regular and immersion education settings, including providing te reo accessible format materials; and will "support Ministry of Education initiatives to promote achievement of Māori learners" (Blind and Low Vision Education Network New Zealand, 2008a, p. 6).

BLENNZ does not have any identified Māori cultural advisors or whānau workers in its services. In order to access the viewpoints of BLENNZ's Māori community, the *Charter* identified that its partnership with Te Whānau o Homai, a local group of kāpo Māori students and staff at Homai's National Campus, would be central. Interestingly, there is no such statement about Ngāti Kāpo, which is a national network of kāpo Māori and their whānau. However, consultation with Ngāti Kāpo, like consultation with Te Whānau of Homai, was listed as one of the steps that will be taken to discover the concerns and views of its Māori communities. Other steps that could be taken included having tangata whenua on its Board, hui, IEP Meetings, and collaboration with RNZFB Māori Services.

BLENNZ's *Charter* stated that it will foster equal opportunities and cultural awareness throughout its operations. It will provide educational services that respect all learners' dignity and individual needs and enable them to achieve their stated goals. It will incorporate tikanga Māori into the school's curriculum by establishing a culture group, having residential students attend monthly waiata evenings, displaying posters in te reo and Pacific Island languages, integrating tikanga Māori throughout its curriculum, and adapting Māori legends and texts to accessible formats (Blind and Low Vision Education Network New Zealand, 2008a).

Table 16: 2006 BLENNZ roll by ethnicity (age 0-21)

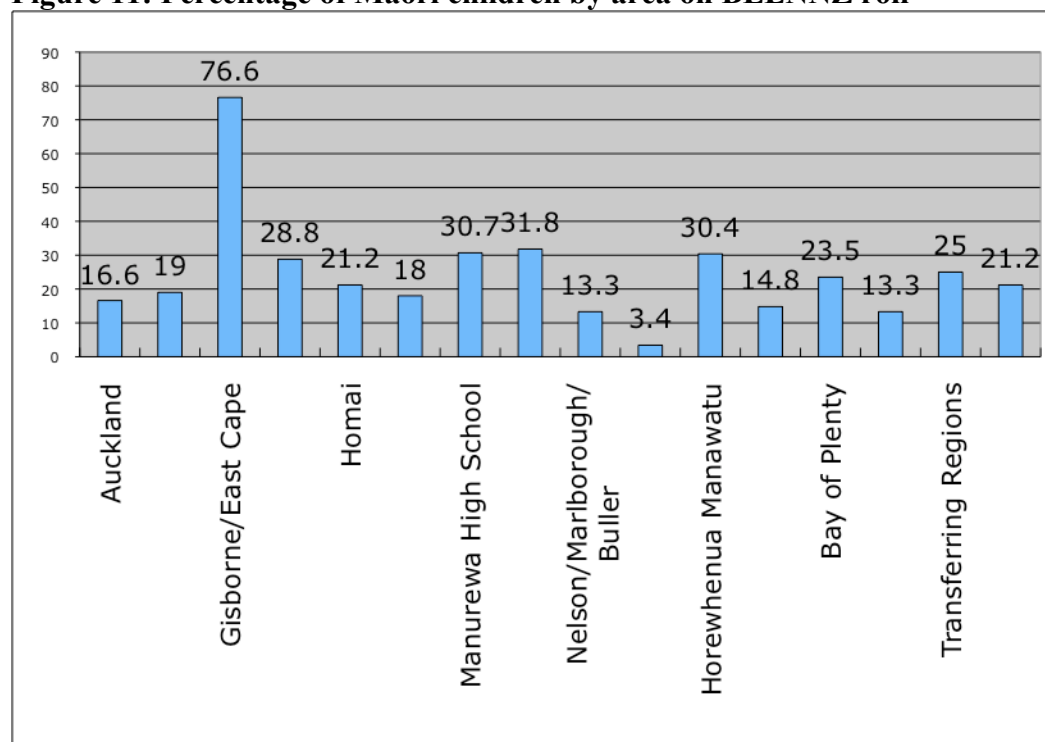
Ethnicity	National %	National Totals
Australian	0.3	3
British	0.6	7
Cambodian	0.2	2
Chinese	1.7	20
Cook Is Māori	1.2	14
Fijian	0.3	3
Filipino	0.2	2
Indian	2.5	29
Middle Eastern	0.5	6
NZ Euro/Pākehā	61.8	712
NZ Māori	21.2	244
Niuean	1	11
Samoan	3.9	45
Sri Lankan	0.2	2
Taiwanese	0.1	1
Tokoleauan	0.3	4
Tongan	1.4	16
Vietnamese	0.1	1
Other African	0.7	8
Other Asian	0.2	2
Other European	1.1	13
Other PI	0.2	2
Other	0.5	6
TOTALS	100	1153

In 2002, 22% of BLENNZ's roll was Māori (Gravitas Research and Strategy & Market Economics, 2006). In 2006, this figure remained the same (see Table 16). An analysis of 2006 data indicated that this percentage also roughly correlates with the percentage of Māori children in 2006, who were under the age of 20 in New Zealand (22%).

Table 17: Number of Māori children by area on BLENNZ's roll, 2006

	Māori Learners	Total Learners
Auckland	57	342
Canterbury/West Coast	38	200
Gisborne/East Cape	23	30
Waikato/Thames/Coramandel/King Country	28	97
Homai National Campus	7	33
Wellington	24	133
Manurewa	4	13
Hawkes Bay	14	44
Nelson/Marlborough/Buller	6	45
Otago	1	29
Horowhenua/Manawatu	21	69
Southland	4	27
Bay of Plenty	8	34
Taranaki	6	45
Transferring Regions	3	12

Figure 11: Percentage of Māori children by area on BLENNZ roll



The number and percentage of kāpo Māori children on BLENNZ's 2006 roll by area, including Homai National Campus and Manurewa High School Visual Resource Centre, are presented in Table 17 and Figure 11. As would be expected because of the demographics of

the geographic areas, there was a high percentage of kāpo Māori children on the roll in Gisborne, Waikato, the Hawkes Bay, the Horowhenua, and Manurewa High School.

The Ministry of Education's National Administration Guidelines: Curriculum (NAG 1) stated that each School's Board of Trustees in consultation with their Māori community needs to develop and disseminate their plans, policies, and targets for improving the achievement of their Māori learners (Blind and Low Vision Education Network New Zealand, 2007). The policies of BLENNZ are generally reviewed every three years, and, according to its 2007 *Policy Manual* provide for the healthy, efficient, and effective governance of the school, with the Principal, as its chief executive, having the overall responsibility of their implementation. (Blind and Low Vision Education Network New Zealand, 2007). BLENNZ's Treaty of Waitangi Policy, which was approved in 2001, is presently under review. The policy noted that at Homai National School for the Blind and Vision Impaired the tangata whenua are the Whānau o Homai (under Ngāti Kāpo and Te Aranga Roopu Kaumātua me nga Kuia o Manurewa) and the principal and staff (under the Board of Trustees) are the tangata Tiriti.

BLENNZ's Treaty of Waitangi's policy recognised that tangata whenua and tangata Tiriti "have certain responsibilities to honour the Treaty and to forge a bicultural relationship" (Vision Education Agency, Treaty of Waitangi Policy, p. 1). It stated that this policy underlies all other policies and will be acknowledged in them, and that consultation will take place in respect to present and future services. It said that learners have a right to be educated in an appropriate manner based on their cultural needs, and requires staff to observe the bicultural policy, act in a culturally sensitive manner, and avail themselves of opportunities to develop their Treaty knowledge and increase their bicultural awareness (Blind and Low Vision Education Network New Zealand, 2007). The Treaty of Waitangi Policy ended with a paragraph that notes that tangata whenua and tangata Tiriti need to first establish their bicultural relationship, and then pursue bicultural relationships with other cultures while recognising the multi-cultural nature of the national school. Despite the Treaty Policy's requirement to be a part of every other policy, there are some policies that do not meet this requirement. For example, the following policies made no reference to the Treaty of Waitangi or cultural issues: Child Protection Policy, Complaints Policy, and Admission and Withdrawal Policy (Blind and Low Vision Education Network New Zealand, 2007).

BLENNZ's Curriculum Policy's statement of intent stated that it aims to enhance student achievement and learning through providing access to the National Curriculum, and that the ethnically and culturally diverse nature of New Zealand's heritage will be respected. In regards to the curriculum, a 2003 publication by the Vision Education Agency about access to learning for children with moderate vision impairment noted that BLENNZ's assessment, intervention, teaching and learning support services involved the delivery and development of the total curriculum for learners with a vision impairment. The total curriculum was described as having two parts: the first part was the regular curriculum, which is provided to all learners in New Zealand through the New Zealand Curriculum Framework and Te Whaariki. The second part was the Expanded Core Curriculum, which is taught by RTVs and Developmental Orientation and Mobility specialists, who are mostly employed at the Royal New Zealand Foundation for the Blind (Vision Education Agency, 2003). The content of the Expanded Core Curriculum includes seven additional skill areas that may be required for learners with a vision impairment to access and participate in the regular curriculum (Vision Education Agency, 2005). More specifically, the Expanded Core Curriculum includes communication modes, visual efficiency skills, physical abilities, orientation and mobility, social skills, living skills, and technology.

BLENNZ's staff deliver the curriculum at a teacher to student ratio of one to thirty-seven. In other countries, such as Australia, the ratio is between one to twelve and fourteen (Kirchner & Diamant, 1999; Nagel, 2000). BLENNZ, the Parents of Vision Impaired (NZ), Ngāti Kāpo, the Association of Blind Citizens (NZ), and the RNZFB have been advocating for a number of years for improved funding for this education sector to improve education service delivery to children with a vision impairment, and a petition was presented to Parliament in May of 2008 with 3750 signatures. Subsequently, the Ministry of Education has received additional funding from the government for BLENNZ, which is the equivalent of fifteen new Resource Teachers Vision, but the Parents of Vision Impaired have pointed out that this only moves the teacher to student ratio to one in twenty-nine, and thus an itinerant vision teacher in New Zealand has more than twice as many students on their roll than a similar teacher in Australia. (Parents of the Vision Impaired, 2008).

The Royal New Zealand Foundation of the Blind's (RNZFB) Children's Services

In early 2008, the RNZFB provided figures to the research team that identified 947 members under the age of 20 are on its roll. Of these 947 members, 162 or 17% were Māori, which is less than the percentage of Māori children under the age of 20 in the 2006 census (46%). The visual diagnoses of 174 RNZFB kāpo Māori members under the age of 22, indicated that 26% of kāpo Māori children did not have a recorded visual diagnosis and 16% of kāpo Māori children did not have a visual diagnosis that fitted into the RNZFB's usual diagnosis categories (see Table 18). Thus, 42% of kāpo Māori children's visual diagnosis was not documented in their database.

According to the RNZFB's website, services to children with a vision impairment are provided through their Children's Services and its staff of Child and Family Social Workers, Developmental Orientation and Mobility (O&M) Instructors, and Developmental Adaptive Daily Living (ADL) Instructors. Child and Family Social workers are identified as the point of contact between families and the RNZFB. It is stated that the work of the Child and Family Social worker is "tailored to meet the specific needs of the particular child within that particular family" and that they will "be respectful of people's cultural diversity." However, the word, whānau, is not used to describe families on the website about Children's Services, and there is also no reference to kāpo Māori or Māori within any of the description about the work of Children's Services. Also, of interest is that the whānau of children that go to the RNZFB website and are able to find the Mana Kāpo Service description, which, like Children's Services, is listed under 'Services for specific groups', will not find any reference to children, tamariki, or children's service under Mana Kāpo services. However, they do work with whānau and children as appropriate, and, according to the RNZFB, bring blindness awareness and prevention education programmes to schools (Royal New Zealand Foundation of the Blind, 2008b).

Table 18: Visual diagnoses of Māori RNZFB members under the age of 22, 2007

Diagnosis	174	%
Not Recorded: .	46	26%
Other	28	16%
Optic Atrophy	17	10%
Nystagmus	12	7%
Optic Nerve Hypoplasia	11	6%
Cataract	8	5%
Cortical Visual Impairment	8	5%
Aniridia	3	2%
Aphakia	2	1%
Lens Dislocation	2	1%
Cortical Damage	2	1%
Cortical Dysfunction	2	1%
Keratoconus	2	1%
Retinal Dystrophy	2	1%
Retinitis Pigmentosa	2	1%
Retinoblastoma	2	1%
Retinopathy	2	1%
Rod cone dystrophy	2	1%
Amaurosis	2	1%
Detachment of Retina	2	1%
Esotropia	1	
Exotropia	1	
Glaucoma	1	
Global Developmental Delay	1	
Hypoplasia	1	
Hypotropia	1	
Amblyopia	1	
Albinism	1	
Anterior Segment Dysgenesis	1	
Congenital Cataracts	1	
Congenitally Blind	1	
Stargardts Disease	1	
Subluxated Lenses	1	
Toxoplasmosis	1	
Trauma	1	
Lebers Congenital Retinal Amaurosis	1	
Myopia	1	

The RNZFB's *Annual Report* (2006-2007) indicated that 354 children learned to adapt to everyday life and be mobile through its Children's Services (Royal New Zealand Foundation of the Blind, 2007). Also, RNZFB Child and Family Social Workers supported 281 children, and the number of members participating in Recreation services through Children's Services

was 312. Children's Services provides services to RNZFB members and also contracts developmental O&M and ADL services to BLENNZ, the Ministry of Education's Group Special Education, and ACC. However, according to the figures above, not all of the children on BLENNZ's role received RNZFB specialist services. Group Special Education also offers services, such as Occupational Therapy, Speech Language Therapy, Physiotherapy, and learning support to children with a vision impairment, who have been verified as either having moderate, high, or very high needs (see discussion below about Group Special Education).

The Ministry of Education's Group Special Education

The Ministry of Education's (MOE) Group Special Education (GSE) administers a range of support options for children to access the curriculum and participate in education through adapted programmes, extra support and specialised equipment and grants. Children who are deemed to have moderate needs mostly receive services through their school or other schools that have therapy programmes for students with moderate needs. In 2008, about 7000 children in New Zealand were deemed to have high or very high needs, and received services through the Ongoing and Reviewable Resourcing Schemes (ORRS). To determine a child's level of need, a criteria system has been developed for children who have moderate, high, extreme or severe difficulty with learning, hearing, vision, mobility, and language use and communication (Ministry of Education, 2008). However, neither the Ministry of Education nor GSE provides a breakdown of the number of Māori students with a vision impairment in the data it gathers on disabled students.

Applications are accepted by the MOE from educators when a child is aged 4 years and 8 months, and older, and are assessed by a verifier from the MOE. If an application is made for child with a vision impairment, in order to be verified as having a very high need, the child must meet Criterion 2.3, which stated:

2.3 Students who rely totally on Braille for reading and writing. (Ministry of Education, 2006).

A child with a vision impairment is verified as having high needs if they meet either Criterion 6.2 or Criterion 9.1, 9.3 and one other, as outlined below:

6.2 Students have severe vision impairment and need regular input from a teacher with specialist skills in vision education to access the curriculum. This criterion is not for students with visual perception difficulties alone. Students who meet this criterion may:

- Have low vision in the severe range with visual acuity of 6/36 or beyond after best possible correction
- Have a loss restricting field of vision to 15-20 degrees
- Be blind but unlikely to learn Braille.

9.1 This sub-criterion is for students who have delayed cognitive development. At five, students will be learning skills and knowledge usually achieved by children up to three and a half years of age.

9.3: Students need specialist teacher intervention and monitoring to assist with moderate vision impairment. This sub-criterion is for students who have moderate vision impairment with visual acuity of 6/24 after best possible correction and/or a loss restricting the field of vision to 30 - 60 degrees. These students need specialist advice and teaching strategies to access the curriculum. This sub-criterion is not for students who have visual perception difficulties alone.

Children who are verified as having high or very high needs may receive specialist expertise (e.g. physiotherapy, occupational therapy, speech language therapy, orientation and mobility) as determined by their Individual Education Plan (IEP) (Ministry of Education, 2006). Also, once verified as having high or very high needs, each child receives through their school, extra teacher time. Children with very high needs receive .2 of a full time equivalent (FTE) teacher, and children with high needs receive .1 FTE. Children in ORRS receive support from paraprofessionals such as teacher aides under the guidance of a teacher. Also, they may receive grants for purchase of small items that are identified through their IEP (e.g. audiotapes) (Ministry of Education, 2006).

Māori children with an impairment and their whānau can also receive services from GSE's District Māori Advisors (Pouārahi-ā-Takiwā) and its Kaitakawaenga (Māori Liaison Advisors). According to the Ministry of Education (2008a), these staff work alongside special education specialists to help them provide culturally appropriate services to Māori children and their whānau and educators. They may be the key contact within GSE for whānau. (Ministry of Education, 2008a) Also, of note is the fact that in Auckland there is a Māori Focus Team, with sixteen Māori and Pākehā staff. They were described as working:

across the early childhood and school sectors providing culturally-appropriate services to Māori tamariki and rangatahi, and their families, within the Auckland City rohe. Included in the team are a speech-language therapist, a psychologist, special education advisors, a Kaitakawaenga, an early intervention teacher and a kuia and kaumātua. (Ministry of Education, 2008a)

Most of the children, who receive GSE services are in regular schools. However, there has been an increase of children who attend special schools over the last decade (Higgins, MacArthur, & Morton, 2008).

Parents of the Vision Impaired (NZ)

Parents of the Vision Impaired (NZ) (PVINZ) is a nationwide society that was established by parents who have children with a vision impairment. It is supported by the RNZFB and has a membership of over 2000 parents (Parents of the Vision Impaired, 2008a). The aim of the society is to achieve the best opportunities and outcomes for children who are blind or vision impaired. Whilst they do not cater specifically for Māori they have two tangata whenua representatives on the committee. However it is not known how many Māori parents are members.

Support and education are a big focus of PVINZ. For example advocacy plays an important role of PVINZ's work in supporting parents. They advocate at the national level with regard

to policy that impacts directly on the lives of their children and at the local level provide training for parents on how to get the most out of IEPs (individual education plans). PVINZ have formal links and relationships with key organisations both in New Zealand and internationally. Internationally, PVINZ has links with the National Association of Parents of Vision Impaired USA, and parent organisations in Israel, Malaysia, Philippines, Holland, England, China and India. They are also keen to develop links into the Pacific. Information is disseminated via a newsletter and annual conferences (Parents of the Vision Impaired, 2008a).

Tertiary Education

The 2004 *New Zealand Code of Practice for an Inclusive Tertiary Education Environment for Students with Impairments* came out to “assist tertiary education providers to achieve a fully inclusive environment”. It takes a rights-based approach to inclusion that acknowledges the Treaty of Waitangi and the centrality of partnership with Māori. The code is presented as a dynamic document that will change with ongoing development and implementation. The aims of the code were to:

1. Set out ‘Best Practice’ standards that describe the outcomes needed to create a fully inclusive tertiary education environment for students with impairments.
2. Assist tertiary education providers to:
 - (a) Understand the status of people with impairments in tertiary education in New Zealand
 - (b) Evaluate their progress towards an inclusive environment
 - (c) Identify potential barriers to participation and achievement that people with impairments face
 - (d) Improve tertiary outcomes for students with impairments
 - (e) Be aware of policy and legal obligations relating to people with impairments in tertiary education (Achieve, 2004, p. 11)

To these ends, the Code provided all tertiary institutions with a ‘heads up’ about the inclusion of disabled people in their programmes, and it can be used as a frame of reference for evaluating or reviewing tertiary services to students with impairments. (Achieve, 2004, p. 12). The Code also stated that inclusive best practice for disabled students included:

1. Equitable opportunities for students to achieve their individual capabilities and participate in all aspects of tertiary education life
2. The respect for students’ rights, dignity, privacy, confidentiality, and equality
3. Participation in an environment that is free from harassment and discrimination where both staff and students are aware of their rights and responsibilities under legislation
4. Policies, procedures, services and facilities, including strategic planning and resource allocation, enable students to achieve
5. Equitable access to tertiary education and the full range of activities that encompass campus life
6. An equitable learning environment is created by considering the needs of

students including course design, curriculum, delivery, assessment and support strategies

7. Being enabled to participate in their course of study on equal terms with other students
8. Trained staff that meet the requirements of students with impairments, that their requirements and requests are treated promptly and seriously
9. Pro-active students, who make their requirements known in advance, where possible share responsibility for negotiating and developing solutions, and advise institutions of any difficulties they encounter (Achieve, 2004, pp. 13-14)

Accordingly all public tertiary institutions should have policies about students with impairments. However, our survey of a number of universities, polytechnics and wānanga websites showed considerable variability in regards to this and in the information that they provide about their policies and services to students with impairments. This may be an indicator of not only the institution's policy but also of their willingness to welcome students with impairments. Of concern are the institutions that have little accessible information about the services they provide. One wānanga, in particular, does not have anything about the services that they provide to disabled students on their website.

With regard to kāpo Māori, the policies at tertiary institutions in New Zealand, which we surveyed, did not highlight any one type of impairment. Most institutions made it clear on their website that they provided a range of resources and equipment for students with vision impairments, such as note-takers, one-to-one tutors and assistants, examination support, alternative formatting of course materials, and adaptive technology. Each institution provided services for students with vision impairment regardless of their ethnicity. The number of Māori students with impairments enrolled at tertiary institutions is not known, nor is it known how many kāpo Māori are enrolled in tertiary institutions. Further, it is unknown how many student advisors or tertiary support staff for those with a vision impairment are Māori.

Conclusion

In this chapter the relevant demographics of, and services for, kāpo Māori have been discussed within the context that it is clear that across a range of well-being and quality of life domains, Māori continue to be over-represented in negative indices (Ministry of Social Development, 2007). Almost half of the Māori population are under the age of 20 years of age, with most living in the North Island. It was estimated from the 2006 Census that approximately 96,000 Māori (out of a total of 644,000 Māori) had a disability. Over a quarter of those were tamariki under the age of 15 years. Further to this, in regards to estimating the number of kāpo Māori, one of the problems is the contested nature of what constitutes blindness and vision impairment because there are a number of definitions in New Zealand. Counts of kāpo Māori seem to be reliant on kāpo Māori identifying themselves as having an impairment and on 'getting through the gates' of service agencies, which have their own eligibility requirements, limited resources, and different approaches to service delivery that may or may not take into account the cultural beliefs and values of kāpo Māori. For example, it is estimated above that there are 78,380 Māori over the age of 30 with diabetes, and that of these 30% (23,5214) have some type of retinopathy. However, in February, 2008, there were

only 32 Māori who were receiving services from and recorded by the RNZFB to have diabetic retinopathy. (RNZFB, 2007)

The lack of a national definition and knowledge about the demographics of Māori with a vision impairment has implications for diagnoses, ongoing treatments/therapies and access to services. The RNZFB is the largest non-government agency providing services to blind and vision impaired New Zealanders. They have historically provided services for all blind and vision impaired New Zealanders. In more recent times they have included statements about tangata whenua in their constitution giving recognition, respect and due regard to Māori cultural and spiritual values, needs and interests. In doing so RNZFB promote the principles of the Treaty especially partnership, participation and protection of the interests of kāpo Māori and their whānau, and the upholding of the their tino rangatiratanga – their self-determination – of kāpo Māori and their whānau in respect to the services that the Foundation delivers. The Foundation services are determined by the demographics of their membership. While the majority of RNZFB members are over the age of 20 years a large number of kāpo Māori are under 20 years of age. There is also a difference between Māori and non-Māori in the types of diagnosis of RNZFB members. Nearly half of Māori members have no recorded visual diagnosis compared to 20% of non-Māori on the RNZFB's database. Thus, despite RNZFB's constitutional and operational policies providing Māori diagnostic, assessment, and easy access to services while meeting Māori cultural and spiritual needs remain a challenge.

Ngāti Kāpo O Aotearoa was established in 1981 in response to kāpo Māori needs not being met. Ngāti Kāpo is a kaupapa Māori service provider whose mandate comes from their kāpo whānau membership. There are 786 members of Ngāti Kāpo of which 582 identify as kāpo, the majority being 25 years of age and older. Ngāti Kāpo is a significant organisation for supporting the identity and cultural well-being of all its members. Whilst Ngāti Kāpo provides a national service that is oriented towards fulfilling kāpo Māori education, health and cultural well-being and is committed to enabling tino rangatiratanga, there are also three smaller local organisations that provide support and advocacy services to kāpo Māori.

Vision impairment in children is identified either by educational or medical services. In regards to the demographics of kāpo Māori children, Statistics New Zealand estimated that there were 3300 children under the age of 14 in 2006. However, in 2006, there were only 244 kāpo Māori children (aged between 0-21) on BLENNZ's roll. Also, of interest was that 46 (26.4%) of the 174 kāpo Māori registered with the RNZFB under the age of 22 did not have a recorded visual diagnosis, and that 28 (16%) did not have a diagnosis that could be classified in any of the RNZFB's 272 diagnostic categories.

Information about the prevalence of vision impairment and the general demographics of kāpo people is important for the adequate provision of health and education services and for the development of preventative strategies (Schwarz, Yeung, Symons & Bradbury, 2002). There is no national database for children with a vision impairment in New Zealand. As a consequence to the lack of coordinated documentation and assessment processes there are wide disparities in access to services whether they be health or educational.

Services for children with a vision impairment have been extensively documented over the course of the last ten years. Services began in 1891 and while there have been changes over the course of the last one hundred and eight years, the RNZFB has continued to play a leading role. Historically, children with a vision impairment were institutionalised in special schools, and the most significant change has been their 'de-institutionalisation'. Currently

BLENNZ, which is funded by the Ministry of Education, focuses on inclusive education and provides specialist services to children with a vision impairment. Enrolled students in BLENNZ only go to Homai for short stays, but students may board at Homai and attend local high schools. BLENNZ provides their support services to regular schools through Resource Teachers Vision (RTVs).

Some children with a vision impairment also receive educational and support services through the Ministry of Education's Group Special Education if they are verified as having high or very high needs. These services may include orientation and mobility, teacher aide support, occupational therapy, and physiotherapy. At the tertiary level, the focus is on the inclusion of disabled students. However, again, little is known about the number of Māori students with impairments, or the number of kāpo Māori enrolled at tertiary institutions. In conclusion, further research to explore and determine the demographics of kāpo Māori of all ages in New Zealand is needed, and would be of benefit to the development of services that can improve their well-being and quality of life.

Chapter Four

Method/ology

Introduction

This research investigated two interrelated issues of importance for kāpo Māori and their whānau: How the impairment of blindness affects Māori; and how health and education services impact on their identity, cultural well-being and health. The proposed research sought to answer these questions by undertaking a narratively inspired project within a kaupapa Māori framework, exploring the experiences of ten kāpo Māori and their whānau using a case study approach. To undertake this research adequately we considered it important to first establish the context of being kāpo Māori in New Zealand Aotearoa. Thus, before case studies were undertaken for this report, and during the first year of this project interviews with 43 key informants (education and health professionals, and kāpo Māori and their whānau) were held to identify overarching issues and concerns for kāpo Māori; a literature review was completed; and an exploration of the relevant demographics and policies was also completed. This ecological approach is consistent with Māori concerns and aspirations for holistic ways of thinking, being and doing in the world (Macfarlane, 2000), and Rose Pere's (1986, 1997) 'wheke' provided the metaphor for thinking about and taking account of the multi-dimensional nature of Māori lived realities. During the second year of the project, ten in-depth case studies with kāpo Māori and their whānau were completed.

An initial analysis from the key informant data has been published in the *Childrenz Issues* journal and has been presented at a number of national and international conferences (Higgins, Phillips, Cowan, & Tikao, 2009, Jan. 2009; Higgins, Phillips, Cowan, Wakefield & Tikao, 2009 Sept, 2009 Nov., 2009 Dec.; Phillips, Higgins, Cowan, & Tikao, 2008 Dec., 2009 May; Tikao, K., Higgins, N., Phillips, H., & Cowan Dec. 2008, May 2009). The initial literature review, and a discussion of relevant and detailed demographics and policies were included in an *Interim* and *Supplementary* report (Higgins, Phillips, Cowan & Tikao, 2008, 2008a). The overarching issues and concerns from the kāpo Māori and their whānau in the key informant interviews formed the thematic framework (discussed below) in which to explore the case study data. The results of the key informant interviews, however, which include interviews with fifteen health and education professionals, has been presented elsewhere, and they are not presented in detail in this report so that the in-depth stories and narratives of the ten case study participants can remain the focus and at the forefront of this study. By focusing on the realities and stories of our case study participants, we hope to prioritise and listen to the knowledge from kāpo Māori and their whānau, and thus avoid professional conceptual dominance about growing up kāpo Māori. Smith (1999) warned of such dominance in her discussion about Māori experiences of research. Thus, this project, in addition, followed a kaupapa Māori framework throughout its duration.

The research design and method reflected not only the location of the research within the kāpo Māori community but also the collaboration between Ngāti Kāpo O Aotearoa Inc, He Parekerekere (Institute for Research and Development in Māori and Pacific Education, Victoria University of Wellington) and the Donald Beasley Institute. It brought together the particular strengths of all three organisations to provide a multi-disciplinary and multi-location approach to the research and a commitment to working together for a common end (Jeffrey,

2003). The goal was to unlock the potential within whānau, hapū and iwi and, in particular, kāpo Māori so that they can live as Māori, actively participate as citizens of the world and enjoy good health, and a high standard of living (MoRST, 2006; Health Research Council, 2004; Durie, 2001). Thus the project was positioned within a kaupapa Māori framework in which:

- the research responds to issues of importance to Māori;
- where Māori are the primary researchers;
- where all the researchers are guided by tikanga Māori;
- where the integrity of the participant is of the utmost importance;
- where new Māori knowledge is created by using mātauranga Māori as its foundation;
- where the research is wholly relevant to Māori;
- where Māori are the primary beneficiaries;
- and that dissemination of the research is taken back to the community (FoRST, 2006).

The seed for the study came from one of the Māori participants' stories from Dr. Nancy Higgins' 2001 doctoral thesis, *Blind people: A social constructivist analysis of New Zealand education policy and practice*, and through later discussions, Ngāti Kāpo O Aotearoa (Ngāti Kāpo) became the initiators of this research. Also, as a result of discussions with Ngāti Kāpo a three-way research partnership was established with the Donald Beasley Institute and He Parekerekere of Victoria University. Ngāti Kāpo involvement in this project through its Research Management Committee, which was a sub-committee of its Tuamaki or Executive. This ensured that the project's and the researchers' accountability to Ngāti Kāpo was direct, and the project was Māori controlled (Bishop, 1994). It also enabled Ngāti Kāpo to fulfil their aspirations in terms of developing their own research capacity and capability (Ngāti Kāpo O Aotearoa, 2004). Mr. Nigel Ngahiwi (Ngāti Maniapoto) (chairperson), Mr. Pura Parata (Kai Tahu, Kāti Mamoe, Waitaha, Hawea), and Dr. Khyla Russell (Kai Tahu, Kāti Mamoe, Waitaha, Hawea and Rabuvai) were members of the research management committee, which met three times a year with the research team and which reviewed and approved all the analysis, publications, and reports from the study.

The Royal New Zealand Foundation of the Blind (RNZFB) and Blind and Low Vision Education Network New Zealand (BLENNZ) agreed to also be a part of this research, in that they were localities in which data could be gathered as appropriate and participants recruited. Ngāti Kāpo was the main locality organisation from which participants were recruited because of its extensive networks and direct involvement within the study. Discussions about the project also occurred at Ngāti Kāpo Biennial Hui in Paihia (2007) and at thirteen Ngāti Kāpo whānau or rōpū hui during the first year of the study, and at Ngāti Kāpo Biennial Hui in Wellington (2009) and ten Ngāti Kāpo whānau, network, or rōpū hui during the second year of the study.

The research team for this project included Dr. Nancy Higgins (lead researcher) (Greek American), Dr. Hazel Phillips (co-researcher) (Ngāti Mutunga), Mrs. Christine Cowan (co-researcher) (Ngāti Kahungunu), Ms. Kelly Tikao (Waitaha, Kāti Mamoe and Kai Tahu) for the first 18 months of project), and, later, Dr. Benita Wakefield (Ngāti Kahungunu and Kai Tahu) for the last six months of the project. Dr. Higgins was the only non-Māori within the project, and was involved because of her interest in social justice and her expertise in the area of qualitative research, blindness and vision impairment. Bishop (1994) has argued that non-Māori researchers need to support Māori researchers because otherwise non-Māori researchers would "abrogate their responsibilities as Treaty partners" (p. 145) and leave the

solutions for injustice and inequity to Māori resolve. Experienced non-Māori researchers can also help novice Māori researchers to develop their research skills.

Within a kaupapa Māori framework, research is concerned to privilege Māori ways of knowing and doing that retrieves spaces for Māori voices and perspectives in which Māori realities are legitimate and social transformation occurs (Smith, 1999), not the transformation of Māori but transformation of policies and services to Māori. The researchers recognised not only the benefits of doing research within their own communities (e.g. kāpo Māori, disability community and Māori education), but also the tensions that are inherent in doing insider research (Brayboy, & Deyhle, 2000). The lack of intellectual and emotional distance when researchers come from within the community in which they are researching potentially constrains the kind of questions asked and the analysis undertaken (Hammersley & Atkinson, 1996). It is argued for this project though that such a lack of distance was not only beneficial but also critically important for eliciting relevant issues in culturally appropriate ways as “the passion from within” enables “the authority to ask new and different questions” based on the histories and experiences of being kāpo Māori (Swisher, 1998, p193).

In seeking to do research that is both rigorous and credible, accurately representing participants’ realities and developing credible findings, we drew on Cresswell and Miller’s (2000) validity framework in which the lenses of the researchers, the participants, and people external to the research were critical components of the research plan as are the paradigm assumptions we also bring to our research design. The three ways in which to ensure the validity and credibility of the research findings were: working collaboratively and reflexively as researchers; having an ongoing relationship with the participants; and our accountability to the Research Management Committee which oversaw the planning, implementation and analysis of the research.

Stories, Narrative and Case Studies

Gathering and telling stories at the inception of this project was considered by Ngāti Kāpo to be the most appropriate methodology to use. Telling stories is fundamental to making sense of our experiences in the world (Bishop, 1996; Phillips, 2003) as well as to providing a ‘forward glance’ to help us to anticipate future situations and encounters (Flyvbjerg, 2006). The art of gathering stories foregrounds the importance of respect, reciprocity and caring between the researcher and ‘the researched’, placing the relationship between the researcher and research community at the centre of the research. To that end stories “are especially viable instruments of social negotiation” (Bruner, 1990, p 55). Not only is this well understood by Māori, but according to Bishop (1996) there is a strong cultural preference by Māori for narrative and conversation. Utilising culturally preferred processes and understandings the research design and method builds on the notion of whakapapa as both an organising tool and a framework for telling stories (Phillips, 2003). In this study, ten kāpo Māori participants were invited to tell their stories using an open-ended schedule of questions that was intended to help prompt participants rather than determine their stories, giving participants time to reflect on their experiences and to envision alternative futures.

In explaining narrative methods, Smith and Sparkes (2008) noted that “a person is essentially a storytelling animal” (p. 17), and that narrative research is a form of social action, a way to know, a psycho-socio-cultural resource, and a reality constructor. Narratives illuminate the

personal, the self, and identity (Smith & Sparkes, 2008), and are particularly useful for disability studies because they are politicised, socialised, and ‘culturalised’. (Goodley, Lawthorn, Clough, & Moore, 2004). Life narratives are shaped temporally and sequentially; can be told from the perspectives of a number of participants; and have characters, plots, and a focus (Holley & Colyar, 2009). Holley and Colyar (2009) pointed out that researchers become the story tellers as they reshape the data that they have gathered to explain participant’s social reality as they see it to readers.

A case study approach to answer our research questions was also considered appropriate for this research because it was consistent with narrative inquiry and it works to get to the heart of the matter and to capture a richly nuanced thick description of the phenomena under study (Geertz, 1973). Yin (1984) noted that case studies answer ‘what, how, and why’ questions through research evidence that is gathered in observations, documents, and interviews. Also, case studies provide a picture of phenomenon over time and, when case studies are combined then the relationship between the cases can be explored with an emphasis on social processes and structures (Stake, 1994; Reinharz, 1992). Multiple case studies thus can form a collective case study that can then lead to a better understanding of an even larger collection of cases (Stake, 1994). Stake (1994) wrote that researchers seek the common and the particular about each case, but the uniqueness of each story is pervasive. Case studies can thus help to elucidate the complexity and uniqueness of individual lives and offers “specificity, exceptions, and completeness” (Reinharz, 1992, p. 174). They also can increase the visibility of marginalised groups that challenge dominant discourses, cultures and perspectives because diverse and unique perspectives and knowledge to the dominant are presented (Reinharz, 1992).

In this project, interviews with participants as they constructed and told their stories occurred as individual interviews or in a hui (meeting). The hui was an important concept for this research project because it informs the way in which we as researchers conduct ourselves when gathering the participants’ stories. In keeping with Māori cultural practice, the hui as a lived practice, was the most appropriate space in which to meet with kāpo Māori and their whānau. Hui are forums in which people are able to stand and have their say on anything pertaining to the kaupapa for coming together. Underlying such practice is the idea that contributions are made on the basis of what people have to share, however small or large. Fundamentally, the coming together as a group to talk and to share stories recognises not just a meaningful cultural practice, but also the culturally specific value of being part of a group. The connection that Māori have with one another, that enables a feeling of belonging, is one of the primary strengths of the hui as a research method (Phillips, 2003). While to be part of a group is to feel a sense of belonging this cannot be taken for granted and it is for this reason that individual interviews with kāpo Māori case study participants were also an option.

There are at least four benefits to using hui as the research forum. Firstly, it can reveal the way in which the participants relate to one another providing insight into their shared perspectives and secondly, in doing so add to the overall soundness of the data gathered. At the same time, it can generate a greater range of responses, as well as richer dialogue as participants prompt and challenge one another. Lastly, hui are forums that enable the participants to expand their own knowledge and understanding of the world by sharing their world with others, and having others share theirs in return. This is one of the traditional objectives of holding hui in the first place. In short, the hui is a facilitative and proactive culturally specific research method in which understanding and knowledge is produced. It presupposes the cooperative and active participation of those present (Phillips, 2003).

The Research Questions and Objectives

The overall research questions for this project were:

1. How does the impairment of kāpo affect Māori?
2. How do health and education services impact on the identity, cultural well-being and health of kāpo Māori and their whānau?

The overall aim of the study was to contribute to the knowledge about kāpo Māori so that services for kāpo Māori will better address the cultural well-being and the health of kāpo Māori and their whānau. The specific aims of the project were:

1. In regards to kāpo Māori and their whānau, to identify current demographic information, government health and education and NGO policy documents, and other relevant documents.
2. To identify the general issues relating to the cultural well-being and health of kāpo Māori and their whānau with regard to identity, cultural well-being and health when interacting with, or receiving, education and health services.
3. To identify how the impairment of blindness affects Māori and how health and education services impact on the identity, cultural well-being and health of kāpo Māori and their whānau.
4. To complete a final report and disseminate results of the study.

Tikanga Whakaaro and Participants

Arohia Durie's (1998) notion of ethicality provided the basis from which the researchers operated in this project. Durie's ethical framework is built around three aspects of mana – mana tangata, mana whakahaere and mana motuhake. Mana tangata is about ensuring that our research practice is people oriented, where people are treated with respect and are able to participate safely. Mana whakahaere attends to the ways in which effective relationships are promoted through the research process. Mana motuhake takes for granted the legitimacy and validity of being Māori and is about Māori self-determination in research processes and outcomes. Such a framework is vitally important in facilitating a common vocabulary for effective collaboration.

Also, because this project involved human participants, ethical approval was sought and obtained from the Multi-Region Ethics Committee, which is administered by the Ministry of Health. Potential participants identified themselves or were identified through Ngāti Kāpo, BLENNZ (Blind and Low Vision Education Network, NZ), or the RNZFB (Royal New Zealand Foundation of the Blind), or through the professional and personal networks of the researchers. Once identified, they received an initial written brief study summary and permission was sought for a researcher to talk to them further. The researcher then met with them at a time and place that was convenient to the participant. Tikanga and marae kawa were followed at relevant research places. The researchers provided potential participants with further information about the study through discussion and a written information sheet

in their preferred language and literacy medium, and informed consent for their participation was then sought.

Participants in the first year of the project were 43 key informants, who included relevant professionals in health and education services, kāpo Māori, and whānau. (see Table 19). From the key informants and participant recruitment activities and in the second year of the project, a range of kāpo Māori and their whānau were asked to participate for the case studies. (see Table 20). Kāpo Māori case study participants needed to have a vision impairment from birth. The reason for this was that experiences of people blind from birth may be qualitatively different to those who have a vision impairment later in life. For the ten kāpo Māori case study participants, a geographic and iwi spread, gender balance and age spread across the five generations of Ngāti Kapo: nohinohi (0-4 years of age – *note: children under age 5 were not interviewed, but their whānau were*), tamaiti (5-14 years of age), rangatahi (15-24 years of age), pakeke (25-64 years of age), and kaumātua (65+ years of age) were sought. These requirements were met except that in total there were six females and four males in the case studies because of the low numbers of known kāpo Māori in the youngest or nohinohi age group. Also, of note was the fact that all of the kāpo case-study participants were considered blind, with only one participant able to read very large print. In total, there were 47 participants for the case studies, including 39 whānau members and 8 kāpo Māori case study participants. In the entire study, there were 78 participants, including 12 participants who participated both as key informants and case study participants.

Participant anonymity and confidentiality was of utmost concern especially given the small and close-knit nature of the kāpo Māori community. Pseudonyms were used for participants. Only the researchers had access to the raw data within the data, and specific identifying information of participants, such as exact age, geographic location or iwi, were not included in reports to the Research Management Committee or in publications about the study.

Table 19: Characteristics of key informants

Key Informants	Number	# Interviews	Sex	Age Group	Ethnicity
Health & Education Professionals	Total= 10	9 (including one key informant hui)	3 males 7 females	10 pakeke (25-64)	3 Māori 7 Pākehā
Whānau Members	Total= 11 2 grandparents 5 mothers 2 fathers 1 sibling 1 partner 6 case study participants (3 whānau)	6 (including four key informant hui)	4 males 7 females	9 pakeke 2 rangatahi (aged 15-24)	8 Māori 2 Pākehā 1 Pacific Island
Kāpo Māori	Total= 22 5 Health/education professionals 6 Case study participants	22	13 males 9 females	4 kaumātua (aged 65+) 10 pakeke 8 rangatahi	22 Māori
Total	43 (8 case study whānau)	37	20 males 21 females	4 kaumātua 29 pakeke 9 rangatahi	33 Māori 9 Pākehā 1 Pacific Island

Table 20: Characteristics of case study participants

Case Study Participants	Number Participants:	Number Visits/Interviews	Sex	Age Group	Ethnicity
<u>Whānau 1</u> Bruce (kāpo Māori) Daniel (brother) Brian (brother) Hine (daughter) Joy (daughter)	5	5 (including one key informant interview)	3 male 2 female	2 kaumātua 3 pakeke	5 Māori
<u>Whānau 2</u> Ngaio (kāpo Māori) Rua (husband) Tane (son) Karen (Ngāti Kapo whānau) Pete (Ngāti Kapo whānau)	4	5 (including one key informant interview)	3 male 2 female	2 kaumātua 3 pakeke	5 Māori
<u>Whānau 3</u> Hoani (kāpo Māori) Miriamia (wife) Hemi (son) Bill (son) Mere (daughter)	5	5 (including one key informant interview)	3 male 2 female	4 pakeke 1 rangatahi	5 Māori
<u>Whānau 4</u> Sara (kāpo Māori) Eleanor (sister) Ropata (brother) Susan (sister in law) Carole (employer)	5	7 (including one key informant interview, and one hui/ group interview with two participants)	1 male 4 female	5 pakeke	4 Māori 1 Pākehā
<u>Whānau 5</u> Tommy (kāpo Māori) Nanny Pearl (grandmother) Sue (guardian) Joe (guardian)	4	4 (including one key informant interview, and one group interview with two participants)	2 male 2 female	1 kaumātua 2 pakeke 1 rangitahi	2 Māori 2 Pākehā
<u>Whānau 6</u> Elizabeth (kāpo Māori) Tim (partner) Vince (father) Jane (mother) Dave (friend) Waiata (Homai residential worker) Betty (Vision Teacher)	7	6 (including one key informant hui interview and one hui/group interviews with two participants)	3 male 4 female	3 rangitahi 4 pakeke	2 Māori 3 Pacific Island 1 Pākehā

Table 20 (continued)

Case Study Participants	Number Participants:	Number Visits/Interviews	Sex	Age Group	Ethnicity
<u>Whānau 7</u> Kahu (kāpo Māori) Ahorangi (mother)	2	2 (including one hui/group interview with two participants)	1 male 1 female	1 pakeke 1 tamaiti (aged 5-14)	2 Māori
<u>Whānau 8</u> Kapua Kore (kāpo Māori) Koro (grandfather) Airini (mother) Māui (brother)	4	6 (including one hui/group interview with four participants)	2 male 2 female	1 kaumātua 1 pakeke 2 tamaiti (aged 5-14)	4 Māori
<u>Whānau 9</u> Marama (kāpo Māori) Hone (grandfather) Mary (grandmother) Frank (father) Maia (mother)	5	3 (including one key informant hui and one hui/group interview with two participants)	2 male 3 female	1 kaumātua 3 pakeke 1 nohinohi (aged 0-4)	2 Pākehā
<u>Whānau 10</u> Cathy (kāpo Māori) George (grandfather) Hine (grandmother) Mane (father) Tania (mother)	5	3 (including one key informant hui interview, and two hui/group interviews with two participants)	2 male 3 female	2 pakeke 2 rangitahi 1 nohinohi	5 Māori
Total	47	47	22 male 25 female	7 kaumātua 18 pakeke 7 rangitahi 2 tamaiti 2 nohinohi	40 Māori 3 Pacific Island 4 Pākehā

Telling the Stories

All participants (key informants, kāpo Māori and kāpo Māori whānau) were invited to tell their stories using an open-ended schedule of questions that was intended to help prompt participants rather than determine the stories that they tell. Interviews with participants took place wherever the participant wished, and included their home, their workplace, marae, and meeting rooms of their choice. Tikanga and marae kawa were followed at these research places. Participants participated in one to three individual interviews, and some kāpo Māori and their whānau participated in a case whānau hui. Interviews were audio-taped and transcribed, word-for-word, in the participant's preferred literacy medium. Participants then reviewed and approved their transcripts for use in the study.

The questions for key informants who were kāpo or whānau included:

1. How did you become kāpo/or become associated with kāpo Māori?

2. What is your age, iwi, geographic location?
3. Who are your whānau? How would you define whānau?
4. How would you define 'kāpo'?
5. In general, as kāpo Māori (or whānau) what type of services did you receive and experiences did you have in regards to Education Services? Education professionals?
6. As kāpo Māori (or whānau) what type of services did you receive, and experiences did you have in regards to health services? Health professionals?
7. As kāpo Māori (or whānau) what type of services did you receive, and experiences did you have in regards to culture?
8. How did these services and experiences affect you? Affect your whānau? Affect your relationship with your whānau?
9. What do you think are the main cultural, health, and education issues for kāpo Māori, and their whānau?
10. What is your connection with Te Reo or tikanga?
11. What do you consider to be appropriate, or effective, support for kāpo Māori and their whānau?
12. How do you think being kāpo Māori, or part of a whānau with kāpo Māori, has affected (positively or negatively) your general well-being and your cultural well-being?
13. Would you be interested in talking again and being part of our 10 case studies?
14. Do you think your whānau would be interested in talking to us as well?

The questions for the key informants who were professionals included:

1. How did you become become associated with kāpo Māori?
2. What age group do you belong to (e.g. 21-30, 31-40, 41-50, 51-60, 61-70), iwi, geographic location?
3. Who are your whānau? How would you define whānau?
4. How would you define 'kāpo'?
5. In general, for kāpo Māori (or whānau), what type of education services, do you offer or think should be offered? What professionals work with kāpo Māori and their whānau?
6. In general, for kāpo Māori (or whānau) what type of health services, do you offer, or think should be offered? Who are the health professionals who work with kāpo Māori and their whānau?
7. In general, for kāpo Māori (or whānau) what type of cultural services or experiences, do you offer, or think kāpo Māori (or whānau) should have?
8. How do you think cultural, education or health services affect, or have affected, kāpo Māori? Their whānau?
9. What do you think are the main cultural, health, and education issues for kāpo Māori, and their whānau?
10. What is your connection with te reo or tikanga?
11. What do you consider to be appropriate, or effective, support for kāpo Māori and their whānau?
12. How do you think being kāpo Māori affects (positively or negatively) general their well-being and cultural well-being? How does it affect the whānau?

The primary questions for case study participants were: Can you tell me your story; What it is like to be kāpo Māori or to have a whānau member who is kāpo Māori; What have been your life experiences; and what have your experiences been like in regards to your culture, your

health and education? The topics of conversation that could be covered in these interviews were:

1. *Early Health Experiences*: Can you tell me about your, or your kāpo whānau member's, early experiences in regards to their health?
2. *First Experience*: Can you tell me how you, or your kāpo whānau member, first came to know that she or he was kāpo?
3. *Disability*: Can you tell me what you were told about being kāpo? By whom?
4. *School Experiences*: Can you tell me about your, or your kāpo whānau member's primary, intermediate, and/or tertiary school social and learning experiences?
5. *Health Experiences*: Can you tell me about your, or your kāpo whānau member's, experiences in hospital, or with health professionals?
6. *Upbringing*: Can you tell me about your upbringing?
7. *Attitudes*: Can you tell me about your, your whānau's, your kāpo whānau member's, and your iwi's attitudes about being kāpo? What do you think about kāpo? What does it mean to you, personally?
8. *Family Ties*: Can you tell me about your, or your kāpo whānau member's, past and present family ties?
9. *Professionals*: Can you tell me about your, or your kāpo whānau member's, relationship with professionals (education, special education, and health)?
10. *Barriers*: Can you tell me about the types of barriers, or things, that disadvantage you, your whānau, or your kāpo whānau member?
11. *Vocation*: Can you tell me about your, or your kāpo whānau member's career interests, prospects, and experiences?
12. *Social Life*: Can you tell me about your, or your kāpo whānau member's social life at present? What was it like in the past, or at various times?
13. *Cultural Life*: Can you tell me about your, or your kāpo whānau member's cultural life at present? What was it like in the past, or at various times?
14. *Issues*: What are the main cultural, health and education issues for kāpo Māori, their whānau, and iwi? How can these be addressed? How can the health and education for kāpo Māori and their whānau be improved?
15. *Cultural well-being*: If at all, how can the well-being of kāpo Māori and their whānau be improved?
16. *The Future*: If you had to describe to a kāpo Māori and their whānau what it is like in New Zealand, what would you say?

For tamariki participants, questions were asked in plain language and in language that was appropriate to the child. Field notes were also taken at times by researchers about the participant's story, and then these notes were reviewed with the participant for and approval was sought to use these in the study as appropriate.

Story Analysis and Presentation

For Smith and Sparkes (2008), narratives embed and help to explain bodily experiences, and they need to be analysed as the object of enquiry with their context in mind. Researchers can explore narratives in a number of ways, in that "the researcher steps outside or back from the story and employs analytical procedures, strategies and techniques in order to scrutinise, explain and think about its features Smith & Sparkes, p. 21). In this project, the ten case-

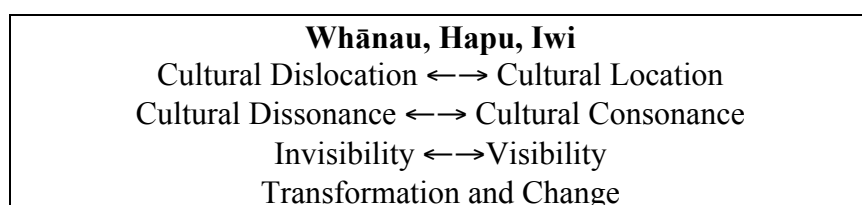
study narratives as stories are presented in the results chapters that follow this chapter. They are discussed within a thematic framework in the discussion chapter of this report. In the result chapters, the participant stories have been told firstly by the participants, themselves, in interviews and then have been reconstructed by the researcher to illuminate an overarching story that the research team acknowledge has been crafted to present the researcher's focus and interpretation of the case studies' stories through the multiple perspectives of participating whānau.

The analytical thematic framework for these stories was developed from the kāpo Māori and whānau key informant interviews, and were again confirmed after the stories from the case studies had been gathered. This framework arose using relevant matauranga and tikanga Māori, and Dr. Higgins, Dr. Phillips, and Mrs Cowan, who were the experienced and named researchers in the project participated in the data and story analysis process, which the research management committee oversaw. They met in retreat hui to discuss and write about the data with the invaluable support and care from Ngāti Kāpo. During these hui, initially, all research transcripts were shared. It soon became apparent though that the data from the key informants who were professionals were different from the data with kāpo Māori and their whānau. The themes within the professionals' discourse were about the available services, the limitations of health and education services for kāpo Māori, limited resources, and the need to develop culturally appropriate and accessible services. The data from their interviews helped the research team understand the context in which kāpo Māori were encountering service. However, it was evident that their perspectives could not richly illustrate or describe the in-depth the nuances of what it was like to 'grow up kāpo Māori'. Thus, it was decided in keeping with the kaupapa of the project to prioritise and focus on developing an analytical framework from the data and stories from kāpo Māori and their whānau transcripts.

From the kāpo Māori and whānau transcripts, four common themes and patterns emerged that structure the case study stories. These themes also directly answered our research questions about how the being kāpo affects Māori and how services impact on kāpo Māori identity, well-being and health (Bogden & Biklen, 1982; Kvale, 1996; Wolcott, 1990). These themes were present in all of the case study stories, but each story also has a rich unique character and each story had the overall thematic umbrella of 'whānau, hapū, and iwi'. The four fluid themes were: (1) cultural dislocation and location; (2) cultural dissonance and consonance; (3) invisibility and visibility; and (4) transformation and change. While the first three themes could be understood, perhaps, as opposites, the reality of each participant's story was that their experience of being kāpo Māori was much more complex and fluid. For example, kāpo Māori may be both visible and invisible to education and health services. Also, their experiences of being visible or invisible could be either positive or negative, depending on the situation.

These four fluid themes under the 'whānau, hapū, iwi' umbrella are presented as a diagram below (see Figure 12):

Figure 12: The themes from the stories:



Thematic meanings

The first theme, cultural dislocation and cultural location, was directly related to participants' identity as Māori, as kāpo and as kāpo Māori, and their whakapapa and experiences of belonging and connectedness. The second theme, cultural dissonance and consonance, was about how education and health services fit with the experiences of being kāpo Māori. Meanings for dissonance for this study can be extrapolated from the field of music where dissonance is another word for discord or "an inharmonious combination of simultaneously sounded tones" (<http://www.thefreedictionary.com/discord>). Consonance can be thought of as harmony in the culture of service delivery and kāpo Māori. Within the key informant data, cultural dissonance and consonance were also linked to cultural dislocation and location. For example, Cultural dissonance within education services led to cultural dislocation, which impacted on their ability to express themselves fully as Māori. On the other hand, cultural consonance enabled kāpo Māori to develop firm cultural locations and positive identities as Māori and kāpo Māori. The third theme, invisibility and visibility, was about whether the participants were invisible or visible to others and to health and education services as kāpo, as Māori, and as kāpo Māori. The last theme, transformation and change, was related to the ways in which the participants believed they could resist, transform, or change their circumstances to meet their desires and their aspirations 'to get on' in the world.

When reading the stories that follow, the reader is asked to think of these themes, and the unique experiences of each case-study participant. Also, it should be noted that each story was primarily developed, and written, by the three researchers within the project with assistance from the emerging researchers. The stories were edited for consistency and clarity by the lead researcher. Scheurich (1995) has noted that the imposition of meaning on stories can be ameliorated by the reader having more knowledge of the researcher's perspectives. Dr. Higgins edited all of the results chapters, and was primarily the key writer for Bruce's, Ngaio's, Sara's, Elizabeth's, and Marama's and their whānau stories. Dr. Phillips was the key writer for Hoani's, Kahu's, and Kapua Kore's and their whānau stories. Mrs. Cowan was the key writer for Tommy's and Cathy's and their whānau stories.

The researchers' stories

Dr. Nancy Higgins

I am a Greek American who grew up in Alaska in Anchorage with Mt McKinley nearby, views of the Aleutian Inlet, and near Eagle River. I now live in a small cottage on an acre in Warrington. Warrington is a small seaside village that is north of Dunedin. At the moment, I have many animals here in my life, including one dog (Banjo), three cats (Dale, Dolly, and Doris), three alpacas (Charlie, Milo and Jack), one turtle (Barney), and one goat (George). I grew up in Alaska with my mother, Thanasea, and two brothers, Gene and Denis, until the 1964 earthquake. After the earthquake, we all moved to Boston, Massachusetts, to be closer to my mother's father, Konstantine Fountas, and my mothers' brothers. In Boston, I studied psychology and drama at Tufts University, and later studied at Boston College where I obtained my M.Ed. in Peripatology, (or developmental orientation and mobility for blind children). I moved to New Zealand on a 'working holiday' of two years in 1988 to work as

an Orientation and Mobility instructor at the RNZFB. 22 years later, I am still here, and I love New Zealand, its landscape, water views, and relaxed lifestyle. I became a citizen in 1993 and have recently been very active in the Green Party. In the USA, I learned about and worked in the field of blindness and vision impairment from 1973-1988 as a residential support worker and Massachusetts Association for the Blind, as an Orientation and Mobility teacher at Perkins School for the Blind, and as a Vocational Counsellor and Rehabilitation Teacher at Washington State Services for the Blind.

I left my work at the RNZFB to complete my Ph.D. at Otago about, and, hopefully, contribute to the inclusion of blind children at regular schools; to have a rest from working; and to spend more time with my partner, Virginia who died in 2001. After completing my Ph.D., I have worked as a lecturer and researcher (2002-2006) at the University of Otago and Dunedin College of Education. At these two institutions, I have taught in the areas of inclusive education, qualitative research methods, and movement development. In 2006, I began research work for the Donald Beasley Institute and have worked on research projects about inclusive education for disabled children, disability art and performance, children who change schools frequently, peer abuse in residential homes for people with intellectual disability, and the working lives of residential support staff for people with intellectual disability. I am presently an independent contractor to the Donald Beasley Institute, and have begun contract work on a new research project for Ngāti Kāpo as well.

I am passionate about social justice issues, and, more recently, about the need to reduce our footprint on the planet so that we can reduce the effects of climate change. I hope that my contribution in this research project will improve the lives of kāpo Māori, as I acknowledge that the project has improved my life. I have met new friends; have been welcomed into the Ngāti Kāpo community; and have learned much from both my personal and scholarly experiences in this project. I wish to acknowledge and thank the participants whose stories I have had the privilege to tell, and hope that you enjoy reading them.

Dr. Hazel Phillips

Ko Taranaki te maunga

Ko Urenui te awa

Ko Tokomaru te waka

Ko Urenui te marae

Ko Ngāti Mutunga te iwi

Ko Te Aho te hapū

Ko Hazel Phillips tōku ingoa

Nō reira, tēnā koutou, tēnā koutou tēnā tātou kātoa.

One of seven children, I was born and raised in Christchurch far from the shadows of Taranaki. Despite living in a city my most vivid memories of growing up were gathering kai moana and going eeling – food for the belly and the soul – and spending time with whanaunga around Waitaha. My parents worked hard to provide for us children, in particular my mother made sure that her daughters had opportunities that she herself did not have when she was growing up in the 1930s. Today, I have five daughters and two mokopuna who are the light of my life. I want the world to be a better place for them. It is those same aspirations that I have for my own children and mokopuna that drives the teaching and research work that I do. Simply I want a world free of the ‘isms’ – racism, sexism and ‘ableism’ – where people are discriminated against and

marginalised. As a kaupapa Māori researcher I want a world in which Māori can be Māori and be self-determining.

Mrs. Christine Cowan

I am an Aotearoa (New Zealand) Māori with Iwi tribal affiliations to Ngāti Kahungunu and Ngāti Porou. I grew up in the coastal community of Haumoana, Hawke's Bay, a region internationally known as the fruit bowl, wine country and the Art Deco capital of New Zealand. I was raised by my maternal grandparents, as a whāngai (cultural adoption) with my birth mother's brothers and sisters of which there were thirteen of us. I am also the oldest of my respective birth mother's and birth father's children, each of whom have five children from other relationships. I live in Hastings, Hawke's Bay, with my husband, Patric, who is of Tahitian descent, and our daughter, Tarewa.

My background is in administration, working in the public service and reaching the level of executive secretary. In 1990 I applied for a position as personal assistant to the manager of the Māori Services division of the Royal New Zealand Foundation of the Blind (RNZFB), the division established in 1989 as a result of the advocacy by Ngāti Kāpo O Aotearoa, a national Māori consumer group comprising of Māori blind and their whānau. The key role of the Māori Services department of the RNZFB was to provide cultural support services to blind Māori who were registered with the RNZFB. I thoroughly enjoyed my work and the interaction I had with Ngāti Kāpo members and the blind community. However, in 1996 my husband and I made the decision to return home to the Hawke's Bay to raise our daughter and be closer to my ailing father and family members.

Upon my return to the Hawke's Bay I decided to complete a business management degree and graduated in 2001 with a Bachelor of Business Studies. During 2001 while completing the Victoria University Diploma in Māori Business, I established my company offering Māori business management consultancy services to Māori organisations or businesses that provided services, which encouraged Māori business development and growth. Additionally, I accepted a part-time position as a lecturer/research assistant with the EIT (Eastern Institute of Technology) teaching business management and employment relations. Iwi, hapū (sub tribe) and whānau activities became a key interest of mine, taking on the position of Treasurer with my hapū marae committee as well as taking on the role of Trustee/Treasurer representing my family's Māori land interests. During this period I worked on projects ranging from teaching Māori land trustees about Te Ture Whenua Māori Land Act to assisting the National Association of Resource Teachers and Advisors of Māori to implement a Ministry of Education service contract.

My relationship with Ngāti Kāpo continued throughout my studies with the Society becoming the key project in the final year of my degree. Additionally, at the request of the organisation's president, I completed an internal systems audit, the request was a result of the Society needing to track its activities because internal fracturing amongst the Ngāti Kāpo executive board had resulted in legal action. My work for Ngāti Kāpo up to 2003 was done voluntarily and during this period I had the honour of being the Society's treasurer and an Executive Board member. In 2003, I announced my retirement from the Ngāti Kāpo National Executive Board and was subsequently offered the position of Operations Manager. This was the Society's first management position. In 2008, my title was changed to that of Executive Officer in order to reflect the increase of the role and responsibilities.

During 2006, I was approached by Dr Nancy Higgins, who wished to conduct a research project that investigated the impact of government policy on kāpo Māori and their whānau - the outcome of our discussions was a collaborative research project that was hosted by the Donald Beasley Institute. This project has provided me with the opportunity to grow my skills and knowledge in the field of academic research. I wish to acknowledge the Donald Beasley Institute for hosting the project, my fellow researchers, Nancy and Hazel, the research advisory board members, and research assistants, Kelly Tikao and Dr Benita Wakefield. I also would like to thank my staff and Te Tumuaki of Ngāti Kāpo for their assistance and support throughout the course of the project. Lastly, I would like to acknowledge and thank the research participants who opened their hearts and shared their stories with us. It is these stories that breath life into this study. Ngā mihi tino nui ngā mema o Ngāti Kāpo O Aotearoa Inc. Mauri ora.

Chapter Five

Growing up in the 1930s and 1940s:

Bruce and Ngaio

Bruce: Growing up in the 1930s and 1940s

Hine: I think dad's just happy as long as he's got a white cane. That's the main thing. Yeah gets him around goes to (the pub). He grows his own veggies, just gave me some silverbeet... He's always been independent ... (Being kāpo is) not a problem for dad. I think half the problem is society.

The Early Years

Bruce was born in a rural coastal community and has a deep connection with the area. In his early years Bruce said that he enjoyed a “normal” life, and had difficulties with his vision as time progressed. Bruce had seven siblings, three sisters and four brothers. The eldest sister, Maire, was considered to be the matriarch of the whānau and Bruce said that he was closest to Maire:

There was nearly two years between the two of us ... so we sort of grew up together ... got pretty close of course and then my youngest brother and sister came along ... and two more, but Maire and I were a lot closer ...

Bruce's mother and father were both Māori and Bruce's father was raised on the coast in what was commonly known as “the Māori house”, which was considered to be not a “proper marae.” Bruce remembers going to the Māori house as a young child and said:

I didn't really have much to do with Māori things ... until we went to this Māori house – they never had a proper marae ... in those days. But when I started to grow up, every Sunday night we used to go there and have action songs and poi dances and learn. And I used to really enjoy it. We used to go along there and stand up and sing together, every Sunday night, just a piano and everyone all mixed in and it was good, good entertainment.

While neither of Bruce's parents could speak the Māori language, they did speak the odd Māori word and knew about Māori customs and ‘Māori ways of doing things’ as Bruce explained:

There were different ways, like mum would mention about kai moana, and there were different things she knew about. She would mention Māori things and dad would too but he couldn't speak the language, but certain words would come out. He would come out and say, “Oh, that's a lot of hui.” Well you know a lot of hui means a lot of talk. And that's what it is. So that was one of dad's favourite sayings.

The whānau lived on kai moana during the war, and Bruce recalled how his mother would gather kai moana from the rocks not far from home.

Bruce: They never had any ration. She just had me and Maire at home and grandfather. Well they used to get pāua and everything and mussels because there was no pollution around there. (At the time) there were heaps of pāua around there.

The whānau also gathered tītī or mutton birds and Bruce has many memories of travelling with his whānau.

Bruce: Well the first time I can remember, I was only 9 when we first went away ... and dad was home of course, back from the war ... So (I went) probably seven seasons altogether.

Bruce was aware that he had problems with his vision. He said that he was the only person to have vision impairment in his community. Daniel, his younger brother, could not remember his parents ever discussing Bruce's vision impairment openly. However, he remembered that his brothers and sisters did express fears about losing their sight and going blind like Bruce. There was some talk amongst the whānau as well of a curse that was caused by the marriage between their grandparents, who were closely related. This belief may have been influenced by the whānau's strong religious beliefs about the "sins and consequences" of such marriages. Daniel said that he felt ridiculed and a sense of shame when people in the community gossiped about this. He said:

This is what happens, small community – social slur ... a source of ridicule ... small community mentality about people with a disability, limited tolerance ... I feel ashamed of what they may be thinking about this whānau ... What are they saying about us behind our backs?

When Bruce was a teenager his vision impairment gradually became worse, and Bruce hoped that wearing glasses would improve his vision, but this did not occur. He said:

I was always given the impression that once I got my glasses, everything would be all right but ... when you have to wear these glasses it will correct itself and everything will be okay. But from the time I got them until I was about 15, I sort of realised then, that things weren't getting any better really ... Like I mean what happened when I was about ten or twelve and then what happened in five years time, you couldn't sort of measure it because you didn't know how much you had lost ... But you knew it wasn't getting any better but it was losing a little bit every time, every day possibly. Over a period of time it did go down and the vision loss was getting narrower and narrower I suppose.

Bruce's younger brother remembered some humorous incidents that occurred during Bruce's teenage years that clearly indicated how bad his vision was becoming but Bruce himself never talked about these incidents.

Brian: I just remember a story with dad, a couple of them when Bruce was going blind where he ... was smoking outside the picture theatre and dad walked up and

he didn't see dad. Dad just walked up and grabbed the cigarette out of his mouth ... Another story I heard was going down the hill on a bike and of course he's running straight into his sister on the other bike and of course smashed both bikes up. (Laughing) You know there are but ... he has never sort of talked about it.

By the time Bruce was 16 years, he could no longer participate in tīti gathering because of his vision impairment.

Bruce: I could do a lot of – still walk around and do things but it was getting harder to walk when you have to do a lot of work at night down there in the bush. It is very hard to pick up mutton birds and see them and all that so the sight thing was starting to pack up then ... My grandfather never asked me again ... he just didn't invite me to go and I didn't say to him, "Can I go down this year or next year?" ... but I didn't actually like going ...

According to Bruce, he was failing school miserably and left school early. He needed employment to financially survive and to become independent. He said that he was not aware at the time that he may be entitled to an invalid's benefit, and therefore didn't actually go on the benefit until he was 20 years of age. The benefit would have made life much easier for Bruce because he continued to struggle to find employment and said that he encountered discrimination because of his vision impairment. His father also believed that taking Bruce on his fishing boat with him would be too dangerous but at the same time Bruce felt that his father didn't want him to be 'lazy'. He said:

When I was 15, see there was about four seasons or three seasons anyway that I was sitting around doing nothing. My father dislikes laziness in any shape or form and felt that I shouldn't be sitting around doing nothing. Of course he couldn't do anything about it because there was no work for me to do around the place apart from digging a bit of a garden ... There was no way he could take me on the boat with him because he wanted to take me cray fishing but realised it was too dangerous for me to go on the boat. I could have fallen off there particularly when it is rolling around and picking up pots was too dangerous.

Bruce did receive a white cane from the Royal New Zealand Foundation of the Blind, but felt that it wasn't "trendy to be blind" and resisted using it even though it would have made him more mobile. Bruce said:

In the early days I used to fold the cane up and put it away. I wouldn't – too vain, I didn't want the cane and that. I was like every young person who doesn't want to carry a bloody big white cane around the place and having to go into things because you would feel a little bit awkward and you don't want to ... When you are a teenager you don't want to be carrying the bloody thing around with you because it is not very trendy to be blind because you are sort of going to get left out in the hoops as far as getting a girlfriend or anything like that ...

Life at the Royal New Zealand Foundation for the Blind (RNZFB)

Bruce said that he felt helpless and had low self-esteem for many years, and his parents also were not coping well and did not understand his blindness. They made contact with the Royal

Foundation for the Blind, who rarely visited his area because there was also only one RNZFB Welfare Officer for the entire country. Bruce had a job at the freezing works at the time, and he hoped that the RNZFB would be able to help him permanently retain this job. However, instead, he had to go to Auckland to the RNZFB adult vocational workshops. He said:

I don't think mum and dad really knew what they were dealing with. It was too big for them to really understand ... They were sort of relieved when I went up there because I was getting into a bit of a spot of bother sometimes because I had nothing else to do. Probably the best thing that did happen I suppose in a way ... I just felt that I could have probably held on to my job at the freezing works with some support from the Foundation, which they didn't do. I found out they had given support to other people who wanted to stay in their job and I could have stayed there.

Bruce's first experience of vocational training at the RNZFB was negative. He said that he learned how to make cane baskets but he didn't feel that he would be able to do this in the community because there wouldn't be a market for flower baskets. He eventually also became proficient at making mats and was proud of this skill. He said:

They put me into training, which was a bit dubious, because most of the stuff it was going into was just doing cane work and I think there was a pretty limited field anyway for making cane baskets and flower baskets and stuff of that nature ... So I only stayed in there a year and went into the mat department ... I kind of pride myself on that probably it was an opportunity to make a bonus because the boss thought I had done a good mat. And they used to give me all these mats.

Bruce said that he no longer had to contend with discrimination in his community, but he said that blind people, whom he called 'blindies', would put him down because he was not totally blind and was young. He said:

A lot of them would come in, and they had been through the mill a bit ... and they had lost their sight ... and be totally blind. They would say, "How old are you and what are you doing here?" ... Saying, "Oh you shouldn't be here because you have got a bit of sight and you can go out and you can work outside." ... I just took it on the chin.

Once Bruce was at the RNZFB, Bruce noted that the RNZFB would not encourage its members to live or work in the community. Bruce said that it seemed that he was only encouraged to develop his interest in music:

They just leave it to you ... if you want to get a job or you want some help in getting accommodation outside or if you feel you want to stay here or anything like that they didn't do anything like that at all. The only thing they said was what other interests do you like and of course there was music. So I joined the band ... They never encouraged you, like being told about a placement officer if you wanted to take advantage of finding another job and possibly getting some employment outside and all that. Nothing happened like that when I was there.

According to Bruce, about 80 percent of the other residents at the RNZFB's workshop were Māori, and Bruce stated that he made some long lasting friendships:

I had some good Māori friends, perhaps all of them were Māori, with the exception of possibly one or two. I used to get on pretty well with them all and the thing I used to like about it was because they were so free and easy and you could have a damn good laugh about everything. We used to have good fun together—and they used to invite me out to their place and I had a couple of good Māori friends of mine and they are still there.

However, there was only one Māori welfare officer available to support them, and Bruce questioned whether the Foundation knew how to support kāpo Māori.

Bruce: Oh I think ... at that stage it (Māori) was very much in the too hard basket ... They just wanted you to go to the workshops and they would leave you there and that was the end of it ... They couldn't care less because we don't want to see you any more ... "Don't make any trouble and everything will be okay." ... You know, you had to sort of paddle your own canoe and sometimes it was a little bit of who you knew in the Foundation to get the plum jobs...

While Bruce was living in Auckland, his younger brother, Harry, and his sister Irene, were starting to also lose their sight because of retinitis pigmentosa. Bruce was not at home to support them while they grew up. He would return home for Christmas every year though and was aware that Irene was struggling to cope and adjust to her blindness.

Bruce: I did hear my sister had some very big problems. She sort of lost her confidence and she couldn't do anything. She had everybody running around after her all the time, and she is still the same ... Just because of other things but also because of her RP.

Neither Irene nor Harry had to leave their community like Bruce. Harry was able to hold onto a job at the freezing works and to continue living in the area. Harry and Irene did, however, travel up to Auckland periodically to attend rehabilitation workshops.

At the RNZFB, Bruce was about 24 years old when he met and eventually married Mara, who was also Māori and worked at the RNZFB as a housemaid. Around this same time, Bruce realised that he needed to make changes in his life. He said:

It wasn't doing much for me in the finish. I just felt if I didn't make a move within a year or two I could see I was going to be stuck there until I kicked the bucket ... I hated the meals there too ... I just hated some of the people in the hostel too. I wanted a little bit of privacy in my own flat. That's what I was looking for. A bit of my own life back again ...

Married Life and Being Kāpo

Bruce married Mara and they moved back to his home area and lived in a small township. He was offered a job at a local factory, and Bruce felt that a new life was beginning for him. He said:

And then we came down here. We got our house built and I got work. I sort of turned my life around I suppose ... Just turned it right around the opposite way. I was married. I had a new baby, a new home, a new job so I was really glad I was out of (the RNZFB).

Bruce recalled that they were both adjusting to married life and a new baby but he enjoyed those early years.

Bruce: When the first son came along we had a bit of a problem to fix him up. There were times when I used to change the baby's napkin and hold him and feed him and I didn't mind that. I quite enjoyed it, giving him a bath and that was all part of family life and I really loved it but there were other times of course when he started crying in the middle of the night ... (I) was not so good at things like that, and that was always a challenge for both of us getting a wee bit on each other's backs and having a few arguments and stuff like that, but no, we loved it. It was great.

Bruce was about thirty when he completely lost his sight and reflected about how he accepted his vision impairment, and just got on with his life.

Bruce: I think it just sort of slowly kept going. I remember seeing the road signs when I was about 26 or 27 and the road signs were starting to dance around a wee bit then and around about [aged] 30. They sort of got all misty, started to get misty. It just happened over a period of probably about a year or so and then they were gone. It was just mist come over and it was the finish ... Well it didn't worry me particularly ... Just took it in my stride ... I have got so used to the fact that it was going down hill, although you really didn't understand what was really happening inside your eyes ... At that stage I hadn't learnt about retinitis pigmentosa (RP). I was sort of ignorant about the whole thing ...

Bruce and Mara eventually had three children and none showed any signs of RP. Initially, Mara's family was not very supportive of their marriage because they believed that her children would have retinitis pigmentosa (RP). Bruce said:

I didn't expect anything else actually I suppose ... The reception from her family wasn't particularly good about the fact that she was going to marry me and said, "all your kids will be blind." And of course when it turned out that they weren't, the reception was a little bit better but I never thought they would be anything else but intact.

Bruce indicated that his children grew up accepting him and that there was nothing different about having a kāpo father:

Bruce: Oh they sort of grew up with it. They didn't know anything different. They knew me as dad and I had bad eyesight. They used to help pick up things for me and bring it back. And of course I was wearing glasses and my son, he used to take my glasses off and take them away. He was fascinated with them. I tried to put them back on but he would always try and take them off. He probably felt that had something to do with if he took them off I probably wouldn't be able to see him and he would be able to get in to a bit more mischief and things like that. It was a

great time, when the kids were growing up and that. They grew up and they accepted I was dad and they had no issues really.

Bruce's second eldest child, Hine, also felt their childhood was no different from other whānau. She explained that her mother said that they should not move the furniture around or to leave cupboards open or other items lying about, which might harm her father. However, she said that on the whole, Bruce was like any normal father but she did try to trick him at times because he was kāpo. She said:

Yeah he read us bedtime stories ... He was a normal parent, you know, give us all a whack if he could find one (of us).

Bruce's children said as well that they grew up in a whānau, in which their mother experienced depression, and this caused their family to be separated at times. Hine said:

Well we kind of got separated, when we were kids, like going to my nana and granddad ... Yeah, so most of our childhood, we were actually separated and not because of dad, but because of mum. She had a breakdown ... They must have put her on some medication that wasn't working and which probably made mum worse and so she never really fully recovered from that.

Joy, the youngest daughter, noted how Bruce became the primary caregiver for them at times:

Oh mum would have her down days, just maybe lie in bed all day and that. It was up to dad to make her a cuppa or run her a bath and ... and there'd be days when mum just, yeah, normal.

Hine said that Bruce was supported by his parents, but eventually hired a housekeeper so that he could keep the family together and support his wife as well, whom he loved dearly. Hine said:

(I asked) dad to get a housekeeper to bring us kids back together cos I didn't want to stay there any more ... I think dad's a pretty proud person ... Dad didn't really need any help. I think at the end of the day I think dad just wanted us all back, well not just us kids, but mum as well.

Joy said that her father was a nurturer, and enjoyed doing housework. She said:

He did a lot of housework. He loved doing housework. He is so blimmin tidy. It is pathetic. If you make the mat loose or crooked, he would say, "Get off the mat and straighten it." He was wonderful like that ... I remember being sick and all that and having to sleep in dad's ... (for) comfort.

Bruce's daughters stated that he was a good provider and a good role model for them.

Joy: The other thing is that, a lot of the role modelling dad did in living, and doing the garden. And having a big vegie garden ... So we were never without kai, if we needed, you know. So we just lived by the role modelling.

As an adult, Joy realised that Bruce was a strong man in that he never stated that he was a victim of his circumstances or vision impairment. She said:

No, he is not a victim ... who think they have things hard. But you see dad would never have victim thinking. He'll get hurt sometimes emotionally ... and, he has been hit by a car a couple of times ... Definitely victim thinking is not in his psyche. But I know that he has had a lot of hurt.

Joy and Hine both said that eventually they started to notice that members of the public would comment upon their father's blindness, and that other children would ridicule them. However, they stood up for Bruce and said that they grew stronger because of it. For example, Joy said:

Looking back now if I look inside the house and how we lived and wherever we lived, in fact because dad held a normal job and mum stayed home. It was quite a normal life. I never went without anything ... Then you start noticing that my family is different. I am different because a lot of people at primary school reminded you that you were different ... I remember when I was young, dad and I would go and do the shopping. So we did quite a bit of walking and (he would) have his hand on my shoulder. And I could hear the kids say, "That man is blind." ... And I might yell out something to them ... Whereas it didn't bother dad, well as far as I know. Or like if we go on the bus to town, and we would have people either in front or behind and they'd go, "That man's blind." And I would turn around and go, "Yeah but he aint blimmin deaf." So people are really stupid ... I remember as a kid a bit of ridicule but it put a bit of backbone in me too.

Cultural Well-being

Bruce pointed out that there was little support available to him and his whānau as he and his siblings 'grew up kāpo Māori'. He advocated for more Māori staff at the RNZFB, who would understand Māori, te reo Māori, and other support systems. He said:

Particularly in so far as some of the Māori, and not so much Pākehā, – seem to be able to be much more relaxed ... They can kōrero in te reo with them you know. There is probably camaraderie or something along those lines but I think they need more – similar to what the Māori welfare officer provided [from the Foundation] - but something more than that. They need to really give them something more than just come up and tell them they are going to be a member of the Foundation and all that. Probably better to try and point out all the other support systems they could get that could help them.

Bruce was introduced to Ngāti Kāpo O Aotearoa in the 1980s, when it was being established, but advocated that, today, further information about their services needed to be given to kāpo Māori. He said:

(A friend) invited me to come to a meeting they were having in Auckland. So I went along and I met other Māori there that I had probably met before ... It was good to get together (and) to coincide with a group of Canadian television people

who came over. They wanted to talk to a group of indigenous Māori kāpo and get some views on different aspects of life and take it back to Canada ... Subsequent to that I have heard different things about the Ngāti Kāpo and how it sort of took off and has grown throughout the country. I think there is still a little bit of lacking in knowledge ... And I think that's where they probably fall down a bit.

Bruce suggested that workshops in te reo and whakapapa would be of benefit to kāpo Māori and himself. He said that he had visited his local marae but found it difficult to continue to visit because he had not been oriented to it, and that the marae, itself, may not understand kāpo people. He said:

No, they don't understand (kāpo) because it probably hasn't happened very often. They do know me as a person because I have been on the marae but I would find it pretty difficult to get around on the marae actually. Like once I have sat down in one particular place, I would find it very difficult to get up and move around and that but they would give me assistance. But as a rule it would be pretty difficult for me just to go down to the marae and wander around through the place and talk to everybody down there and come back and walk out again because I don't know my way around there, not at all.

Bruce said that he wished he had learned te reo Māori and tikanga while he was growing up, and acknowledged that this prevented him from teaching his children about tikanga and te reo. However, Joy, his daughter did become proficient in Māori and her children are attending the local kōhanga reo.

The Future

Bruce has two of his adult children living in the area, and there are ten mokopuna, in total, scattered as far away as Australia. Bruce's wife passed away a few years ago, and Bruce described himself as content with his life, but he still missed his wife.

Bruce: Well I am probably a lot more content now than I was probably – I am pretty content, I have got no sort of problems. I am content just as far as – of course it would be great to have somebody here, if my wife was still here, but I am still quite content the way things are. I am still able to cook a meal and go out and come back when I like and I am mortgage free and things like that. I am reasonably well – I am not too badly off I suppose compared to some people, a lot of people.

His brother similarly stated that he felt that Bruce had coped well with his life, and had 'got on with life.' Brian said:

Well as a blind person, Bruce can cope. I think he copes with it pretty well. ... He can do things for himself ... Bruce can get around and do what he needs to do, whatever ... He just seems to have accepted it and gone on with his life actually.

Bruce recently retired from the job that he held over all these years and now spends much of his time enjoying his music, and said that he may even start another band. He said:

I think that guitar is actually nearly 40 years old and I have had it up and down the country, right from Auckland, right down here and all around the place. I have got a piano accordion there I try to play and my uncle left that to me when he died. It is a '48 bass, not a very big one but I play that too and then I have got a ukulele actually in there ... I think it would be good if I could get somebody to do that and somebody could play the guitar and I could play the piano accordion. We might be able to have a bit of music.

Over the years Bruce has remained actively involved with the Foundation in his community and his children remembered the many Christmas celebrations that they shared. Bruce planned to have all his mokopuna and children attend a Christmas function at the Foundation in the future as well.

Bruce: Oh I do, I want the kids, I am hoping to get them all together, the 14 of them, on the stage down there at the Foundation and sing a couple of songs and get them on the video and get them all down there together singing. That would be great but probably their music is not what music I like really, but hopefully they don't – as long as they don't get up and sing any of that rap, I would be quite happy. They can sing anything else but that stuff. I can't stand it.

Joy commented that Bruce's interactions with his mokopuna were actually teaching her about what it was like for her as a child to grow up with a kāpo father.

Joy: A couple of years ago when dad came up and was staying with the kids. When my son was really young and he couldn't speak yet, and ... he was holding something up to granddad and he didn't say anything he was just holding it up to him to give to him ... My father couldn't see him and I just actually got that absolute understanding at that point of time that that's actually how it has been for all of us as children. We've misinterpreted his messages not because he didn't care or couldn't see. It was because he couldn't see what we were wanting ... But also there's a lot of laughs in that too. I mean when granddad was in the bedroom once listening to the races, he loves the races, dad likes to have a beer and so he had a beer and my son went into the bedroom and he came out with the can. I got it on video. Luckily it was empty and he walked down the hallway with it and I said, "Come here you." Oh it was hilarious. I've still got it on tape.

Hine has been concerned about her Dad living on his own and his personal safety. She understood that her dad was still very independent, grew his own garden and was capable of looking after himself. However, Hine has asked her dad to come and live with them and is planning to sell his house in the next year. Hine said that she knew her father liked his peace and quiet but said that the whānau would adjust. They might even move to a bigger house. Hine would like to see people treat kāpo people like 'normal', which is how her father wanted to be treated. He was no different from anybody else and as he grew up, he became a husband, a dad, a good provider, and a loving grandfather to his moko.

Ngaio: Growing up in the 1940s and 1950s

Karen: Being a kuia is not something like a person like Ngaio expects to happen. ... It doesn't happen like that ... It's not even age-related. It's more their wisdom and the way they behave. Her status of kuia very much has evolved into that and was based upon deeds that she did, especially round kōhanga reo and even in Ngāti Kāpo. But a real tribute to Ngaio is that she's one of those people who gets things going ... She'll call the people together and she'll get things going.

Early years and whānau

Ngaio's whānau was one of many in their iwi who scattered from their land to find jobs. Ngaio said:

I was still a baby when mum and dad moved ... It was at a time when there was a big migration around about that time ... A lot of them came down to work, coming down this way ... And when they did they got jobs down here and I think it was nearly about a quarter of them went back home and the rest married down this way and had their children. So that's why we are all scattered now.

Ngaio is now the matriarch of her whānau. She has eight grandchildren and three great-grandchildren. Ngaio's first language was Māori, and as a youngster she grew up in a rural Māori community along the coast with her older sister and brother, and five younger brothers. Throughout Ngaio's life, Ngaio greatly loved her mother and said that she would do anything for her. Ngaio described her mother's life as "tough" because she married her father. She said:

(I'd do) anything for my mum. She had a sad life. Tough life ... (My dad) was pretty violent to her ... But like she was telling me, you know, she said her father said to her: "There will always be tears with you my dear if you marry him." That's what her father said to her, you know, if she married our dad, she'll always cry all the time.

Ngaio said that she also became tough because the times were tough too:

Ngaio: Over the years as I grew up, you know, I suppose I was so tough in those days, you know, just going through life ... but my brothers, they were well behaved – very, very good. You know it was such a tough life, we had no lights, no power, there's everything in candlelight. We had water outside, you know. We had to get the kerosene tins in those years. No toilets inside, you know, it was all outside.

Ngaio's father eventually left her whānau, and Ngaio said that her brothers' felt ashamed of their circumstances and their subsequent poverty, but Ngaio remained positive, supported them, and was proud of her whānau:

Ngaio: The boys used to go round ... and get the water and I used to feel sorry for them, you know. They had a long, long branch, and they had the two kerosene tins on the end. And of course they used to hear the farmers coming back along the road. They'd get so ashamed and throw it down the bank and they jumped down the bank so they wouldn't get seen. Oh and I felt sorry for them ... I said: "Come on I'll come with you, you know. You don't have to hide." ... The farmers in those days were really lovely to my mum. They used to bring us a free mutton, a whole side of mutton. They were lovely people. Oh yes they were very good to us, you know, but that's why the boys were so ashamed. And I said: "Never feel ashamed because they can see that you are doing that for mumma there."

Ngaio and her whānau discovered that she had a vision impairment after she returned from being hospitalised because of an accident when she was seven years old. She had run into a pole, and it was believed that she had injured her eyes because of this encounter. She stated:

I went over to get some icecream for the family ... and my sister wanted to race back across the road to mum ... We both took off across the road and that was it. That was the end for me. I hit the pole ... and I got a bang right there and (passed out) very fast. I was in the hospital for six months. They actually thought I would never see because I had gone blind when I hit the pole. Everything, even this part here was all black and they were worried that I might have a head injury as well. ... Well they had the bandage around my eyes of course. I had done something because it was all blood in my eyes all the time ... Well before I came out of hospital, I was sitting there on the bed just before they went to take the bandages off and I said, "Oh mummy, you are there." And they knew straight away, mum came rushing to me and she was crying ... And I said, "You have come to take me home, mummy."

However, later when Ngaio was an adult in her forties, her vision impairment was diagnosed as being due to retinitis pigmentosa. This affected Ngaio's field of vision and night vision. Thus, it seems that while Ngaio grew up, she believed that her vision impairment was caused by her accident, but it may have been that her accident was caused by her vision impairment because she said that she never remembered seeing the pole into which she crashed. Ngaio traced the genetic links of her vision impairment to her father's side. His sister was kāpo, and some of his brothers were also kāpo. However, this whakapapa was not discovered until after Ngaio had completed her education without assistance from specialists in the field of vision impairment.

Ngaio's education

Once Ngaio was out of hospital and back at school again, Ngaio said that her vision impairment affected her education. She had difficulty playing sports, and was teased by other children.

Ngaio: Well school was the hardest part for me. I was forever getting a growling. I couldn't see to play any sports. I would sort of get the vision and it would go away again and I would think what is happening to me. I could see, half way, the

top of the goal, and it was as if the goal had moved and they would say, "The goal is over there." And I was thinking 'oh my goodness, what has happened to me?' And they said, "(Ha ha) you can't see." And the teacher came up and I think the headmaster came up and just whacked this boy across the head and he said, "Don't you dare." And he called me into the office and he said I wouldn't be able to play any sports because he said, "The accident that you had has affected your eyes."

Ngaio noted that it was difficult for her to do her homework because of the dim light of candles at home. However, her brothers helped her and were impressed by her natural talent in maths. She said:

We never had any electricity and you got your hair singed with a candle. And it was so hard to see. Everyone used to do drawings, the boys were very good and give me some work to do, whatever they were doing. My brothers were very very brilliant, all clever. But they always helped me out with things, but that was one thing they were saying to me, "You know sis, for a woman like you, one thing we say about you (is that) you know what you are doing and you are brilliant at maths."

Ngaio also had difficulty at school because she spoke Māori at home and was not allowed to speak Māori at school:

Ngaio: I didn't want the strap when I went to school. (We were) told, "You can't speak that." And I thought to myself: 'One of these days, I said, it's going to be speaking up and down in the schools'. Sure enough they've got that going through the schools now, through university ... It's sad that, you know, because when you're born, you know, that's the first language you hear is your own mother's tongue and you go to school and they tell you, "No you're not allowed to speak it." Well hang on, you know, don't strap us because we learn our mihi. Of course I used to argue with them many a time and I got a strap across the knuckles.

One particular teacher, Ngaio remembered as, both, verbally and physically abusive when Māori was spoken. This teacher told her students that Māori were a 'mud race' who needed to be kept out of sight. Ngaio said that she stood up for herself, though, but that this resulted in broken skin and trips to the doctor. Ngaio said:

One of the boys ... saw me standing in the passageway and right there the skin came off. It was bleeding, and he said to me, "What's the matter? What happened?" ... And then the teacher came and he said to me, "Your hand is bleeding." And I said, "Oh I just got a caning from that you know what." He said to me: "You can go home." But he sent me to the doctor first ... She had all the other ones cringing, you know. They were too scared. And I'm afraid I was one of those, who was just straight up. And I said to her, "Well if you spoke properly to us, we'd be able to do things nicely." "Oh you're a naughty girl." Whack! ... She (would) say, "It's a horrible language." She said, "It's like the black people." I said, "How dare you." You know. "Yeah," she said, "The black people, they don't know what they're doing." She called us 'a mud race'. She said, "You shouldn't be seen and you shouldn't be heard, and you should be just trampled in the mud."

Ngaio worked after school milking cows to “get food in the cupboard”, and then left school at age 12. She said that the headmaster was understanding because she was behind at school anyway, and knew that she had to work.

Ngaio: I was only 12 when I finished and the headmaster said, “You know, with your time being in hospital, you are way back and I can quite understand.” And my mum told him about the circumstances, that our father had left. And with me being the eldest, 12 year old, my sister was up in Auckland. ... So I went out to work getting what I could get off the land. Going to work for the farmers and things, and they used to give me meat.

Adolescence and whānau

After working for a couple of years, Ngaio was sent to be with her elder sister to work in a Catholic orphanage and convent in the big city. She worked in the laundry and despite being away from home at a young age remembers some beauty while she was there.

Ngaio: We were working ... My sister was with a nun and of course when you work up there you're always under a nun ... And the one I had her name was – what was her name? – She was a proper witch too. She was tiny but she was like a parrot, she had a little wee face, all squashed and like a real parrot. But she was all right, you know. We were both in the washhouse. We did all the laundry. In the laundry and get out and hang it up. Work was hard, but oh it was beautiful. It caught the breeze, you know ... We slept in the dormitory with the rest of them. I felt very sorry for them, cos they were orphans. At least we had a mum.

At the convent, she began to notice that she could not see well in the dark. She said:

I always used to get up early in the morning, and ... that's when I noticed my eyes were tired. Very tired and sometimes when I get up early in the morning I'm banging into things. And I said to myself, 'heck'. You know, Mum gave me a torch to go out with.

Ngaio's mum became ill and Ngaio was called back to care for her. She went to work as a cook in a hotel “about twenty miles up the line” and went back home on the weekends.

Jobs and whānau

Ngaio worked and lived near her whānau in the hotel until she was in her early 20s, and then told her mum that she was going to move to the nearby city, get a job, and find a new home for her mum and the younger brothers, who were still at school. She and one of her brothers saved and soon her mother and her brothers were living with her. She said:

We were working very hard to get into like a state home, you know. And oh well that was really Christmas for her, you know, having everything in the house, you know, toilet, bathroom, showers and everything. It was the first thing my brother

and I got to do was to get a washing machine for her washing, being able to use all those electric lights and everything else. It was Christmas. Yeah it was beautiful ... And she went to work in town, they had a place there with caterers, you know. And serving out. Oh she loved it.

Ngaio worked in a shearing gang, was a “jack of all trades”, but eventually settled into a long-term position as a cook at the hospital. She continued to live with her mum until she passed away about twenty-five years later. They were very close and Ngaio said, “And I still miss her. I miss her very much.”

Ngaio met her husband, Rua, soon after she moved to the city. He didn’t know that she was kāpo until after they were married. He said that when they first met, he worried that she was refusing to shut farm gates at night because she was “lazy” and so he thought he “was in trouble”. However, he loved her, and when they married, Ngaio told him about her vision impairment:

Rua: I first met her at a party. And when I was ready to go home she asked me if I’d like to take her home. So anyhow, okay, hop in my car, away we go, come to the two gates on the front and I said: “Would you like to open the gate?” She refused to open the gate. I had to get out and open the gate and the second gate and: “Would you like to open this gate?” She refused. She reckoned that she was laughing to herself. She wouldn’t tell me that she had a eye vision problem. She couldn’t see at night-time. After when we got married then she told me. Oh well her and I used to laugh about it, you know. And I was cursing to myself, ‘oh gee what a lazy woman, don’t even open the gate and I was in trouble’. Yeah, but she was a wonderful woman.

Ngaio got tuberculosis when she was about 24, and she said that because “it went right through my body”, the doctor told her that she would “Never have a child.” She felt that she couldn’t get married, and told Rua this, who had previously been married and had had children. However, the doctor was proved to be wrong but he did not acknowledge this. Ngaio said:

Because it went right through my body (the doctor) said to me, “You will never have a child.” ... I said to Rua, you know, “Look dear, I can’t marry you.” And he said, “Why not?” I said, “Because I can’t have any children.” I said, “I will tell you this. I will fix that doctor.” I said “I am going to have a baby’.” And he looked at me, and ... I was away shearing at the time ... I said to our boss, “I have got to come home.” So he brought me back to see my GP and it was the same one, the same one ... Well the thing was he never told me, he said to me, “You had better ring your partner.” And as soon as I heard that I knew. I jumped with joy. I was so happy. Rua come around and I dragged him out of the car with joy and was cuddling him. And he said “What’s the matter with you? One minute you say come to the doctor.” I said, “I am going to have a baby.” ... So we went to the doctor and he said to me, “Yes, you are pregnant”. And it was some miracle.

Ngaio and Rua got married, and Tane was born. Tane said that he believed that he has caused his parents “grief”. He left home when he was 14, and then did not stay in regular contact with them for a few years. Now, though, Tane visits more regularly.

Tane: I used to go back on the car, first it was the bus ... and then I started flying down, which was quite good and then I stopped for a while. And yeah I know I need to go back and see them more often ... cos they're not getting any younger. Yeah it didn't occur to me oh about twenty-five years ago, you know, but now yeah I have to.

Tane was not aware of his mother's deteriorating vision or vision impairment while he was growing up. Tane did, however, remember that he needed to help his mother and nanny across the road at night when they went to play cards at his uncles.

Tane: We used to walk to my uncle's house ... yeah there's an alleyway across the road and we used to walk down the alleyway and then hang a right. We used to go over and play cards sometimes. I used to go with mum and my nan ... She couldn't see properly at night ... I just tagged along so that I could bring them home.

Tane said that what he remembered most about his childhood was that Ngaio taught him a lot about cooking and cleaning:

The most problems that she had was with me, going to school and – but she was good even though I didn't know about her ongoing blindness, you know, the slow one. Yeah well she didn't – I don't know mums not supposed to tell their young ones that they're having problems and all that. As I said, she toughed it out and you know she taught us a lot. Taught me a lot, how to cook and how to clean the house. And those are real solid now. I show my kids, and I get that from her.

In the end, Tane was not an only child. Ngaio fostered a number of boys while he was growing up. Tane remembered one, who was like a brother and who then left them after nine or ten years:

I know that we had a lot of foster children come and go ... We had one, to this day I still call him my brother. I think I would have been one or two when we got him and I think we had him for about a good nine/ten years. Yeah then he had to go back into the boys' home. I remember that day, the social worker picked me and my mum up, with my brother, and yeah we went for a ride down to Levin, dropped him off and yeah ... He (became) a drifter. He would just pop in and see mum.

Ngaio counted eight or nine boys and a baby for whom she was a foster mum and who still keep in touch with her. She said:

We had about eight or nine foster children. I looked after them, plus a baby that I had at the time, you know. They were looking for places for baby and he was about three months old. And of course they were all boys (that) I had. Well I would have had all girls but because of Tane I had all boys. When they all grew up, they still keep in touch ... Some of them have joined the Mongrel Mob and they know Aunty don't like that, you know. Well they keep well away.

Like Tane, Ngaio also pointed out that she taught her foster boys how to cook for themselves:

I've been teaching these children, all the way through, you know, how to cook, to clean and everything, you know. As they grew older how to do their washing and that, how to cook for themselves when they leave home, you know, instead of living out of tins and that, you know. Making them each take a turn or two. ... Oh well yes, you know, even the cleaning. Cleaning up, like vacuuming and learning to make their beds properly. So, oh yes, they were pretty onto it.

She said, "every time [the Social Worker from Social Welfare] used to come here she'd smell all the goodies, simple meals like making curried sausages." In total, Ngaio worked with children for twenty-seven years. Some of this time, about six years, was also spent running "Social Welfare's" family home where sixteen boys lived. Ngaio did this work when she was in her fifties and said that usually a couple ran the home, but that she convinced Social Welfare to 'give her a go' and she was able to manage it on her own:

I said, "You [Social Welfare Social Worker] say I can't handle it."... And of course the big boss came down to see me and she was a woman too and she said to me, "Are you sure?" I said, "Look, let's put it like this, you give me a go, put me on trial for about a week, okay, see how everything goes." She said, "All right." And she said, "There's sixteen children here." I said, "So ... don't worry about that. They'll all have something to do by the time I've finished with them." ... Hey by the time that week was over, they just couldn't believe it when they came back in ... The boys were outside there washing the windows of the home. Others were doing the weeding in the garden, others were ... I used to send about three boys out to do the wood, if the wood fell down again they've got to get out there, do it again, make sure it's stacked nicely. I showed them how to stack.

Ngaio lived at the family home, Rua visited, and she returned to her home on her days off. The boys called her 'nanny' (grandmother) and Ngaio said that they worked with her and were well behaved, polite and helpful, when visitors came:

And of course with the children, they used to be so behaved. Oh the manners were brilliant. You know they said, "Would you like to have a cup of tea (to visitors)?" ... I'd take out the tablecloth and the boys will get a cup of tea out. And I said, "Now I wonder what we've got for pudding." And they say – they always call me "Nanny" – "Oh Nanny would we be able to have cake?" I said, "Oh they might like that. Get the bread plates out." They had some dainty dishes there I put it on, put it on the table. "Do you take milk?" And I said, "Don't bother about asking if they want the sugar, just put the bowl of sugar on the table on both sides." Well [the visitors] were just blown away.

When Ngaio retired from her years of caring for others, she finally went on an overseas holiday.

Ngaio: And then when all the children went, you know, I thought, 'Oh yippee!'. I said, "I think time I went for a break." So I went overseas. I went overseas on holiday. I went to Western Samoa. And I wanted to go there especially to go up to see that poet [Robert Louis Stevenson's] house, up on the hill anyway.

Health and Education Services

In her fifties Ngaio had a car accident because of her vision impairment, and it caused her to seek services from the Royal New Zealand Foundation for the Blind (RNZFB). She had not had any health or education services at all up to this point to help her cope with her vision impairment. Ngaio described the accident as distressing. She said:

I had an accident actually but thank goodness I didn't hit anybody. What I did, I hit the mudguard and of course the woman in this other car got out and called me all kind of names ... (My husband) said, "Lucky she didn't swipe the car and you would have ended up on the island." ... I couldn't see where I was going ... So I went straight to see a specialist and he told me to stop driving.

Ngaio's visual fields had gradually decreased over the years until she had no peripheral vision, and today Ngaio is almost completely blind. Karen, whom Ngaio thought of as whānau from Ngāti Kāpo, said:

When I first met her, her eyesight was actually very good but I have noticed the deterioration, especially in the last three years. She was able to move around quite freely, but now she is very hesitant. And she was still very much out there plus she did a lot of things, like she used to go to housie. She was very involved in kōhanga reo. She was a kaiako when I met her but it's only of late that she's no longer actively involved in kōhanga, only I think because of the deterioration of her eyesight.

Ngaio was referred to the RNZFB after her car accident, but was not impressed with the wait that she had for services. She said:

[The specialist] said to me, "I will sign you up with the Foundation for the Blind." And gosh I was waiting like a hundred years, wasn't I? They take their time ... I was waiting and waiting and waiting and I thought, 'Oh bugger you, I am going to see them myself.' So I went in and [the specialist] had sent all the things to me and I just took it with me to the Blind Foundation and that was it. I signed up and was registered with them.

Ngaio said that she had good services at first from the Orientation and Mobility instructor and enjoyed her cooking classes at the RNZFB, where she developed an alliance with another kāpo woman so that they could still smoke cigarettes during their time at the RNZFB:

Ngaio: Well Judy was the one who took us for cooking, when I was losing my sight and with the microwave, cooking in the microwave. And she got us that there (microwave) for Braille. Well it was like going back to school again, and I went with another lady. She was a good lady. I would take a pumpkin and she would bring an onion ... and we thought we will make pumpkin soup. And then for our dessert we had chocolate fudge. All done in the microwave. I said, 'Hmm, you want a smoke?' She said, "What? You want me to go out. We are not allowed." I said, 'When you go out for a smoke, just go across the road and get some cream.' And we had a lovely lunch. And we had our secret.

Over the years, though, as staff changed, Ngaio, her husband and the rest of her whānau, as well, indicated that they felt that the RNZFB did not provide sufficient or effective face-to-face services. For example, Ngaio said:

I will tell you now. They are useless. You know instead of them coming out to see me, they wanted me to go in and I said, “You can go jump in the lake. That is your job to come and see us in our homes.”

Her husband, Rua said:

The new staff in [the office], they’re hopeless. Judy rang her up, “There’s a cooking course at The Foundation.” I don’t know what the new staff do but when you go there they’ve all got flash cars, all station wagons, all lined up in front of the office ... The blind people, they expect those staff to go and pay them a visit. They expect the blind people to go and see them instead. Well they’ve got vehicles, you know. I said to Ngaio, “That’s strange. They should be there to support the blind, not the blind go and see them.”

Karen said that after Ngaio’s initial access of services, that Ngaio has not had any further services despite her deteriorating vision and her need to be independent because the RNZFB, including the Mana Kāpo Services at the RNZFB, have been unresponsive:

She’s never gone back and accessed services. But in saying that, I know that she’s rung like the aronga but he’s never shown. So she’s pretty pissed with him. I would say that she’s one of those women she likes to be able to keep her independence ... And I don’t think she’s been for a while because she’s said it to me a couple of times about going to those ABC or Foundation funded ‘dos’, she goes, “Oh they had this trip to go to a paddock to look at daffodils.” “What do I want to look at daffodils for?”

Similarly, another Ngāti Kāpo member, Pete, whom Ngaio also nominated as a whānau member for this study, stated that he also was dissatisfied with the RNZFB because they didn’t acknowledge that his main service need revolved around access to information. He said:

I should be using a computer. Well I can’t get the Foundation to train me. “Oh well, we’ll set up a programme and we’ll train you.” “You will? Go for it. When can I expect to be trained?” “Oh I don’t know.” So, you know, three years down the line I’m still asking the bastards ... My primary fundamental need as a blind Māori is communication, communication, communication ... The Foundation should be researching the ways and means to enable affordable manageable communication ... It could be through computer and a lot of people like emailing. It could be through Braille or it could be Skype. Now nobody’s got a fundamental handle around that, my primary fundamental need is communication. What they’re busy doing is they’ve broken it all up and gone in every direction saying, “Yes we’ve got a bit of this and a bit of that and a bit of something else.”

Karen believed that because of Ngaio's wait for services and the fact that the RNZFB did not know what kāpo Māori wanted that Ngaio would not access services. Karen said, "Ngaio said to me that (the RNZFB) don't really do what we want to do, Māori, you know?"

Karen suspected as well that Ngaio's age and subsequent health problems would eventually see her withdraw from her involvement in Ngāti Kāpo and kōhanga reo. Tane also was worried about Ngaio's active involvement. He said:

But when they go on trips, I mean like they go away on the rainy days and you're hopping in and out of the van and it's raining, you know. Elderly they're going to get sick. You know and then while they're home, you know, they get better and then the weekend comes around and they're off again.

Cultural Health, Kōhanga Reo and Ngāti Kāpo O Aotearoa

Ngaio spent much of her life caring for her whānau and others who became her whānau. Karen said that Ngaio did this work because of her love of Māori and tikanga:

Well at the end of the day I think it's just Ngaio's love for her people ... And the kaupapa of Ngāti Kāpo she really connects to. And it's more than just the words. It's that whole, because she lives it on a daily basis. You see it in her history with raising CYFS kids. She's always been someone that's caring for someone else. You know and so it's a natural. What we promote in Ngāti Kāpo is what she naturally was raised to do. Again though, it's the era that she was raised in, because if you look at our younger ones it's a different way of thinking. But you're "raised to serve" I suppose that's the term for it.

In her retirement years, Ngaio worked at her local kōhanga reo in the mornings on Wednesday and Thursday. As a native speaker, she taught te reo to both the teachers and the children there and she said that she would never give up this particular job because she loved it. She said:

I've seen a lot of life, you know. I've been there and done all that, you know ... And then of course, honestly where I am at what they call the kōhanga with the children, it's lovely. I get more pleasure with them ... Oh my goodness ... Yeah and, of course, someone was saying to me, "Mum I think it's about time you gave up." I said, "You know I'd be lost. I'd be lost without it." I said, "I can't just stay home and do nothing." I said, "You know I've always been one to work, do work.

Karen also pointed out that Ngaio had high standards because Ngaio, herself, made an effort to learn what she had been taught. Karen said:

Oh kōhanga reo is very, very important to her ... One of the frustrations with Ngaio is that the kaiako (teachers) aren't really fluent in te reo Māori. Cos she'd spent a lot of time tutoring the teachers, you know. And also some of their behaviours of how they treated the children. And her frustration is around that fact that they hadn't learnt the lessons. Cos with Ngaio if she teaches you something you learn it, you know. Again it's the old school and I know that was

her frustration. She thought they were sloppy too. She was a bit upset. Cos once she gets a handle on something and she understands it, she very much sticks to it.

About nine years ago, Ngaio became a member of Ngāti Kāpo O Aotearoa and soon rose to a leadership position. She discovered Ngāti Kāpo accidentally after a visit from Karen, who was doing some local research about kāpo Māori at the time. Karen said that Ngaio was attracted to Ngāti Kāpo because it was a Māori organisation with Māori values. Karen said:

[Ngaio] was quite surprised to know there was quite a number of Māori in the the area ... that were visually impaired ... Because one thing with Ngaio, she's very what we would call "tūturu Māori", very true to her Māoritanga. And when she realised there was a group that actually was Māori that really caught her attention.

Also, later when Ngaio had actually become the leader of her local Ngāti Kāpo rōpū (group), Karen stated that Ngaio advocated strongly for Ngāti Kāpo kaupapa to maintain the organisation 'for kāpo Māori by kāpo Māori'. For example, Karen described an incident in which sighted volunteers were attempting to direct the members in the rōpū. Karen said:

Quite a big issue happened a couple of years ago where a group of sighted people, who she invited to help support them with their housie, came in and then started to play up. And it caused quite a furore within the rōpū because it was the sighted people trying to tell 'blindies' what they should or shouldn't do. And so Ngaio and them basically shunted these three particular sighted people out of the group. Yeah, well how Ngaio has run it is very much on how the national structure is run. In that, you know, kāpo should be heading it. And she's kept very true to that but I do know because, you know, they caused a hell of a lot of grief. And she kept very strong through it.

Ngaio also pointed out that her Ngāti Kāpo rōpū was distinctly different to the RNZFB. She said:

The Royal Foundation for the Blind is on their own and we do our own thing. Yes, we do our own thing but I still go to the meetings of the Royal Foundation for the Blind. Go out for the meetings and for the dinners they have."

In Ngaio's rōpū, Ngaio explained that what was special about the organisation was that everyone learns from each other, te reo Māori, and about Māori culture in their hui. She said:

Well, Ngāti Kāpo, I think it is just ... I can't put a finger on it really. They just want to come in. They hear from different ones, like the ones who are sighted too. The ones, who are in my group now, we tell them, "You want to join the group you know. We have a great time." There's sort of learning Māori, learning Māori, and doing all these things in there. That is one of the basic rules for Māori, is learning Māori. Learning Māori is the main thing and, of course, singing is always involved. We have that. And then another time we might talk about making ketes, Māori ketes, like that one I have got up there.

Both Karen and Pete said that Ngāti Kāpo was about making connections and relationships or "whakawhanaungatanga". However, what impressed both Karen and Pete was that Ngaio was

able to lead and “gather the troops” to follow her to tangi or events, and to learn Māori. For example, Pete said:

Many of us not often are we invited to marae, not many of us participate in tangihanga unless it's of our own. But of course, there are situations, for example, if a kāpo member passed away well what does anybody and everybody do? You've got to pay your respects as much you can. But Ngaio took on the responsibility of gathering the troops up and saying, “Well we'll go as one and we'll go tonight and we'll stay there and this is how we'll get there. And that sort of stuff.” So she became a bit of an organiser I suppose. ... Secondly the second biggest step I think she took was when we decided that a few of us knew or understood te reo Māori. She organised, well they wouldn't be called formally, ‘classes’, but as part of our monthly meeting we would spend time sharing phrases and terminology in terms of te reo. And then growing from that came the other side of it, which was, “Well if they can't speak it let's see if they can sing it.”

Karen also pointed out that the rōpū members were also passionate about going places together, like to the local swimming pool or to housie. She said:

They all love housie, they're housie crazy. Yeah, they're all housie crazy. So, you know, they all go to housie. When we were at a noho when it finished on the Sunday, there was ten of them that were there and they wanted to leave early cos they wanted to get to the one o'clock housie.

Karen and Pete said that Ngaio's role as the leader of the rōpū came to her, not so much because she strongly identified as kāpo, but because she was known and respected in Māoridom and in the community. She was also prepared to learn and take on new challenges. Karen said:

Well within the rōpū, she's very respected cos she's one of those ladies, you know, she'll tell it like it is. She can be quite dictatorial but then that's just of her make-up, it's the right of a kuia as we would put. But she's also very much, you know, respected by her peers in the community. In respect of Māoridom able-bodied, she's known but I don't think that they were aware that she was blind.

Pete said:

I think she's a person who, with her age in mind and her Māoriness in mind and her willingness in mind, I think she's a person that's prepared to pick up the challenge, pick up the stick and run with it. She's certainly prepared to learn.

Ngaio, herself, said that she had to learn how to chair meetings, and a number of other things in order to lead the rōpū, and that she was always learning:

I didn't know anything about how to run meetings and everything like that, didn't know what an agenda was, you know. I wasn't interested in that kind of thing. But boy when I had to do it, you've got to learn all that. As you go along, you're picking up things all the time

The Future

As Ngaio grows older, Ngaio's whānau said that they were worried about Ngaio's health, as well as her ability to continue to be in the foreground of Ngāti Kāpo. Ngaio also wished to pass on the leadership of her Ngāti Kāpo rūpū to another member. Pete specifically acknowledged that Ngaio had helped to build the rūpū's confidence in te reo Māori and as a group, and that it was appropriate that Ngaio let go and pass the leadership to another. He said:

It's taken (our rūpū) all this time to feel okay about itself as a group, you know, because it lacked confidence ... You know: "Well who's going to speak for us?" ... So we've become very much I suppose organised, you know ... Now we're quite happy to go and sit in the church's meeting room and have a meeting. And we're quite happy, confident to go on to a marae and knowing, 'Well it's not just me. There's five of us or there's two of us or there's one of us and it's okay for us to be here because, you know, we can,' and that sort of stuff. But I tell you what, mate, it takes a bloody long time to get that confidence into people, bloody long time! So, when we can focus around communication, because that builds that confidence, once we've got that confidence we also have to have the ability to let go, let it go. We're going to be all right now. Get on with it. Well you get them to pass it on. You pass it on. They pass it on.

Ngaio said that she was actively looking to pass her leadership position to another. She had attempted to switch places with another executive member, but was unsuccessful and was worried that the rūpū would eventually not be able to continue if another leader wasn't found. She said:

Well she was my treasurer, so I said to her, "We should change places, you go on as president and I'll be the treasurer." "Oh no I wouldn't know what to do, I wouldn't know how to lead like you do." You know and I said to her, "Oh my goodness me, here we go again." So, as I said, if we don't, it'll just sit. ... We'll just close shop."

Karen stated that she believed that Ngaio realised that it was her responsibility to strengthen her rūpū for the future and step back. Karen said:

I think the other reason she's trying to move away from heading the group is to prepare others to come through cos she knows she's not going to live forever. And she knows too that if she wasn't to make the move now the group could well disintegrate. And like there was a big hoo-ha (at the noho) cos ... she got on this high horse saying: Well I'm not going [to the biennial conference]. And it really upset her group. But she said to me after, she says, "Oh I only said that to get them going. You know I'm coming." ... It's that thing of them assuming she will do something. It's not the trying to make herself important. It's assuming that she will automatically do something ... That's right, 'don't take it for granted', you know. (Ngaio said) "If yous can't get yourselves organised, then why can't yous? You don't need me." Like she was saying to me, "They don't need me there and they've got to learn that." And I think a lot of it's to do with the fact that she knows she needs to get them ready.

Karen also thought that because Ngaio had some health issues and was now totally blind that she had lost some confidence in her mobility skills, and thus wanted to free up some time to focus on being independent again. She said:

But medically she hasn't been a healthy woman for the last two years and I think that's why ... and again how she will mentally cope with her total blindness. I don't know, she may have talked to other members in Ngāti Kāpo about it but she very much goes on voice now ... I think this whole thing she's on at the moment is to give herself her own time, you know.

Similarly, Ngaio's son, Tane was worried about Ngaio's health. He said:

She's got to pull back and just stay in the background but still be with them but not up the front. Yeah well I hope so because there are some that are there much younger than her and I think they could take the reins from now ... Yeah and I'm thinking that's a lot of hard work for her to keep up with all the time so. Yeah maybe if she does [pull back], you know, maybe she won't get as sick as often.

Tane and Ngaio also pointed out that Ngaio has had an active life with many friends, and now also needed time to focus on her mokopuna. Tane, for example, said:

I know she loves her friends and so I don't think that they're going to stay away from her and she's not going to stay away from them, she's always surrounded by friends and family. I know she always hints and wants me to go back home. ... I don't know how much I missed it till every time I go back home, mainly to see mum and dad.

Ngaio, herself, also spoke about travelling in the future. She said that she would like to try the oysters in Bluff, itself, and perhaps go to Australia on a trip. However, what her whānau told us in this research was that wherever Ngaio went that others would follow, if she wished, because she held great mana within Ngāti Kāpo. For example, Karen said that Pania, another respected Ngāti Kāpo member, would drop everything for Ngaio if asked:

Yeah, well see Pania, Pania's a tough nut. But I tell you what, around Ngaio – and again it's a true reflection of what we say within Ngāti Kāpo about whanaungatanga and Māoritanga, that Ngaio and Pania have a very close affiliation to each other. And, yeah, I'll give you a good example, if Ngaio phoned Pania to say, "I want you to come to something." Pania would come. And it's not because she's a dictatorial lady. I can't really put it into words. It's just that status she has with us but it's a status that she doesn't throw in your face. That is Ngaio.

Chapter Six

Growing up in the 1950s, 1960s and 1970s:

Hoani and Sara

Hoani: Growing up in the 1950s and 1960s

E tipu e rea mō ngā rā ō tōu ao
Ko tō ringa ki ngā rākau ā te Pākehā hei ara mō tō tinana
Ko tō ngākau ki ngā taonga ā ō tīpuna Māori hei tikitiki mo tō māhuna
Ko tō wairua ki tō Atua, nāna nei ngā mea kātoa.

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

One of eight children, Hoani was born into a large and prominent whānau who were and continue to be intimately involved in the affairs of their iwi. Apirana Ngata's whakatauki (proverb) that heads this case study encapsulates the underpinning philosophy of Hoani's upbringing and orientation to the world, as it did many young Māori men and women across Aotearoa who were born in the 1940s and 1950s. It was in this context that Hoani grew up secure in his tribal identity, with te reo Māori as his first language, acculturated into iwi cultural, social and political life, and instilled with the values and benefits of a work ethic and an education in order to be a contributing member of the iwi, Māori whānau whānui and to society in general. In doing so, his upbringing has shaped his desires and determination to be successful as a husband and father and to live an ordinary life in extraordinary circumstances.

Early Years

Hoani was the first of his eight brothers and sisters to be born after the war in the 1940s. He was born into a small farming community within his iwi's boundaries but some distance away from his papakāinga (home land). His father, a veteran of the 28th Battalion, had been 'rehabbed' on to a farm when he came back from the war. Hoani said:

I was born one of eight children, two sisters and five brothers. The younger ones, three of us, were born after the war, that meant my dad went to the Second World War and the others were born before he went, and upon coming back from war, he was rehabbed on to a farm in Greens Bay ... and I was the first born after the war.

He grew up in a community in which he had whakapapa connections to many of them. Even where community members were not related the same notions of whānau and whanaungatanga were applied. He said:

We grew up in a valley where everybody was related, so it really was a oriented valley. There was a farmer there who had no whakapapa connection to us but they were aunty and uncle. Their kids were [our] brothers and sisters.

Hoani was named after a respected elder and tohunga of his iwi, and has carried the importance of his name ever since. Guided by tupuna and Apirana Ngata's whakatauki education was of utmost important to Hoani's parents. As a consequence much care and attention was given to the education of Hoani and his brothers and sisters. For example, Hoani said:

Both mum and dad come from what was the philosophy of the time, relative to Apirana Ngata's whakatauki, so they were followers of that and that's why hence, sending the older ones off to Te Aute College or to Queen Vic. That's the mindset that they were in, you see.

Hoani's early schooling was at the local native school. While native schools were established to assimilate young Māori and acculturate them into the mores of European society, they also tended to operate in contradictory ways to support and affirm Māori knowledge and practices. Thus, it was at school that Hoani was first exposed to the English language, while, at the same time, Māori practices such as whanaungatanga were affirmed and embedded in practice. Hoani said:

The language spoken at that time was all in te reo and the only time we were exposed to English was when we went to the school. Really the moment we got on the bus to the moment that we got off the bus back home ... Everybody was whānau and we did lots of things, so not only did we learn to read and write but we rode horses to school, all that sort of stuff. We played rugby together. There was strong competition between schools so it strengthened that whānau resolve to clean up the other teams. One of the interesting things that I remember, was how it was required of the senior students to nurture and awhi [help] the younger kids ... So you did things like read to the little kids and when there was a mishap, for the little kid, you were encouraged to awhi that kid through that, whether they teko their tarau or whatever. So we were encouraged to awhi them. We were there to learn English, learn, whatever the curriculum required them to teach, that's what they did. But the whānau thing, the whanaungatanga thing came in other ways like I am describing, the nurturing and the awhi that was required of you.

By the time Hoani reached high school, the farm, on which his father was working, was not doing so well and, as a consequence, he was not able to go to Te Aute College like his father and brothers before him. He said:

When it got to my turn to go to secondary school, the farm wasn't doing that well so I, and my younger brother, went to the local high school and even today we always have bit of a chuckle and claim that we had a much more well grounded

(education) than those who went to boarding school. I suppose that's to get over the possibility of us feeling somewhat left out.

Reflecting on this some fifty years later, Hoani considered that this was perhaps not such a bad thing:

Well, certainly the influence of divinity that was taught through the schools was a key part of the church type school curriculum because it follows that whole thing of missionaries going out to countries like us to educate the savages. Look at Canada, the residential school situation, where they took native Canadians away from their homes with a view to knocking it out of them and teaching them the ways of the new world. There are signs of that [here] but the difference I suppose was probably that we weren't taken from the age five, stripped at the gate, given clothing and put in to a residential school. But the influence of Hukarere and Queen Vic, being like ladies and that sort of thing, the graces of mother England and its values and that stuff.

Hoani went to his local high school and said that it was at this time his "sight was beginning to fail." To begin with Hoani endeavoured to hide his increasing vision loss. He said:

It was at the age of about 12 that it was becoming apparent that my sight was starting to fail. And mum noticed that. When she told me to grab something, I would be feeling around for it you know, instead of putting my hand straight there and so she thought that was funny. At the same time, the schoolteachers were also making an observation. So yeah, I was obviously ... you hide things and I was no different from anybody else. Hiding the fact that I couldn't see and trying to find some way of overcoming that problem in whatever way, so that's at about 12.

Hoani acknowledged that it was within the context of whānau and the practice of whanaungatanga that enabled him to participate and excel at school in spite of his increasing vision loss. He said:

I was in the top stream of the school and nothing seemed to be of concern for the teachers in terms of my achievements at school despite the fact that by a year later, it might even be less than that, it became obvious to the teachers, more obvious to myself even. But one of the interesting things was, because it was a very close community, they supported me. My peers would read what was on the blackboard, they would help me with my notes, all that sort of stuff ... I was doing the sorts of things that showed quite clearly I wasn't seeing that well but I went through that period doing reasonably well. I couldn't play all the games but, see this is where the whānau thing comes in, for boys in these sorts of schools, it was a big thing to play rugby ... I played rugby but I was only able to do that because of the whānau support. They helped me to achieve the goal of playing rugby for the first fifteen of the school. I wouldn't have been able to do that anywhere else. So that's an example where that whānau thing played out.

Diagnosis and a mother's love for her son

Hoani was diagnosed at 12 years of age with retinitis pigmentosa. He and his mother traveled to the local town to see the eye specialist, where he was prescribed glasses as part of his treatment despite them having no benefit. However, he said that wearing glasses meant he was singled out for teasing. It also put a strain on the whānau's finances. He said:

We went to the eye specialist and they tested me and they prescribed the lens and I went to the optometrist and then ... I was given glasses, which I hated, and the kids used to call me four eyes. Mum paid for them, I think by that time things were getting even worse with farming so they were farming to survive really.

Hoani was the first in his immediate whānau and direct whakapapa lines to have his eye condition despite it being hereditary. Subsequently, one of his children has been diagnosed with the same condition.

Hoani: My father and his brothers and sister, down their whakapapa line there is nothing. My mum is the same, down their whakapapa line, her brothers and sisters, their children, my cousins, absolutely nothing. [Just me] and then my boy has got it.

When he was diagnosed, Hoani's mother prayed for her son and consulted tohunga to find a cure.

Hoani: I remember quite clearly going to (one tohunga) and to other tohunga around the area and I know my mum was a very spiritual person. Before she went to bed, I could hear her praying all the time. She prayed not only for me though, she prayed for everybody, as mothers do. She always went to bed late after they did whatever they needed to do, their chores and the rest, but from time to time I wouldn't sleep and would be restless, I would hear her do her karakia and read her prayer book and so on and so in her karakia she would bless or ask for blessings of everybody, including me, in the hope that my sight would not deter me from achieving what needed to be achieved. I don't remember her saying please god fix him up. I don't remember that ... She did all that she could to make sure that I had been to a tohunga [expert], my mum always lived by and practiced those traditional medicines... There were a whole heap of karakia and he would use methods of ridding me of all impediments.

Hoani: Then around my teens came another tohunga ... By that time my sight had deteriorated quite significantly and I was at this stage a bit more realising of my situation. And so he used this stick up and down my back, over and around my head and all that sort of thing and his stick would shake ... This happened over a number of days and at the end of the week he concluded that I would never be able to see – my sight will continue to deteriorate, it was something to do with the optical nerve and its connection to the brain.

The tohunga's diagnosis of Hoani's eyes wasn't too far off what is known about his condition. By the time Hoani was in his late teens, his mother came to accept her son's condition, although it was not until the mid 1980s that she was able to share that with anyone. Hoani said:

It's interesting ... We developed our (local Ngāti Kāpo) rōpū of which my mother and her friends were very much involved. Anyway we went to establish a [another] group and a vanload of people [went over]. My mum was in one of the minibuses. And as we [began to] hui people started to share. In the evening, blow me down, my mum gets up, quite teary, and starts talking about me, yeah. [It was] some time [later] when it was prompted in a place that she felt secure and safe to actually start to talk about how she felt about me and about my sight.

A first foray to the Foundation

Given that Hoani was diagnosed around the time he was starting high school, it was felt by the school, his mother and the field officers from the Foundation for the Blind (as the Royal New Zealand Foundation for the Blind was then called) that he would benefit from finishing off his schooling at Parnell, where the Foundation's school in Auckland was located. Hoani said:

I had achieved really all that I could achieve at that school and it was felt by the principal and my mum and others, and by the officers of the Foundation that it would be a good idea for me to go up to the Institute for the Blind and finish my schooling off in Parnell ... I couldn't read books other than the big headings and I couldn't see the blackboard at all. From their point of view it seemed like a good idea to send me to the blind school.

Leaving his close-knit whānau and community was a great wrench for him. Hoani reflected on this period as being outside of his comfort zone because he was leaving the safety and support of his whānau. He said:

You could call it today your comfort zone, but I think it was a bit more than that. I was leaving a community safe but not safe because that's all I knew, safe because of whanaungatanga and what that meant.

Initially, though, Hoani considered the potential move to Auckland as an adventure and it was only when the realisation hit that he was going to be left at Parnell that he protested. Fortunately for Hoani, it was agreed by everyone that he was better off finishing his schooling back home amongst his whānau, friends and community. He said:

Mum and I flew up and the day we left the whole school turned out to bid me farewell before I hopped on the bus. And the thing about that was, it had no impact on me at that time because of the whole idea about going to Auckland or going to the big smoke and the feedback at that time from the kids were (they were) sort of envious. You see a lot of us had never been out of the town, out of the valley. We had no TV. The only access to the world was through radio and newspapers ... Eventually me and mum got on our way and bussed through to town and on the plane to Auckland and guess what we were met with? Whānau! My mum's aunty, two aunties and their families and it was just like a big tangi. I was thinking what the hell is going on here. It was quite packed with emotion for my mum to see our aunties who had moved away from home many years before

to Auckland and reconnect. Now I don't know how that was arranged but they were there. So they accompanied me and mum to the Blind Institute and we were taken in to the waiting room. I remember this very clearly. We were sitting and the secretary came out – “Mrs Smith, Master Hoani Smith come this way please.” And then the whānau stood up to come and she told them, “No the director will only see Mrs Smith and Master Smith.” So anyway we went in to the director's office and they started talking, have a kōrero, then I heard something that really disturbed me. He said to mum, “It is okay Mrs Smith, your boy will be okay here.” I realised then that I was being brought here and I was going to be left here and my mum was going to go home and of course I protested like crazy. What was to happen later was that he called up the principal of the school, who came to show us around the school, and I tried to be very calm about it all. So I just clung on to my mum and away we went around the school. The principal was showing us around. We went into the gymnasium and saw all these blind kids in a circle doing a dance, showing us what they do and all that sort of stuff. I wasn't too interested in that. I was just busy hanging on to mum ... We got back and then I started to get a bit louder in my protestation. And this is the good part of the story. The principal said to the director, “Mr director, I don't think it is appropriate for this boy to come here. I think, for a whole list of reasons”, which he went through. “He should return to his school and the challenge to us is how effective we can support him in his school.” I went home and carried on my schooling. Suffice to say there was no support from the Foundation but I didn't care, I was at home, I was at home.

Hoani's relief at being back home amongst his whānau to finish off his schooling was in part directly influenced by his exposure to other blind people at the Foundation. Part of his anxiety of being outside of his 'comfort zone' was that he had never experienced so many blind people before. While Hoani reflected on the potential for this to be perceived as denial, it could equally be argued that, given his upbringing within the bosom of his whānau and being considered 'normal', it could be perceived as Hoani coming face to face with the idea of difference and disability. As Hoani himself admits “it [being part of whānau] was all that he knew”. He said:

What is interesting about that story about going to the Foundation [was] up until that time I had not considered it [my blindness]. Yeah, I couldn't see the blackboard but there was so much else happening around, it didn't seem to matter. I contributed. I was one of the clever kids in the school so I was able to dine out on that. I contributed at home, milked the cows, I had my own horse and dogs, and you know, a part of my anxiety I spoke of in that story up in Auckland was all of a sudden being confronted by all these bloody blind people. I mean I was horrified by it. I didn't think too much about why, but the sooner I got out of there the better. I suppose you know, people could read that as being denial, I don't know.

A second foray to the Foundation

As Hoani got nearer school leaving age, it became apparent that his father was asking him to do less and less around the farm. This may have arisen out of the costs associated with

‘mucking up’ on the farm, but it also arose out of concern that Hoani might hurt himself. This hastened decisions about Hoani’s last year of schooling and what he was going to do once he left school. He said:

Less and less dad was asking me to do things on the farm because of his fear that I would muck up things. And sometimes [he] masked [this] by saying don’t get hurt, but I was still a young fellow and wanting to – just things like breaking in a horse, [he would say] “You shouldn’t be riding a horse son. You can hit your head on a tree or something.” So that was sort of a protection stuff around me and that was starting to hit home really in terms of not only school, but also relationships. A lot of my mates were starting to leave (school) and go for apprenticeships. It was becoming inevitable that I wouldn’t be a carpenter or a plumber or a teacher, all that. What was going to be my future? I had got to the stage where I didn’t think that shearing was going to be for me, scrub cutting, or whatever.

At 18 years of age it was decided that Hoani would complete his education in Auckland. The impetus for this was twofold. First, it was clear that he did not have a future in farming. Second, he wanted to live up to his namesake and follow in the footsteps of his high achieving family, and prove a point to himself and his whānau at the same time. He said:

I wanted to achieve because I come from a very high achieving family. So when I turned 18, I left the area. I mean my mates were all gone – a lot of them had established a relationship with a girl and I hadn’t – I was beginning to doubt myself and so I went to Auckland. I went back to Auckland with the idea of going to high school just to finish off my high school year. So I went to Manurewa High, that’s when the school moved from Parnell out to Homai. So I boarded at Homai and then went to Manurewa High and that was good. I enjoyed that because all I did was board at Homai but in the weekends I would bugger off ... still that thing about not wanting to be around other blind people. It was still in me but I made good friends with Māori in the community.

His experience at Homai was illuminating. It showed him how long-term stays at the Foundation’s residential school had institutionalised its students, in particular Māori students who were dislocated from their whānau. Hoani said:

Oh they had some (Māori students) there but they were really institutionalised. They were there for a long time. A lot of them couldn’t talk Māori and so I couldn’t have a conversation in te reo with anybody. So I used to go to the cooks, because the cooks were all Māori you see. Fortunately, the headmaster or the chief there at the time didn’t frown upon that, and in any case, most of the cooks were all my age. They were straight out of school and had gone to be kitchen hands so we had a good time, yeah, I had good fun and that was probably why that year I didn’t achieve anything really. I went to school and had a good time.

After a year at Homai and Manurewa High School and by his own admission of not achieving much Hoani went back home and got a sales job.

Hoani: So anyway I went back [home] and got a job in retail, selling furniture and whiteware and all that sort of stuff and I was managing quite well. I was a

commission salesman and I was pretty good at it. I lasted there about six years, and I became a senior salesperson.

A third foray to the Foundation

In his late twenties, it became inevitable that if Hoani was going to become independent he needed to leave home. Hoani said that his eyesight was getting worse, he was drinking heavily and taking his mother for granted. On reflection, Hoani saw his move back to Auckland as much for his mother's sake as his own. He said:

By the time I got to about 29 I think, 28, or 27 it might have been, I was really struggling with my sight. The other thing that was happening for me too, I was heavily getting in to drinking, gambling, I was knocking off work at five [and going] straight to the pub ... So that was the pattern. I was going to work, selling up, doing very well, straight out of work, straight to the pub, get home at ten o'clock, demand that kai be on the table from Mum. She did it. She would wake up in the morning and have breakfast on the table for her boy. All my clothes ironed and cleaned and away I would go again. Mum did all the things that a good mother does, she fed me, she watered me, when I got home [at] two o'clock in the morning and I thought nothing of it, I just thought, 'Well good on you mum. Thank you very much. You're a lovely darling mother.' And she never thought too much about it cos that was what she knew. But in terms of being able to express that – cos she was a very karakia person, she probably prayed every night for me. I mean that's one of the reasons I left town, I realised one, I wasn't going anywhere and, two, that I was actually abusing her.

Independence and carving out a successful career

While Hoani was striking out on his own by going back to Auckland, he still went to live at the Foundation's hostel and work in the workshop. It was not long, though, before he left the workshop and hostel to go flatting, securing a job as an x-ray technician at Auckland Hospital. He said:

The thing about going back to Auckland is I went back to the Foundation and went in to their workshops and once again, I entered this environment of all blind people and I hated it. I mean there were some really good fellas there. They were bloody champion. But I just didn't like it. It wasn't me. So I stayed in their hostel and I just went there to sleep, have breakfast and go to work. It wasn't me. So my mate and I went flatting. So yahoo, I was released. And then I got a job with the hospital in the x-ray department. It was a boring job, working in the dark doing this and that, going nowhere but it paid well. And socially I was developing a good lot of friends.

It was while he was working at the hospital he met his wife Miriama. Later, after ten years at the hospital Hoani was approached by the Foundation to become a Māori field worker. Hoani said:

Around about then I met Miriama and we lived together and eventually married. I was ten years at the hospital, and then there was a fella at the Foundation for the Blind and he rung me up and he says, “Hey there is a job at the Foundation that has got your name written all over it, apply.” So I applied and they gave it to me. That’s when I started my employment with the Foundation.

Since then Hoani has gone on to carve out a very successful career in his fieldwork for the Foundation, later in his work as a health professional for the government, and in his volunteer work for Ngāti Kāpo O Aotearoa. He said that the two primary drivers for his work were the commitment that he has to his community and the demonstration to the world that he is as capable as the next man. He said:

I think it’s also partly to do with what I see as taking responsibility. And there is a hint of proving to the bloody world that I’m not useless. I’m just driven by the need to be successful, to feel good about it, and accept responsibility ... You see one of the drivers for me in terms of where I wanted to be and where I wanted to go, coming from a high-achieving family [was that] I was always determined that I wasn’t going to be seen to be, not so much a failure, but not up there with the rest of the buggers.

Whilst being kāpo has defined much of his life Hoani saw his determination to succeed as also stemming from being Māori, his strong iwi identity and the ‘gut refusal to be subjugated’. He said:

There is no doubt in my mind that [my] determination derives from being Māori. In that I mean that what I was going through was no different to what many other Māori were going through at the time. The difference was, by and large, that I was blind as well. We were being kicked to hell and back again as a people. You either had to bloody well go down with it or you rose above it, yeah? So it goes back to that strong sense that I had to do well way back in terms of, you know, sense of responsibility to our whānau to make sure that we all did well because that was what the dream was.

Marriage and children

Hoani and Miriama’s first home was a flat in one of the Foundation’s old houses on the Parnell site, but their cat got in the way of some of the residents, and so they struck out on their own and moved. Miriama, Hoani’s wife, said:

When we first got married we lived in Parnell in one of the old houses that was where the Foundation is. It was a beautiful old place. It was divided into two flats and I enjoyed living there. And why did we leave there? Because we had this cat called Frosty and he was a huge chinchilla and oh he was just enormous. And he used to insist on lying across the front door and all the other tenants used to trip over him.

Miriama also grew up in a large and loving whānau that was connected to the Ringatū Church. Growing up with a granduncle who had a disability, influenced the way in which disability was normalised and considered part of the everyday world for her. Miriama said:

I grew up in a house with a granduncle that had polio so I've been around disability from the time I was born. I was born into a house where we all lived together in my grandparents' house, in a two-bedroom house with a little back out the back. There was my mother, father, me, my three aunts, that weren't married at that stage, my uncle, my young uncle, my granduncle that had polio and my grandparents, so that's 10 people in that two-bedroom house. And my grandparents who were part of the Ringatū church and so we had people coming and going all the time.

Miriama and Hoani, themselves, have three children, one mokopuna and another on the way. As with his own naming, Hoani's children and moko have been given meaningful names, some of which are from tupuna. The whānau eventually moved to a part of Auckland where their children's upbringing was semi rural and like being back home for Hoani and Miriama, where local community members became aunts and uncles. Their neighbourhood was close-knit and became the family's extended whānau irrespective of whether they were Pākehā, Māori or Samoan. Their son, Hemi, said:

There were a lot of young families like Mum and Dad. We knew all our neighbours as Auntie and Uncle. We lived in a small cul de sac growing up. Mum a stay at home mum until [the youngest] turned five. So if Mum wasn't at home by the time we finished school, a neighbour would be waiting at the bottom of her drive and we would stay up there until mum came home. They sort of all pulled together and helped one another out in times of need. And also painting each others' houses, doing working bees around the place. I remember that a lot. Everybody knew everyone else.

The determination that drove Hoani as a boy and independent young man also extended to him being driven to be a good provider for his family. Miriama also began to develop her own career as well. They both went on to get degrees as adult students. Hoani said:

Even with my kids I was determined that I was going to be a good provider. A good provider meant to me that I had to have a good job. And be well paid. I was determined that their mother was going to be able to be a good mother to them and that meant I wasn't going to accept second-best as a job ... So when my kids were born, Miriama was at home, We could afford it ... [However], she didn't spend all her time at home. She became involved in the community, did all the training and upskilled. So by the time she went back into the workforce, she had a whole range of skills. She had a degree. So it was a determination to do well, to do well by her, by the children, our home and with work as well.

Hoani's determination to provide for his family has not gone unnoticed by his children. His daughter, Mere said, "My father has always been a good provider ... I suppose it is not PC now but that's what fathers did. They went out to work every day and were good providers."

Hoani was equally determined to provide a 'normal' upbringing for his children. In this he was also successful. He ran marathons, played the piano and guitar, mowed the lawns, built

pergolas and letterboxes and along with Miriama was involved in their community. A testimony to this is that his children considered that their upbringing was normal. As they grew up, they played with other the kids in the neighbourhood, and sport on the weekend. They went swimming in the summer, went on camping holidays, laughed and argued, and they also guided their father and went to Christmas parties at the Foundation. For example, Hemi recalled:

When I was young I always remember Dad in the pool at the [local] primary school pool. Me, holding onto Dad's back and him diving under the water and coming up and diving under the water and having that, "Oh I am scared." Even though I knew that Dad had a visual disability but knowing that I had my hands around my father he was always going to make sure that I was safe ... Growing up was normal. I can't remember the point that I knew that Dad was visually impaired. It just meant that there were other things that we had to do, like lead Dad, yeah, be Dad's eyes.

In many respects their lives were enriched by the experiences that their father provided. Some were to do with being Māori, and some to do with his work within the blind community. All of Hoani's children remembered going to work with their Dad. Hemi, for this research, also talked about his father's involvement in establishing the local kōhanga reo. All three children recalled going overseas with Hoani to conferences to do with blindness.

Bill is the oldest of Hoani and Miriama's children, and once he was old enough, he became a guide and driver for his father. Bill acknowledged, though, that this was as much to help his mother as it was to help his father. Up until that time Miriama had been Hoani's guide and driver. Bill also reflected on the irony of guiding his father, who was in turn guiding him. He said:

As soon as I was old enough to be behind the wheel I was. That was more to help Mum. When I was six or seven ... I was guiding Dad but the thing is it was more like Dad teaching me how to guide ... So we'd catch the bus ... I remember the first time we hopped off the bus and he goes, "Look to your right son. Look at the signs above you. You'll see a sign that says C5. That's where we're going." You know he knew that but he also knew that it was to his right in a diagonal ... It is quite funny that he was actually training us up to be his eyes. You know there was no training for people to guide people with visual disabilities, but Dad I guess created his own training programme.

Hoani's children also noted that their parents emphasised through their own lives that education, and being proactive were the keys to being successful. For example, Hemi said:

It was encouraged between Mum and Dad that education was key and then Bill still in education, me still in education ... Our Dad would love for us to be better than him ... I think at the end of the day it would make him so proud if one of us had a PhD or something like that or was the Secretary General of the UN or something along those lines.

The impact of having a hereditary condition

When it came to having children little thought was given to the impact that Hoani's eye condition might have on them. Rather it was passion and love that determined Bill, Mere and Hemi's arrival into the world. Hoani said, "I thought about it. But love and being infatuated by it all that sort of takes over in terms of any relationship." Nevertheless, having children and now grandchildren was of concern to both Hoani and Miriama, given that retinitis pigmentosa is hereditary. Hoani stated:

Of course those feelings went through me and I celebrated inside when Bill was okay. You're always asking the question. I mean I'm asking the question now, although not for myself – what about my mokopuna? Hemi, you know, he's got my eye condition and I am sad about that.

Miriama noted that she thought that because vision impairment was not seen previously in any of his whānau, that Hoani's vision impairment was not a hereditary condition. She discovered, though, that retinitis pigmentosa was hereditary when she went to a conference with Hoani for his work. She said:

I tell you the impact was when Hoani and I went to the RP Conference ... Hoani [had] always said to me it's not hereditary in their family. Okay so I'm at this conference, and I go into one of the kōrero [talks] and they start talking about it being hereditary. And I'm sitting there and I'm thinking, 'I've had three children and I've not even thought in terms of what the impact would be on them.' And that had a huge impact on me because that's when I was actually faced with the reality that one of the kids may have it.

Once Miriama had time to process the fact that Hoani's condition was hereditary she accepted the possibility of it being passed on to her children. She said:

Because I had time to process the information that I got in Ireland I thought, 'well hey if it happens it happens.' By that stage I was hoping that it wouldn't happen but when it did well it did.

Hoani's son Hemi's sight has been deteriorating since his early teens. Hoani said that he has responsibilities 'to be there' for Hemi and all of his children, just as his own mother was there for him. Given his own personal experiences and those that he has witnessed as a Māori field worker for the Foundation, Hoani knew that there might be low times ahead for Hemi. Hoani said:

What is important is that we're there for him because you can't stop it. You can't halt anybody from reaching a low. What is important that there's somebody there. And I suppose it goes back to my mum again because even though it wasn't around my blindness, but it was around, you know, boozing and race horses, she was there. So my position is to make sure that I'm there for them, not only him but for these other ones too.

Mere, his daughter, stated that even though she knew that retinitis pigmentosa was hereditary that she wouldn't consider not having children because her father had a full and successful life. Mere said:

I have had people ask me prior to having Moko whether or not it would stop me having children and most definitely not because I have seen the life that my father has had and the successful life that he has had.

Despite his own lived experiences and his work as a field worker for the Foundation Hoani was aware that he rarely talked about his blindness with his family because he wanted to emphasise that he was normal. Hoani said:

What was important for me was to demonstrate to them that I was normal ... The thing is I never talked to them. They'll probably tell you that. I never talked to them about it. I talked to them through my actions. And there was an amount of discomfort in that as well ... Discomfort in the sense that, yeah, probably more inability to knowing how to verbalise that or to discuss it with them. And, you know, that's funny. That was my profession.

Miriama was determined that all of her children would grow up in the sighted world even though, Hemi, had a vision impairment. She said that she didn't want her children to be "just runners and fetchers" or exposed to the drinking culture that she saw in the 'blind culture'. She said:

Well I suppose what I was saying about Hemi growing up in a sighted world I made a conscious decision and it wasn't about not wanting to be part of the blind culture. It was just that I felt with three children I wanted them to see the life away from [it]. I had observed the kids of kāpo, the kids were just runners and fetchers, you know. Well that was my perception. It may not have been like that. And also there was that drinking culture that went with it and I didn't want my kids to be part of that drinking culture.

On Hemi, a 'chip off the block'

Hemi was diagnosed with the same condition as his father when he was around nine years of age. Hemi said:

The first time I realised that my vision was really really bad was when you have those school eye tests and you have to read those books. You'd get called up in twos from your class to go to the eye test. I went in and the person I was with went zip through it like in two minutes. And I was still going. I think that was when they called Mum and Dad. I distinctly remember being quite sad about it. Yeah that was definitely a moment I knew something was up.

Like his father before him, Hemi said that he didn't see himself as being any different once he had been told of his vision impairment. He said, "I didn't see myself any different. I still kept on playing sport." Hoani said that he believed that Hemi's aspirations to stay in the mainstream, be successful and "get on with it" may have come from him. Hemi said:

It is partly Dad's influence, 'get on with it boy'. Part of Dad's attitude towards those systems. I never encouraged him [to access specialist services] because I was working in the system. The thing is, he achieved everything that he needed to achieve.

Hoani's experience as a manager for the Foundation gave him a deep understanding of the limits of what could be offered to young kāpo Māori, and, as a father, Hoani wanted the most for his boy. He said:

That (specialist) support might have just had the effect of getting in the way. Now the only thing that they would have been able to help him with was to teach him Braille. But he was able to cope. He was able to read, write. He has achieved. He is like me. He wanted to play rugby league so he played rugby league. And he got the wrath of the team support systems when he missed the ball when they threw it at him but eventually his mates and the team got to know him. He was part of everything that went on at high school. He was leader of the kapa haka team. He wouldn't have got that at the Foundation. He wouldn't have got that at Homai. And now he is the leader of the university kapa haka team. He is now their tutor, my boy, he is now their tutor and he is teaching them getting them ready for the competitions. He wouldn't have got that [at the Foundation]. ... He kōrero te reo fluently. He wouldn't have got that at Homai, not a shit show. Now I knew that all along and that's why I wasn't encouraging him to go there. I was at the coal face. I was one of the managers of the system. I could see what was happening to our Māori kids. I didn't want that for my boy.

Hemi said that his father has given him the tools to be an independent and successful man in his own right:

I think there is something to be said about learning by experience and seeing Dad use his skill, the tools that he has at his disposal to I guess wade through life. And I've picked up those things as well.

A whānau and a world coming to terms with being kāpo

Despite Hoani's achievements he sometimes felt isolated from, and patronised by his wider whānau because of his vision impairment. He said that as he has gotten older, he has learned to deal with such exclusion without anger. For example, he described how he needed to explain to his brother, that even though he was dependent on sighted guide help, at times, that his guide dog always made him independent and should not be excluded from marae. He said:

You know from time-to-time – and sometimes you're more sensitive than others – you do feel isolated, you can feel patronised even within family. Not by Miriama and the kids though but by my wider family. And you just feel those. They won't ask you to do certain things or you're not included in the discussion, those things. But I've got on top of that. Sometimes it bothers me. Sometimes it doesn't. I don't have to prove to them anymore that I have a brain, I'm capable. I

don't have to justify to them. So in many ways I remind myself of that, I say, "What the hell." And it sort of gets me over that hump. The alternative to that is to hit them and that doesn't make any sense anymore ... Sometimes you let loose and – yeah, but what a waste of time. Cos one of the things that used to happen a lot was whenever you displayed some behaviour that's sort of unbecoming and expresses some real anger, the immediate response always used to be that you haven't come to terms with your blindness ... But as you grow and develop other mechanisms you get over it more quickly and move on ... The most difficult part about that is in some aspects of your life, you are dependent on sighted help. I always remember one of my brothers saying to me – we were just talking about guide dogs you see – and I said, "Oh well, bloody terrible about this, you know, marae not letting my dog on." And he says, "Oh well, you know what's wrong with my elbow?" You know basically saying, 'Well if you can't accept my bloody elbow well to the hell with you.' Well there are two ways I could have responded, one angrily. I said to him, "Well it's kind of like this, you're not always around but my dog is." Now I don't know to what extent people went away thinking about his comment and my response. It's hard to know. So you get better at responding to those situations.

Miriama told a story of a recent experience in which Hoani stood and spoke on the paepae [threshold of meeting house] ahead of his older brother and was rebuked for doing so. The point that Miriama makes in telling this story is that while Hoani's whānau acknowledged his achievements in the context of his being kāpo they do not always follow through with acknowledging the practical effects of being kāpo. She said:

Recently I was really annoyed because we were at Hoani's aunty's tangi and I would normally sit behind Hoani so I can tell him who was there and who was not there. But we were moved over to the other side. So he was sitting on the pae and his brother came in and sat down ... [But] as far as Hoani knew when I left him there was only him and his uncle sitting there. And he got up and spoke. Well his older brother give him a slap, you know not a physical [one] but a verbal slap. And you know it hurt Hoani. One of the uncles picked it up too and he told him [his brother] off. I went out and said [to the brother], "Hey you know Hoani hasn't gained his sight overnight. What's the problem with reaching over and saying: "Hey I'm here." I think at the end of the day it's about tikanga, you know. It's about how things are for you and how you behave.

Hoani was asked for this research whether he had any struggles with growing up kāpo. He said that his main 'niggle' was the constant reminder of being kāpo, given, for example, that he wasn't able to drive and that he didn't have access to all visual information, such as how his children were doing during a game of cricket. He said:

Like for example the constant reminder that you're a 'blind bugger'. So you go to the bus stop in the rain, on a cold day, [when] everybody is going to work in their cars. You've got no bloody choice but to stand in the rain and get wet and soaked, to catch the bloody bus. So you think, 'Oh I wish I could' – yeah. There are those sorts of things. You know you go out with your kids to take them to cricket and you sit there and you think, 'I wonder how they're doing?' And at the end of the day you can't contribute to giving them a bit of a pat on the back and saying, "Well done and good shot. You played well." – You know, those sorts of

things. So those are challenges but you've got to keep trying to find a way forward.

Hoani also talked about the aspirations he had for Māori, and for kāpo Māori in particular. However, he recognised that this was a challenge given the pressures that face Māori. But, he also pointed out that “it has become a responsibility for institutions to contribute to the retention of those things that are important to Māori.” Hoani noted that professionals should, at least, have a “strong Māori bias”. It is as simple as that for kāpo Māori. He said:

I think there needs to be a mix of professional support systems, like orientation and mobility techniques of daily living. I am not necessarily saying that they should all be Māori, but I think that there needs to be a strong Māori bias to the way that they approach things and apply themselves to them ... Like say half of the population is Māori. You are never going to get half of the nursing staff Māori. We are not going to achieve that. Similarly in the area of education, we can make a big dent in it. We have got 25%. We are not going to get 50%, not a hope in hell. But we can work hard at increasing it by 2% at a time or whatever. So what is needed is how we improve the capability of these professional staff to provide appropriately to Māori. So it requires a number of things. One is improving the capacity, but it is providing the support system that sits in behind it ...

He emphasised that with a focus on tikanga and te reo Māori, kāpo Māori will be well grounded and have a strong identity, and then will be able to learn how to cope with being kāpo. Hoani felt that being Māori came before being kāpo. He said:

The outcome is that [kāpo Māori] are well grounded, well equipped to meet the challenges that are out there. So you see the aim is having kāpo Māori well rounded in their tikanga, te reo Māori, as well as in the world. I mean respect, having respect, showing respect, you know, manaaki, awhi, and love. These are so embedded in our value system [but they] are challenged by a whole range of societal pressures. We know that, but at the same time there is no question that they are shown to be what are needed to ground people, to give them a good start, to give them confidence in who they are and what they are and to lead the kind of life that is consistent with being Māori ... At the end of the day, I am a Māori who happens to be kāpo. It is not about values of being kāpo. It is about values of being Māori, which is leading the way. And the issue around kāpo is the skills that you need to make up the deficit in your armoury as a result of being kāpo. So what does that mean? Braille, computer skills, being able to walk around reasonably independently, those are the skills or part of the skill set that allows you to map your pathway ... but the over riding thing is those values. And I mean the thing that I began to realise quite early in the piece, was that people were looking at things around the other way. Being kāpo and then being Māori! What is needed for you to live with an impairment is your own confidence in yourself, your pride, your learnings and to apply them, to gain new learnings and to apply them ... Now if you aren't in a position to accept any new learnings, emotionally, then I think it becomes hard. When I look back on what I have achieved, the central thing that has helped me, is being able to feel confident about myself, the values that I grew up with, whanaungatanga. That's not about being reliant on others, it is about the process of whakawhanaungatanga, being

able to appreciate what that means and what that can mean in any of your endeavours.

Being Māori and being blind: traditional narratives to understand contemporary understandings and stories that talk back from the margins

In one interview for this study, Hoani was asked about the use of traditional narratives in enabling Māori understandings of blindness. He considered that contemporary stories are also important in providing ways to think about and understanding vision impairment and being kāpo. The story of his Auntie Jane, who was kāpo, is especially telling as it reflected Hoani's and his iwi's orientation to valuing the contributions that people make rather than their ability to see.

Hoani: Well ... one of the significant people in the story of Tawhaki was Matakerepo. She was deemed to be the guardian of knowledge, of education and was part of the narrative that Tawhaki made in the journey to the [heavens] ... Then there is the story of Mahuika, everybody knows that story. The only other story that's related to kāpo is the one I saw in Te Māori. ... There was a carving [in the exhibition] from Te Arawa and it was a carving that told the story of one of their chieftainesses ... The carving of the face had no eyes. That suggests that she was blind, but between her legs were depictions of children. So if she was a chieftainess, as the story suggests, she bore significant children that ended up becoming considerable leaders. So from those stories it would suggest that there was a significant (kāpo) contribution to Māori society or the community ... Subsequent to that then we've had, over time, some quite significant tohunga, who are blind ... Just as long as people are being given the opportunity to tell those stories. Now subsequent to that we can identify some kāpo people who have made significant contributions (in my life time). Now one of my aunties, who died last year, was from quite a well-known family. Auntie Jane was blind and she came from a family who are culturally, socially learned. Now Auntie Jane was a repository of a lot of the stories, the whakapapa, the songs of the iwi to the point where she was deemed an expert.

However, as Hoani pointed out, there are many kāpo Māori who have not had opportunities to realise their potential and live in their communities because they were institutionalised on the basis of their disability. Hoani said:

A lot of people that I know were removed from their community, you know, and taken up to Auckland. So who knows what would have happened to them if they stayed back in their communities? Whether they would take up leadership roles or significant roles in their community or whether they would be sort of subservient, just live from day-to-day.

The future

Hoani and Miriama returned back to the rohe of their iwi once their children had grown up. They live on their own and continue to work in their respective professions. Their children continue to be very important to them and despite the long distances between where they all live they make sure that they stay in close contact with one another. Relationships, whether they be whānau, iwi or community, are important to both Hoani and Miriama. Miriama, for example, said, “It has been the relationships with and learning from people over the course of his working life that has helped Hoani understand his own life and sense of place.” Hoani, himself, said that he had “seen it all” and, like Miriama noted that because of his work in the field of blindness that he has learned much about himself as well.

Hoani: The other thing of course is that I’ve seen it all, having worked in the area of welfare for the blind and ... I’m still learning from people. The main source of learning that I have had is other blind people, even those that make big muck ups in their lives. I’m indebted to them. [They] have helped me to consider my own life.

To sum up Hoani’s view of being Māori and of being kāpo was simply put. He said, “I am clear I am a Māori, who happens to be blind. That’s it in a nutshell.” It is in this context of an unwavering identity as Māori that Hoani has navigated his successful journey.

Sara: Growing up in the 1960s and 1970s

Eleanor: She's such a wonderful personality. She's fought hard and long for where she's got ... I don't know how it was, only from what she said about blindness being normal in the family ... I think she's got the potential to do all sorts of things. And certainly because of her experience in the disability field, she's up there. She could be the Minister for Disability or whatever, you know. She could be. She's pretty good orally and articulately and academically and she could be. She could go really, really far but it's hard. It's too hard, the driving bit, not being able to get to places, all of that sort of thing.

Sara described herself as a “city girl” and one of eight brothers and sisters. Her parents were Māori from two different iwi, and being kāpo was nothing new to her whānau. Sara's grandfather was kāpo, three of her siblings were kāpo, and some of her nephews and nieces were also kāpo. Sara said that being kāpo was “normal”. However, despite her whānau's experience with being kāpo, Sara was believed to be seeing well and her whānau did not notice the severity of her vision impairment because she was able to see better than some of her siblings, and it was assumed that she saw like her older sister. She said:

Well I think I was born with glasses on. I don't ever remember a time not wearing glasses. And I have brothers who are severely vision impaired and a sister who wears glasses. My brothers, their impairment is, like I said, it was severe. So my parents, when my sister was born, it was determined that she needed glasses too but she's not as badly affected as my brothers. And like she drives and, you know, was able to attend mainstream school. So when I came along ... they just assumed that I saw like she did because I wasn't as bad as my brothers. But they assumed that I could see as well as my sister, but I couldn't, but no one actually ever asked me, “How well do you see?” You know. And it never occurred to me to say anything.

Sara said that even though she saw an eye specialist and an optometrist for her glasses, the severity of her impairment was not recognised. She explained that because of the size of her family that it would have been difficult for her parents to keep track of who could see what. She said:

And it's not like the optometrist said, “Wow this one's not quite as bad as that one but far worse than...” You know? So I just don't think they questioned it. And I think when you've got [eight] kids, you know ... Yeah and I don't think it was intentional or anything like that I just think it was just one of those things and I didn't know or didn't have the language or the skills to go, “I think I see a little bit worse than what you think I do.”

Also, as soon as she was able, Sara went to her eye appointments on her own. She encountered difficulties, though, not with the exam, but with choosing frames for herself. She said:

As a little kid mum would send me to the optometrist on my own. “You’ve got an appointment.” You know, “Go down there.” And off you go. And the worst thing about that was when it came time to like get new glasses, and they’d be like, “Here, try any.” You’re trying on the new frames and I had to take my glasses off, so I had no idea what that frame looks like. It’s like, ‘That’ll do.’ You know get home and the glasses frame, and I’m like, ‘Oh my god, what was I thinking?’

As an adult, Sara said that she wanted to know more about, and talk more about her eye condition. She felt that the more that her whānau’s vision impairment was understood, then the more her whānau would be able to cope with it because some of the older members of her whānau believed that the family had a curse. She said:

I don’t suppose anyone in my mum’s generation wanted to hide it but I just think they just never talked about it. And there’s the sort of thought within the family that it is a curse and that’s what my mum always used to call it ‘the family curse’ ... If it is a curse, and a big part of me believes that if there is a curse and if we’re ever to sort of do away with it ... Like, maybe that’s why it’s still lurking around because no one talked about it. They all just ignored it ... I don’t know if we’ll ever get rid of it but it may be the way to cope with it better.

Sara’s parents, and subsequently her siblings, did not “make a big deal” of being kāpo, and so she did not know exactly when she became aware of the fact that her vision was actually impaired. She said:

We grew up with parents who didn’t make a big deal about it. So I guess that’s kind of why we don’t. I can’t even remember when I ever became aware of it but I don’t think it was a shock. I think maybe on some levels I did know ... I knew that I needed to wear glasses but didn’t, you know, had no concept of how well everybody else saw or how badly I saw compared to everybody else. And when you’d see, you know especially as a little kid, when you’d see other people wearing glasses, I think maybe made the same assumptions that they saw like I did when realistically they probably saw a lot better than what I did.

Sara said that she did discover that she had a vision impairment until she was in her early twenties and went to the eye specialist with her children, who were being assessed. When she did discover this, she was actually overjoyed. She said, “It was great to finally be able to say I was blind. Shout it from the rooftop.”

Growing up ‘normal’

Eleanor, Sara’s sister, said that Sara was popular, outgoing and always had friends. She said:

Well I think she was quite happy. I think she was. Mind you, she still is today, you know. She meets anybody, she’s really outgoing. Whereas we’re all quite reserved, you know, until we get to – she’s actually quite outgoing. But she was like that when she was little too I think. She always had people flock to her.

Eleanor, who described herself as “a bat”, said that Sara was a “double bat”. She also said that while they grew up, Sara was “a softy”, while she was not. She said that Sara did get attention but not because of her vision but because she was “the baby” of the whānau at the time. Eleanor still humorously remembers a time when Sara was pouring some milk and because her enthusiasm got the better of her, Eleanor had to clean up after her. She said:

She’s a big softie and I never wanted to be looked at as a wimp ... I was stuck between her and (my kāpo brother) ... And then she was the baby. So if he did something wrong, I got the whack cos he couldn’t see, and she was little and couldn’t see type of thing. Hence, the milk story: ... Dad was home for lunch and they were having a conversation and ... she was too busy flapping and wasn’t watching what she was doing (pouring). It wasn’t cos she couldn’t see it. She was sort of like hands up and not watching what she was doing, and of course the cup overflowed. It started going down all the bench and through the drawers and stuff like that. ... And I said, “Look what you’re doing, you’re spilling the milk.” And I got told to clean it up ... The youngest is always the – it seems that they’re spoilt but you know it’s probably our fault as much as hers. I think that’s just the normal family thing, you all spoil them but then they make you mad ... But I think that’s normal. So the vision sort of didn’t really come into it.

One of Sara’s kāpo brothers, Ropata said that while they grew up, his parents were “good” because kāpo children in the whānau were treated the same as the other children. He said:

Mum was good, she didn’t treat us any different, you know, like she just treated us like normal kids. You know what I mean and that was good, you know, no special things. I mean no allowances and all that but, yeah, she just treated us normal like the rest of us ... Well (being kāpo) was just a normal everyday thing. You know she just treated it as normal because well we weren’t going to get any better so as far as she was concerned we were just normal children. Her father was totally blind ... (My dad) treated us normal as well.

Similarly, Sara said that her whānau attitude about being kāpo helped her to feel accepted and to be independent. She said:

I think what helped is the way that my parents were, or the way that the family unit was, that (being kāpo) was never really spoken about. And not that it was hidden but it was just, you know, like having brown hair and, you know, it just was.

She said that her older kāpo siblings were role models for her, and that Ropata had a significant, but unconscious, influence on her because he was independent, very able, and “out there”. She said:

I don’t think he consciously helped. I just think being around him helped ... I was never aware of any or conscious of any special allowances being made for him or him making them or excuses, you know using his vision as an excuse or a reason why he couldn’t do anything. And I followed him everywhere when I was little. I went everywhere with him. And I don’t think as a little person, as a child, I don’t think I was even aware that he couldn’t see well ... And you know

he went out flatting and I'd go out with him and I'd go places with him, go to listen to his band practice with him, you know, and things like that. Yeah and I don't know when I became aware that he couldn't see properly but then as a little kid I didn't know that I didn't see properly either.

Culture and Growing up

Sara indicated that because she was one of the youngest children in the whānau that she was not as involved with Māori culture as she grew. Over time her parents, who did speak Māori at home, decreased their involvement with their extended whānau and marae. Sara said:

I know my whakapapa and I know who I am but I don't, you know, we didn't sort of every weekend tramp off to the marae and do all that kind of thing by the time I was around.

Similarly, Ropata and Eleanor indicated that Sara was too young to be involved in the kapa haka group in which they were involved, that their church was like a marae, and that their parents did not teach them Māori even though it was spoken at home and at gatherings. Eleanor said:

We were never taught Māori, to speak it, because mum and dad didn't see the need. Well because in their time ... you got in deep trouble when you spoke it at school and I think that transferred to us. Oh, they spoke it to each other at home and you picked up words here and there but to speak it speak it, no ... We were all in the haka group ... I'm not sure if she did. She might have been really little and sort of come right in at the end ... Oh cos you'd have Māori mass on a Sunday and you'd sort of go down there and then you'd all congregate in the hall. And like I said, we were in a haka group and so you'd do all that and you'd have talent quests and stuff like that at night ... I suppose you could call it a sort of semi-marae, cos it's a Māori congregation. Yeah mass is done in Māori and then you've got the hall next door and then off that is the kitchen, you all have your cup of tea, like you do just like in a marae, you know, everybody's sort of coming in ... Yeah so when we were little we were around it a lot even though we never spoke it and it was spoken a lot around us.

Ropata and his wife, Susan, stated that they believed that it was difficult for Sara and her siblings to learn Māori because their parents spoke different dialects. They said:

Susan: And they're all different, every marae that you go to has got a different code of ethic thing that, you know, different type of language. Well it's the same language but it's just spoken differently.

Ropata: Yeah sort of like my mother and my father, mum's from X and dad's from Y. It's a totally different sort of protocol and the meaning of some of the words they speak are different. So it was quite hard to sort of like – was quite hard for – well me anyway – to learn the language when mum spoke sort of – well I suppose a different dialect than dad.

Education Services

In regards to Sara's education while she was growing up, Sara's vision impairment was not fully uncovered by those around her despite the Vision and Hearing Testers at school sending a note home once to her parents. Sara said:

You always have those hearing test people and the vision test people that come through school, and I think they were fairly well aware that I couldn't read the eye chart. I can remember one note going home to mum that said you know, "Sara couldn't read the eye chart." And mum said, "Well what letter did you get up (to)?" And it was like, "No I couldn't even see the eye chart, I didn't know where she was pointing." (The tester's) like "Read letter blah blah." And I'm like, "Where am I reading?" And they knew that, yeah, that I was obviously that bad but no one said, "Oh I think this child needs extra support or needs schooling through Homai."

Sara thus never did receive any educational services from Vision Resource Teachers or from the Royal New Zealand Foundation of the Blind. Interestingly, though, she stated that some of her siblings attended Homai College at various points in their life, and that she actually didn't know that this was a school for kāpo children. She said:

It was all just pretty natural. And I knew that they went to Homai College but I don't think I knew that they went to Homai College for the Blind. You know, I don't think I ever knew that.

Sara said that she coped with her vision impairment in various ways at school. She said that every year she told her parents that she couldn't see the board. She said:

I mean I'd come home from school some days and I'd say, "I can't see the board." And mum would say, as parents do, "Well sit up the front of the class." You know and I'd do that. So I'd start every school year off saying, "I can't see the board." And I'd have to sit up the front of the class, but when you're sitting at the front of the class and you can't see the board it's, you know, 'where do I go from here?'

She said that, fortunately, she could read normal size print with good lighting, good contrast, and when a book was brought extremely close to her eyes. However, she couldn't read for long periods of time without getting a headache, but she said that this didn't matter because she "just had to get on with it." She said:

Like I can read normal print. I have to have the right lighting and I have to hold the book extremely close and if it's like good contrast, if it's good clean white paper and dark print, yeah that'll be good. But, yeah, I can't read for too long without – without getting – like I used to get severe headaches probably from reading. But yeah and it was difficult. I don't think at the time I thought it was difficult, but now I know it was difficult. But then you just had to get on with it.

Throughout her schooling, Sara only had one teacher in third form that made an effort to address the difficulties that she was having in accessing the curriculum. As an adult, Sara was surprised by this because of her whānau history at the school. She said:

I had one teacher in maths, Mr D, I was actually sitting at the front of the class, and I'm not sure whether I said to him that I couldn't see or he picked it up, but anyway he'd said to me, "How would this help? How can we help you?" So he actually sat me at the back of the class, and he was quite tactful about it, he sat me at the back of the class next to someone who would read the board for me. Which I thought was quite tactful and I still remember that ... And by the time I was at high school there were still teachers there who were aware of – because Ropata had actually gone through (there) as well. So there were still teachers there who were aware of him and how bad his vision was. So sort of now that I think back on it, I'm actually quite surprised that they sort of didn't go, "Hey, let's not be rude but let's just have a look at the sister shall we?"

Sara thought that it was easier to manage in primary school than in secondary school because of the social stigma that was attached to being kāpo as she grew older. She said:

And I think in primary and intermediate it was easy because you could just, you know, if I couldn't see the board I would just walk up to it. You know and that wasn't, you know, that whole social thing that got in the way. And, I think in high school, being a teenager sort of got in the way of not being able to see. So I just don't think I bothered. I had a really good memory.

Sara started to hide her vision impairment and that this carried on into her working life. She said:

High school's such a shitty time for any teenager, and I think I hid my vision. I hid about how bad my vision was cos you just don't want to be any different to anybody else and I think that carried on after I left school and started working. I think that was the same.

Both Sara and her sister, Eleanor, stated that Sara also was teased badly at school because she also had nystagmus, which causes involuntary eye movements. Eleanor said that because they were Māori that further teasing occurred as well:

It wasn't till you got older and moved further through school that you got the name calling and it sort of hit you then. Yeah. 'Four eyes.' 'Goggle eyes.' And because we've got the nystagmus. And I think Sara, she got it bad. Cos there was a programme, 'Battle Star Galactica', and cos she's got quite a bad nystagmus and they used to call her 'Cylon'. ... It had these bad people and they had this red eye and it would just keep going like that all the time ... Yeah some of the names you were called were unpleasant. And then that's when the cultural thing, you'd be a ... 'a black goggle-eyed idiot.' I think she got it quite bad ... Yeah. Cos I remember her coming and crying about that.

Sara thought that perhaps, if she had had support during her education from Vision Resource Teachers, that she may have been better able to speak up for herself because she would have more knowledge about her vision impairment. She said:

Looking back I think it definitely would have been beneficial. Like maybe if I had that access to resources to help educationally, I might have had the ability to say, “Look I can’t see. I need help.” And I’d be able to sort of talk about it. Because I think I hid not just my vision, but because I’ve got nystagmus as well, I think that I sort of hid my eyes really from my peers, from my friends. I probably had a chip on my shoulder and didn’t even know why. I think you build all these like, you know, defence walls. And I think I was probably quite an aggro teenager just cos you built all these walls to protect yourself from being teased ... and ‘Well, yeah, so I am. Yes I am blind but so what?’ You know not being able to – yeah I don’t think I had the skills to say, “Well this is actually what’s wrong with me and this is why this happened.” My first reaction was probably to lash out cos I didn’t have the support. I walked this funny line where I wasn’t blind enough but I didn’t see well enough. So I didn’t fit in one group and I didn’t fit in the other.

Ropata remembered that, despite difficulties, Sara spoke up for herself and was a leader at school. He said:

She went to the public schools all the way through to the six form. Well she’s a very forward person is Sara, and she speaks her mind and she’s done that, well, ever since I can remember. You know even at school she’d be the enthusiastic one, you know. She’d gather all the pupils in and, “We’re doing this and blah-blah-blah-blah.” A good organiser.

Having a Whānau and being a Kāpo Mother

After Sara left school, she found a position in a government department as an accounts clerk. She developed her own coping strategies that enabled her to do her work without revealing that she had a vision impairment. She said:

I did accounts receivable ... But even then, there were like all these little coping strategies you had to develop, like I couldn’t see the computer. I’d have to get really close but I’d have to find excuses – only because I didn’t have the confidence or the skills, cos I didn’t know how bad my vision – well I knew how bad my vision was but sort of not really. I couldn’t say, “Hey look I can’t see it. Can I bring it closer?” You know and that’s all it would have been a matter of doing but I didn’t have that confidence to be able to do that without feeling like a blind twit, I suppose, or without thinking people were going to look at me funny or make fun of me.

Sara met her partner in a pub in her early twenties, and they eventually had four children together. However, they decided to live separately until about ten years after they had met. Sara explained that her partner was young and that her mother did not initially approve of their relationship. She said, “Like my mum didn’t like him ... and then twenty-three year old men don’t turn twenty-three I think ’til they’re about thirty.” She said that it was easier financially to live separately as well.

When Sara did begin to have children, she suspected that, like others in her whānau, her sons were kāpo. She took them to a paediatric eye specialist with her mother, and they also ‘officially’ discovered that she was kāpo as well. She said:

It wasn’t until my sons were born and (the ophthalmologist) was saying, “Well what’s your vision like?” And I said, “Oh my vision’s really bad.” And she tested me and she said, “Your vision is really bad, did you go to school at Homai?” And I said, “No I didn’t, I went to my local high school.” And she was shocked and my mum was really shocked to find out how bad my vision was.

Sara continued to see her son’s eye specialist because she was “treated as a person” and not as a “condition” or “freak”. She said that her experience with other eye specialists, however, have not been positive. She said:

One of the reasons why I love (my specialist) is because she doesn’t stand any of the bullshit, she tells you straight what’s happening. But one of the things I really liked about her is that you actually felt like like a person ... I mean I’ve had an experience, and it’s happened a few times, where ... you race in (an emergency) and get to see someone and they’re like, “Wow, wow look at your eyes. Have they always done that? Do you mind if I just get someone?” And I’m thinking, ‘oh they’re getting someone for a second opinion.’ And then suddenly you feel like a freak, and they love it. And all these people ... And it’s happened time and time again “I’m just going to get one of my colleagues. Come and look at this and isn’t that amazing. I’ve heard of this but I’ve never seen it not up close.” You know. And – and just, you know, and I’ve cried – and I’m not a very emotional person, but I’ve just cried, I’ve come out of there feeling like an inch tall and cried and – and felt all freakish and things like that. And so I’ve gone through that, then I started to get angry. “Stop, no you cannot march people through, not less you’re prepared to pay me.” ... So if that situation happens now, I just say to them, “I’m not comfortable, I’m either going to ask you to refer me to someone else or I’m going to have to go private because I don’t like the way you’re treating me.” Cos they’re treating – you get treated as a condition.

After being diagnosed as legally blind, Sara soon registered herself and her sons as full members of the Royal New Zealand Foundation for the Blind (RNZFB), and said that, for herself, she felt freer and more confident because with registration she was able to identify as kāpo and explain her vision impairment. She said:

Just membership kind of frees me up enough to be able to say to someone, “Oh, could you please read that for me? I can’t read that.” I had trouble in a restaurant reading the menu ... or even in a takeaway bar, I can’t see what’s on the board. ... If no one had actually said to me, “Yes you are as blind as a bat and you need to register yourself with this, that and the other organisation.” I still think I’d be doing what I was doing. ... As a teenager, developing all those coping strategies. ... But now I can just say, “Oh look, I don’t see very well. Can you read it to me? Can you help me?” And I think if anything, more than any service that I’ve ever received, that’s probably the one thing that being a member of an organisation has allowed me to do.

Sara stated that she mostly received advice from the RNZFB about what she may be entitled to receive, and didn't feel that she "had much support" from the RNZFB. She was also concerned that she was initially referred to Māori services without permission, and felt that she was, in a sense, segregated and labelled. She said:

I found it really weird when I registered with the Blind Foundation that my name was recognised and they said, "Well you have to register yourself with Māori Services." And I said, "Well, why's that?" They said, "Oh because you're Māori." You know this is over the phone I've never met any of these people. And I'm saying, "Well yes I am." But I didn't appreciate being told that I had to. And they went, "But the numbers are low." And I thought, 'That's not my fault. I don't want to be a number.' And I really didn't have a choice it was, "You pretty much have to register yourself. We'll register you with Māori Services." Which was okay, but sort of not okay. It didn't sit well with me being told that, you know, another label. Yeah, 'I'd just been labelled blind, legally blind, now you want to label me a Māori.' Which I didn't have a problem but there was no choice ... I didn't have a choice with the kids either. So that was okay and we had a couple of rocky moments in those early days ... I've never really, for myself, had a great deal of support from the Blind Foundation.

Sara also noted that when she did go to a social meeting through Māori services that she felt like an outsider because she felt the social situation wasn't 'normal'; she was not as kāpo as others; she did not know anyone; and there were no children at the meeting. She said:

I felt like an outsider. I felt like an outsider cos mine were the only two babies that were there ... And I felt like an outsider because all these people knew each other. They'd all gone through, if not (to) school together, if not through the Homai system together, they've all gone through some form or other of the Foundation's service. So they all knew each other and the only way in which they could relate to me was through my brothers ... It was only one meeting I attended, but I almost felt like a fake. 'So where have you been?' And I'm like, "The last twenty-three years I've been living like a normal person." And that's what it felt like and I was sort of there under false pretences ... And it wasn't that anyone was treating me like that, that's just how I personally felt ... And it was horrid for me cos it wasn't like a normal social situation where people'd come up and speak to you because out of the group of people that were there, other than the drivers, I probably saw better than the majority of the people in the room.

Sara indicated that she had a minimal amount of direct services from the RNZFB and had never had a service assessment. She only received some Orientation and Mobility services and this was "by accident" from her sons' Orientation and Mobility instructor. She said:

No one's come out. I've never had an assessment. The only input I've had was O&M ... and that wasn't through an assessment or any form of, "We're ringing to see if there's any service we can offer you." It was actually ... It fairly much happened through the boys' involvement with Homai and I wanted to learn some guiding techniques and then (the O&M Instructor) came out and said to

me, “You’re vision impaired.” And I said, “Yeah I am.” And he says, “Have you had any O&M yourself?” And I said, “No.” So he said, “Well I think that’s the first step.” And so he took me – did the routes all around (here) for me. And that’s actually been a benefit, something that came out of having the boys.

Sara became a member of both Tamaki Ngāti Kāpo, a local organisation for kāpo Māori, and only recently become a member of Ngāti Kāpo O Aotearoa, the national body of kāpo Māori. She said though that being a member of these organisations is like being in a whānau. She also found that being a member of Ngāti Kāpo O Aotearoa was more comfortable than being a member of the RNZFB because “criteria” for membership was not the “first issue on the table” and she felt she belonged with Ngāti Kāpo. She said:

I think I’m more comfortable with Ngāti Kāpo because the flexibility’s obvious, where ... with RNZFB, and I’m not being critical when I say this, it’s eligibility factors. Whereas with Ngāti Kāpo there’s like, “Yeah come along, join in, be part of us.” And, you know, there’s no criteria. There probably is but you know the criteria or the illegibility, it’s not the first issue on the table. I think this happens in all Māori and Pacific Island services in all organisations, the difference isn’t that they’re managed or administrated differently. I think the difference is in the invitation to join ... It certainly isn’t in the language or protocol. I think it’s more in the belonging feeling ... I can see the – the work that’s gone into Ngāti Kāpo Aotearoa ... I’m proud that there’s an agency out there that represents me. We’re members of all these other agencies, but not one of them have fitted to our family ... I think the positive thing about being Māori kāpo is that’s there is actually an agency that’s specifically designed to deal just with us.

Career and Whakapapa

Sara’s sons were kāpo and had additional impairments, which caused her to interact with a number of special education professionals. She became confident as a kāpo mother of four, and as able to learn much about how to enable her kāpo children to access education services. She said:

I had to learn the talk and for a few years there I faked it till I made it ... But I definitely did learn. I think I’m a stronger parent today because I had to make a lot of mistakes, like just having a visually impaired child and having a vision impairment, yourself. If [your children] have any form of disability or impairment, you get this whole group of other people that then become part of your decision-making for your child and when you’ve got two, the amount of people that just had a say or disagreed ... I think we had some meetings where we (have) had fifteen people in the one room ... And I think I pretty much had to learn how to play the game. And that’s probably cruel and maybe a bit clinical to look at it like that but that’s fairly much what it is and what it still is. You’ve got to learn how to present your child, when it comes to funding. To get the best for your child you can’t make them seem too able or you miss out, but then you can’t lie about it. And as a parent you never want to say, “Oh my child doesn’t do this, that and the other.” You know you want to have some pride in

your child. I had to learn to let that all go and if there was problems, say it otherwise you're never going to get any help.

Sara said that her life was full and busy. She spent much time caring for her children. Typically, she said that she did not stop for dinner until about nine o'clock at night. Her day began around six a.m. and below she described her typical morning juggle with her children:

I get up between quarter-past and half-past six, although I should really get up earlier. So I get up, the first thing I do is I make the kids' lunch and then [one boy] gets up ... He jumps straight in the shower, then [the second boy] gets up and goes on the toilet while [the first one's] in the shower. Then I wake [my daughter] up because baby's already awake and he's playing quite happily. So I don't go anywhere near there cos then he'll just start to get up. Then she gets up, makes her bed and sort of hangs around in the bedroom ... Then [one's] out the shower and [the other's] in the shower. One boy's getting dressed and then after [the second boy's] been showered, cos he loves water so he gets to hang out in the shower while I do [my daughter's] hair. And once they're all done the baby can get up, unless of course by this stage he's screaming. So if he's screaming he's in the pushchair and he's in the doorway of the bathroom where he can see what's all happening. And yep then it's breakfast and then after breakfast [my daughter's] doing her teeth and her face and I do the school books. Taxi comes and then I do the babe. So I don't actually do [the baby] until everybody's left for school. And he's fairly happy to just wait ... And then it's just housework.

Sara's whānau said that they helped her whenever she needed them, and Sara said that her whānau was certainly her "safety net." Sara's current employer noted that her whānau was supportive as well and, as did her siblings, described Sara's life as being restricted because of transport difficulties. Carole said:

Her social life has been very difficult and not just because of her vision. She has to rely on other people to get her to places. She has to rely on her partner. She has to rely on family and whānau. So her social life revolves around her colleagues at work ... It restricts her to going out with sort of like out on the town with mates that she might just be sort of friendly with, you know. It restricts her ... It's both (being kāpo and a mother). It's both. It's both. You know I can just jump in a car and go and see somebody. It's not as easy for Sara.

Sara's competence and experience was also soon recognised by others and she was able to pursue an education and a career in between and while having children. Sara's paid work revolved around her whakapapa, her culture, and the education of disabled children. Her first position involved being a research assistant in a study about her whānau's strain of retinis pigmentosa by tracing it in the family tree of eight generations, beginning in 1830. This research project established that this particular eye condition was X-linked as Sara described:

It was established that it's passed from, you know, it's X-linked, so it's passed from the, if the mother has it, yeah. Yeah so it's kind of carried by the woman and passed to – passed onto the children but the boys are more severely affected than females. But females can get it. Females can get it as well and they also

carry it ... [Boys can carry it] but they can only pass it to their daughters cos of the X-link.

Eleanor said that because of her work, Sara had more knowledge of their whakapapa even though she was the youngest child. Eleanor said:

(The kāpo whakapapa) goes on and on and on ... Sara's the one that sort of gets right into it and if you want to know anything, you ring Sara. Funny that and she's the youngest. We sort of just plod on. We know who we are, where we're from. But she's the one. She's the digger.

Sara stated that some of her whānau didn't want to take part in her research and this was understandable, but she felt that her generation was more willing to talk about being kāpo. She said:

Yeah my uncle, he probably would have been the one to know more about how far the eye condition went but he wouldn't agree to take part in any of the research and at his age I don't blame him one bit. I found that a lot in the sort of oldest generation that they weren't keen to take part. But in like my mum's generation, like her and her half sister were brilliant ... The stuff that they'd heard as kids as stories ... that we sort of had to rely on for information. I don't think we would have gotten as far if those two hadn't been around. And then like in my generation is where we're quite open about it and talk about it. Whereas, I think my mum's generation and older it was, 'Oh well that's the fact of the matter. This is the way your vision is. Stop your whinging, get on with it.' And although I think that in my generation we're not sort of waiting to be felt sorry for. I think we're able to talk about it more.

Sara's next position involved working as a teacher aide at a whānau unit, where she said she learned to karanga and became comfortable speaking basic te reo Māori because she had the experience as a child of hearing her parents speaking Māori and thus "learnt by osmosis". She also said:

It's certainly not my first language and I wouldn't want to get up in front of a fluent speaker and pretend to know what I'm talking about but I could hold a very basic conversation. I'd more than likely find it easier to follow a conversation than I would be to make any once we'd done the "hello how are you?" and your sort of "my mum's from here, my dad's from". I could do a mihi about my background and I could hold a polite conversation.

Sara's next position was as a teacher aide at a school for disabled children. Her employer, Carole, whom Sara nominated as a whānau member for this study, said that her skills were valuable because of her lived experiences. Carole said:

You know she has those skills because she's had to develop them with her own children and we found her really valuable with kids, who needed, and she understood their needs. So we employed her to work with some of our kids who had more severe disabilities, who needed care, who needed someone, who was empathetic to the way they were.

Sara said that she was very happy with her current work and her colleagues were very supportive of her. However, she also noted that there were times when her workmates went 'over the top' to help her fully participate at work. For example, she described one staff seminar when her paper was enlarged to "wallpaper" size. She said:

Enlarging a piece of paper doesn't necessarily change the font size, and yeah sometimes we get quite extreme. Well we've got this wallpaper story where I work where I'd been on a professional development course and everyone had been given their A4 booklets. And then the person running the course remembered about my vision impairment and decided to get my work enlarged but she got the thing photocopied onto A2 size paper so that I couldn't sit at the table with anyone else. I had to have a table all by myself. And while she's reading through the booklet, everyone is sort of on page three and I'm on page sixteen cos I have to keep turning away. I'm getting lost and it's not because I can't see, it's because everyone has a seven-page booklet and mine's twenty-one pages and I'm losing the page. And it was hilarious, my face was burning, I mean at the time I was slightly embarrassed but now we laugh about it.

Sara also stated though that in the beginning at her work, there was some discrimination against her because she was kāpo. She said that she was once told that she could be a health and safety risk to her students when they went on a restaurant outing by a staff member. She said:

There was a time there ... when I was deemed a health and safety risk to the kids that I work with. That if we were out in the community and a fly landed on a student's hamburger and I didn't see it and the student ate the hamburger with a fly on it, you know, I'd be a health and safety risk. And this was detrimental to me in my professional role. I think it violated quite a few of my basic human rights as a vision impaired person, cos I thought, 'Well I've got four children of my own, and not once, to my knowledge, have any of them eaten flies.' And ... you're more aware of your limitations or your shortfalls than anybody else is, so you naturally make up for those. If we were out and there were a lot of flies around, my focus would be on making sure there were no flies on kids' hamburgers more than anything else. And the group of children that she was talking about in particular were quite high functioning, so they really all have the ability to shoo their own flies away.

Sara no longer encounters such barriers at work, and Carole, her employer, stated that Sara was well regarded, had worked in a number of classrooms at the school, and that the next step would be for her to become a teacher with some further training. Sara had worked hard, and had also completed a Bachelor's Degree in Social Sciences. Carole said:

She's such a wonderful personality. She's fought hard and long for where she's got. I mean that college degree she did. I mean I did that degree as well. Yeah Bachelor of Human Services, yeah I did that as well and quite honestly she's done amazingly well.

Sara said that she held the privilege of having a kuia role at the school, but she was concerned that the school did not fully understand the meaning of this role. She said:

We have laughs about my vision. We also have laughs about me going to ‘play Māoris.’ And I say that because it’s almost tokenism, like they want to present themselves as very culturally sensitive and a school that acknowledges tikanga Māori, which is fair enough, but it’s only in sort of pockets. It’s not like, “We acknowledge it and we incorporate it into every aspect of our school.” It’s, “We dust off our pois when it’s time to play, when there’s a show to be put on.” And I’m probably being a bit unfair in a sense to the powers that be ... If they’re going to ask you to be that role then they need to ask your advice on how best you think the role should be played in the school or the size of the role or the areas. And the word kuia has taken on a different meaning in a sense because then it’s only for formal occasions that they’ve asked me to perform powhiri and that’s really the extent of it. And I think, well that’s not the role of a kuia, it isn’t just to do a karanga for you, it’s to represent the needs of the people of your marae, which in this sense is our school. And to make sure that all the aspects of the culture are being ... are being at least acknowledged in all areas of the school, like in the curriculum and in the mission statement, in the strategic planning, in everything.

Sara felt that her kuia role was in conflict with her role as a staff member, because she didn’t feel free to speak up about issues because of her employment contract and place in the staff hierarchy. She said:

And I may be at fault because I haven’t stood up and gone, “Look I’ll take on this role if and if and if and if.” ... As a teacher aide, there isn’t – I’m not quite sure how to put this – but it’s almost like you’re slightly powerless ... Like I couldn’t go in there and make all these demands. ... I’m there to do as I’m told from this hour to this hour and I think there’s no formalised piece of paper to say that I’m kuia, not that I’d go in and brandish that kind of power and say, “I want this, that and the other done.” But I think they’ve asked me to perform this role and that’s pretty much what it is, “perform this role” ... There’s a very ‘them and us’ thing ... There’s certainly tiers of power and support staff don’t really have any ... I am aware of all these different aspects and different roles that I play within my job and I think when they conflict I don’t often think – but I could be a bit biased – but I don’t often think that the conflict is me. I think the confusion comes when everyone else messes up my roles because I’ve some fairly rigid lines about what happens and how it happens.

The Future

When Sara was interviewed for this research, she was thinking about her future. She talked about getting further qualifications in special education, because she actually didn’t want to be a mainstream teacher and needed a better income and a career. She said:

I’m thinking about going and doing a graduate diploma in teaching. I have no desire whatsoever to be a teacher, but with (my children) I seriously need – well it would be nice to start earning some decent money and I think I – without sounding arrogant – I think I’m far too skilled to be on teacher aide wages, although I love the job it’s just the money that’s not really worth it. But I need a

job where – I don't know of any other job where I could have twelve weeks off a year to stay at home in school holidays and watch the kids and that ... I certainly do not want to do mainstream teaching. I'd like to do special ed ... That's a one year programme, one year full-time or something. I know Wellington were doing an online degree.

Her brother and sister-in-law stated that it was natural for Sara to continue working in the field of special education, because she had already demonstrated such a great commitment to her work. They said:

Ropata: Oh I think she'll do very well in the future because well she's finished her papers now so ...

Susan: Yeah well the youngest one ... he's not even one yet is he? ... I mean I guess that once he's a bit older she'll go back to the school.

Ropata: Or move onto something else.

Susan: Or move onto something.

Ropata: Use her degrees.

Susan: It'll be in the same field of what she's doing ... Yeah she has been quite committed because it took her so many years to get through it, all that, yeah. It's not for nothing.

Sara said that she felt that she was being selfish, but that she was also looking forward to the future when her sons moved from home and received care in the community. Carole noted that Sara may have more freedom in the future, but that she would always make certain that her sons were settled and happy. She said:

All that freedom ... boys will always be at the top of her list I'm sure and as long as they're settled and happy she'll be able to – and I think she will, she will relish it, absolutely relish it ... But, you know, she'll still be very much in control of them and what's happening to them I'm sure and supportive of whoever's looking after them ... But I tell you if it was me, I'd be chomping at the bit for it to happen and the sooner – well she's worried, I mean she is worried about their care in the future because there's not much out there that's good

Sara's sister thought that Sara deserved to have some time for herself at last so that she could enjoy herself. Eleanor said:

Her future? Oh she's going to be good is our Sara. You know she'll get the boys settled and no matter how long it takes her, she'll get them settled. She'll make sure her other two children are on track. She's going to lay back and enjoy it and I think she deserves it. I see that for her. Cos she's determined and she'll do it ... She's good. How she copes, I have no idea. Better than me. But then again in saying that you don't know until you're tested.

Chapter Seven

Growing Up in the 1980s, 1990s and early 2000s:

Tommy and Elizabeth

Tommy: Growing up in the 1990s and early 2000s

By all accounts Tommy would be viewed as a typical adolescent Māori male in modern Aotearoa, trying to come to terms with life, puberty, NCEA, social and peer pressures. The only difference for Tommy is that he is also kāpo.

Whānau

Tommy is the youngest of five, is partially sighted, and, along with his older brother, Jimmy, has been kāpo from birth. The condition, which Tommy, Jimmy and other members of their whānau have, is a result of a genetic disorder that causes different types of vision impairments. Tommy described his whakapapa:

Yeah, I am the youngest, ko au te pōtiki – there's five of us altogether. All my brothers are half. Yeah, just me and Jimmy have got a blind disability. My other three brothers, George, Jim, and Hone, who is deaf in one ear, are fully sighted.

Tommy is very proud of his name and when asked in his interviews for this research project, he quickly rattled off his whānau whakapapa, hapū and iwi affiliations. His full name also reflected both his father and mother's whānau. As Tommy explained, "Yeah, so I got it mixed. I have got both family sides mixed in my name." Tommy was aware that, through whakapapa, both his mum and dad were related. He said:

Yeah, well unfortunately back then, back when my parents and that were young, they didn't know that they were cousins, not close but distant cousins because my Nan and them didn't tell them any connections between them. But by the time they knew it, it was all too late, but it is fine. Everyone doesn't really care about it.

Tommy understood the hereditary nature of his and Jimmy's vision impairment and comfortably explained that the condition comes from his mum's, Josie's, side of the whānau. He said, "So the sight disability comes from my mum's side. It comes from my Nan because my Nan is blind too. So is my mum and so is my Uncle Pita."

Tommy in his interview for this project also acknowledged that his grandmother, Nanny Pearl, has been a key influence in his upbringing. He said:

Oh yes, she played an important role because she used to look after me. She helped my mum out so she kind of well helped me out too. When I used to go back to school in Auckland, she would tidy up my clothes.

Whakapapa

Nanny Pearl is Tommy's maternal grandmother and the family matriarch. She traced her earliest recollection about the whānau eye condition to her paternal grandmother, who passed this gene onto her father, an uncle, and two of her aunties, all of whom were kāpo. Nanny Pearl, her two sisters, and brother all inherited the same condition, which she passed onto two of her children, Pita and Josie, and subsequently to Tommy and Jimmy. She stated:

Well I say 'on my grandmother's side' because I don't think it's on my grandfather's side because it just seems to be on that one line, like from our grandmother. My father was visually impaired as was his brother, who went under another surname and two of his sisters.

Nanny Pearl verified her belief that the condition was inherited from her paternal grandmother by explaining that the condition did not affect her half-brothers and half-sisters. She said:

Both my parents were married and then they got together and had us, me, my brother and two sisters. So that's why I have half-brothers and half-sisters but my half-brothers on my mother's side were okay.

Nanny Pearl was unable to trace the condition prior to her grandmother and hoped that research, which was being undertaken by some of her own whānau in an attempt to trace the gene for an eventual cure, will be able to clarify whether her grandmother's mother was the original carrier. Nanny Pearl also hoped that her whānau research would be able to shed light on why some whānau members inherited the condition and why some didn't, as well as why there is such a diverse range of vision impairments within her immediate and extended whānau. She said:

Yes, well it came through some of the boys and the girls – it seems to be the older ones, the next minute it seems to come down to the younger ones, like the babies. You know, sort of like Pita, he's my baby – I had three boys. And I thought, 'oh well he's, you know, okay.' But no, he turned out to be partial. He can see something further than something close. I think Josie's got what they call tunnel vision. I think it's straight ahead or something. But each one of us seems to have different ... well (for me) as far as I know it's shortsighted. I was about sixteen and I went to the optician. He just said to me that there was no hope for me. I thought, 'Oh okay.'

Tommy and Jimmy were the fifth generation of the whānau to carry the condition. Tommy was aware of the whānau research, about which Nanny Pearl spoke, and although not taking a great interest in its progress, hoped that it would result in his not having kāpo children. He said:

It is in the genetics so they are trying to find a cure for this disease. For now, there are some people working on rats and mice and I don't know. I don't really get some of the things they are doing because I wasn't hardly listening but they are trying to find a cure for this disease, not disease really but ... they call it disease, so yeah. My mum and nan think that it's kind of good and just hopefully my offspring don't have to have it in the future.

Because of his own medical experiences, Tommy understood the medical information about his eye condition and he seemed to have a wide knowledge of medical terminology and diagnoses. He was also thankful for the medical support that he has received and said:

I say these people are good, ae. I like to thank them for all of their jobs, the therapists and all that. The eye doctors, they kind of do a great job. I have to thank them very much for doing my eye operations and checking up, making sure they know all the right symptoms so my eye just doesn't sort of slip off. In 2004, I had a corneal graft, which is a corneal transplant and in two years the doctor is going to do a cataract removal because that's what is blocking some of the sight in my left eye."

Tommy was resigned to the fact that he could eventually lose the sight in his left eye because the cornea transplant operation, which he had, had a short longevity. He said that the body ultimately rejects the transplanted cornea. Tommy had thought about his future options and was adamant that he did not want to undergo any further surgeries on his left eye. He preferred, instead, to get a glass eye or prosthesis because he believed that his right eye would retain its sight. He said:

No, I won't have it done again. I guess I will just leave it like that and get a glass replacement. At least, I will be able to see where I am going with my other eye.

Generally, Tommy was very happy with his doctors and treatment, and he said that it was very important for him to have all of the information about the medical procedures and treatment that were available to him.

When asked if being kāpo had effected his 'growing up normally', Tommy was amused and quipped:

Oh what's normally? I have grown up with this disease not having ever seen fully. So it is quite normal to me. If I had the sight fully maybe I would think differently but unfortunately I don't, but that's fine. I am happy. Yeah, it is normal for my mum too. You know people don't think my mum is blind and me either, and will say "Well look here is a normal person." And I kind of turn and I go, "Hello." And then sometimes I don't see them and they think, 'why isn't he (saying hello)' – they come up to me, and "Hello and do that kind of 'why don't I see them'". And I say, "Well I am partially blind but the way I walk and all that, it doesn't look like it." "Are you sure?" And I am like "Yeah, I am partially blind."

Tommy also found it interesting that fully sighted people thought that there would be limitations for him in terms of establishing relationships with people with sight. He said:

Yeah, and my nan and mum had babies to people who can see fully. So you know some people say even though you are blind or low vision and you don't know how to dress and all that, they get it quite wrong. It might be. But we know how to cause an attraction. That's what I am saying.

Tommy's education at home and in Auckland

Tommy was born in a coastal town and, until he was in his mid-teens, grew up in a strong Māori rural community. He attended kōhanga reo and kura kaupapa. He said:

I grew up in the country. It was pretty wild at times but it was fun. I went to the local kōhanga reo and then to a kura kaupapa Māori total immersion country school. I was the only blind person at my kōhanga and kura. Then I was sent to Auckland and attended a mainstream high school.

Tommy said that he had happy memories of his kura kaupapa school days even though there were difficulties with receiving the necessary resources to support his education. He said:

Some people found it a bit hard to understand and to get what I needed and all that in schooling. Eventually they found some RTV teachers who taught me Braille. I was five, I think, Year One, and teacher aides to come and support me. I also taught my teacher aides a bit of Braille and how to read it, just because most of my work was done in Braille. Yeah, the only downfall in my primary days was I went through about seven teacher aides.

Tommy also in a sense provided an education to those around him. He said:

I had to kind of explain myself and how I did things. They would tell me something then I told them something about blind people. Just had to explain to them how we got our information, how we wrote Braille. The normal teachers couldn't read it so they would get the teacher aid to write the words over the Braille.

Like his mother and Uncle Pita, Tommy was sent to Auckland to complete his secondary school education. Moving from the country to the city did not faze Tommy and Tommy seemed happy to move to a place where there were more shops. He said:

I guess I adapted quickly into the city. I don't know if it would be the same for people from the city adapting to the country because people in the city are used to going down to the shop. In the country I say, 'I want to go to the shop now.' And it is like yeah, yeah. The nearest shop is 45 kilometres away so it is kind of yeah. I can adapt to the city.

Shifting to Auckland meant that Tommy had to leave his whānau and board at BLENNZ (Blind Learning Education Network of New Zealand) Homai Campus, Manurewa. During this period, Tommy's mum and dad shifted overseas to pursue employment opportunities and left the responsibility of the day-to-day care of Tommy to close friends, Sue and Joe in Auckland. Joe was a whāngai son to Nanny Pearl. Tommy acknowledged that this period

caused an upheaval in his life and although he liked living in Auckland, he missed his whānau. Tommy said:

Leaving the whānau was a big thing. It didn't affect me at first you know, I kind of liked it up there but then I got homesick and all that.

Tommy enjoyed attending high school in Auckland, and said that he had learned "a lot over those past three years." Tommy stated that his educational support came from his teacher aides, and he related most to Mr Hona, because he was male and Māori. He said:

They got really good teacher aides there. They get to know you and your needs after a while. They know how you take in information. Mr Hona, oh he was good and since he is Māori I can talk to someone, you know, because all my teacher aides before that were female and you know me as a male. I need a male adult to talk to.

One subject that Tommy did not continue at high school was Māori because he might know more Māori than his teacher, and because his teacher was inexperienced in regards to kāpo students. He said:

I wanted to do it but I don't really like the teacher – He might be afraid that I know more than him. I can understand but he also didn't know how to – since I am Māori but also he didn't know how to teach blind people, he hadn't had a blind person in his class before."

While in Year 12, Tommy was expelled from BLENNZ. Tommy, his parents and his guardians, Sue and Joe, were shocked when Tommy was sent home. The reason that was given for his expulsion was based upon what Tommy and the whānau believed were unproven accusations of drug and alcohol use. Tommy acknowledged that his attitude and behaviour did not help. However, he was adamant that he was wrongly accused. Additionally, the speed at which Tommy was expelled not only shocked Tommy, but, also, his guardians, Sue and Joe. Sue said:

Friday afternoon we were rung and they said that they've been having problems with Tommy, that they'd confiscated five lighters, that he'd been lighting fires and admitted to one. They'd found alcohol bottles in his room and they suspected that he had marijuana. All I was told was that Tommy was coming back to us and I said, "Okay." And she said, "I've got to sort him out a flight." And then one of the other teachers from the school rung me a couple of hours later and said, "Oh you've heard about Tommy? You know he's coming tonight?" And I was like, "No, I wasn't told tonight."

On Tommy's return home Sue and Joe asked Tommy to explain what happened. Sue said:

We sat down and spoke to Tommy and he said the empty bottles were from when he first moved up there. Yes, he did have a lighter. He started to smoke because he was finding things a bit stressful and hard up there and it was his way of coping with it, you know. So that's fair enough I suppose, you know, knowing no real family up there. And as for the fires he said it was one confidential letter that he'd lit and it was sitting in his rubbish bin, not fires or like when they said

‘fires’. And Joe thought, “Oh my god.” you know ... something real big. And so after sitting down and talking to Tommy, it was like, you know, obviously they didn’t want to take the time to sit and down and obviously I don’t know whether they wanted to listen to what he had to say or, yeah I don’t know, it was just really strange how they ... So I don’t quite know what was up at BLENNZ. I don’t know whether they just wanted him out or what. Like I still haven’t heard from them since that day.

Sue was also perplexed about why Josie, his mum, was contacted, given that she and Joe were noted as Tommy’s legal guardians. She said, “Josie knew before we did which we thought was quite strange too, you know. For sure his mum has to know but as they knew, we are his guardians, that he’d be coming here.” Tommy also said that he was confused about this, and saw this as a way to “block out” Sue. He said:

I didn’t see the reason for blocking Sue and Joe out because they knew that Sue and Joe were my guardians legally, you know that’s why I went there. And they knew it really well. So I don’t see why they can block Sue out because she’s legally looking after me and stuff.

Sue has since spoken with Josie about the matter and although there was agreement amongst the whānau that BLENNZ had the right to expel Tommy, Tommy’s behaviour was seen by Josie as not much different from any other sixteen-year-old. Sue said:

Like Josie said, “Well he’s sixteen.” If he’s going to smoke – you know we’d all prefer him not to, I mean we do, but, you know, he’s sixteen. You can’t stop him, he’s only going to do it behind your back if ... and no, he shouldn’t have done those things. But yeah for me and Joe too, it was a bit of a shock. Josie also knew that he was missing family as well, and everything and, yeah, definitely blown away by it.

Sue and Joe were also shocked and angered to hear from Tommy that three days prior to his expulsion from the BLENNZ hostel he had been asked to attend a meeting with BLENNZ staff but without any support. Sue said, “We didn’t even realise – sorry – that he knew on the Wednesday.” For Tommy, the meeting about his expulsion was not only a surprise but also ruined what had been a ‘good’ day and had made him feel vulnerable and powerless. He said:

See even like on the Wednesday and I was having a good day, cos that’s the day that they spoke to me about it, and I was having a great day, you know, that day – what did we do? – First of all I did music, then after that I did an individual lesson, cos the first music lesson is like a band thing. And then after that had interval, cooking and then we had a good session of cricket. I was loving it and I was enjoying it and then the talk came after the cricket session which just blew my whole day. The talk about these things and I had no support in that room, literally they were all like ganging up on me and putting me on the spot. See I asked for support, named the person but they didn’t let him. So literally I was put on the spot.

Tommy also believed that the meeting had sorted the matter and was not informed about its ultimate outcome. He was also surprised at the speed at which he was flown out of Homai. Tommy said:

The thing that really annoyed me was, you know, just like the speed and I didn't even get notified. They didn't even tell me. My mum rang me up and told me. I got the information from my mum. I was quite shocked that mum knew before even my teachers did. I told mum to explain what was going on cos when she said I was flying home that night I was like, 'Whoa. I didn't know they were going to go this far.' I thought – 'Obviously we'll see what happens after the holidays', meaning that I was staying there for, you know ...

Tommy said that, in the end, though he was happy to leave BLENNZ but sad to leave his friends, to whom he could not say goodbye because of the speed of events. He said, "I was happy in a way but sad in a way. The sad thing was (leaving) my mates ... I couldn't even pack much because it was literally a speed pack." Since returning home, Tommy has had the opportunity to think and he said that although he enjoyed school, the life at the Homai hostel was not natural and he felt that he was at school all the time. He said:

It wasn't the school that gave me a problem it was the actual home lifestyle at the BLENNZ hostel. It's like being at school twenty-four-seven. You know how school's got to be on a schedule? Well that's what happened to us too, five o'clock tea, six o'clock this, seven o'clock that. You know it's kind of like, 'Well why can't we just cruise in and have tea whenever we want?'

Tommy further explained that the longer that he was at Homai, the more rules were introduced. He noted that he could not visit another whānau member who was in the Kickstart programme at Homai, and that he had little privacy when his whānau visited. He said:

Like back in those days when I first went there it was kind of easy, like everyone was kind of laidback. It wasn't really like tense. All these rules come in and all that. And all the staff and all that were laidback, that's when I liked it. But gradually over the years, going onto my third and fourth year, that's when things started, you know. I don't like it ... the other rules that they've brought in now, you're not even allowed to go to Kickstart. They can come and visit you, like if it's family, but even so they're not even allowed in your room. And also you can't just go in your room. You've got to kind of be out there where other people can see you. And other people come along, like other students come along to have a nosey, "Oh what are you guys talking about?" You know, and it kind of gets on my nerves."

This constant surveillance and supervision annoyed Tommy, and he felt that like he had no freedom to make his own decisions about his life. He said:

Well they've been in control for quite a while ... like even just with home and all that, you know. I just feel that someone's telling us what to do all the time. See that's the thing I don't get about staff, even some of the staff that are just working there. Generally they always make up these rules and then they get actions. But at least 'you can go home and relax back in your own bed or relax back in your own home and feel home'. It's what we don't have.

Tommy openly admitted that his behaviour had changed during his time in Auckland, A classic example of this was that he started to smoke cigarettes, which was an activity that he had no prior interest in. As he explained he took up the habit as a means of coping with the stress of his life at BLENNZ. He said:

The schoolwork was fine. I don't mind school. But that's why I started doing those things like smoking at school cos I couldn't do it there (BLENNZ). Like the school wasn't a problem I was trying to get rid of the stress from the home style (at BLENNZ) and have a good day at school basically. Like I mean I'd be stressed in the morning and then I would like, you know, take a puff or two and then straight away feel good for the rest of the day at school. And I mean the school thing is fine but I just wanted to get the stress off it from the school.

It was the opinion of not only Tommy, but also Sue, Joe and other whānau members that BLENNZ could have handled the situation differently. However, the focus for the whānau at present was to get Tommy settled and enrolled at a local high school. Sue and Tommy both agreed that the local RTV (Resource Teacher Vision) had been very helpful and had worked hard to place Tommy. Placement, though, has not been as easy as was first envisioned. There was an unspoken reluctance by some local high school principals to enroll him. For Tommy, being back at school meant that he could get on with his education, make new friends and socialise with his peers. Tommy appreciated his friendships, and, like most adolescents, stated that he felt that he needed to have friends with whom he could talk. He said:

You can find mates, yeah, but you have got to find mates that you can properly express yourself to. I know a couple of people that I can properly express myself to and also you get those people that you can't express yourself properly to either. But you know, I have got a couple of friends that I can express myself to properly and kind of make them understand how I feel or what my views are on a specific topic.

Tommy noted as well that as he has become older that he has found it more difficult to communicate with his nan. He said, "It's kind of weird between me and nan sometimes I guess, like you know, I try to talk openly but I just can't tell her what's going on."

Tommy did not view his vision impairment as a barrier to his ability to socialise. He stated that being kāpo had not affected "his brain", and that he was fine. He said:

Yeah, and they (friends) can see fully and that doesn't stop me from just going out with them. I might have a bit of difficulty in some places with visual but other than that it is fine. As I explain to people the only thing wrong with me is my sight, not just some whānau that don't know me properly but also like friends, just kind of don't know what to say. And in school it is kind of like saying, 'Well I might be blind but it doesn't affect how I think.' I have still got a brain and it is kind of like trying to get them to understand that sight doesn't really affect how I think and how I understand things.

In his interview for this research, Tommy was confident that he would have no difficulties making friends at his new school and that they would treat him "normal" like his other friends in Auckland and like his whānau treated him. He said:

They kind of get used to how we are blind and all that. Relate to how we are kāpo, they kind of don't really care because we can see enough to walk around and see objects in front of us and maybe a few metres away or even further away but we get around you know. Like our cousins don't really care and they treat us like normal people and they don't really treat us like special people, just what I like about some of my family and some of my friends and some of the staff. Yeah, they don't treat us like blind people. How like other people treat blind people with special care. They treat us like normal people and you know I might have a few difficulties there but they kind of just tell me and all that but as long as they treat me like a normal person and all that you know."

The Future

Tommy has been thinking a lot about what he wants to do in the future and has determined that his future career lies in technology, which also could help him as a kāpo person. Tommy said:

Actually I want to be like a computer technician but I don't know if I want to do just programming or programming and also – what do you call it – also rebuilding computers. I am kind of up to date with the technical things and I am technical minded, yeah. I have grown up with it but the technology they bring out is quite good. Like I go, "Oh this can help kāpo."

Tommy said that he had learned a lot about computers at BLENNZ and attributed his learning to one particular friend, who was also a staff person at BLENNZ. He said:

I had a friend called Sammy, who used to be one of the staff at BLENNZ, and he taught me a lot. And also I have had other people know about computers and I learnt off them. So it is kind of like getting bits of information, how to do things and all that.

Tommy said that he preferred to learn about technology from his friends, rather than in a classroom:

I wouldn't really do it as a subject at school because at school you know, and sort of like learning from mates and all that, it is kind of like – I find it more comfortable working with mates.

In conclusion, although Tommy said that he was hurt about how he was expelled from BLENNZ, he was excited and positive about his future and advised other rangatahi kāpo to get and be involved. He said:

Well yeah, just getting involved in a sport or getting involved in something, an activity or whatever. The most important part for rangatahi is just getting involved in things. Get involved where you meet new people, get involved where you kind of socialise a lot or get together with people you have got things in common with, or get involved in people you can rely on about giving you information so you are like, "Oh yeah, I didn't know that before." Not only

information about how to live in the world as a blind person, but also information about what you're interested in.

Elizabeth: Growing up in the 1980s and 1990s

Dave: Very, very bright. Very smart, very clever. Sometimes that cleverness, she was able to wrap anybody around her finger to get to do things for her, you know what I mean? ... But, in general, I just think she's very intelligent, very clever, very multi-talented, especially (in) music.

Early Years

Vince and Jane were both seventeen when Elizabeth was born. But within a year the traumatic events that took place had devastating consequences on the health of their baby. Elizabeth seemed better but later she became sick again and they immediately took Elizabeth to the hospital again:

Vince: Then when they did all the tests here, it took three months to actually find what was wrong with her. She had – what was it called?

Jane: It was where the fluid goes into one side of your brain. You've got two valves goes in and one goes out and that valve had blocked. So her head was swelling, which had caused pressure on her optic nerve, which eventually caused the blindness ... But if they'd bothered (at first) to do any tests they would have found that ...

Vince: Well no one – no one had measured her head.

Jane and Vince said that Elizabeth had to endure many surgeries and that they had to cope with the knowledge that Elizabeth would be kāpo and that this was irreversible. They said that when they first learned about Elizabeth's blindness that they were concerned that she may not have a full life. However, they were reassured, after talking with staff at the Foundation of the Blind, that kāpo children could achieve.

Elizabeth, herself, said that her parents wanted her to be an ordinary child, who grew up with her whānau, and so they did not send her to Homai College, the special school. Elizabeth explained:

A lot of people asked them why they raised me themselves instead of putting me in to Homai. It was just they wanted me to learn like an ordinary person ... I would have had to live away from home and they wanted to raise me, not somebody else raising me, I guess.

Elizabeth also said that because her parents were quite young, that her mother's parents cared for her as well at times:

I guess they had support. I mean my grandparents were there. I mean we did live with them for a little while but ... So it was usually just us, although we had whānau input obviously but never to the extent where they weren't the ones who were raising me. It was always them raising me.

Education – Kōhanga Reo

Jane, who was Māori, was adamant that her daughter would attend the local kōhanga reo because she had learnt Māori through school and wanted the same for her children. Jane did not believe Elizabeth would learn about her Māori culture at Homai's early childhood centre. The local kōhanga reo was very receptive to Elizabeth enrolling and they set out to ensure that her learning needs were met. This included planning for her attendance and talking to the other children about Elizabeth's attendance. However, initially there difficulties in making certain that her Māori books were accessible.

Jane: It's not a normal thing that they would just say, "Yeah, of course you can come along." They had meetings, they made sure their other kids could cope, and Elizabeth could cope. All the implications of incorporating a disability, and how they were going to work it with their curriculum, it was quite a big thing. And then we found there were no Braille books in Māori. So they all chipped in, the teachers at the kōhanga, the visual resource centre, the teacher aide, mums. They all wanted to make a little book for Elizabeth, you know, with tactile things and just little things that they wanted Elizabeth to know about ... Then they started reiterating to the itinerant teacher we had ... saying, "Look this isn't good enough. You need to get some material organised." And so they did. They just did it!

Elizabeth enjoyed her time at the kōhanga reo making friends with sighted children, and this made her feel no different to them.

Elizabeth: I am very glad I went to kōhanga reo. I mean right from the beginning I learnt my Māori fluently. I was in a different environment being able to associate with sighted children instead of kāpo children. It is really a skill that a lot of people who are institutionalised have trouble with making friends ... They make friends within their circle whereas I didn't have other kāpo children around me ... It made me feel I wasn't that different. That was a big thing because now I know that I can do anything.

Jane was determined her daughter would be treated as a 'normal' child and learn how to cope in the 'real' world as an adult. She thought that this would mean that Elizabeth would face discrimination and need to work harder than a sighted person in order to compete with them.

Jane: Talking to her about like say her real world, "What it's going to be like when you're an adult?" People are just so nasty. It's really competitive out there as well, Elizabeth, when you go in there you're going to have all these sighted people that are competing for the one job or this or that and because you're visually impaired you're going to have to try ten times harder just to show that you're capable because these people have preconceptions because all they'll do is say, "Oh you're blind". And with that in mind, that's pretty much how we raised her. ... I didn't treat her like a blind kid. That was my only thing. I treated her like she was sighted and just everything with her took a little bit longer, whether it was playing games or doing role play with some characters. I could do a lot of those things with her.

Elizabeth's father, Vince, was of Pacific Island descent and had a large family. Elizabeth said that she felt very supported by her dad's family, and, especially by an aunt who took time out to teach her about her culture:

Yes. I have strong both sides. I did not learn how to speak [the Pacific language] ... though. But my family were fantastic. One of my aunties ... used to take me for the weekend a lot just for fun. And I used to learn a lot with her. She was a teacher. Well she was at university then, writing plays and what not. And it was good so I got the cultural side because they are very strong. So yeah, she had a big input when I was small.

Elizabeth said that her whānau sought the support of other whānau with kāpo children when Elizabeth was growing up. Elizabeth explained as well that she felt similar to the kāpo children in these whānau because they grouped together and because they were "the same as me":

I met plenty of kāpo that were my age. And their parents helped my parents out a little bit and just gave them some advice ... I think every month we used to have a day where they would all meet up and that was really good. I got to know them. A lot of them I grew up with as well because obviously we always had social events. They already knew each other because they were all in the same class. And I really loved meeting them because I felt they were the same as me and that was good.

Education and Cultural Well-being

From kōhanga reo Elizabeth went to a primary school with a Māori immersion class, and said that she could think in both Māori and English at the same time. She also said that she was readily accepted and was never excluded from activities:

I did immersion all through primary school ... Like I would think in English and in Māori at the same time ... They always had marae trips obviously because I was in immersion for the kaupapa side. And we always went every year to lots of different marae. It was good, very good ... By then my class was used to me and we had been with that class since we started. And it was like everybody was just normal I guess and saw that I was normal and that's just the way it was. I don't think I really felt any different because I was used to it ... I was just living my life and I really enjoyed it. I enjoyed going to the marae and I was just a normal child. I mean I went on all the hikes and all the fishing trips and everything. I never was excluded.

However, Elizabeth also said that she was aware that people would stare at her in curiosity and that "it was just uncomfortable." She also noted that sometimes Māori, like Pākehā, did not know how to treat her:

Elizabeth: Māori look at you and think 'Oh' – I mean it is a personality thing I think whether they can accept me or not I guess and whether they can look past

the fact that I am blind but that is all. My mind is fine but a lot of Māori see blindness as you are dumb as well, or that you can't hear, because I often get people who talk louder and more clearer ... It is uncomfortable and plenty of Māori make me feel uncomfortable but there are also plenty who have accepted me and it is good. Depending on the person I guess.

Elizabeth said that she was rebellious, independent and “wanted to be like everybody else” so she resisted using the white cane and was determined to learn how to write print instead of learning Braille. She even learned to read Braille with her feet so that others in her class would not know that she was using it:

Elizabeth: I never used my cane ever. I would learn my way around everywhere without my cane ... I really wanted to be like everybody else ... I was a bit rebellious right through my life. But I didn't want to learn Braille ... I even learnt how to write print ... I just learnt the letters. I got tactile like my mum helped me working on an alphabet board and I used to practice writing them. I learnt Braille too, so that first time it was cool that's new, but when I went to primary school nobody had it and it was like I don't need to do Braille any more. I ended up reading Braille with my feet so nobody would see that I had Braille.

Jane and Vince encouraged their daughter to do other activities, which children with sight did, like riding a bike. Jane said:

[Vince] taught her how to ride a bike. I was quite scared. I was horrified actually, like roller skates I can handle cos you're like – you can still control it. But we saw this – it was a video wasn't it? – a New Zealand one of a teenage girl, her dad had taught her how to ride a bike to the point where they would ride to school and him beside her on the bike, they just used voice as direction. Vince: So I was going: ‘All right, we're going to teach you how to ride a bike ... and she loved it, cos it was a sense of freedom.’

Vince admired his daughter's courage and determination, and said that she inspired him to pursue his own life-long dream of playing a sport at a national level:

It was Elizabeth who pushed me ... I thought, ‘Oh my gosh she's doing all these things, I've got no excuse not to give it a go.’ And I used to take her for runs with me ... Elizabeth was amazing and I think she gave me a personal insight that I could only believe in my own little things. It enabled us to ... try and get a professional contract and it was about her constantly doing her things, ‘Oh gosh I've got no excuse not to give it a go.’

Elizabeth had a beautiful singing voice, which was a surprise to her whānau, and which Elizabeth took further through the support of her whānau, her teachers, and the RNZFB. Jane said:

And then Elizabeth had this – it freaked all of us out – she had a beautiful singing voice and that just blew everybody away and then things got heightened even more. Elizabeth wanted to learn more singing [and to] take her to choir ... and Elizabeth took up music ... The funding [from the Foundation] for her to pursue a lot of things, we probably wouldn't have been able to afford ... which

was just incredible for Elizabeth to be able to experience so much more than what we could give.

She also became recognised in her community because of her talents, which Vince said gave her confidence.

Jane: Elizabeth was so talented ... She was doing all the welcoming [for the school] in Māori ... and when people realised – “Oh my gosh that girl’s blind.” And she just kept drawing people to her ...

Vince: And for Elizabeth it just really – after that she just went chung! Anything and everything, it’s just no fear.

Elizabeth said that while she was at primary school, and later at intermediate school, that she had support from vision teachers who helped her to learn Braille and to access the curriculum. She stated that there were some issues around that fact that her vision teacher at primary school was not Māori but that this teacher did appreciate tikanga and “was fantastic”. She said:

I had a Braille teacher ... and I had problems with her because she wasn’t Māori and I was in a Māori unit. She didn’t really appreciate the culture but she was fantastic though. I had her quite often while I was at intermediate and I had occasional resource teachers.

Education and Exclusion

Elizabeth attended a regular girls’ intermediate school without an immersion unit and found it difficult to adjust. She also said that she had few friends because of her ‘culture shock’ and vision impairment. She said:

As soon as I left primary school, everything was different. I went to an all girls’ school and girls are very gossipy, and yeah, it was hard for me to make friends there because I had just come from Māori immersion. I was getting my English up to scratch even though I never had problems with English, but you know writing it is a whole different story though I love writing now. I just felt different with not being able to see and they had never had somebody who was blind ... I just felt very different because the other children at my other school, I mean I had grown up with them pretty much so they were used to me ... [intermediate] was – I did not like it.

The decision to send Elizabeth to a mainstream school caused some problems for Elizabeth’s parents as well. They stated that Elizabeth was causing havoc at school, and that the school itself was not keeping Elizabeth interested in school.

Vince: When she went to the intermediate school ... that was a big learning curve for us ...

Jane: They didn’t have te reo there ... Like she could do it but she’d do it away from class ... Elizabeth just caused havoc there, you know. They weren’t stimulating her enough.

Elizabeth's parents said that she did do well academically at intermediate school but that she did not always live up to others' expectations.

Jane: Cos she'd done quite a few naughty things and lied to a few people, which you do as a teenager. It's no excuse, you know. Some people had sort of lost like faith in her ... She'd turn around and sort of do fantastic and then do something so silly. She decided to go and steal a watch ... Then wore it to school the next day after they had all searched.

Vince: Then ... with her teacher aide ... she felt she was being mocked.

Her parents also stated that Elizabeth from the age of eleven was interested in boys like her peers but that Jane and Vince felt that this would distract Elizabeth from achieving and having a good life.

Jane: Elizabeth was getting quite a bit of attention and wanted to go on dates ... But I just was like "No". Mainly because the job we have with Elizabeth, I wouldn't say it was a 'burden'. It was just so full-on! It was so much work put in, not just by us, but by a lot of other people to make sure that she had the best shot in life. ... But she sort of made us know from eleven that that wasn't really going to happen that way, but we still tried to push it.

Elizabeth's parents stated that because of Elizabeth's educational issues that they decided to enrol her at Homai College (the special school) to live in the hostels, attend a nearby regular secondary school, and be with other kāpo rangatahi at Homai:

Jane: She was being a bit naughty ... and her qualifications at school were still up there but it sort of came through that perhaps it was good for her to go to Homai and develop a bit more.

Vince: Yeah she was just a bit of a handful and also there were other blind kids there ...

One of the residential workers at Homai, Waiata, whom was nominated by Elizabeth as a whānau member for this study, believed that Elizabeth's reputation preceded her and that this caused her difficulties with 'the management' at Homai. Waiata said:

She was just nose to the book when she came in ... We probably could have been a bit lighter on her but when Elizabeth came in she came in with already the stigma that she was going to be trouble, which was quite sad cos management do that ... Elizabeth was never given a chance ... Our manager of residential made sure that her whole waking hours was to torment Elizabeth ... If Elizabeth was sitting having lunch, "Oh Elizabeth you are so loud." ... Or "Elizabeth you're not using your cane properly." Who cares? If she bangs into something it's her fault, you know.

Elizabeth found Homai to be very restricting and did not agree that kāpo people should all be taught in the same manner because they were all individuals. She suggested that kāpo students should have more choices in regards to where they lived and where they went to school. She said:

We only have one option and one way. That is a problem with all the services at the moment. With Homai they are taught to train in a textbook way that you must follow but I don't believe in that. I believe that everybody has their own way of doing things and therefore should be given the choice in how to live their life. So e.g. if somebody wanted to go – because the high school has got the best resource centre in New Zealand – (to) Wellington, they have to stay at Homai. But it is very restricting there. You have to follow lots of rules and regulations and it would be best maybe if they had an option that they could fund maybe staying with a family.

Elizabeth also noted that being kāpo meant that kāpo people seemed to have only one option in regards to services, and this was that services had to come from the RNZFB. She said

I just think it is narrow mindedness. I mean [the RNZFB] want to be the main service provider and I mean that's fine but it is not fair because there is a lady in orientation in mobility and she works for [another company] ... She has only just started her business. And she is fantastic but they won't fund her business at all. The high school [had to pay for] her to teach us. But she can't have other business because the Foundation want to be the only option. Do you know what I mean? So they are not open to competition, which is not very good.

Betty, Elizabeth's vision teacher during her secondary education, who was nominated as a whānau member by Elizabeth for this research project, said that she sympathised with Elizabeth's feelings of frustration in regards inflexible rules and regulations at Homai. She also recognised that kāpo children at Homai had no time for themselves. Betty said:

She was really not very happy actually at Homai because there was just too many rules and regulations that restricted her from doing what she really wanted to do ... They put rules in place that will apply to the younger students but the older ones shouldn't have to comply ... There is room for very little, very little time and with the lessons, like they have tutorials, so there is limited time for them actually to have free time or space or just go in to their own little space. Everything is so 'at this time you need to be here, at this time you need to go to tutorial, bed time is nine, all mobile phones handed in' and things like that.

Betty felt that Elizabeth was an independent thinker, and a strong advocate for herself, whereas her kāpo peers were not as confident in themselves. Betty said:

I think because Elizabeth's outlook on life is different and Elizabeth has dreams for herself. She has a brain and she can see it for herself. I would say that she has advocated for herself and says, "No I don't like this." She would openly come and speak to other people whereas the others at the hostel won't. They are too scared to speak to other people.

Elizabeth was critical of being taught regimented social skills at Homai because she believed that an individual's social life and interactions would come naturally to them. However, she did state as well that how a kāpo child had been raised would affect their social competence. She said:

I mean there are people who give advice to kāpo people about how to get a girlfriend and how to get a boyfriend and how to do normal every day things. And it's wrong because they don't know. I mean everybody is different. You can't tell them a specific way on how to live ... We always had called social groups and it was like group counselling on how to make friends and how you should talk to a person and greet them. I mean those things you should have instilled in you from being raised. And I do it. Some kāpo have problems in making friends but I think that it actually comes. I mean when you are in a situation where you have to talk to somebody, you will. You don't need to be taught how to speak to a person.

She also noted that some of the advice that was given to them was not appropriate because they were kāpo. She said:

We went through this thing that you always compliment your friend. Just go around and do compliments. "You have a nice hair." When you can't even see my hair!

Waiata was concerned by the lack of willingness of staff to learn Braille and to provide cultural support for kāpo Māori. She also noted that when staff were Māori, there was more attention paid to tikanga. Waiata said:

Yeah well unfortunately actually I was the only staff member who upskilled in Braille ... I don't know why management allowed that because I keep pushing that every staff member that works with these kids should have some basic ... understanding of Braille. But it just didn't seem a priority for management to push ... It wasn't only the Braille. It was also the cultural safety that kept me there ... I think it was also certain staff members who were – I don't think they were racist or anything but they just did not want to do anything Māori and felt that if students were Māori why should they have to go [to Homai] ... It never used to be like that When I came along we had our manager of residential, she was Māori. She was really good and she made sure that everything that was put in place for the kids ... But when she left, it did seem like we've got no Māori as managers, you know.

Eventually Elizabeth left Homai, and went to live with her favourite aunty. She said that there was some domestic violence at home, and Betty, her vision teacher, stated that Elizabeth was not wanted at Homai. Betty said:

She has been through a really really hard time and nothing got her down ... The hostel didn't want her there. It was very painful ... She would just pick herself up and the amazing part is we couldn't understand how Elizabeth could do so well at school, having all this going on behind her. She just did.

She still attended the same secondary school, and according to her vision teacher did well. She was able to use the technology that was available to her at the school. Betty said:

Yes, she used Braille Write and she used a Perkins, and that was probably her life. The Braille Write was a big thing for her because she would get all of her documents electronically given to her ... Elizabeth's final year at the school was

probably the best I would say because it was exactly what she needed. She needed that huge technology switch because going from school to university would require that from her.

Elizabeth excelled at music, tutored younger musicians, and was actively involved in various activities. Betty said:

Oh her music, her singing, she has got a certificate. She has got Grade 6 singing music. She is fantastic and she goes to the music school. She used to go down here and she used to be the teacher so she acted as a tutor for the younger musicians, as they were upcoming. She is so fantastic and she has taken part in a lot of things that were out there. The music department of our school is fantastic. It is the best I have ever seen. And they give children opportunities and advantages and it is just the world is their oyster in music. They can do what they want to do. Elizabeth used to sing in assemblies and she used to sing in the choir at school. She used to sing in musicals and she was a 'really out' there girl with her music.

Elizabeth described music as a way to see. She said:

Yes, piano, flute and I sing as well. And I write music, and that's another way of seeing what people are like through their music, or [what] a place is like. It is kind of hard to describe but I mean a lot of people would hear the birds and not realise how beautiful it sounds but I pick all that up.

Elizabeth was in her seventh form year when she met her current partner, Tim. They met at a social sporting event, although Tim had previously noticed her in one of the school's musicals. Tim was older and like her father, had Pacific Island ancestry. However, Elizabeth's father did not cope well with the news that Elizabeth's boyfriend was six years older than her, and the fact that she would be influenced by "another man on the scene." Vince said:

I guess just having the boyfriend who's six years older, which I'm not that happy about, you know, as a dad. I think that's the hardest part is him being an influence ... I've got to sort of respect her more as an adult and that's a bit hard at times, you know, cos I can see that she's still influenced by the boyfriend, influenced by other people and ... I don't want to know that there may be another man on the scene or whatever ...

At the completion of her final seventh form year, Elizabeth moved to another city to attend university, where there was support for her as a disabled and a Māori student. She said:

They are very good at cultural support as well. I have only just started everything but the Māori unit there ... They have mentors and buddy you up with somebody, and free food. They have study rooms where you can go. They have the marae there where you can just chill out. People that can help you I guess if you have any trouble and student advisors as well. So it is really good to have that cultural support there.

Health Services

In terms of what health services should be offered to kāpo whānau, Elizabeth believed that kāpo Māori should know what their eye condition is, and said that she was surprised by friends who did not know. She said:

Yes, it seems to be – I have noticed a lot of people don't actually know what their eye condition is. One of my friends rang recently and said I know why I am blind.

Elizabeth also noted that there were orientation and mobility issues for kāpo people at doctor's waiting rooms or in chemist shops that needed to be addressed. She said that she felt uncomfortable when she needed to see her doctor or a chemist:

Accessing the doctors and the chemist is a problem. When I was in Auckland, I usually have somebody to take me and I am not used to going on my own. And as I got older obviously, I couldn't just ask my dad to take me to the doctor. And so I started going on my own. It was kind of an uncomfortable. I would walk into a waiting room and you don't know where the counter is. It is a silly thing but honestly, and [I thought] the receptionist should say, "Hi" and then you would find it. But when I went, she was a little bit vague and I thought, 'Oh great'. I found it myself eventually. Going into a chemist, I had never done that on my own before. I was independent except for that if you know what I mean ... The taxi driver actually helped me and he took me to the counter. And they were fine but I mean it is not very accessible.

Ngāti Kāpo O Aotearoa

Elizabeth also stated that the support that she received from Ngāti Kāpo O Aotearoa was also vital to her successful adjustment to university. Elizabeth said that her whānau first became involved with Ngāti Kāpo because her parents needed support:

I think my mum heard about Ngāti Kāpo because she was young and she needed support I guess on how to raise me and she hadn't met anybody. I think she met Rawiri ... He helped my mum a little bit.

When Elizabeth herself became actively involved with Ngāti Kāpo, she said that she was not very happy with the organisation's focus on Māori, but now loves the way that they provide services. She said:

I sort of lost contact until last year when we had a hui and they just happened to be there. I didn't actually fully believe in everything they offered, which is why I only just got in touch with them just recently ... I wasn't happy with the fact that they only catered for Māori ... I mean they always made it clear that they would accept any culture but they had to follow the rules and the rules were that it is an organisation run by Māori for Māori ... And I just felt that my other culture wasn't being recognised, which I am over now. And it's fine and I love the way that they provide the service.

Later, Elizabeth attended a forum about disability on behalf of Ngāti Kāpo and observed that there was a lack of Māori representation at the forum. She said:

With attending the forum, I just noticed there's a total lack of Māori representation. And it was a disability convention but it was ... There were some quite big companies involved like People First, CCS Disability Action, and Disabled Peoples Association ... and it was a little bit shocking to see that there were pretty much no Māori attending.

Elizabeth was thus very concerned that Māori were not being well represented in decisions that were being made about Māori with a disability. She said:

Because they tend to choose representatives that so aren't Māori ... Quite a lot of big decisions are made in regards to funding issues and just general policies and things that possibly could be created. And not having a say in that tends to put you at a disadvantage especially if, in the end, when the policy comes out you don't agree with it. You could have said, "No."

Elizabeth acknowledged, though, that kāpo Māori may not have enough information or confidence to speak up for themselves and their rights. She said:

It's quite difficult and there's a lot of avenues you have to go down in the system in order to get what you want and if you don't know what you have to do then you won't get anything pretty much ... It's good now to go and say, "Well here's all the flaws in that process and that's what you should change." And a lot of it is that my goal is to make it easier for the next generation. So maybe they don't have to fight the system so much.

Whānau as an adult

Elizabeth missed her whānau when she lived apart from them, but she stated that she had other whānau, who were not "blood related" who were there for her. She defined whānau as those people to whom she was close. She said:

Whānau to me is the people I am close with. Whānau is everybody you are related to I guess, but I mean I call my whānau the people I have been brought up with, that I am close to. There are plenty of people that I am close with that aren't blood related, but I would call them my family. But my whānau are the ones who have been there for me and who I will be there for and I would do anything for really ... Tim and his family have been quite supportive especially through hard times and my family have their moments but they're usually supportive.

Tim eventually joined Elizabeth in her new city, and her parents have now accepted their relationship. They acknowledged the support that Tim provided to their daughter.

Jane: But the bonus of having Tim there is that she's not lonely and, generally, when you're happy and in love you do so much better. And it did take me a little while ... You know, your daughter is happy and obviously loves him enough to want to live with him. He loves her. I've seen him with her ... It's slightly harder because she's got that visual impairment but I think it'd be doubly hard if Tim wasn't there because she actually has a full weekend, she has a full social [life] ... When she's not with uni, she can kick back and relax at home or she can go out and experience things.

When asked about their relationship, Tim said that he felt very protective of Elizabeth, that it was his first relationship, and that he wished she would do more of the dishes. Elizabeth said that, as a kāpo woman, she had no different requirements for a partner, but did appreciate Tim's cooking and sighted guiding. She said:

Just somebody trustworthy, honest and loyal I guess. I don't really have any different requirements than anybody else to be quite honest. I guess personality comes into that quite a bit though and he's a good cook ... He guides me a lot around. Like especially if we're going to new places that I haven't been to before. No matter where we go really because it just means that I don't really have to pay attention to where I'm going. I just let him lead me and that's easier.

The Future

Elizabeth said that in the future she hoped to keep in contact with both sides of her whānau and that it was important for her to fully acknowledge both of her cultures. However, of late, she acknowledged that she needed to do more to maintain her Māori language skills, because it had been some time since she fully used her reo. Elizabeth also has not been able to visit any of the marae in her new city. At the moment, though, Elizabeth is focusing on her relationship with Tim, and establishing an independent life for herself.

Elizabeth said that 'being kāpo' was not about 'being wholly blind' because she could see in other ways, and neither her spirit, nor her emotions were blind:

Elizabeth: I mean kāpo is not 'being' to me really. I am blind but only in one sense. I am only blind because I can't see. I am not blind in the sense that I am able to pick up plenty of things that possibly others wouldn't. My spirit isn't blind and, just because my eyes are, doesn't mean that my spirit is. I can see in other ways.

Chapter Eight

Growing up in the 1990s and 2000s:

Kahu and Kapua Kore

Kahu: Growing up in the 1990s and 2000s

When Kahu was born he was ‘only one and a half biro lengths long’, which is less than the width of this page. At twenty-two weeks gestation, he was the smallest baby in the southern hemisphere to survive. As a consequence of his prematurity Kahu has multiple impairments, including vision. On the day that a researcher for this project met him he was recuperating in hospital after knee surgery. This was the first of a series of operations that will hopefully enable him to walk. Despite the after effects of his surgery, he was more interested in playing video games than being interviewed. Chocolates, however, helped Kahu’s concentration as he and his nieces and nephews munched their way through a box as the whānau talked with the researcher. From a fragile and very sick baby, Kahu has grown into a typical teenage boy, much to the proud delight of his parents and whānau.

The smallest baby in the Southern Hemisphere

Kahu’s birth was a ‘life changing’ event for the Smith whānau. Unexpectedly, Ahorangi went into labour eighteen weeks early. At twenty-two weeks gestation Kahu was born and was at the time the smallest baby in the southern hemisphere to survive being born so young. That first night the doctors did not think he would survive so they waited until the next day to call for specialists’ help. When he did survive, he was transferred to Hamilton Hospital where he stayed for the first six months of his life. Ahorangi, Kahu’s mum, said:

Kahu was born in 1995 and eighteen weeks early. It was the doctor’s opinion on that night that he couldn’t survive cos, not only was he at twenty-two weeks gestation, but he also weighed only four hundred and eighty grams. At twenty-four weeks, children are vulnerable. They would wait until morning and if he was still alive then they would call for help. But I convinced myself that he would live. And I’ve kept that ever since. A team from [another city] came to get us and we flew through a hailstorm to [the hospital] ... Kahu was the smallest child in the Southern Hemisphere to survive. To put it into proportion, he was a biro length and a half long – They used a biro pen to take the length of the babies in the early days at (the hospital) because sometimes tape measures stretch at birth.

When Kahu’s whānau took him home, he was still a very little baby, only weighing four pounds. Despite Kahu’s fragility, he had a strong will to live even when the doctors thought that he could not survive another night. Ahorangi said:

He’s got a will of his own and we just kind of helped him, like with the feeding and the toileting and the not being able to speak and swallow.

Early Life and Whānau

Notwithstanding his early and traumatic entrance into the world, Kahu was born into a large and loving whānau in a small coastal township close by to his parents' tribal land. He has three sisters, six nieces and nephews and a large number of aunties and uncles and cousins. The whānau firmly identify with their iwi and place importance on tikanga within their daily lives. For example, despite the fact that Kahu's oldest nephew is 18 and his other nieces and nephews are nearer his own age, Kahu was recognised as their senior. The whānau strictly adhered to their whakapapa relationships.

Ahorangi: We've taught our children to get it right and so even though Kahu's one of the youngest in the family, the grandchildren know that he is the uncle.

Te reo Māori was also very important to Kahu's parents and initially they had the desire that te reo Māori would be Kahu's first language. That was not to be because those charged with taking care of his medical and health needs could not speak Māori. However, his whānau balanced this by only speaking to him in te reo Māori. It also clearly delineated the whānau from hospital staff.

Ahorangi: As a whānau we only spoke Māori to Kahu in the unit because we wanted him to know that we were whānau and that the nurses were other people there to help him, so it was clear.

Speaking to him in te reo Māori in the early days also had the intent of healing him at the same time. His parents took turns to caress him with their words. Ahorangi explained:

When the babies are so small, you're not allowed to touch them, for the first month or so he was in an open, small type of bed and you can't handle them – but we used to do healing with Kahu – and then they move into an incubator so you really can't handle them. So it's only really your voice that gives him the closeness.

Ahorangi and her whānau believe that Kahu got through some very rough patches because of the healing from the whānau. She said:

We were called into the consultants' offices [a number of times] they just said, "This child cannot live through the night. Call your whānau. Go and say your goodbyes." And I just said, "No, I'll go and love Kahu but I won't say my goodbyes." And I'll never forget one of the top consultants almost running down the corridor to embrace me [to acknowledge] that through the will of the family Kahu had lived. The medical stuff wasn't enough to keep him alive because he was just desperately ill, you know, and they would just say, "He just can't." You look at the machines and, "He's just going to go today." But he just never did and so we just helped him to – you're not going to say goodbye to your child, are you, when he's still alive? No!

Kahu's whānau were very protective of him during this time. Two days after he was born, his parents made the decision that there would be someone from the whānau with him at all times. This decision came after Kahu had a brain hemorrhage, which the doctors thought he would not survive. His mum stayed with Kahu during the day, while his Dad did the night shift. Ahorangi said:

When he was two days old, he had a massive head bleed. At that time the doctors gave us the indication that if anything else should happen they would turn off his support. And we made our minds up then that he would never be left without a whānau member with him in case that had happened. If he had another health problem as bad as that [the head bleed] then they wouldn't administer adrenalin. So we decided we were just going to be there the whole time. So if a decision came up we would be able to be part of that.

When Kahu went home, the whānau were still vigilant in protecting him even if it meant that they were not able to go near him. His father, Pou, in particular, made sure that Kahu remained safe. The whānau thought that Kahu has made the whānau stronger as well, because they all had to consider his health and education needs. Ahorangi said:

Pou was great. I must acknowledge him because he almost used to have a thermometer at the door when people visited, so you didn't come round home if you had anything because that could mean death for Kahu. So he was vigilant. He was really vigilant. Sometimes the children weren't even allowed near Kahu and that was something we had to keep in place to keep him safe. So it was hard where we lived because we didn't have the services, but I think, in a way, it probably made our whānau stronger because we had to think about his health and education.

The whānau was determined to be for there for Kahu. They all had a role in supporting Kahu's health and well-being, along with his development. Ahorangi talked about how she persevered with getting Kahu to breastfeed and his nephew taught Kahu how to go to the toilet. She said:

It was a terrible time. Like no one touched him without our permission because it was just how it had to be. They said, "You can't breastfeed this child." But I was determined, I was determined to breastfeed him and so he breastfed till he was five years old. But there were many days in the intensive care where I sat on the breast pump crying. So he only had breast milk, you know, we just said, "No, don't give him any of the other milk." You know, I mean if it was a life and death situation, yes, but use the breast milk first cos he needs it, yeah. Then they said he wouldn't toilet train and so we persevered. Jason, our eighteen-year-old moko, had to stand while Kahu crouched near him and watched how you aim and fire, and "this is how you sit on the toilet."

Because Kahu had a range of health issues common to premature babies he has required ongoing care. For example, he also had a chronic lung disease. Ahorangi said:

So he had chronic lung disease. So had to use a ventilator, and so probably the first five or six years there was a lot of trying to keep him alive. I think it's roundabout seven/eight years of age when the lung is able to completely regrow.

It was as a result of his prematurity that Kahu also has cerebral palsy and retinopathy of prematurity, which caused the retina to detach. This condition can lead in some instances to some sight loss for some and complete blindness for others. Kahu had some sight, and was a member of the RNZFB.

Kahu had regular checks to ensure that his eyesight did not deteriorate. When he was a baby, he had laser treatment on both of his eyes to stop the retina from detaching, and his mum said that while his sight will not get any better, it may get worse because the retina has already been weakened. She said:

His eyesight won't improve. When he was three or four months old, he had laser therapy on both eyes to try and stop the detachment of the retina. They've already been weakened so they watch him. He has an annual checkup just to watch that nothing happens. When we last visited Homai, we saw the specialist there. She said – in her words, “It's just something that sometimes can happen ... because they've already been weakened. The damage to the nerve, the blood vessels in the eyes, [it] has already happened and so they've tried to fix them but sometimes as they grow they just detach. They can just detach off again.”

Ahorangi said that Kahu's vision impairment has an impact on his development along with his cerebral palsy, and thus he has twice the battle to fight. She said:

I think for Kahu it's probably two-fold because up until about a year ago he was able to kind of walk. His feet are locked in a tip-toe position so as a younger little boy he was able to walk maybe from seat to seat, short distances. But if you double that up with a visual loss, cos children when they have cerebral palsy usually are off balance. So I think for him it's been twice the battle.

The whānau and education and health services

Over the years Kahu has had access to, and received, a range of health and education services. According to his mother, though, the services can be overwhelming and so she has begun to say 'no' to some of them. More specifically, when she talked about the education services that they receive for Kahu's vision impairment, she said:

I think sometimes the services are overwhelming, so in recent years I've really thought about the services that I've let come on board with Kahu. Right now we're down to Group Special Education, having a little bit of input, and the visual resource teachers, having the most input, and PVI (Parents of the Vision Impaired) are our main support. All the other services I've been able to thank them, and say, “No.” In the ... years, we've counted that there's been about twenty-seven different services, yeah, not all at once but at different times. Parts of group special education, occupational therapists – just different – I don't want to name ... too many ...

Kahu and his whānau have continued to live in the small rural town where he was born, and this has had both advantages and disadvantages when it came to his health and educational

well-being. While living in a small community and being surrounded by and amongst whānau has helped Kahu, there have also been disadvantages when it comes to services. Ahorangi said that the services that Kahu can access were provided from the two towns that he and his whānau lived between. As a consequence, the services have tended to be fragmented, limited in their provision, and overwhelming for his parents who wanted to do the best for him. Ahorangi said:

The advantage of living in our community is that we're surrounded by whānau, the disadvantage is that education services come from one provincial town, health from this other one and I believe that sometimes when the services come, sometimes it's at the end of the day. Sometimes they've had to see thirty other children in that one day that they're here. I don't say it's personal. It just might be their workload and things like that. I think sometimes if you have too many services – like I said earlier about the speech language therapist that confused me, sometimes they're very willing to share their knowledge but sometimes – it can be overwhelming and you get confused in it all. And sometimes there can be a judgmental thing that happens as well, "that we have a belief as a service that your child must have this." But as a whānau, we don't see that it's absolutely necessary in his care. So you know you get a bit of discussion around it, sometimes it's better to say, "Thank you, we will call you."

Of equal concern was that there are few Māori service providers or practitioners in their area. While Ahorangi acknowledged the importance of having well qualified and professional services, irrespective of their ethnicity, she said that she would like to see more Māori involved and not just as support people. She said:

And the lack of Māori staff as well, if a person is specialised I don't mind what race they're from, but sometimes it's nice to see Māori there as well because they just kind of get you ... Count them on a couple of fingers. And sometimes when they do come, they come down as support people to the specialised person, which is nice because you've got a support person, but sometimes they sit on the side, yeah. So I want more Māori to be trained in specialised areas. That's a must.

Ahorangi recounted the time when her and Kahu had difficulty being understood by providers, primarily because of their differing cultural values and practices. She said:

In the last few years there's been a bit of pressure on us to apply for a lottery funded van and I haven't wanted to. One, because I work and part of my working is so that we can give Kahu what he requires and needs; and two, I think there are other people worse off. So I prefer to go out and get them an application and help them fill it in. We were told recently that we're not really thinking of Kahu by having that view. But the vehicle that we have for Kahu now is – well up until his operation – is great. It's a good vehicle. It takes us where we need to go. And so to hear from people that – somebody has noticed that Pou will often carry Kahu from the car into the pool – it might not be a good thing for a teenage boy to be carried. So my thing is that 'well he's always been carried, he doesn't mind, I can't carry him anymore cos he's too heavy but dad can.' And sometimes it's that opposed to crawling and I don't know what else works when you see a little boy that has to crawl from here to the exit sign along the wet tiles in the pool.

And then for me, soon Kahu will be able to decide for himself what type of vehicle he wants.

Kahu's schooling

Prior to his birth, Kahu's mother was working at a kōhanga reo where his sisters had all attended. It was expected that he would also attend and then go to kura kaupapa for his primary schooling because Kahu's parents had the desire for Kahu's first language to be te reo Māori. However, given the circumstances of his birth and his ongoing educational, health and developmental needs, his mother came to understand that this has not been entirely possible. Despite the challenges, the whānau have made certain that Kahu has always been exposed to te reo Māori. Earlier in this narrative this was highlighted when he was desperately ill in hospital. This continued when his grandmother, who is a native speaker of te reo Māori, became his early childcare worker. This was very important to Ahorangi and Pou because they wanted to consider his 'whole being' rather than just either his health or educational needs, even though these were considerable:

Ahorangi: We had to consider his wholeness. So what we did at an early age, right from when he was little toddler, was that my mum – I had lengthy discussion with the Ministry of Education – became his ESW worker. Kahu wasn't able to go to an early childhood centre or kohanga reo because he was too vulnerable. So he used to go to my mum. And there were three reasons for that, one, cos she's his kuia; two, was because I wanted his first language to be te reo Māori; and three, because she's a nurse. So I knew that in her care he would be well taken care of.

Kahu, in his discussion with the researcher, recalled his Nan looking after him when he was young with fondness. Kahu did not start school until he was six years old, and considerable thought went into his schooling options. One option was to home school him but, after looking into it, Ahorangi found that, if she did, they would not be eligible for specialised services. In the end, the decision was made to send him to a school where he could get specialised educational care for his developmental and vision needs. She said:

So I felt my own pressure in the end to put him into a schooling system because I knew that he was going to need some specialised educational care. He had been a part of the early intervention team, Group Special Education. So we already knew that there were problems with his development.

Kahu has always been mainstreamed. Initially in a kura kaupapa and, subsequently, in two local state primary schools. Kura kaupapa was Kahu's parents' first choice but after a year and a half, the whānau made the decision to take him out of the kura. The primary reason for this was that Kahu required specialist services, which were not able to be delivered in the kura, because they insisted that only people who could speak Māori could work in the school. At the time Kahu was there, there were no specialists who could deliver the support that Kahu needed in te reo Māori. Ahorangi said:

[Kahu] has always been mainstreamed. His first school was kura kaupapa Māori and he was there for about a year and a half and, in the end, I made a decision to take him out of kura kaupapa Māori and into mainstream. And my reasoning for

that was, at that time in our community, there were no support people that could deliver the specialised care in te reo Māori. And the kura were most insistent that if people came onto the school they came on with te reo Māori.

Upon reflection, Ahorangi thought that the situation that arose with the kura and the specialist services was a 'two-way thing' with the school not wanting English being spoken and the services being reluctant to work at the kura.

Ahorangi: I think it was a two-way thing. It was the school but it was also the services picked up on the vibe and were sometimes reluctant to turn up. And it's unfortunate but it happened.

The kura's response to Kahu's situation disappointed his parents. Given the time and energy that Ahorangi had put into the kura kaupapa movement, she felt that she had been let down by the kura. Seeing it as a cultural battle, the whānau were more concerned about ensuring Kahu's educational rather than linguistic or cultural needs were being met. Ahorangi said:

I hoped at the time that the school would be more lenient because, you know, as a young mum I had been involved in the kōhanga movement for almost twenty years and helped establish several of them and sat on the founding committee for the building of the kura kaupapa Māori. So I was tūturu [true] in the kaupapa but I saw the need for children that needed specialised services to be able to get it in whatever language. It didn't matter. But what was happening was that the specialist person would come into the classroom (for Kahu's vision in particular) and talk to the teacher about what Kahu needed, like in large print, and the teacher wasn't happy to receive the information in English. And the poor person couldn't deliver it in te reo Māori and so it just got too wide. And the kura was newly established and no one could see that Kahu was the important person. It was kind of a cultural battle, as opposed to 'let's just see how we can make it work for Kahu.' And so in the end, I knew that pulling him from the kura he would lose some stuff but that as a whānau Māori, we could still give him what he needed but he needed to move on. I needed to move him on with his education. And I think too that because Kahu was born so young, no one really kind of knew where things were going for him and so there was a fear that, you know, if he didn't reach his milestone, you were going to lose time. So it was just about, "come on let's move him on and see where we can get him to."

Despite Ahorangi's initial reluctance for Kahu to go to a state primary school, it has worked out well. Ahorangi said:

And that was hard because I wanted nothing more than for him to stay at kura kaupapa Māori but he needed other specialised services and we couldn't come to an agreement. So he then moved into mainstream. And it's been brilliant.

However, attending a state primary school has meant that the language he spoke was English, rather than Māori. His mother had regrets about this. Upon reflection about his early life in and out of hospitals and, especially, in the speech language therapy that he required, his mum noted that his first language has always been English. Over the years, Ahorangi's understanding of Kahu's needs and her resolve for her son have strengthened and she said that she would no longer accept such a compromise. She said:

English is now his first language and I mean I always have regrets about that as English is my first language as well. In the early days when he was in early intervention, a team believed that he would have problems with swallowing – cos when you're born that premature you don't always get the swallowing. So some children can never eat, they can never speak and that was the fear that they had for Kahu and they really needed to get some speech and language going and they couldn't deliver it in te reo Māori. And I pressured myself into believing that all those years ago, I wouldn't do it now, he must have all this. But then I was pressured into thinking that ... when you're vulnerable and you've got a child that's so sick and you've got specialists coming in, you want to believe what you're being told. But you learn as you grow.

However, te reo Māori will always be a part of Kahu's life because it is the language predominantly spoken in the home. Ahorangi said:

He will always have te reo Māori around him cos my mum's a fluent speaker and we speak Māori to him and he's always back at home where Māori is the first language.

When Kahu was at intermediate level, his education was interrupted again and he had to change schools. His local school was closed because it was too small. Ahorangi explained:

Trevor Mallard came in and they had that whole school closing thing happening. The school, which was a little country school, closed. So all the children were moved into a school in town. But they couldn't cater for the year sevens and eights so they built a new attachment to the college and we looked at it several times but I didn't think Kahu was ready to be amongst [high] school kids. The school Kahu now goes to were taking a few extra children at the time and we were lucky enough that they took Kahu.

According to Kahu's whānau, his present school was 'brilliant'. The school have welcomed him into the school and have put in place support systems to ensure that Kahu is a successful learner. Ahorangi said:

The school was fantastic. The principal there is Māori, and he was brilliant and the deputy principal was as brilliant. They hadn't worked with a child like Kahu so they completely opened up their hearts and their homes right down to the point where they said they wanted me to choose the teacher aide. That doesn't always happen; sometimes parents don't get a choice. And whatever services he needed just bring them in to meet them. And I think that was really good because they didn't have any pre-thoughts on how it should be so they were very open and that was great.

However, according to Ahorangi, Kahu's current teacher felt that she was on the 'backburner' in regards to his multiple needs. The teacher had also not been informed by his previous teacher about Kahu's needs. Ahorangi said:

Well I think the week before we came up here [to the hospital] was the first IEP that we'd had this year with Kahu and the teacher did admit that she felt that she

was a bit on the backburner, that she hadn't really been kept up-to-date with what Kahu needed. And that's unfortunate, I hadn't realised that there hadn't been a discussion cos the teacher he had last year was brilliant but there hadn't been a discussion about that. But she was part of the IEP and she was very keen on knowing how she could help Kahu.

Kahu was learning Braille and he saw his vision resource teacher once a week. However, his mother had been requesting that he learn Braille ever since he started school, but he hasn't had the opportunity to learn until this year because of the lack of resources, both in people, who can teach him, and in funding. Ahorangi said:

Kahu is doing level two Braille. So they're there weekly. And that was big. I felt that was big because from the time Kahu entered into school and until last year [in] every IEP, I (have) brought up Braille, Braille, Braille and... I wanted him to learn and I wanted him to have a backup in case anything went down with his eyesight. But because of resources he wasn't able to start Braille until last year when he was twelve – human resources and funding.

When Kahu first went to school, his mother became his teacher aide. This was not easy to negotiate with the Ministry of Education but it did set the precedent so that when Ahorangi stepped down three years ago from this position, his sister, Mata, took over as his teacher aide:

Ahorangi: So then when he first went to school, I went into a lengthy discussion again with the Ministry of Education and I became his teacher aide, which was frowned upon at that time but that was where I set the line. I said, "I know he has to be in school but he will be coming with me." Cos that way we were able to take care of not only his health needs but his education needs and make sure that he was getting what he needed. And I stayed his teacher aide or 'mama support' up until it must have been about three years ago and we went into lengthy discussion again with the Ministry of Education and Mata, who you might meet this afternoon, his middle sister became his support person.

Kahu thought that his mum was the best teacher aide whom he ever had "because she's mum", although he liked his current one because she helped him with his work.

When Kahu changed schools because his primary school was closed as above, the whānau decided that another member of their local community could become his teacher aide, and they were included in the decision about who was chosen. Ahorangi said:

After another lengthy discussion, we decided that another member of the community could come in and take care of him. And it's worked well – just choosing the right person.

The impact of Kahu's impairments on his whānau

Over the course of Kahu's life, it is clear that the whānau became staunch advocates for Kahu, in particular, but also for other children and whānau in similar situations. They have

also become politically astute. Their advocacy and political standpoint has been born out of learning from their experiences and their aspirations for Kahu. Ahorangi talked about how learning about the IEP process had been helpful for her to be able to assert her and Kahu's needs. This came about several years ago when she attended a workshop for parents on the IEP process. The workshop has benefited both Kahu and his mum whom it seems has become a force to be reckoned with. She said:

For me learning about the IEP process was brilliant. It didn't happen in the first few years but in the last couple of years now, I've controlled the hui. There was a brilliant training [workshop] that went round. The parents in our local community that came never thought they could. They didn't know what their rights were and they learnt about it. I put something in place just a couple of years ago where none of the services are allowed to visit Kahu unless they come via me first so I know a hundred percent of the time who's on school site with Kahu. That never happened before but I've put it in place. So I control the IEP. And last year I changed the format so that now they use the te whare tapa whā model for Kahu's IEP. And I wanted to do that because there were too many years of mucking around. We may be luckier than other families cos although I'm a mama, I also work in community Māori health so you learn about the services (and they) know me on a professional level and on a whānau level. So they won't muck me around.

Another way in which the Ahorangi's politicalisation has been expressed was through her role in a national parent advocacy group. While she became a member of this organisation when Kahu was a baby, for the past four years she has been a board member. This organisation, not only, caters for the specific needs of Kahu and his whānau, but they have also been inclusive of Māori. She said:

Four years ago now we were invited to a conference, Kahu had an operation several weeks before then so I phoned them and said, "Look we can't come now cos Kahu's had an operation." They said, "Rubbish, bring Kahu." And that was a big thing for me that this organisation had said, you know, "Bring your child." I went to the next conference and out of the blue I ended up on the board. So they have two tangata whenua rep seats and that came after I had a talk with them. I gave one board meeting a small talk about the meaning of tangata whenua and what it would mean for the organisation to be seen to be supporting Māori as tangata whenua. And so the tangata whenua seats have been written into the new constitution and will probably last another ten years and those seats will remain hopefully. The organisation has been brilliant. I think they're very understanding of families' needs and it's somewhere where I'd like to be because of the support that they give families. I like their philosophies.

Ahorangi's role as a board member has contributed to her development as an advocate. In 2008, her organisation was one of the many who supported an increase in the number of vision resource teachers and the upgrade of Homai. She said:

I didn't want to go but the EO and the chairperson and myself went up in front of the Science and Education Select Committee over a need of an increase in the visual resource teachers and the refurbishing or rebuilding of Homai. I was terrified. So I went and it was scary but I felt that I went on behalf of all kāpo

Māori you know. And you're questioned and you know that there's a lot on the line. And you're only given about twenty minutes and ten minutes belongs to them and then they throw a few questions at you. So I knew that I had a couple of minutes to say something. So all I was really able to say was that thirteen years ago when I stood over my dying child I never thought that I would be now standing here in front of you all begging for services. You know I felt at the time, 'Why am I going and standing in front of the Select Committee? Where are the people that are supposed to do it for us? I'm just a mum.'

Alongside her work in community health Ahorangi was also active in her local community. During her interview for this project, she was concerned that there was a lack of support, especially in small rural communities, for whānau who have children with specific health needs. As a result of this she developed and facilitated a workshop for whānau using the whare tapa whā model. The focus of this workshop was on the importance of parents looking after themselves. She said:

I facilitated a workshop last weekend and used the te whare tapa whā model as an example of self-care. We run a small monthly group that's been going about three years now, that came from a group of us mums feeling that we didn't have any local support and it's strong. We've found that every mum and some of the dads that come to our meeting, their health has declined. So after lots of talk, we've put it down to our life with a child that needs special care. So I facilitated the hui the other day. It was about self-care and remembering who you are. It's very important now.

Another issue that Kahu's mum considered to be important is the need for whānau respite care. Current policy means that respite carers who are whānau get paid less than those who aren't, moreover they are not allowed to be living with their disabled whānau member. Ahorangi stated:

I really think there should be some discussions about needs assessments and respite care for children ... If we're talking about Māori children, the concept of whānau must stand because with respite now family can look after the children and be paid but they're paid at a lesser rate and they can't be living in the home. So for our whānau, my children have always looked after Kahu. There's no respite facilities in the town where we live. It's very difficult for children, for young people, to have a break from their families and vice versa. So even though we desperately love Kahu, as an adult woman, sometimes it's nice to break away and have a coffee or go and have a hairdo but that can't always happen when there's no one for Kahu.

Despite the policy and the difficulties of respite care, the values, which are inherent in the concept of whānau, also made it difficult for Kahu's sisters to take money for caring for Kahu. It has also made it difficult for Ahorangi to ask her daughters for respite. She said:

My children refuse to accept any money for respite but my discussion with them was, "If you don't, then I might stop asking you to look after your brother." So that when I come to meetings, for example, or if Pou isn't available, I may not go if my children don't accept something for it [respite care] because sometimes you feel hurt about asking all the time and sometimes you get hurt if they say, "No

mum I can't." So at least if you can offer them something, in a way it feels like it's their job, you know, for that day or two. They're getting a koha so that I can have a break and that doesn't happen under the current system.

On reflection about Kahu's life, his mother reckoned that there has not been enough educational support for him or the whānau in regards to his vision impairment because he had other and pressing physical needs. She said:

I think two things, one thing in hindsight, when Kahu was a little boy, even though he had these bad physical problems, I don't think there was enough support or information about blindness. It was not until Kahu was at school really that we started to learn about his eyesight problem. But I think we should have known about them at the beginning when we knew about his physical problems.

Kahu's Future

When asked about what has worked well for Kahu over the span of his life, his mother talked about the importance of whānau, in particular the love of whānau. Ahorangi said:

I think what's worked well for Kahu and his development is the love of the whānau. And it helps to have my brother-in-law always on the end of a phone cos he's a medical doctor married to my little sister. So we're lucky in that way ... All I do is text and say, "Ring." So if the doctors have said to us that they've had a change in plan, they're going to do this, I say, "Taihoa", and I'll ring for a second opinion. So nothing really happens without us checking it out. So we've been lucky in that way. So it's been the love of the whānau. Pou's really brought him up. I'm there. I attend all the hui and if he's sick, Pou stands back but during the times when he's well he's a full-on dad. And he's a house dad, so he's there. He takes Kahu to school every day and he picks him up every afternoon and he takes him swimming. Kahu is a brilliant swimmer and he's a brilliant swimmer because his dad puts in the effort most afternoons. It [swimming] started because Kahu needs to keep strong.

Kahu's long term health remains uncertain, and his physical vulnerability will always be in the back of his mother's mind because there is no way of knowing what Kahu's future health will be. Arohangi stated:

It always sits at the back of your mind and we don't know. The operation that he's having now, we had to think about them, really think about them. I get frightened of the anesthetic because of the bad times he's had before. So to put him to sleep means a lot and there has to be an outcome. There's got to be something at the end of it. But he's going through a big growth spurt now where his bones are growing and he's turning into a big long boy and his muscles are tightening. Everything's just kind of seizing up.

Despite the operations that he will be having over the next two years to help him to walk, there is still uncertainty whether he will ever be able to walk. This, in turn, has implications

for his long-term health because there are associated health issues with using a wheelchair. Ahorangi said:

So they're giving it a couple of shots and the specialist surgeon, who did his operation, the other day says she still thinks that he may still prefer a wheelchair. But being in a wheelchair full-time comes with health issues. So it's always in the back of your mind.

Kahu is growing into a young man and as he grows, his parents expect that he will be making more and more decisions for himself. For example, while the decision to have the current surgery on his knees was made by his parents, they recognise that it is, at the end of the day, Kahu's choice whether he walks or not. Ahorangi said:

It's not something that we could have waited until he could make his own decision cos of the growing so we had to at least think – look at safety for him and then think, you know, we'll give it a go ... I thought that at twelve Kahu wasn't old enough to completely make decisions because he would say, "Shall I get cut up or not?" He'd say, "Nah." But, you know, we had to think more. And if they get to a point – you know when he's sixteen if he wants to say no, that's fine he can say no.

At present, in small ways, the whānau was giving Kahu more opportunities to make his own decisions. Ahorangi said:

He gets a lot of rope. We let him decide. Like I put it to him yesterday, "How about staying up on the ward on your own cos there're other children in the room and they're staying up there on their own." So you let him decide and in the end it was, "Nah." So it's like that. If he said, "Mum I'm cool to stay on my own." It would be I'm out. Now dad might stand outside the door all night as a security guard but mum would be in bed asleep. So he does, he does.

His parents have hopes for Kahu as every parent does. They recognised that he is capable of being and doing anything that he wants. Ahorangi said:

I hope that Kahu will choose where his life needs to go and we'll support him with that. He's capable of doing anything he wants to do. I think it will be more of the same and I just think like everything that he's had in his life, there'll be just a natural occurrence into the next stage. I'm not panicking about it yet ... So if you think about the brain and the amount of blood that swamped his brain and that now at thirteen he is right up where his peers should be ... it's impressive because he's only been able to really function on the tiny amount that's left.

In summary, Kahu's short life is a story about resilience of spirit and the tenacity for life. As for Kahu, he said that he wants to be a nurse when he grows up because he has seen and experienced a lot of nurses who have taken very good care of him.

Kapua Kore: Growing up in the 1990s and 2000s

Kapua Kore loves to sing. One of her favourite songs is *All Kinds of Everything* and when she sings it her voice is clear and lilting. Kapua Kore was diagnosed with a vision impairment when she was a baby. In her case, her eye condition was aggressive and subsequent treatment over a two-year period left her totally blind. This does not deter her from living her life to the full. Just like she does with her singing, Kapua Kore puts her whole being into it.

For this case study, the researcher spent many days with Kapua Kore's whānau, wrote field notes, and interviewed Kapua Kore. The rest of the whānau were whakamā (shy) about being interviewed but agreed to this story as written.

Whānau and Aroha: 'Sailboats and fishermen and things of the sea'

Kapua Kore is the second to youngest in her immediate whānau and has older brothers, an older sister and a younger brother, Māui. She also has two nieces and three nephews, the youngest of which is Harry, who is her godson. Beyond that, she has a large whānau of aunts and uncles and cousins, many of whom live nearby and are a part of her daily life, while others live as far away as Australia.

Kapua Kore is a teenager and was born into a lively and loving whānau. In her interviews for this study, she talked about how she used to be put in a drawer when she was a baby so that her older sister, who was three at the time, could not reach her. She said:

You know when I was a baby, my Mum used to put me in a drawer to sleep so that my sister couldn't reach me because she was only three. She used to take me to her bedroom and they'd be like, "Eh we can hear that baby crying. Oh Hana you've got the baby in your bed." Yeah, she would just pick me up and carry me to her bed. So they put me in a drawer so that she couldn't reach me.

When Kapua Kore and her whānau were first approached to take part in this research, Kapua Kore was living with her mum, Airini, Airini's father, whom Kapua Kore affectionately called Koro, her younger brother, Māui, and her older sister, her partner and their baby Harry. Sadly, some months into the research, Koro, who had been diagnosed with cancer, died. Kapua Kore was particularly close to her Koro and his death affected her deeply.

When Kapua Kore was born, her whānau were living in a relatively isolated, small coastal community within the region of one of the iwi that she has whakapapa links on her mother's side. As a coastal people Kapua Kore's whānau spend a lot of time fishing and gathering kai moana. It was clear from the way in which they live and the way in which Airini talked, that the land and the sea defined who they were as a whānau – spiritually, culturally and economically. In tangible ways the land and sea provided the whānau with the means to put kai on their table not only for themselves but for manuhiri or guests that came to their house. Despite being on a limited income, the whānau and, in particular, Airini's heart and generosity was huge.

Values such as whanaungatanga, manaaki and aroha underpinned all that she did. These extended from being a good provider and host to being the best mother that she could be, not just to Kapua Kore, but to all her children. It was in this context that the researcher in this project was welcomed into the whānau on a hot afternoon despite a stressful day for Airini in which Māui had been sent home from school for being naughty.

Two years ago Kapua Kore and her whānau moved to a provincial town where they now live. Despite the move, the whānau still remained within the boundaries of their iwi. The primary reason for the move was to be closer to the services that Kapua Kore and her younger brother, Māui, who has the same eye condition, needed. This move was outside of Airini's personal comfort zone, but it was the love and aspirations that she had for her two youngest children that 'drove' her to town. She was determined to ensure that both Kapua Kore and Māui had access to the best possible ophthalmologic and educational services that were available.

When Airini moved her whānau to town, her father came to live with them too. Airini's generosity and the importance that she attached to whānau saw her open up her home to care for her increasingly frail father, despite the difficult upbringing that she herself had. Her mother died when she was teenager and, by her own admission, Airini had had a very strict upbringing, which had left her with hurts that she continues to carry. It was a challenge for Airini, who was already the primary caregiver of two kāpo children with high needs, to take on the added responsibility of caring for her father. She also at the same time was supporting Kapua Kore's older sister, her partner and baby. From an outsider's perspective, Airini's life seemed hectic and demanding. For example, her father had frequent hospitalisations and Māui's school experiences demanded her attention. However, her life was her whānau and she wouldn't have it any other way.

Kapua Kore, like her mother, thought her whānau were important and this was reflected in the way that she nurtured her whānau members and looked after her godson, Harry. She helped with her Koro's care as well. She said:

I help Mum look after him [Koro], and rub his back and stuff, make his bed, and clean his room. And I grabbed a box for his dirty clothes.

Despite Koro's failing health, he contributed in important ways to the cultural well-being of Kapua Kore and her whānau. When Koro went to live with the whānau, they became actively involved in the local marae and cultural customs, including tangihanga. They would take him down to the marae and support him as he sat on the paepae. He was a native speaker of te reo Māori and he would constantly flip between speaking in English and Māori. Although Kapua Kore had a growing understanding and vocabulary of Māori words, she was shy about speaking Māori without her koro being present. She said:

I'd be shy of [talking with] other people and when it comes to te reo Māori I'm better to have my granddad around.

Kapua Kore and her whānau were fortunate to have been exposed to te reo Māori me ona tikanga on an everyday basis. In many ways, Koro provided the whānau with a cultural compass in which they oriented themselves to the old world of Māori and to the 'new' world of town living.

Even though Airini and her children were not fluent speakers of te reo Māori, they nevertheless embodied the values and practices that define what it means to be Māori. During one of the interviews with Kapua Kore, she was asked about being Māori. It was evident by her response that Kapua Kore did not see herself as Māori, rather she saw herself as being 'normal'. However, she knew her pepeha and was accustomed to standing and reciting it and finishing off with a waiata. These signs gave an indication that in Kapua Kore's view being Māori was normal.

Kapua Kore's dad, Ira, has also played an important role in Kapua Kore's upbringing despite moving in and out of her life. While his relationship with Kapua Kore's mother was turbulent, his relationship with his daughter was a loving and gentle one. She adored her father and looked up to him. Over the course of this research project, Kapua Kore talked a lot about him and, according to her, he was the 'best musician' she knew.

Kapua Kore: My dad's good at playing the guitars and playing the keyboard, you know, and all his beats are cool. Actually he has got good words and a good voice to those songs.

Whakapapa and being kāpo: 'Winds that go howling, breezes that sigh...'

Kapua Kore and her brother inherited their eye condition from their dad, Ira. Two of his sisters and a number of his nieces and nephews also have the condition. The condition is a cancerous condition that affects the retina, and for those who are genetically predisposed, usually appears in young children before the age of three. In some cases, the condition is aggressive and in these situations there is often no alternative other than to remove the eye. Not removing the retina when it is in its aggressive form opens up the possibility of tumours spreading to other parts of the body. Kapua Kore has had both of her retinas removed. She said:

I remember when I had cancer and when I was a baby I lost one eye. When I was four I lost the other one. They had to pull it out or I would have been dead.

During her childhood, Kapua Kore has also had a number of other tumours removed. Airini worried about her daughter's long-term health and the ongoing possibility of tumours growing elsewhere in her body. She talked about the dread that was associated with never knowing when or if they will find other tumours.

Māui's condition is less severe than Kapua Kore's. Just before this research project, he underwent chemotherapy to kill cancerous cells and since then his x-rays have shown that his tumours have reduced in size. This is an enormous relief to Airini. For now Māui still has sufficient eyesight that enables him to read print. However, he has to have the print very close to his eyes and at an angle. Similarly, when he watches TV he stands right in front of it.

Despite the whakapapa of Kapua Kore's (and Māui's) eye condition that links it to their father's whānau, her mother's whānau continue to wonder why their family has been inflicted with this eye condition. During one discussion with some members of Kapua Kore's whānau, the condition was linked to makutu (magic) in which a tupuna who had been cursed had

never had the curse lifted. It was clear from Airini's body language during this conversation that she was not comfortable with this explanation and as she left the room she made the comment that she did not believe in makutu. In te reo Māori her father also went on to make the point that his grandchildren's condition was God's will and not the result of makutu. Some months after this discussion, Airini learnt that there was some history of blindness in her own whānau.

Airini felt that she is still learning about being the mother of kāpo children. While her relationship with Kapua Kore's dad has given her insight into being kāpo in a disabling world, she felt that she does not have the words to describe all that they have experienced and the struggles that they have faced. Airini, reflecting on her relationship with her husband, thought that much of the turmoil in her husband's life was because he has had difficulty coming to terms with being kāpo. Airini recognised that Māui, and, to a lesser extent, Kapua Kore exhibited the same challenging behaviour as their father. Even Kapua Kore recognised that her father found it difficult accepting that he was kāpo. In response to a question about whether her father taught her to use a white cane, she said:

He doesn't know how to use a cane but he knows how to get there, he knows.
Sometimes he thinks he can see. He doesn't really want to believe he's blind.

Kapua Kore went on to tell the story of how when she was a baby her father would walk her, and take her for walks. He helped her learn to walk and taught her how to remain oriented. She said:

When I was a baby he used to keep on walking me and walking me until I was about eight months. I started walking then. Yeah. Whenever he would take me anywhere I would know exactly where to go too, like to the playground.

Kapua Kore spent a lot of time in her room, and this behaviour coupled with Kapua Kore's outbursts worried Airini. Comparing Kapua Kore to her older children, she saw that she behaved differently, and outside of what she expected to be the range of usual teenage behaviour. Airini wondered how much her father has influenced Kapua Kore's behaviour or whether it stemmed from Kapua Kore's developmental disability.

Kapua Kore said she enjoyed her life and it was clear to the researcher that she got enormous pleasure out of experiencing life to the full. Because she has been kāpo since she was a baby, being blind is normal. In her interview, she thought it was okay to be kāpo and, in some instances, it has some benefits. Kapua Kore said:

I've been blind ... I don't have to, you know, see people violence and, you know, things going on. I don't want to be seeing people fighting and stuff. That's horrible. I don't want to see horrible people. It's all right being blind for that good reason.

While Kapua Kore did not dwell on her blindness, she sometimes wished that she could see. She said:

Sometimes I wish I can see but sometimes it's all right being blind for a good reason, you know, and yeah. I'm all right as I am, it's just sometimes I wish I can see.

***Kapua Kore's schooling:
'Budding trees, autumn leaves, a snowflake or two ...'***

Kapua Kore attended her local high school where she was enrolled in a special unit. Before high school, she was enrolled in the regular classes of her local primary and intermediate schools. For the most part, Kapua Kore enjoyed going to school. She saw the benefit of going to school to get a good education for her future. She said:

I just go to school, like to get a good education ... and plan for what I'm going to do after high school. Better than sitting at home.

When Kapua Kore was at primary school, she had Orientation and Mobility instruction and support from a vision resource teacher (RTV). She can use a white cane and reads Braille. She continues to see her RTV regularly. She has also had support from three teacher aides since she has been at school. She was very fond of the first two teacher aides but her recent one Kapua Kore was still getting to know and she was finding it difficult adjusting to the new relationship. Kapua Kore thought her new teacher aide did not respect her, but she was able to stand up for herself. She said:

You know people can't use their manners, she [teacher aide] was like, 'Put your bag down.' I said, "Excuse me, can you use your manners? Don't talk to me like that. I really don't like that."

Of more concern for Kapua Kore was the fact that her new teacher aide did not know Braille like her predecessors. Kapua Kore made the point that as long as her teacher aide can't read Braille she cannot help her in her schoolwork. She said:

Yeah I kept on telling her, "You've got to practice." She said, "Oh I'm allowed to have a rest from it." She thinks she's allowed to have a rest from her Braille work and I said, "I really don't think so." Yeah, I don't say that to her but I think: 'oh I don't think she can do that otherwise how's she going to help?'

Like any young person transitioning to high school Kapua Kore's first experiences were hard. She said:

Well at primary and intermediate I mostly found a lot of it easy but I think at the moment I must find it hard at school. Some of it I'm finding easy but just some I find so hard. I find it very hard sometimes.

One of the difficulties that she experienced when she initially started high school was making friends. She said:

I just sit on my own and make out I've really got a friend but I haven't. Yeah.

However, later during the year when asked about school, she talked about having made 'lots of friends' at school.

At high school Kapua Kore was enrolled in the special unit but attended mainstream classes. Her classes included English, music, social studies and, for the first elective, cooking. Part of her experience at school was also about teaching sighted students what it was like to be kāpo and, especially, what it was like for Kapua Kore. She used the example of making 'poi', long strips of carefully folded newspaper, which she used to beat a rhythm as one way of helping them to understand her. She said:

I just like help them around, you know, show them what it's like being blind and sometimes I actually taught them how to use a cane. I teach them how to be blind. I just taught them the different ways. Cos they don't know how I make all my poi(s) and stuff – you know out of newspaper. I explain it to all the kids.

Despite Kapua Kore enjoying school, she has experienced bullying by other students. For example, Kapua Kore talked about being teased and hit at intermediate school and how her teacher did not treat her complaints seriously so it was left up to Kapua Kore's sister and her partner to go to the school and sort it out. She said:

I have got picked on at intermediate. [They] throw toys at me and poke me in the face with their silly toys. They whack me in the head. I'm like, "Can you stop it!"

Yeah and then that time I actually told my brother-in-law that the kids were picking on me and my brother-in-law and my sister came in and growled at them. They were scared. But they didn't come in just to scare them. And the teacher, every time I would tell the teacher that the kids are picking on me she would tell me to prove it.

***A whānau coming to terms with blindness:
'City sights, neon lights, grey skies or blue ...'***

Despite Kapua Kore living in a whānau where blindness is a part of everyday life there were times when Kapua Kore was challenged by other whānau members' perception of her. One of Kapua Kore's biggest frustrations at the time of the research, was being teased by her younger 'half blind brother' about her blindness. Kapua Kore doesn't like her brother calling her names. This is what Kapua Kore said about being called 'blind arse':

Especially 'blind arse'. Especially that name, especially when it's coming up to 'blind ass', 'scabby' ... 'ugly' – especially those. And I don't like it when he's cheeky and going "Mum's got a fat bum and Kapua Kore's got a fat bum." I don't like that cheeky mouth. I don't like being called ... Yeah. I just tell him, "You stop it."

The researcher observed that when Māui teased Kapua Kore, he did not listen to her, or anyone else who told him to stop his teasing. In these instances Kapua Kore, in frustration, would hit out at Māui with her cane and threaten him. When this happened this escalated into challenging situations where both she and Māui would become upset and reactive.

Kapua Kore also talked about a time when she was upset when her aunt told her that she was lazy because she ate with her fingers. She said:

Because she growls me all the time and she said she's going to snap me so I ran away and she said I'm lazy. She called me lazy because I can't use a knife and a fork and I can't even use a spoon either.

Kapua Kore and other family members recognised that she did not use a knife and fork not because she did not wish to, or was not able to, but because she had not been taught.

Kapua Kore: I haven't learnt, do you see what I mean? And my other aunty said, "She's not lazy. She just hasn't been taught." I find it hard cos, you know when I was using a knife and fork, I actually found it hard. I actually thought, 'Oh I can use my fingers cos it's easy.' And that's what started it off and now that's why I'm cleaning up every time because now I'm still affected from what my aunty called me when she called me lazy that day. I'm still affected.

Kapua Kore made it clear to her aunt that what she had said was hurtful to her, and after telling her that she had nightmares about what she had said, her aunt became upset. According to Kapua Kore, her mum tried to explain to her that her aunt did not understand about being kāpo. However, Kapua Kore remained perplexed about how her aunt could react to her blindness in the way that she did:

I did make my aunty cry after that. I told her I had nightmares about her saying that I'm lazy and I'm dumb-ass and about her trying to kill me off. She just cried 'cos she thought I told her that she didn't like me but it wasn't (that) – but yeah she thought I said that. She was crying and she was like grabbing me and trying to cuddle me, didn't want to leave me. She was like crying. And then mum was like, "Oh Kapua Kore who wants to hate you? You know, who wants to hate you?" Yeah that looks unfair. And then I had a dream and I went to my mum, "Oh doesn't she like me?" And then mum said, "Yeah she does." And I said, "Well why is she being so nasty to me and calling me all those names like "lazy"?" And my mum said, "Oh she doesn't mean to. She just doesn't understand about the blind." And then I don't understand their reacting.

As a consequence to being told that she was lazy, Kapua Kore was determined to prove to everyone that she was not. At the first meeting between Kapua Kore and her whānau and a researcher in this project, Kapua Kore spent a lot of time cleaning the lounge. When asked about why she was doing this, Kapua Kore said:

She actually hurt my feelings. Yeah she doesn't understand ... so I just clean up, clean up... and I'm like, 'Who can call me lazy!' And I'm like getting angry.

Kapua Kore also talked about looking to her kāpo father for guidance about being kāpo. She noted that he did not react as much to being called names:

Kapua Kore: It's just the blindness. He's sort of like me sometimes. Yeah. He's sort of like me, can't handle kids or – yeah – or just a bit frustrated – but he doesn't get affected when people call him names he just says, "Oh, whatever." He's better than me – but I'm not meaning that [he is better than me]– but he is better than me when he has to be.

As part of her overall care Kapua Kore was on three different medications. Kapua Kore has been given melatonin to regulate her circadian rhythm, diet reduction pills for her weight, and Depo Provera to stop her from having periods. Not surprisingly, these medications have had an impact on Kapua Kore's everyday life. Notwithstanding the implications of women gaining weight while on Depo Provera, Kapua Kore also experienced sleepiness during the day as a result of the melatonin.

When Kapua Kore talked about the medication that she took, she said that she understood why she had to take her various pills, but did not like taking them. Her kōrero indicated that she did not have a choice about taking the pills she has been prescribed.

Kapua Kore: Sleeping medication for sleeping cos I stay up till one or four or five or six o'clock [in the morning]. For some reason I can't see day and night ... I should just have a clock that can tell me which is night and which is day. It has to be better than the pills and it can tell me what time I have to get up and go to bed.

Interviewer: So you don't like taking the pills?

Kapua Kore: Well sometimes I don't, but most of times I just have to, and I even have diet pills cos I eat too much.

Interviewer: So you've got diet pills now as well?

Kapua Kore: Yeah, cos I'm like eating two plates of kai every dinnertime ... every breakfast and lunch. I'll eat heaps. I don't know what it is. The food must be too nice. Yeah I just eat too much.

Access to services

Over the 14 years of her life Kapua Kore has had access to a range of health and education services. This is in stark contrast to the services that her brother, Māui has received despite the fact that he had the same eye condition and this has caused the whānau much stress and concern. While Māui had formally been diagnosed and treated for tumours, he has had no formal assessment of the extent of his vision impairment and as a consequence has had no support at school. Thus, he has had no teacher aide to support his learning and social interactions at school.

Māui was frequently in trouble at school. The day that the researcher arrived to meet the whānau, Māui had been sent home from school because of his behaviour. Despite the school knowing that he was Kapua Kore's younger brother, the whānau explained that they had not taken into consideration that Māui's vision impairment might be impacting on his learning and behaviour. Rather, the school considered that his behaviour arose out of his family's circumstances. This has caused his mother, Airini, considerable concern. However, Māui seemed to be a very intelligent boy, and his mother said that he was in the highest reading and maths groups despite not being on task much of the time. It is quite possible that his behaviour at school was a combination of boredom and resistance due to the lack of consideration that was given to his impairment and the lack of affirmation of his abilities when he does well.

Before the whānau moved to town, they experienced a measure of isolation from other kāpo Māori. In the last year the whānau have become members of Ngāti Kāpo O Aotearoa. Up until then the only contact that they had with the blind community was through the service providers from the Royal Foundation for the Blind, RTVs and ophthalmology services. Airini and Kapua Kore made the point several times during this research that they have benefited from meeting and talking with people who have similar experiences to their own.

The future: 'Postcards to write?'

When Kapua Kore grows up, she said that she wants to do mirimiri (massage) for a living. This has arisen out of her learning to do mirimiri on her koro, her practicing on all her whānau, and her desire to please and nurture. Kapua Kore said:

I've been doing it on my granddad and, you know, my mum, my sister ... I've been doing this on everyone.

As of yet, Kapua Kore's immediate future is uncertain. There has been talk of her going to board at Homai so that she can get the kind of learning and specialist support that others, including Airini, consider that she needs. Taking Kapua Kore out of her whānau, however, would have considerable consequences given that her world and her happiness is tied to being a part of her large and loving whānau.

Chapter Nine

Children of the 21st Century: Marama and Cathy

Marama: A child of the 21st Century

Frank (father): It is quite interesting. She taught herself and taught us ...

Maia (mother): It is just amazing how much information she takes on.

Frank: We encourage her to do that a lot because later on in life she is going to need it and it is going to be a good skill.

Marama's early years and her whānau

Marama is the bright light of her whānau eyes. Her nanny and koro (grandparents) described her promising future:

Koro (Hone): Oh she might be the next Prime Minister.

Nanny (Mary): I think she's going to have – with the right backing and the right schooling – she's going to have a bright future ...

Koro (Hone): Yeah we're just going to sit here and wait ...

Nanny (Mary): I think she can go a long way.

Koro (Hone): [We'll] help her if we can.

Marama will be starting school sometime this year, and her whānau is hoping that she will grow up as “normal”, and as all other children. Marama's whānau has many members, and is close as well. Maia, Marama's mum, defined whānau as being very special:

Yeah, whānau to me, it's a very – well it is special to me. My whānau, my family is everybody is so supportive, family, friends and always helpful. Like my dad, if we are not ringing him, or my sisters, he is always like, “Have you heard from that girl? You know, how is Marama? and how are they doing? Are they all right? Blah blah, blah.” So yeah, I just think to me, it is a group, yeah, people that come together and help one another and help when you need help basically and yeah, have suggestions.

Marama's mother is descended from a northern iwi on her mother's side and her father is Pākehā. She has four grandparents, eight aunties and uncles, and eight cousins, who all live within an hour's drive of her home in the ‘big city’. Also, Marama's whānau has coped with vision impairment before. Maia, Marama's mother, is legally blind.

Marama, her mother, and father used to live near her nanny and koro in a small rural town, but moved to the ‘big city’ a couple of years ago. Marama's grandmother, Mary, said that she was sad about this move, but Maia indicated that the move was necessary for Marama to be

closer to services because despite many phone calls from professionals, no one was willing to come to the rural town in which they lived. She said that she felt “bamboozled” by “ten million and one people” and yet she still was not able to receive any help. Maia also said:

I was just getting so many people ringing up and saying: “Oh ‘blah-blah-blah’ and, “we can do this for you and ‘blah-blah-blah’.” But I’d just had enough, I was just like, “No I’m not going out of my way to ring up anybody because they’ve all told me they’re going to come to me and I haven’t heard from them.” ... That was another reason why we moved into town cos it was just like, “Yeah yeah we’re going to come out. Yeah yeah.” And we still didn’t hear from anybody. We were just getting phone calls, “Yeah we’re coming out. We’re going to be doing this and we’re going to do that.” And it was just like, “Well, where are you guys? I need the help now.” ... It was only an hour [away] ... See with here I can just ring or get other services if I need some.

However, it is interesting that Maia, herself, as a kāpo Māori woman, has become invisible to services in the big city. She has not received Orientation and Mobility Services from the RNZFB despite asking for training around her new town three years ago.

Maia: I’ve given up on the Foundaton, eh, it’s just like, “Oh yeah we’ll be there, we’ll be there.” And it’s like, “ Oh yeah whatever.” I’m just, you know, do to my best ability I’ve done right through schooling and whatever so I’ll do it right until, yeah, someone turns up on my doorstep.

Maia’s mum, Mary, though noted that Maia has learned a lot since moving to the big city, and that she was able to help Maia learn the bus routes to and from the nearest mall for her shopping.

Mary: She has grown a lot more since she’s been in town as well so ... Yeah she’s managing her money and walking to the kindy and back and doing the shopping ... And of course she didn’t really know how to use the buses there and I thought: ‘Crikeys.’ I said: “Righto Mais we’ll do this together.” And sort of picked it out and she was sweet after that.

Maia’s vision impairment is unrelated to her daughter’s impairment, whose optic nerve didn’t develop and so she is totally blind. She said that Marama’s impairment was simply an unusual coincidence.

Maia: We had a genetics person come in ... And they discovered that there was nothing there, it was just a one-off thing that happened ... And, you know, we even went down on both lines and it was ... just happened.

Marama’s grandparents stated as well that there was no history of blindness in the family before Maia. Hone actually noted that he had “the best eyesight in the world”.

Hone: I’ve got the best sight in the world ...

Mary: He’s the best sighted of anybody.

Hone: Yeah I can see lot of what most people don’t see.

Both Maia and Mary, though, do think that sometimes they were to blame for Marama's vision impairment. Mary said that she used to work with chemicals:

Cos it doesn't happen very, very often does it? ... Yes well I used to work out on a chook farm, you know, we used to have a chook farm years ago and I used to work there and for a while they thought that it might have had something to do with that, just all the chemicals and stuff. With Marama anyway. But they never carried on with that either. They come out and asked me a few questions and that's as far as it went.

Maia indicated that Marama's blindness may have been due to Maia's medical conditions. She said, "I think it was just probably my health condition as well. It might have been a bit of a toll." However, the medical professionals told the whānau that it was just an unexpected event that happened.

Maia's medical conditions were unspecified in her research interviews. However, Mary, Maia's mum indicated that Maia was not supposed to live beyond 21 years of age:

I think her eyesight's actually gotten worse over the years ... But she can see the texting ... The [vision teachers] were very good actually. They came to school up here and periodically they come up here. Cos she was in a special needs class anyway. She was quite slow in her learning and everything like that cos she was a very sick child right up till she was about sixteen. She was in and out of hospital all those years cos she had violent headaches. She had a few operations. And she was never meant to make it till twenty-one, let alone get married and have a child. Yeah. Anyway so she got a trip to Disneyland.

Maia also did not expect Marama's birth and thought of Marama as her "miracle baby" because she was told that she couldn't become pregnant. She said, "I wasn't myself seeking to get pregnant, I was told I couldn't get pregnant So yeah, everybody was calling her a miracle baby."

After Maia's birth, the health and education professionals that worked with Marama and Maia did not discover Marama's vision impairment. Instead, her grandmother discovered that Marama was kāpo when she was about three months old. Marama's parents, Maia and Frank said:

Maia: I had her and unfortunately it was about a year later we found out that she was actually blind. She was born and they did all the tests and it didn't really show, like if you look at her naturally, you think, 'Oh yeah, she is okay.'

Frank: Her eyeballs are perfectly normal, she just hasn't got that nerve.

Maia: ... It was only through my mum actually, because we were staying with her. "I actually got a daughter!" [We were] all excited and she was still in her crib or something and mum or dad went to switch the light on, and mum was just watching her and she said: "Oh do that again, turn the light off and switch it back on." And because she had just woken up and mum said, "Hey she didn't flinch." And I said, "Like whatever, mum, you're joking." And mum is like "No, serious." And mum was jiggling something just lightly in front of her eyes and she said, "Yeah, I have a real funny feeling she can't see." And so it was only through mum. Marama went to the doctor just down the road because mum knew

them and they knew me real well as well. [Later] the nurses worked out that Marama got assistance because mum pushed to get things done and yeah ... and we went to the eye specialist in (the big city).

It took a year to confirm that Marama was totally blind, and Maia and Frank were devastated by the news but also were determined to do the best that they could.

Maia: I think we were a bit gutted, like it was just basically so blown away because we were so used to like saying, yes she can see a little bit or whatever and then bang, you get told like, "Sorry, she ain't got no vision" and we were just like ...

Frank: It was a shock

Maia: A bit of a shock and basically we just sat down and said, "Right, well okay, this is our child, she is blind, we are not going to treat her any other different, and we will just bear and grin it and just look forward and do to what the best of parents we can be for her and guide her along to wherever. Things are going to get pretty tough but things aren't always easy even for a visioned person."

Maia noted as well that they were lucky that Marama didn't have any other impairments:

It's not as if she had any other disabilities just like other children can have. And so, yeah, we just basically treat her as normal as like another child that has vision and, yeah, we just do as many activities as we can do with her, just treat her as normal as we can.

Marama's whānau stated that the health and education professionals, which the whānau have encountered, have all been responsive to their needs. Maia, for example, said:

Yeah like I went up there and it was just so awesome, like everybody was just so – like people were helping us and just showing us, you know, like what we could do with her and stuff like that.

Mary said:

[At the] hospital, yes ... That was all very good and helpful and we met some lovely people there and, yeah, we always used to go all the time [before the move].

Maia indicated though that there were inconsistencies in regards to obtaining information about the benefits to which she might be entitled through WINZ. Maia stated that the rural branch of WINZ provided her with less information than the city branch:

They said, "No, sorry we cannot help you because your partner is working and blah blah blah," and I was like, "What?" ... Yeah, this is Winz telling me I can't get anything ... and then I went to (the city) branch and it was like, "Woah, you are joking. You should be getting a child disability allowance for Marama." ... And you can get that.

In the general public, Maia also noticed that some reactions to Marama were “ignorant”. For example, they did not acknowledge Marama’s right to move freely without interference, and Maia thus needed to stand up for Maia’s rights. Maia said:

There’s a lot of ignorance out there, like people can be quite ignorant and nasty towards people that do have disabilities and I think that’s quite disgusting really ... I think it was a couple of months ago, my mum was in town and she had Marama. Marama had a cane and she was walking along and these people were just like walking towards her so mum was moving her ... I said, “No mum they can see. She can’t. Don’t you move for them.” ... I’m like, “She has a right to be in this mall like anybody else.” I said, “They’ve got sight.” ... And one person actually got quite ignorant, like me not moving, I said ... “If you can see that she’s got a cane ... you walk around us, not us walk around you.” And mum got a bit of a shock and like dad knew, it was like, “Good on you, she has rights to be in this mall.”

In fact, Marama and Maia spend a lot of time at their local mall and Marama was known by the shopkeepers. Hone, Marama’s, grandfather said, “It’s amazing, you go down to the mall and all the people down there sort of know her.”

Maia takes Marama with her shopping on the bus, and said that she knows the number of the bus, as well as its colour. Marama’s whānau all commented about her accurate memory. For example, Hone said:

Tell you what Marama’s got a great memory. Yeah she’ll ask you what your name is, if you tell her she’ll know you all the time, all you have to do is speak and she’ll know who it was.

She also is able to manoeuvre in home and new environments without difficulty. Maia said:

When she first started to walk, she would hold on to the wall and go around the house and tap on the doors and we would say what room it is. And eventually she would go up and walk around herself tapping doors and ‘that’s the lounge’ and ‘that’s the bath room’ and ‘that’s the kitchen’. I have noticed she knows where she needs to go. You can take her to a new environment and she walks straight to the door.

Marama’s upbringing

Marama’s whānau have encouraged Marama to be active. Maia said that as a child she had a short attention span, and was “hopeless at reading, writing and all that sort of jazz.” She explained that both she and her partner, Frank, were sporty, and that she played every sport. She said, “I played netball, hockey, soccer, rugby, just everything.” Marama has thus often been taken to playgrounds and encouraged to climb and play like every child.

Maia: Like some parents dwell on, you know, when [their children] get hurt and stuff. We’ve never done that and we’ve always like, “Oh well you’ve had your wee cry. Okay get up, it’s time to get up on the ...” You know we’ve never said,

“Oh no well we won’t get back up on that.” We’ve always pushed her to like, “Oh well shall we have another go.” ... Well not pushed her but, you know, encouraged her more to do things, you know, so that comes to it next time well then, you know, she’s like, “Oh well I fell off this but I’ll have another go.”

Marama’s grandparents stated that they spoiled her.

Hone: She’s unreal.

Mary: She’s a very amazing young lady ...

Hone: She’s got her own mind. She’s the boss.

Mary: ... I think well probably cos they’re grandkids we are inclined to let them get away with a little bit but the others think, “She’s too spoilt you let her get away with too much.” ... But we don’t see her that often now ... But I know when she does something wrong she does get a little bit of a growling. They put them in time out now which I don’t like.

Maia stated that Marama’s personality, at times, clashed with hers and that she realised that as Marama got older that Marama would become stronger and more knowledgeable.

Maia: Just trying to tell her sometimes and then she’ll bite back and it’s just like, “Ah.” Cos she’s at that age now. Yeah she’s at that age now where she knows what you’re saying and, you know, so ... Yeah I find she’s pretty outgoing and pretty onto it and yeah ... Yeah she’s pretty onto it to know what you’re saying and what you’re talking about. So sometimes you do need to be careful in what you do say around her.

Maia also noted that she would have liked some support with cleaning and practical domestic activities when Marama was younger, and that this may have helped her cope.

Maia: I think it was more like trying to get out of the house, and probably a bit of help around the house and stuff at that time, because I think it was a bit more help around the house ... and I mean not to be wholly doing my house because I hate people just coming in and thinking ‘oh what a messy house I was living in.’ ... But it is just certain little things, like the hard ones like washing clothes, that was the main one, to try and get done and folded and dried and things like that. Yeah, it was only little things.

Sleep deprivation seemed to be an issue for the whānau when Marama was younger because she would wake at 4 a.m. However, Maia stated that this situation was improving:

Like she used to get up about four/five o’clock in the morning. And just like, “Blah-blah-blah.” And we’re like, “It’s still ni-ni’s time, you know, you need to go to sleep.” But I think because now we’ve started school and that we’ve found that she’s actually sleeping a bit longer, just with the last couple of weeks I’ve noticed. She’ll get up and have a wee gabble but we’re noticing she’ll go back to sleep and probably sleep right through until half-past eight. So it’s been quite good.

When visiting her grandparents’ house, her grandparents noticed that Marama doesn’t like having her hair brushed or loud noises, but that she loves going outside.

Hone: But she hates doing her hair. She hates doing her hair?

Mary: Her hair is not her favourite.

Hone: She'll start crying when you do her hair, it gets sore or something.

Mary: She just loves being outside I think. I think it's just the country ... She doesn't handle noise very much. Yeah like Bob next door might start up the lawn mower or something and she'll come running inside. So can't handle that, yeah. Or if we've got the Hoover going in here she'll go outside ... Every little thing she just ... [wants to know] what it is.

Hone: She's got great hearing.

They also were concerned that Marama fights with her cousin, Lindsey, but thought that this could be because he once pulled her hair.

Mary: Loves coming here, walks up and down the driveway and talks to the kids next door through the fence. Cos they all know, all the people round here are aware of her ... Yeah so the thing is with these two, Lindsey always likes to go up and give her a hug every now and again but she seems to think he's going to try and hit her. So she'll get in first. She's quite sneaky really, and push him for no reason and thinks nobody's looking ... And you tell him, don't do that. I don't think kids do that unless something's happened to them.

Hone: Why that is I think is because he used to pull her hair all the time. He used to grab her hair and pull it.

Both Marama and Maia have few friends in the 'big city'. Maia explained that she did have a friend who has older daughters but they had moved away:

We don't know much people around this area. We know a few people, like he has got a work mate that I have just met up with who has a partner and she has a couple of kids and we were just getting on fine until they moved out to the country so it is like okay, start over again.

Marama was very well liked at her early childhood centre, and Maia said that the other children will "come and grab her and take her over to play with the toys and whatever. So it's quite good." However, Marama didn't have friends who visited her at home, and her 'favourite' friend had gone on to primary school.

Maia: Yeah there was (one friend) but we haven't seen her for quite a while so, yeah, her name was X. Yeah but we haven't seen her for a while ... She was at the same kindy but she was just a bit older than Marama, She started at school ... So they'll catch up with each other at school.

Mary, Marama's grandmother worried that Marama lived in a "lonely world", and said that she had developed an imaginary friend.

Mary: She's got this little friend, imaginary friend, Julie, and she has to go everywhere ...

Hone: Julie, yeah that's it.

Mary: ... She'll sit there quiet – well she's not quiet by any means. Marama isn't – and she likes to sit ... like with a belt but obviously they've trained her to use a softer belt and ... she just bangs it on the door and “yabba-yabba-yabba-yabba-yabba.” [She] talks away just to her friends and whatever. Yeah and she'll just have that time with Julie, that's her time. And ... if we're talking you forget that she's there and she gets louder and louder, cos we're getting louder and then you suddenly realise, “Marama be quiet.” Which is probably not really fair on her but she does quieten down. But I don't like seeing that happen too often ... And I've thought, ‘Oh gosh.’ It means that we should come in and give her something to do or do something she likes to do, you know, in their world.

Since Frank works during the day. Maia is mostly home with Marama, or travelling with her to take her to her early childhood centre or shopping, and Marama's parents are aware though that they need to encourage Marama to develop friendships so that Marama doesn't just grow up in an ‘adult world’. For example, Frank said that they didn't “want (Marama) to be clinging on to [them] and hanging around with adults which we are having a bit of a problem at the moment.” Maia stated that she is looking forward to returning to the workforce, having time to herself when Marama attends school, and that she thus did not wish to have another child:

I've had my moment being at home, being a mum at home ... I'm sort of like I want to get out more now, now that she's a bit older and just, yeah, I don't think I'll have any more kids. I think we're just happy with the one at the moment, you know, now. Yeah I just don't think I probably would. I think it's just a bit of a scare as well for us too thinking: Is the other child going to end up blind again? You know do we need to go through that period again?

Marama's education

Marama's parents have decided that she will attend a regular school because they don't want her to be ‘pushed aside’ and want her to believe that ‘she is normal’. Her father, Frank said:

From the crèche that she has been at, she didn't seem to be having any troubles. She likes meeting people. I just remember when I was going to school, there was a wee blind girl and she was like lost up [at Homai]. She was pushed over to one side sort of thing and we don't want that for Marama. She can stay with the mainstream and she can have all the support. All the support is there for her ... Just want her to be ‘full on’ and confident enough to believe herself that she is normal and she is.

The nearest primary school is just around the corner and walking distance from their home, but, unfortunately, her mother noted that most of Marama's friends will be at another school:

Marama will be going to X school which is just around the corner but her other friend goes to Y School. A lot of them are going to Y School but because with me, thought it was a better idea, you know, it's just around the corner.

The teacher at X School is preparing for her entry and seems to be very inclusive, when she has visited. Maia explained:

She's in a normal class and the teacher's actually real nice. They've got their own little chart, you know, their own little names on their desks and on their lockers and they'll just put Braille on hers with her name on top. And the kids have their own board to draw on and he gives her a board to actually draw. You know she might be only just doing scribbles but at least he's still involving her and they're going to give her a board, cos they do alphabet in the mornings. And hers will just have the Braille as well as the actual alphabet. So, yeah, just everything that he does with her, well with the kids, she'll have too, but it'll be just in Braille.

She has been assessed at Homai (BLENZ's national assessment service), and Maia and Frank explained though that they do not need to return to Homai unless they request further assessment or services from Homai. They stated that Homai only noticed that Marama may need speech therapy in the future, but Maia and Frank did not agree that this was an issue. They described Marama as very bright without learning difficulties.

Maia: It is only up to us as parents now ... Somewhere along the line it came out that, "Oh we think that she needs a speech therapist." And me and Frank looked at one another like, "What? There is nothing wrong." ... We did have the speech therapist come around and she goes, "Oh do you really need me?" She actually agreed [with us].

Frank: I think a lot of people are over cautious I suppose. Like some parents want to wrap them up in cotton wool. I think most people that we meet who see her, they are straight away like that, "Watch your head" or won't let her walk anywhere.

Maia: Mm, or will pick her up and carry her around. Well no, sorry.

Frank: 'Leave her alone. She can walk.' ... They don't think [she is] able to do it and even with teachers ... They won't give her a chance for her to show you that she is very clever.

Marama has a teacher aide when she is at the early childhood centre, and also has contact with the Vision Resource Teacher and a Developmental Orientation and Mobility Instructor, who are, respectively, beginning to introduce her to reading Braille and walking with a white cane. Interestingly, though, Marama's whānau couldn't quickly remember the name of her vision teacher or O&M instructor, and it appeared that Marama's whānau were her key educators at the moment.

Maia says that she is also learning about Braille, and enjoying it:

Well we've got her own Brailler here and her cane. Every time I go out with her, if I'm walking, she uses the cane. The Brailler, I haven't done much this week or last week ... Like I'm teaching her like what fingers to use and then what numbers. Like say, I don't know, 'one-two-three and four are 'a''. I mean it's not actually that but, I teach her what numbers and then the letter it will make. ... Well I don't know [Braille], myself, but I've got a chart here that helps me to show what to write for her and stuff like that. It's actually quite fun though.

Her grandparents are also encouraging Marama to use her white cane. Mary said:

Yes we've been trying and I keep explaining to her that, "You wouldn't crash into things if you use that Marama." But she doesn't seem to like it for some reason ... I mean it's not too heavy but I suppose its awkward isn't it?

Marama's Cultural Well-being

Marama's parents and Maia, Frank, and Marama have little contact with their local marae. Hone, Marama's grandfather, moved away from his iwi and community as a young man. However, he had been a native speaker of te reo Māori, and had got "plenty of straps" for speaking te reo at school. Currently, he has little contact with his siblings but stated that a number of his whānau had moved away from their iwi:

See I've only got my older brother up there that's in our family, that's all that are left. And he's the only one up there. Well apart from all his children and kids and, yeah. But I notice now that half of them are down here ... Yeah can't keep up with them.

Hone said that he kept up with the Māori news on television, and Maia noted that Hone was very proud of being Māori. She said, "He's like real strong, you know, proud thing Māori, and has his own beliefs, like just how we have been brought up and stuff." Maia also returned to her father's marae with her sister, Frank and Maia after Marama had her Homai assessment. Maia was deeply affected by this visit, and now felt that she knew where her father had 'come from':

It was my Aunty's unveiling and mum and dad couldn't get to it because he was really ill and I was a bit like, "Oh god, what are we going to do." and ... I ended up [there] for a week ... and we just hung out and went up home. We stayed in the house that actually my dad was brought up in ... and I am like, "This is dad's bedroom." Like, "This is where he was born," and I was like "What!" and yeah. ... It was just like "Woah." I think it was seven kids – how in a two pokey bedroom place? And it is just like, "Woah." Just seeing all the bush as well. It was amazing ... My dad has always said I would love to take the lot of you back up home before I pass away or whatever but in a way we have all got to see where he comes from.

However, Maia noted, when asked whether she was involved with her local marae, said that she did not have any knowledge about the marae where she was now living, but that she would like to be involved in the 'art side' of Māori culture:

I don't think there is anything and that's another thing really we don't know of anything ... The art side of it, I would try and get into. That would be really cool.

Maia noted as well that she only knew "basic" te reo Māori, but was teaching Marama and was also learning some more words, herself, through Marama's early childhood centre.

Maia: We teach her the basics. Well I do. Frank wants to learn as well. And so he's starting to pick up on some of the words that I'm saying to her, I'm only

saying the basics really to her. Yeah with her at kindy as well learning a bit of – cos that’s part of the protocol anyway – with her coming home and she’s teaching us again as well. So it’s quite good.

Marama’s whānau were involved though with Ngāti Kāpo O Aotearoa. Ngāti Kāpo made contact with them after Marama was born. Marama had been referred by the RNZFB, and Maia found Ngāti Kāpo help and support invaluable when they were moving to the city.

Maia: Well for me, because they are Māori themselves and I am a person, if you are going go hard, I am Māori. And I suppose because you have got to really know them, they are really helpful with Marama. Yeah and the Community Worker has always said, “You know I might be away but give me a text or ring and leave me a message and I will get back to you.” ... And she does. Or if there is other little problems, I always ask her and she is like, “Oh well we are going to go hard and get on to this.” And it has been pushed and it has been there for us, like we have got a response back and stuff.

Frank also found Ngāti Kāpo helpful because he was able to find out more about being kāpo. He said:

And a young girl who has just started university ... and she was born with sight, but ended up fully blind. When she joined the group, it was a great help for us to ask her questions about Marama ... She is very helpful.

Maia was most grateful for the help that she got from Ngāti Kāpo when they were looking for a new house while staying with friends, who lived just outside the city.

Maia: But through [the Community Worker] we went through Housing New Zealand ... and it was through her. She actually pushed and said, “Look, you know, they can’t really stay where they’re living, where they’re at the moment, they want their own freedom and, you know, get their daughter out.” And I think it was about three or four weeks after she actually really pushed and we were in this house.

Maia, Frank and Marama were quite involved with Ngāti Kāpo O Aotearoa for a number of years. However, recently, their involvement has become sporadic. Maia stated that she simply became too busy to keep up:

I mean I haven’t been [involved] for a while. Only cos I just had a bit of family – there was just through my dad getting a bit sick and stuff like that. Yeah so I didn’t go for a while cos I’m pretty close to my father so it really did hit me when he got quite sick ... and cos I’ve been just so busy at the moment just, yeah, getting her school gear ready and stuff.

Interestingly, she also stated that she felt that there were no particular issues that were relevant to her being both Māori and kāpo. However, she did emphasise that of most importance to her was her whānau and friends.

Maia: I haven’t really like gone, “Oh okay,” because I’m, you know, this nationality – It can happen to anybody really, that’s how I put it out. How I find

it is you need family and friends to be able to help you along and I think that's where I've come quite strong cos my family are quite close, we're quite close and we're there to help one another out.

Marama's Future

Marama's whānau expected her to do well in the future, and that they would also be there to support her. Maia said that she hoped that Marama would have a better life than hers:

Just hopefully a better future than what I had. Earn heaps of money. No, just whatever, you know, again we're there to support whatever she ends up doing.

She said that Marama liked to draw and paint, and predicted that Marama might be a teacher:

I noticed she might end up being a teacher, I don't know, but she likes to try and be a teacher and sits up on her seat and reads a book and does that sort of jazz. She likes drawing, painting sometimes ...

Her father stated that he hoped that she wouldn't have to fight for that which she was entitled. Whereas, her mother was proud of the fact that Marama was strong, intelligent, and would be able to advocate for herself.

Frank: I would like her to be able to be like [the young kāpo woman from Ngāti Kāpo]. If she wants something it should be there for her. She shouldn't have to fight to get something she is entitled to.

Maia: To me already, I can see it in her too. She is starting to get that strong minded, like if she wants something, she will fight for it.

Cathy: A child of the 21st Century

Tania (mother): I want everything that can be possibly done for Cathy so that she can live a normal life like anybody else, as normal as possible.

Cathy and Her Whānau

Cathy is the first daughter of Tania and her partner, Mane. In fact, Cathy was an unexpected surprise to Tania and Mane. Tania said:

I was still at school when they told me because I had polycystic ovary syndrome and yeah, they told me I had that, and there was the possibility I wouldn't be able to have kids and when I found out I was pregnant with Cathy, I was happy.

Both Tania and Mane are from the same iwi and hapū. They grew up together in a small closely-knit rural village, which was a predominantly Māori community. The closest town was forty-five kilometres away and Tania stated:

We are from here. I was born in town but brought up here, yeah basically lived here all my life give or take a couple of years in town.

Tania had known Mane most of her life, and they actually lived down the road from each other.

Tania: His sister was my friend, yes, so I basically stole him off his ex-girlfriend, that's what I say anyway.

Mane was described as very shy and reserved, and he preferred that Tania do most of the talking for this research project. They are young parents, in that both of them, when they were interviewed, still had not reached their 20th birthdays. They have two children under the age of five, Cathy and Tina, who was the youngest. After finishing high school, Mane held various labouring jobs in order to support Tania and their children. When he is not working, he helps Tania at home to care for their children and the house.

Tania's mother, Hine, stated that Mane was not her first choice of a partner for Tania, nor was he the first choice of her husband George. Also, George's parents did not approve of Mane, either. After the birth of Cathy and then Tina, there was a lot of animosity towards Mane. Hine felt that this was because they only wished for the best for their daughter, Tania. She said, however, that they have slowly "come around" to accept Mane:

Yes we are old-fashioned and we had always seen something or someone else better for our children. You never accept what they want. But my husband, his parents and I have slowly come around for the children.

Both Cathy and Tina were each born with a disability. Tina's disability was diagnosed while still she was still in the womb. Her legs were hape (facing inwards). At her birth, Tina underwent corrective surgery and was put into a body plaster. Cathy's impairment was blindness, but this was not detected until she was three months old.

Cathy's Early Years

At Cathy's birth it was not identified that she had a vision impairment. However, her whānau stated that they and their friends started to observe that her eyes moved strangely, but they did not share their concern with either Tania or Mane because they did not want to hurt them. Hine said that eventually someone spoke to Tania and they took Cathy to the doctor. However, they still hoped that their observations were not accurate. Hine said:

We could see [the vision impairment], not that we wanted to see anything with Cathy but we did mention it now and again but it was hurtful. We would see her eyes roll and then they went from side to side. And most of my family noticed it but we didn't want to say anything in case it hurt. And it did hurt when we were trying to say to Tania, "I am sure that there is something wrong with baby's eyes. We should go and have it seen to." Then finally they did have a look at her and that was a real shocker to us. You know you always have this hope that it will never happen, but when it does, you wonder why, why us?

Tania remembered that it was her grandmother, Kiri, who first spoke to them about Cathy's eyes. She said:

Actually my grandmother noticed that Cathy's eyes were wiggling backwards and forwards so we went to the doctor who referred us to a paediatrician.

Tania's memories and emotions during this period were mixed and included confusion, anger, frustration and grief. She also said that her attempts to find an accurate diagnosis involved many trips and referrals to different hospitals in different cities for different tests. She said:

We didn't find out until she was about three months and we got sent down to [a hospital that was six hours away] for eye testing there. And they said there was nothing wrong with her eyes, no reason why she couldn't see. And then they sent us to a paediatrician and he referred us to Starship, Auckland. And they had an MRI and a CT scan, a lumbar puncture and heaps of blood tests. Oh it was awful because when we went to Waikato, they said there was nothing wrong with the eye. There was no reason why she couldn't see so they thought it might have been something in the brain not connecting to the eyes and that's why they went for an MRI and those were all fine. They were saying her head was small, but no.

They also were referred for tests that the whānau did not understand. They said:

Tania: A good example was last week – she had her kidneys and that all looked at. I don't know what kidneys have to do – I don't know how that is related to her blindness.

Hine: I mean they are looking at everything else but the actual problem and I want to know what about her problem with her eyes. My husband gets wild because they are going in there for her eyes and they are looking at something else and he says to me, "Look you know we took her in for 'blah blah blah' and they did something else."

Tania: When we ask them what they are doing they sort of fob you off. And then there is no report back.

For Tania and Mane, a solution to overcoming these barriers was simply good communication. They felt that if they could sit down with medical professionals and talk to them about test results then their experiences would be positive. Tania, for example, said:

Yes explain what is going to happen and then report the results back to us, you know, sit down and report. "This is what we saw and this is what we think, and blah blah blah!"

Hine said that she felt left out of the discussions, and emphasised that involving the whānau, especially Cathy's grandparents and great grandparents, would increase their understanding as well, and would ultimately help Cathy. She said, "Tell us what is happening and why are you doing any of these instead of leaving us to figure it out."

In conclusion, the lack of support and indecisiveness of medical experts to determine the cause of Cathy's vision impairment exasperated and intensified the negative feelings that the whānau had about health services. However, they remained hopeful about Cathy, and held onto the fact that they were told that Cathy's vision may improve with time. Tania's mother said:

We were confused! We didn't know who to believe! They reckoned she could see twenty centimetres in front of her and there was still a bit of hope that maybe she would come out of it or whatever because they reckoned that it is something to do with periphery or something. Then they said it could enlarge so she could see a little bit more, or something like that. That's what they were telling us you know. There is a little bit of hope that when she gets a bit older that she might see just a little bit more.

Being Kāpo Māori and Whānau

Vision impairment was a disability that neither Tania, Mane or their respective whānau had ever encountered before, although there was whānau history of other medical conditions such as hape legs in both Tania's and Mane's whānau. Their whakapapa also did not indicate that vision impairment was a possibility for their children. Thus, the discovery that Cathy was vision impaired was a shock for, not only, Tania and Mane, but for all the whānau, whereas Tina's condition was not. Hine said:

We were able to accept Tina's hape legs, you know, whereas with Cathy it was a bit of a shock.

After Tina's birth, Tania, herself, also experienced a range of medical complications, which included diabetes, gall bladder problems and postnatal depression. The combined effects of these medical conditions resulted in Tania having to go into town to be admitted into hospital for tests. Both she and Mane, who stayed at the hospital to support her, had to leave their babies with her mother and whānau. Tania said that she was not taken seriously, and did not feel supported by the health professionals, who seemed to ignore her. She said:

I didn't think they were all that supportive. Said I was paranoid and just basically left me there.

The support of whānau and friends was integral to supporting Tania and Mane to care for their daughters, as well as to have 'time out' to relieve some of the pressure that they felt when caring for their children, who each required 'one on one' attention. Tania and Hine acknowledged, though, that this sometimes caused tension within the whānau. For example, Hine said:

We do what we can to help Tania and Mane. We do what we can and I am always here to take over when she is getting stressed out and whatever but it is hard. It is hard. They are having their ups and downs, and because I am constantly here and I stay here weekends and I have got a husband saying that you should be here with me you know, I am missing out. We have a lot of conflict going on.

Hine said that Tania's siblings, despite being understanding and supportive, themselves, have expressed frustration about the support that Hine needed to give to Tania, Hine said:

They say "Hey mum you have got grandchildren up here, so you come up here because she can't have it all you know." But they understand because Tania has got two children that are like that, so that's why we do what we can. They also try and help Tania with accessing services. Cathy is named after one of my other daughters – She is the namesake and she goes out of her way as well to find things to help Cathy. Like she got glasses that she was supposed to see things with. A budget advisor, she can go out and help Tania to get these aids and whatever to help Cathy or get people to hurry up, hurry them up and do it and at no cost to Tania.

However, what seemed to be evident in the whānau interview for this research was that whānau support for Tania and Mane was strong. There was always someone, be it whānau or friends, available to offer a lending hand. Hine said:

We will take over the children or all the friends will take the children. Take them for a walk so she can get on with her housework without darting in and out or taking one when she goes to hang the washing out. So there is always someone here during the day, be it whānau or friends, there is always someone here to help Tania.

Tania acknowledged and appreciated the support of her parents, grandparents, whānau and friends. She also acknowledged the attempts of external providers and professionals to give her support and services to help in Cathy's care and development. For example, she was aware that she could receive respite care for Cathy. However, a source of contention in regards to this service was that her whānau has not been permitted to be her respite caregivers. She said:

The respite support, they said they were going to get respite care and I said, "That's not good because if Cathy doesn't like them, she won't go to them." I said, "It has got to be family."

Tania has had several respite carers, who were both Māori and Pākehā. However the whānau have not found any of them suitable. Their Māori caregivers were not affable and Pākehā caregivers did not understand the concept of whānau. Hine said:

I have to say they have sent out two Māori support ladies and the bedside manner, so to speak, was horrible. I turned off from them as well. The two Pākehā ladies that came, yes, they were meant to help people. They didn't understand what we were trying to tell them how we as a whānau work and what we are on about with our children and they were, "No, no, it should be like this and it should be like that." But that's the Pākehā sort of stuff. It is not the Māori system. So nah, it is okay. We will look after Cathy ourselves.

Education and Health Services

Cathy was eventually registered with the mainstream provider of rehabilitation and habilitation services to blind persons in New Zealand, the Royal New Zealand Foundation of the Blind (RNZFB) about a year after her whānau noticed her vision impairment. She was referred to the RNZFB by her paediatrician. At two years of age, Cathy was also referred to the Ministry of Education's Blind and Low Vision Education Network New Zealand (BLENNZ) at Manurewa, Auckland, for an assessment. Tania and Mane knew nothing about BLENNZ, its service, or what assessments Cathy would undertake while in Auckland. Tania acknowledged that she had received a DVD that outlined the BLENNZ programme. However even after viewing the DVD, the whānau was unclear what the visit would entail. For example, Tania said, "We thought we were going to learn Braille and stuff like that." Hine and other whānau members also viewed the DVD and as a grandmother, Hine stated:

I was totally excited about it, and went, "Oh look at that, they are going to hone in on Cathy and see what they can do and upskill Tania to help Cathy."

However, Tania does not have positive memories about the trip for Cathy's assessment. In fact, she said that she and Mane felt more traumatised and stressed. They had expected to be welcomed at the airport. They also were told that they would be shown around the facilities at BLENNZ, but were not. They thus became lost and were late for their first assessment. Tania said:

When we arrived at the airport there was nobody there to pick us up. They expected us to hop in a taxi and get driven there and they would pay for it. And

then we got there and they said, “We will give you a tour in the morning.” And they didn’t even take us for a tour. We had to find everything ourselves and we were like an hour late for our first assessment.

Cathy and her whānau were, in a sense, invisible to BLENNZ, because tikanga was not being followed, and their reactions to the assessment did not seem to be acknowledged. This invisibility of the whānau was evident in the comments that were made by Tania about the assessment process. She said, for example, “Hmmm, some of them only spent, like, 15 minutes with her.”

The whānau also found the Assessment Report that they later received from BLENNZ confusing. Tania was especially annoyed and hurt about statements that were made in relation to Cathy’s language skills She said:

They said she was just parroting ... But you can have a proper conversation with her.

Hine also raised concerns about the report about Cathy’s language skills. Hine said:

Don’t we all learn that way? Everybody learns from parroting but they reckon that she parrots with us and doesn’t understand but she does. We will go “Would you like a biscuit?” And she will say, “Yes” and then she will say “Would you like a biscuit?” You know, she is saying what you say. But that’s how you learn to say ‘would you like a biscuit’ or ‘may I please have a biscuit’, you know. It is the same words and that’s the way I have looked at it with Cathy.

Tania, Mane and Hine stated that they felt that BLENNZ didn’t fulfil their expectations and a full assessment wasn’t given to Cathy. They felt that they were misled about their visit to BLENNZ. Hine, for example, said:

None of that happened. All they wanted to do was a little bit of testing. Do a little bit of observation on Cathy and that was it.

Tania and Hine felt that the information and advice that they received in Cathy’s assessment was not helpful, and that they still struggled to know “what we can do for her” and Tania stated as well that she believed that there was not “much support out there.” She said:

So we are struggling to do what we can for her, to help her on her way. But there is not much support out there that has been happening to help us with Cathy.

Once back home, services specifically to assist Cathy with her own development and growth were provided through BLENNZ and the RNZFB. In particular, they have received services from Jane, the vision teacher, and Tom, the developmental orientation and mobility instructor. Both Jane and Tom separately visit Cathy at home. Tania and Mane viewed their visits as important. However, they and other whānau members have observed distinct differences in how each interacted with Cathy and the whānau. Tania said that Cathy loved Jane:

Jane has been with us almost a year and a half and she comes once a week. Cathy loves her, she loves her. Jane she brings a lot of things to help stimulate Cathy to

use her eyesight. She has a capacity at the moment problem solving with the muffin tin and the same size objects.

Tom's relationship with Cathy is different to that of Jane's, and Tania, Mane and whānau members stated that they believed that Tom does not listen to, or appreciate, their opinions. For example, Tania said:

It frustrates you. We ask him to explain what we are doing wrong, but he doesn't. He doesn't say what we are doing right either. Like we've found what we are trying to teach Cathy is way better than what he is trying to teach her. The only problem we have with Cathy now is getting her to walk – the confidence to walk on her own. She can stand on her own. Once you let her go, she will stand there and she will realise she is on her own. And he is telling us that she doesn't walk because we are not teaching her to fall over and make her hips – you know movement in her hips. Because she is too stiff, she is going to end up walking like a robot.

Hine said:

He is the one that tells us we should do this and do that and that's why this is not working. Blah blah blah. And you are talking to him and he is not listening and he just carries on doing what he likes – talking past us.

Tania believed that Cathy was more responsive to Jane because of Jane's calm and warm manner, whereas Tom was more forceful. Tania said:

Jane is calmer and warmer. She connects with Cathy. It could be a personality thing. Jane doesn't force Cathy to do what she doesn't want to do, where Tom will. And I think that's why Cathy is not responding. And I feel that is what is holding Cathy back – her mobility, learning to walk.

Cathy's Cultural Well-being

Tania comes from a large extended whānau and her immediate siblings include half brothers and sisters from her mother's, Hine's, first marriage. Tania was born as the first of two children from her mother's second marriage to George, who was also from the same little community. Tania is very close to her father's parents and was raised by them, and they are thus very involved in Cathy's life as well. Hine described this relationship:

My husband is the only child and they took Tania on board when she was young ... and they took her on board and just left me the other one to bring up and they spoilt her horribly and that has moved on to Cathy.

The concept of grandparents raising their grandchildren can be traced back through previous generations of Cathy's whānau. Hine said:

My mum was whāngai by her grandmother. I was brought up by my mum's dad I am one of those, a love child, yeah. And there is fourteen of us. I am number

seven on my father's side and on my mother's side I am the oldest and mum had two other sons.

Between them, Hine and George have eighteen grandchildren. Tania and Mane's children are the youngest of Hine's mokopuna. For George and his parents, Cathy and Tina are particularly special to them. Hine said:

All the other grandchildren, they are ours but mostly he says they are mine. And he says, "Please let me have these two." The same with his parents, "Please leave them [with us], these two", you know. And that kind of jollies them up, bonding with them.

For Hine, supporting her children and caring for her grandchildren was her priority in life. She said:

That's me, I am always here to help Tania and be with my grandchildren. My life has always been children.

Cathy was also adored by her papa, George, who indulged her by cooking special tidbits for her. Tania's grandparents, Kiri and Tane, are, very much, the doting great grandparents and they play an active role in the day-to-day activities of their mokopuna. They take Cathy to the marae, talk to her, sing and play with her, and chastise her when she misbehaves.

All the whānau are involved in marae activities, not only in their community but also in other marae to which they linked through whakapapa, and te reo Māori is spoken around Cathy. Hine said that she was a kaiako at kōhanga reo for years, but noted that their local kōhanga reo did not have any educational expertise about vision impairment, and so she teaches Cathy at home. She said:

I am a kaiako (teacher), graduated and I finished at kōhanga because of my legs, because I can't keep up with the children, you know to get down to their level on the floor. So I finished. I was a kaiako for ten years but I refused to let my own granddaughter go there, even when I was there, because I can teach her everything. I know that if we send her to kōhanga she is not going to get the things she needs. Not to put the kōhanga down, they love the children like Cathy because they can pick up the quality funding and other things like that. But I have been involved with the deaf and dumb that come to kōhanga and there is no one to teach those children in the kōhanga to develop, and that's why I am dead set against it.

Cathy has also just started to go to the playcentre with Nanny Kiri. However, she and Mane resisted this at first because they felt Cathy had enough interaction with her peers at home. Tania explained:

They all come to me. They come here and they all come for Cathy you know. And they spend a lot of time with Cathy, playing with her.

Tania was introduced to Ngāti Kāpo O Aotearoa for support while she was in hospital. Her mother, Hine, had had a visit from one of their fieldworkers while she was in their area and gave the fieldworker Tania's contact details. Interestingly, up to this point, none of the

education or health professionals that worked with the whānau had referred them to Ngāti Kāpo, instead, they were referred by a local café owner. The Society's field worker was told that there was a kāpo child living down the road, and she was sent to their house and met Hine, Cathy and Tina.

Later when the whānau told their visiting professionals about Ngāti Kāpo, they did not receive a positive response. They said:

Tania: He knew the fieldworker but he went – I don't know, he gave us this look.

Hine: To me it was like he thought we were going to change and do it the Māori way rather than their way. That's what I am trying to say. That's the impression I got from Tom and Jane.

Hine said that she was proud of being Māori, and said that she would rather that Māori worked with Cathy. She also wished that her mum was still alive because she could learn from her and the "old Māori methods." She said:

I don't want to do any other way. I would rather the way Māori do it. I only wish that my mum was still alive because she would have been right into doing things with Cathy. That's how I learnt to do – with my other daughters, through learning those old Māori methods you know.

Cathy's Future

Coming to terms with Cathy's vision impairment has been, at times a painful journey for Tania, Mane and their whānau, with some whānau members being more accepting than others. Living in a close-knit and small community has created positive experiences for them. For example, Nanny Kiri regularly gives updates about her mokopuna progress during her cup of tea at the local café. They also have had some negative experiences because some of their friends do not understand that Cathy is 'normal'. Tania said:

I think our mates, they don't really understand but they do try and treat her as normal as possible. I just say to them, "She is just like a normal child. She just can't see."

Tania, Mane and the whānau had concerns about how the wider community will treat Cathy, after having been exposed to the reactions of people while in town. Hine said:

We go into town and they treat her like she is handicapped. We don't put up with that, and the comments about putting Cathy in a home. I want to get in there and choke the living daylights out of them you know because it is hurtful when we hear some of the comments that are made out there.

Cathy's education is an issue that Tania and Mane knew that they will have to address in the near future. It is a dilemma for them because they have reservations about Cathy going to the local school because she might be segregated and excluded. Tania said:

The services at the school are a bit hairy and I am sure that they would probably separate her from the other kids.

Tania and Mane acknowledged that sending Cathy away to a special school was an option. However, the whānau did not want to be separated from Cathy. Hine said:

And then there is the separation from Tania and Mane too, which is what we don't want. Does that mean that if Tania and Mane have to leave? If Cathy is away from home, how can we visit her?

For Tania, taking or sending Cathy away would cause great distress to her dad's parents. Tania said, "They are not well people and Cathy is what is keeping them alive." The ideal solution for Tania, Mane and the whānau would be that Cathy would be able to access local education services that will enable her to stay close to the whānau.

Hine and George hoped that Cathy would also be prepared to interact with, and cope with, other children. Hine said:

I know children. They can be really cheeky and cruel and I don't want to see that happen to Cathy. But then again, I don't want her to be sheltered either.

Tania said that Cathy's future is not yet mapped, and that the whānau prioritised taking one day at a time, and the immediate tasks at hand:

We want lots of things for Cathy, but she is only two and it is a bit hard to look that far ahead. What we want at this time is to deal with things day by day. At the moment just focusing on getting her to walk.

Chapter Ten

Thematic Discussion of ‘Growing up Māori who happen to be kāpo’

Introduction

The participants’ stories reflected a diverse range of experiences of growing up kāpo Māori across the generations. While there were notable similarities of experiences between many of them there were, at the same time, some stark differences. Overall, their narratives talk of struggle, where the outcome of being both Māori and kāpo results in being on the margins of society despite a raft of policies and programmes that speak of rights and inclusion. At the same time their stories are imbued with hope and generosity of spirit that reflects a resilience that comes from being firmly grounded in their identity as Māori. This chapter integrates the ten case study narratives and relevant literature in explicating the lived realities of the participants and their whānau and highlights some of the challenges they face in relation to being both kāpo and Māori, and the impact that health and education services have on their identity, cultural well being and health. The chapter is organised around the four themes of cultural location/dislocation, cultural consonance/dissonance, visibility/invisibility, and transformation and change.

Cultural location and dislocation

Across the generations the ten case study participants’ and their whānau talked of the importance of place and location to their identity as Māori. Most of them were born into rural or small town communities where they had whakapapa connections to not just the people, but also to the land. Hoani, Tommy, Kahu, and Cathy’s identities are embedded in iwi cultural and physical landscapes. However, for some, such as Bruce and Kapua Kore and their whānau, the sea also provided a reference point to their identity as Māori. Notwithstanding the diverse locations of the participants, they all strongly identified themselves as members of whānau, the primary social institution within Māori society. However, it was clear in the narratives that there were diverse ways in which the notion of whānau was understood, configured and operated. For some whānau was strongly related to hapū and iwi intergenerational relationships, while for others it was understood in the context of a single generation. For some, whānau extended to the wider Māori community while for Elizabeth it meant everybody that she was close to.

Elizabeth: Whānau to me is the people I am close with. Whānau is everybody you are related to I guess, but I mean I call my whānau the people I have been brought up with, that I am close to. There are plenty of people that I am close with that aren’t blood related, but I would call them my family. But my whānau are the ones who have been there for me and who I will be there for and I would do anything for really.

Whānau is as much a lived reality as it is felt and it was in everyday practices such as gathering kai moana, going to marae, and being raised by nannies that the participants and

their whānau were exposed to Māori cultural mores and values embedding further their identity as Māori and for some their sense of belonging to hapū and iwi. For kāpo Māori whānau remains an important cultural locator and marker of identity. In doing so it has also become a reference point for culturally appropriate education and health policies and initiatives, and a mechanism for the delivery of education and health services.

Te reo Māori is also central to Māori identity and the survival of mātauranga Māori and Māori cultural practices. All but one of the ten participants talked of te reo Māori being spoken in the home. Of the participants that were te reo Māori speakers there was a mix of native speakers and second language learners. For those who were not speakers, such as Bruce, there was a longing to have learnt to speak the language not just for their themselves but also for their children and mokopuna.

Whilst the participants in the study spoke of their firm identity as Māori who acknowledged their impairment, the majority of them saw themselves as ‘normal’, that is, not being any different from anybody else. Many actively strove to lead ‘normal’ lives and be ‘normal’ in a world that disabled them from fully participating in society (Higgins, 2001). They acknowledged that society was not only disabling them because of their impairment, it was also disabling them as Māori. All the participants recounted stories of stigmatisation and discrimination. For example, Hoani was teased for wearing glasses. Ngaio was teased for not being able to see and Sara was made to feel like a freak. Eleanor, Sara’s sister, recounted Sara’s experiences of teasing at school because of her eye condition and because she was Māori.

Eleanor: It wasn’t till you got older and moved further through school that you got the name calling and it sort of hit you then. Yeah. ‘Four eyes.’ ‘Goggle eyes.’ And because we’ve got the nystagmus. And I think Sara, she got it bad. Cos there was a program, ‘Battle Star Galactica’, and cos she’s got quite a bad nystagmus and they used to call her ‘Cylon’ ... It had these bad people and they had this red eye and it would just keep going like that all the time ... Yeah some of the names you were called were unpleasant. And then that’s when the cultural thing, you’d be a ... ‘a black goggle-eyed idiot.’ I think she got it quite bad ... Yeah. Cos I remember her coming and crying about that.

Many of the participants came from impoverished communities but for Ngaio it was an added stigma. Being othered occurred in subtle ways too, such as the friends of Cathy’s parents treating Cathy differently because they did not understand that she was a normal child and that her impairment did not make her less so. Maia, Mārama’s mother, talked about the ignorance people have towards disabled people and their rights to be, and move in, public spaces.

Maia: There’s a lot of ignorance out there, like people can be quite ignorant and nasty towards people that do have disabilities and I think that’s quite disgusting really ... I think it was a couple of months ago – my mum was in town and she had Marama. Marama had a cane and she was walking along and these people were just like walking towards her so mum was moving her ... I said: no mum they can see. She can’t. Don’t you move for them ... I’m like: She has a right to be in this mall like anybody else.

Nor is 'fitting in' and a sense of belonging guaranteed within Māori communities. For example, Elizabeth talked about the way in which she had been made to feel uncomfortable by some Māori reactions to her blindness.

Elizabeth: Māori look at you and think 'Oh' – I mean it is a personality thing I think whether they can accept me or not I guess and whether they can look past the fact that I am blind but that is all. My mind is fine but a lot of Māori see blindness as you are dumb as well, or that you can't hear, because I often get people who talk louder and more clearer ... It is uncomfortable and plenty of Māori make me feel uncomfortable but there are also plenty who have accepted me and it is good.

Like Bruce, Sara felt she did not fit in the blind world because she was not blind enough. But she also talked about not fitting into the sighted world because she was too blind. She talked about not having the skills as a young person to deal with the othering that she endured in both the sighted and kāpo world.

Sara: I think you build all these like, you know, defence walls. And I think I was probably quite an aggro teenager just cos you built all these walls to protect yourself from being teased ... and 'Well, yeah, so I am. Yes I am blind but so what?' You know not being able to – yeah I don't think I had the skills to say, "Well this is actually what's wrong with me and this is why this happened." My first reaction was probably to lash out cos I didn't have the support. I walked this funny line where I wasn't blind enough but I didn't see well enough. So I didn't fit in one group and I didn't fit in the other.

The marginalisation and oppression of kāpo Māori cannot be understood outside the context of New Zealand's colonial history and the inherent racism within it, and the historical discrimination of disabled people. Othering occurs within Māori communities as well and provides another layer of oppression to that which happens between the dominant and marginalised cultures, and between society and disabled people. Whilst these can be understood as separate and discreet practices demarcating difference (Petersen, 2008), they can also be understood as mutually reinforcing and interconnected practices that serve to both draw attention to difference and to silence it at the same time (Soldatic and Fiske, 2009).

All the kāpo Māori participants were born into, and culturally located within, whānau. Whānau provided a mostly safe place in which to grow in their early years. While their experiences of 'growing up' in whānau were diverse, when the participants reached school age their experiences became even more so. Some of the participants recounted how they stayed within their whānau and went to their local schools, while others went to Auckland and were schooled at the RNZFB's school for the blind, or in more recent times boarded at Homai/BLENNZ and went to local schools in South Auckland. The participants, who did move away from home to go to school because of their impairment, became dislocated from their whānau, hapū and iwi, and te ao Māori in general. They were indoctrinated into another world that was based on difference and disability. However, remaining within whānau contexts and being schooled locally in their own community did not necessarily mean that kāpo Māori were either culturally or educationally better off.

Cultural consonance and dissonance

The majority of health and education services that the participants have experienced have been inadequate. Perhaps this is not surprising given that since colonial times health and education provision have been assimilatory and framed within a monocultural world view (Phillips, 2003; Cram et al, 2003). With notable exceptions very few providers fulfil Māori aspirations for services that are culturally relevant and appropriate. Those exceptions are the kaupapa Māori providers that have established themselves over the last twenty years. In education these include kōhanga reo and kura kaupapa Māori, and, in health, iwi and community Māori health providers across Aotearoa/New Zealand.

Education Services

Historically New Zealand's education system has reflected the dominant group's cultural values, practices and understandings with its intent of assimilation. This has had a detrimental impact on the majority of Māori students' experiences in the school system and their educational outcomes. Add to this mix the often forced dislocation of kāpo Māori from their whānau and community to attend specialist blind education in Auckland. For the most part, the narratives of the participants, irrespective of when and where they went to school, reflected the stories of struggle and alienation that Māori have told since colonial times. These narratives that span eighty years tell of cultural mismatch and dissonance between home and school as well as their marginalisation and subordination because of their vision impairment. Alongside stories of educational struggle and frustration some of the participants also talked about their positive educational experiences where they were embraced as both Māori and kāpo. Positive experiences mostly occurred within kōhanga reo and kura kaupapa Māori. These were established by Māori for Māori in response to concerns over the survival of te reo Māori and what Graham Smith (1997) has called the Māori education crisis. From preschool to tertiary provision, kaupapa Māori initiatives provide a learning setting that takes being Māori for granted, prioritises te reo and mātauranga Māori and operates according to tikanga Māori cultural values and practices. Positive experiences also occurred in mainstream schools. In general, these schools operated within an inclusive ethos.

Cultural Consonance

Since the establishment of New Zealand's education system in 1867, Māori have been educated within state schools, including the now disestablished native schools. Initially, native schools were set up to ensure the quick assimilation of Māori in rural areas into Pākehā society. However, as Hoani experienced during the 1950s, the outcome of native schooling had contradictory outcomes given that those schools often served to reinforce Māori cultural practices rather than break them down (Simon and Smith, 2001). Hoani found that whanaungatanga was embedded in the everyday practice of the native school he attended. Similarly, when he went to the local secondary school, he found that they too were a close-knit community. Hoani's success at school belied the 'standard story' (McCreanor,

2005) of Māori educational failure. He attributed his success at school to the support that he got from his school and his community.

Hoani: I was in the top stream of the school and nothing seemed to be of concern for the teachers in terms of my achievements at school despite the fact that by a year later, it might even be less than that, it became obvious to the teachers, more obvious to myself even. But one of the interesting things was, because it was a very close community, they supported me. My peers would read what was on the blackboard, they would help me with my notes, all that sort of stuff ... I was doing the sorts of things that showed quite clearly I wasn't seeing that well but I went through that period doing reasonably well. I couldn't play all the games but, see this is where the whānau thing comes in, for boys in these sorts of schools, it was a big thing to play rugby ... I played rugby but I was only able to do that because of the whānau support. They helped me to achieve the goal of playing rugby for the first fifteen of the school. I wouldn't have been able to do that anywhere else.

The other times when participants had positive schooling experiences were when they were in schools that made an effort to take into account the whole child, and accommodated both their cultural identity and their impairment. Elizabeth and Tommy talked about their experiences of kōhanga reo and kura kaupapa Māori. In these settings their identities as Māori were affirmed. They reflected the cultural knowledge and practices of the home and were inclusive of their educational needs despite a lack of resources. Elizabeth's mother, Jane, recounted how Elizabeth's kōhanga reo took into account her blindness where they "all chipped in, the teachers at the kōhanga, the visual resource centre, the teacher aide, mums" to make her tactile books. Elizabeth recalled her experience in the kura kaupapa Māori that she attended as:

... just living my life and I really enjoyed it. I enjoyed going to the marae and I was just a normal child. I mean I went on all the hikes and all the fishing trips and everything. I never was excluded.

Kahu, on the other hand, was welcomed at the mainstream school that he eventually attended. Not only was Kahu's cultural identity and vision impairment acknowledged and validated, his parents were also included in the decision-making about his schooling. This whānau were not just being consulted, rather they were enabled to fulfil their aspirations to be actively involved in their son's education and at the end of the day to be self-determining.

Ahorangi: The school was fantastic. The principal there is Māori, and he was brilliant and the deputy principal was as brilliant. They hadn't worked with a child like Kahu so they completely opened up their hearts and their homes right down to the point where they said they wanted me to choose the teacher aide. That doesn't always happen; sometimes parents don't get a choice. And whatever services he needed just bring them in to meet them. And I think that was really good because they didn't have any pre-thoughts on how it should be so they were very open and that was great.

Cultural Dissonance

Growing up in the 1940s and 1950s Ngaio's educational experiences were very different to Hoani's. She was educated at her local school, and talked about how she was punished at school for speaking and being Māori.

Ngaio: the teacher came and he said to me, "Your hand is bleeding." And I said, "Oh I just got a caning from that you know what." He said to me: "You can go home. " But he sent me to the doctor first ... She had all the other ones cringing, you know. They were too scared. And I'm afraid I was one of those, who was just straight up. And I said to her: "Well if you spoke properly to us, we'd be able to do things nicely." "Oh you're a naughty girl'." Whack! ... She (would) say, "It's a horrible language." She said, "It's like the black people." I said, "How dare you." You know. Yeah she said, "The black people, they don't know what they're doing." She called us "a mud race." She said, "You shouldn't be seen and you shouldn't be heard, and you should be just trampled in the mud."

Yet her experience has had a lasting effect on her in that it drove her to work in kōhanga reo and she wished to ensure that kāpo Māori did not have the same experience as her.

In more recent times with the advent of kōhanga reo and kura kaupapa, Māori educational options have been created for young Māori to be immersed in te reo Māori me ona tikanga. As a consequence, there is no longer a stigma attached to speaking te reo Māori as was the case when Ngaio went to school. However, there continues to remain a dearth of speakers, especially in the education system. Whereas Ngaio's generation was ridiculed and punished for speaking te reo, today it is widely accepted. Yet it remains a challenge to find schools outside of the kura kaupapa system who offer te reo Māori as a subject and have teachers who are fluent to teach it (May, Hill & Tiakiwai, 2004). Even if there were, there are philosophical and pedagogical differences between being immersed in a language and its underpinning values and practices, and it being taught as a subject. Elizabeth, Tommy and Kahu were all initially educated very successfully in kura kaupapa but eventually went to mainstream English speaking schools. None continued with te reo Māori. Tommy's narrative highlighted one of the problems when learning te reo Māori in a mainstream setting after coming from a kura kaupapa Māori.

Tommy: I wanted to do it [take Māori] but I don't really like the teacher – he might be afraid that I know more than him. I can understand that, but he also didn't know how to – since I am Māori –to teach blind people, he hadn't had a blind person in his class before.

For many Māori whānau there are no choices about where they send their sons and daughters to school. The majority of Māori students attend mainstream schools. For Elizabeth, Tommy and Kahu their parents' decisions to eventually send them to mainstream schools was fraught. For example, Elizabeth was initially sent to a girls' intermediate school that did not have an immersion unit. She rebelled and as a result her parents, Jane and Vince, sent her to Homai.

Jane: She was being a bit naughty ... and her qualifications at school base were still up there but it sort of came through that perhaps it was good for her to go to Homai and develop a bit more.

Vince: Yeah she was just a bit of a handful and also there were other blind kids there ...

In doing so they paradoxically ended up marginalising their daughter further (Connor and Ferri, 2007).

While the impetus was different for each whānau, in each case educational placement decisions were made prioritising the educational needs of their kāpo tamaiti, rather than prioritising their holistic needs as Māori. Kahu's mother's narrative exemplified the dilemmas that these whānau faced.

Ahorangi: I wanted nothing more than for him to stay at kura kaupapa Māori but he needed other specialised services and we couldn't come to an agreement. So he then moved into mainstream.

At the end of the day these whānau were effectively having to make choices that focussed on their children's impairment rather than on their cultural identity and well being. If kāpo Māori identity and aspirations are to 'be Māori who happen to be blind' then what is happening currently in education is falling very short of enabling the fulfilment of this aspiration. Kāpo Māori and their whānau should not have to choose between aspects of their identity in order to access services (Ferri, 2008).

However, it cannot be assumed that kura kaupapa initiatives provided kāpo tamariki with an appropriate education. Kahu's experience of kura kaupapa Māori was different from Tommy's and Elizabeth's. Kahu's whānau wanted him to attend kura kaupapa, because it was their desire that his first language be te reo Māori. For the first 18 months of his schooling Kahu attended a kura kaupapa Māori. The focus and political orientation of the kura which he attended was on te reo Māori, and this resulted in tension between the school that insisted on te reo being spoken in the school and the specialist vision teacher who could not speak te reo Māori. Kahu's whānau chose, in the end, their son's educational needs over his cultural ones. The whānau moved Kahu to a state school where he could get the specialist support he needed. Kahu's experience in this kura highlighted an issue that was raised in most of the participants' narratives: the lack of Māori teachers, especially those who can speak te reo Māori, and the lack of specialist vision resource teachers who are Māori and/or who are speakers of te reo Māori. Currently there are few vision specialist teachers who are Māori and none that can speak te reo Māori. Moreover, there is also a lack of specialist teaching and learning resources in te reo Māori.

Historically, it has been accepted practice for vision impaired young people to be sent away for all and, in more recent times, for part of their schooling. Initially this was at the RNZFB site in Parnell. Since the 1960s, young people have been sent to Homai in South Auckland for assessment and special schooling, primarily in the early childhood and primary school years. However, for many years, Homai has had a boarding hostel for high school students who attend local schools. Many of the participants in this study went to Homai for at least some of their schooling.

While the Homai policies speak to the Treaty of Waitangi and meeting Māori cultural needs, the participants' experiences suggest otherwise. Rather, their experiences speak of marginalisation and exclusion (Ferri, 2007). Hoani went to Homai for the last year of his schooling in the 1960s and was shocked at the institutionalisation of some of the Māori

students, who were dislocated not just from their whānau but also from their cultural and language heritage.

Hoani: Oh they had some (Māori students) there but they were really institutionalised. They were there for a long time. A lot of them couldn't talk Māori and so I couldn't have a conversation in te reo with anybody.

In more recent times, the participants who boarded at Homai spoke about the lack of culturally appropriate practices. Tommy liked school but talked about missing his whānau and the lack of culturally inclusive practices with regard to not being able to spend private time with his older brother who was in the Kickstart programme.

Tommy: Leaving the whānau was a big thing. It didn't affect me at first you know, I kind of liked it up there but then I got homesick and all that.

Tommy: You're not even allowed to go to Kickstart. They can come and visit you, like if it's family, but even so they're not even allowed in your room.

For many a sense of belonging was not found within the formal set up of Homai but rather with Māori who were employed there. In doing so, they reconfigured, as it were, 'whānau' relationships in the absence of their own whānau. For example, in the 1960s Hoani used to go to the cooks for company.

Hoani: I used to go to the cooks, because the cooks were all Māori you see. Fortunately, the headmaster or the chief there at the time didn't frown upon that, and in any case, most of the cooks were all my age. They were straight out of school and had gone to be kitchen hands so we had a good time.

Elizabeth, who went to Homai after her earlier schooling in kōhanga reo and kura kaupapa Māori, befriended Waiata, one of the residential workers. Waiata recalled the lack of support both practically and culturally for Elizabeth and in the process highlighted the lack of training given to staff to support their young charges.

Waiata: Yeah well unfortunately actually I was the only staff member who upskilled in Braille ... I don't know why management allowed that because I keep pushing that every staff member that works with these kids should have some basic ... understanding of Braille. But it just didn't seem a priority for management to push ... It wasn't only the Braille. It was also the cultural safety that kept me there ... I think it was also certain staff members who were – I don't think they were racist or anything – but they just did not want to do anything Māori and felt that if students were Māori why should they have to go (to Homai) ... It never used to be like that When I came along we had our manager of residential, she was Māori. She was really good and she made sure that everything was put in place for the kids ... But when she left, it did seem like we've got no Māori as managers, you know.

Another issue that was raised by Elizabeth and Tommy was the way in which the students at Homai/BLENNZ were all treated the same in that their individuality and their individual circumstances were not taken into account. Students have limited privacy and time for themselves.

Tommy: You can't just go in your room. You've got to kind of be out there where other people can see you. And other people come along, like other students come along to have a nosey, "Oh what are you guys talking about?" You know, and it kind of gets on my nerves.

Elizabeth: We only have one option and one way ... With Homai they are taught to train in a textbook way that you must follow but I don't believe in that. I believe that everybody has their own way of doing things and therefore should be given the choice in how to live their life. So e.g. if somebody wanted to go to – because the high school has got the best resource centre in New Zealand – Wellington, they have to stay at Homai. But it is very restricting there. You have to follow lots of rules and regulations and it would be best maybe if they had an option that they could fund maybe staying with a family.

Central to kaupapa Māori education is a collective ethic. To that end the whānau is viewed as the most important location for successful educational outcomes and social change. However, the philosophical underpinning of state educational provision has centred on individualism and the individual pursuit of knowledge. The specialist educational facilities for blind students in addition to operating within this world view extend this to focusing on individual student's impairment and then this serves to maintain the status quo (Barton, 1997). Educational provision has therefore revolved around the individual and the individual's impairment, rather than considering kāpo Māori in a holistic manner or as being culturally situated as part of whānau, hapū and iwi.

While Cathy and Mārama were not yet at school, their experiences of BLENNZ to date suggested that specialist educational services remain unresponsive to Māori aspirations for an education that reflects who they are and which provides culturally appropriate services. For example, Cathy's parents talked about her mobility instructor's lack of understanding and little appreciation of whānau.

Hine: He is the one that tells us we should do this and do that and that's why this is not working. Blah blah blah. And you are talking to him and he is not listening and he just carries on doing what he likes – talking past us.

In this study a critical issue for Māori in general and, specifically, for kāpo Māori was the way in which Māori are seen through a 'deficit' paradigm. One way of understanding Cathy's and her whānau's experience of her mobility instructor is through the notion of deficit thinking. The whānau in this instance were seen as deficient and not capable of understanding and considering their daughter's mobility needs. On the one hand, this may have arisen out of long-held assumptions of Māori intellectual and cultural inferiority, on the other, it may be because of the privileging of unexamined expert knowledge and assumptions (Kalyanpur, Harry and Skrtic, 2000). Professionals who are blind to their own cultural and intellectual lenses are unconsciously limiting the potential of children and their whānau (Harry, 2008)

Finally, a number of the participants talked about the lack of access to an appropriate visual diagnosis and assessment. This had a considerable impact on the learning and vision support that kāpo tamariki and their whānau were able to receive at school or in rehabilitation services given that eligibility and funding for services follows assessment. Without an assessment, whānau and kāpo tamariki were unable to appropriately access RNZFB,

BLENNZ and teacher aide support. In most cases, but by no means all, access to diagnosis and assessment was connected to the degree of vision loss.

In an evaluation of special education, Bevan-Brown (2000) found that schools did not consider that attending to the cultural needs of students with disabilities was a priority. Rather, they saw that culturally appropriate practices detracted from the special needs that these students had. However, in an inclusive environment the needs of the whole child is seen as the priority. Given the rights contained within the United Nations Declarations, New Zealand's Human Rights Act, the Bill of Rights and the Disability Strategy the whole child should be the focus of education. Currently it remains a challenge for schools and professionals to be inclusive of all children and to meet their holistic learning needs (Ainscow, 2008). But by not attending to inclusiveness is to maintain the dominant exclusionary and assimilationary ideologies and practices (Barton, 1997).

Health Services and the RNZFB

Across the health sector Māori health outcomes have historically been poor. Research to date has shown that Māori are less likely to access health services and when they do their outcomes are more likely to be poorer than for Pākehā (Ellison-Loschmann and Pearce, 2006). The findings of this research project confirmed what has been found elsewhere in health. Fewer kāpo Māori access services; and were less likely to have a diagnosis or be assessed for vision loss and have treatment for their condition. Furthermore, there was a lack of services that were culturally relevant and appropriate for Māori.

A number of participants experienced delays in accessing diagnoses and assessments. Sara, for example, was not formally diagnosed until she was an adult when she took her sons to a paediatric ophthalmologist. Kapua Kore's brother, Hamish, and preschooler, Cathy, at the time of this research were still waiting for diagnoses and assessment. Both of the preschool participants' eye conditions were first noticed by their grandmothers. In Mārama's case this was despite her mother, Maia (who is also blind), working with health and education professionals when she was born.

Maia: I had her and unfortunately it was about a year later we found out that she was actually blind. She was born and they did all the tests and it didn't really show, like if you look at her naturally, you think, 'Oh yeah, she is okay.' ... It was only through my Mum actually because we were staying with her ... Mum or Dad went to switch the light on and Mum was just watching her and she said, "Oh do that again, turn the light off and switch it back on." And because she had just woken up and Mum said, "Hey she didn't flinch." And I said, "Like whatever, Mum, you're joking." And Mum is like, "No, serious." And Mum was jiggling something just lightly in front of her eyes and she said, "Yeah, I have a real funny feeling she can't see." And so it was only through Mum. Marama went to the doctor just down the road because she knew them and they knew me real well as well and the nurses worked out that Marama got assistance by Mum pushing, to get things done and yeah ... and we went to the eye specialist (in the big city).

Tania, Cathy's mother recounted that Cathy's grandmother was the first to notice that her eyes were 'wiggling backwards and forwards'. Cathy had several trips and referrals to

different hospitals for a diagnosis but her whānau were yet to find out what her eye condition was.

Tania: We didn't find out until she was about three months and we got sent down to [a hospital that was six hours away] for eye testing there. And they said there was nothing wrong with her eyes, no reason why she couldn't see. And then they sent us to a paediatrician and he referred us to Starship, Auckland. And they had an MRI and a CT scan, a lumbar puncture and heaps of blood tests. Oh it was awful because when we went to Waikato, they said there was nothing wrong with the eye. There was no reason why she couldn't see so they thought it might have been something in the brain not connecting to the eyes and that's why they went for an MRI and those were all fine. They were saying her head was small, but no.

Moreover, Cathy's whānau remained frustrated with their dealings with the services that Cathy has been subjected to. Not only have they not been told about the kind of tests that have been done nor have they been told about the outcome of the tests in any meaningful way. The whānau felt that they have been left out of discussions.

Tania: When we ask them what they are doing they sort of fob you off. And then there is no report back.

Tania: Yes explain what is going to happen and then report the results back to us, you know, sit down and report. "This is what we saw and this is what we think," and blah blah blah!

Then there are the difficulties that kāpo Māori face in getting to health services because of orientation and mobility issues.

Elizabeth: Accessing the doctors and the chemist is a problem. When I was in Auckland, I usually had somebody to take me and I am not used to going on my own. And as I got older obviously, I couldn't just ask my dad to take me to the doctor. And so I started going on my own. It was kind of uncomfortable. I would walk into a waiting room and you don't know where the counter is. It is a silly thing but honestly, and [I thought] the receptionist should say, "Hi" and then you would find it. But when I went, she was a little bit vague and I thought, 'Oh great'. I found it myself eventually. Going into a chemist, I had never done that on my own before. I was independent except for that if you know what I mean ... The taxi driver actually helped me and he took me to the counter. And they were fine but I mean it is not very accessible.

Some whānau have moved towns in order to ensure the best services possible for their tamariki/mokopuna. Take for example Mārama's parents who moved into a city so that they could more easily access services because no one was willing to travel the hour to where they used to live.

Mārama's mother, Maia: I was just getting so many people ringing up and saying: "Oh 'blah-blah-blah' and we can do this for you and 'blah-blah-blah'." But I'd just had enough, I was just like: 'No I'm not going out of my way to ring up anybody because they've all told me they're going to come to me and I

haven't heard from them.' ... That was another reason why we moved into town cos it was just like: 'Yeah yeah we're going to come out. Yeah yeah.' And we still didn't hear from anybody. We were just getting phone calls: 'Yeah we're coming out. We're going to be doing this and we're going to do that.' And it was just like well: 'Where are you guys? I need the help now.' ... It was only an hour [away] ... See with here I can just ring or get other services if I need some.

Access issues are further compounded by the way in which services are organised and funded. The configuration of services for blind and vision impairment New Zealanders are primarily split between the Ministries of Health and Education. The Ministry of Health funds specialist services for preschoolers (aged under 5) and funds through the RNZFB rehabilitation services for adults beyond 20 years of age. School aged children between the ages of 5 and 20 years are usually funded by the Ministry of Education for all services, including assessment. The Ministry of Social Development funds vocational services and the Accident Compensation Corporation provides funding for services for those whose vision impairments are a result of accidents. Having multiple funders and meeting multiple policy requirements for funding makes for complicated service provision. It is in this environment that kāpo Māori and their whānau do not always know what services are available nor where to go to access them.

Despite the multiple funders, all specialist services, except Vision Teachers, for kāpo Māori usually come from the RNZFB whatever the kāpo person's age. The RNZFB provides rehabilitation services for all New Zealanders who are assessed as being blind or vision impaired, and are registered as Foundation members. However, some participants questioned whether the Foundation was able to provide appropriate services to kāpo Māori of all ages, and whether the Ministry of Education should provide all specialist services for kāpo children like it does for all other disabled children.

Elizabeth, when questioning the lack of choice of service providers, argued too that the lack of competition meant that the Foundation, as the primary provider, did not have to work at delivering services to kāpo Māori.

Elizabeth: I just think it is narrow mindedness. I mean [the RNZFB] want to be the main service provider and I mean that's fine but it is not fair because there is a lady in orientation in mobility and she works for [another company] ... She has only just started her business. And she is fantastic but they won't fund her business at all. The high school [had to pay for] her to teach us. But she can't have other business because the Foundation want to be the only option. Do you know what I mean? So they are not open to competition, which is not very good.

Also, there are few Māori staff available to support kāpo Māori who register with the Foundation. Take for example Bruce's experience with the Māori Welfare Officer, which left Bruce questioning whether the Foundation knew how to support kāpo Māori.

Bruce: Oh I think ... at that stage it [Māori] was very much in the too hard basket ... They just wanted you to go to the workshops and they would leave you there and that was the end of it ... They couldn't care less because we don't want to see you any more ... "Don't make any trouble and everything will be okay." ... You know, you had to sort of paddle your own canoe and sometimes it was a little bit of who you knew in the Foundation to get the plum jobs...

While the Foundation policy documents referred to the Treaty of Waitangi to guide their service provision for kāpo Māori, their service to Māori was limited and not well received by the participants. At the time Sara registered with the Foundation, kāpo Māori were automatically referred to their Māori services whether they wanted to be or not. Sara felt she had been othered and labelled because she was Māori.

Sara: I found it really weird when I registered with the Blind Foundation that my name was recognised and they said, “Well you have to register yourself with Māori Services.” And I said, “Well, why’s that?” They said, “Oh because you’re Māori.” You know this is over the phone I’ve never met any of these people. And I’m saying, “Well yes I am.” But I didn’t appreciate being told that I had to. And they went, “But the numbers are low.” And I thought, ‘That’s not my fault. I don’t want to be a number.’ And I really didn’t have a choice it was: ‘You pretty much have to register yourself. We’ll register you with Māori Services.’ Which was okay, but sort of not okay. It didn’t sit well with me being told that, you know, another label. Yeah, ‘I’d just been labelled blind, legally blind, now you want to label me a Māori.’ Which I didn’t have a problem but there was no choice ... I didn’t have a choice with the kids either. So that was okay and we had a couple of rocky moments in those early days ... I’ve never really, for myself, had a great deal of support from The Blind Foundation.

Support meetings may often have the opposite effect of what was intended. When Sara went to a support meeting for the first and only time, she was made to feel like an outsider. She made the point that a focus on being kāpo rendered her experience as abnormal and marginalised her in the process (Petrou et al, 2009).

Sarah: I felt like an outsider. I felt like an outsider cos mine were the only two babies that were there ... And I felt like an outsider because all these people knew each other. They’d all gone through, if not school together, if not through the Homai system together, they’ve all gone through some form or other of The Foundation service. So they all knew each other and the only way in which they could relate to me was through my brothers ... It was only one meeting I attended, but I almost felt like a fake. ‘So where have you been?’ And I’m like: the last twenty-three years I’ve been living like a normal person.’ And that’s what it felt like and I was sort of there under false pretences ... And it wasn’t that anyone was treating me like that, that’s just how I personally felt ... And it was horrid for me cos it wasn’t like a normal social situation where people’d come up and speak to you because out of the group of people that were there, other than the drivers, I probably saw better than the majority of the people in the room.

But then when kāpo Māori do access services, their experiences are not always positive ones. Mārama’s mother, Maia, had given up on waiting for the RNZFB to provide mobility training for her after her move to the city over three years ago.

Maia: I’ve given up on the Foundation, eh, it’s just like: oh yeah we’ll be there, we’ll be there. And it’s like: oh yeah whatever. I’m just, you know, do to my best ability I’ve done right through schooling and whatever so I’ll do it right until, yeah, someone turns up on my doorstep.

While most of the participants in this study did not receive adequate services, in two instances in this study kāpo Māori were overwhelmed with services. The overly medicalised attention that Kapua Kore received was in stark contrast to her brother who received none. Kapua Kore at the time of this research was on three different medications, of which only one was for her eye condition.

Kapua Kore: Sleeping medication for sleeping ‘cos I stay up till one or four or five or six o’clock [in the morning]. For some reason I can’t see day and night ... I should just have a clock that can tell me which is night and which is day. It has to be better than the pills and it can tell me what time I have to get up and go to bed.

Interviewer: So you don’t like taking the pills?

Kapua Kore: Well sometimes I don’t, but most of times I just have to, and I even have diet pills cos I eat too much.

Interviewer: So you’ve got diet pills now as well?

Kapua Kore: Yeah, cos I’m like eating two plates of kai every dinnertime ... every breakfast and lunch. I’ll eat heaps. I don’t know what it is. The food must be too nice. Yeah I just eat too much.

Kapua Kore’s ‘hyper visibility’ and her brother’s heightened invisibility, as discussed further in this chapter, can be understood as resulting from their racialised othering (Soladtic and Fiske, 2009).

Kahu, also with his multiple health needs, was exposed to a plethora of services that have been overwhelming for his whānau. As Kahu’s mother came to see, not all of them were necessary.

Ahorangi: I think sometimes the services are overwhelming, so in recent years I’ve really thought about the services that I’ve let come on board with Kahu. Right now we’re down to Group Special Education, having a little bit of input; and the visual resource teachers, having the most input; and PVI (Parents of the Vision Impaired) are our main support. All the other services I’ve been able to thank them, and say, “No.” In the last thirteen years, we’ve counted that there’s been about twenty-seven different services, yeah, not all at once but at different times. Parts of group special education, occupational therapists – just different – I don’t want to name ... too many ...

Māori do not just want access to appropriate and skilled services, they also want culturally appropriate ones. Services tend to be monocultural and monolingual in their provision. Kahu’s parents wanted te reo Māori to be his first language, yet from the beginning their rights and aspirations were compromised because the staff who cared for him could not speak te reo Māori. Kahu’s language development was further compromised by ideas about the physical development of his mouth and the need for early speech and language therapy. Similar to Kahu and his whānau’s earlier educational experience, there was no one who could provide speech language therapy in te reo Māori.

Ahorangi: English is now his first language and I mean I always have regrets about that as English is my first language as well. In the early days when he was in early intervention, a team believed that he would have problems with

swallowing – cos when you're born that premature you don't always get the swallowing. So some children can never eat, they can never speak and that was the fear that they had for Kahu and they really needed to get some speech and language going and they couldn't deliver it in te reo Māori. And I pressured myself into believing that all those years ago, I wouldn't do it now, he must have all this. But then I was pressured into thinking that ... when you're vulnerable and you've got a child that's so sick and you've got specialists coming in, you want to believe what you're being told. But you learn as you grow.

In the context of 'kāpo Māori aspirations to be Māori' and, in particular, the centrality of whānau as the anchor for cultural and physical well-being, the issue of caring for whanaunga who are kāpo is important. It is preferable that whānau look after their own whanaunga who are vision and/or multiply impaired, yet funding policies and arrangements make it extremely difficult for whānau to be recognised as carers and adequately remunerated for the work they do. Whānau also talked about the lack of respite care and the lack of whānau being able to be employed to undertake it.

Ahorangi: I really think there should be some discussions about needs assessments and respite care for children ... If we're talking about Māori children, the concept of whānau must stand because with respite now family can look after the children and be paid but they're paid at a lesser rate and they can't be living in the home. So for our whānau, my children have always looked after Kahu. There's no respite facilities in the town where we live. It's very difficult for children, for young people, to have a break from their families and vice versa. So even though we desperately love Kahu, as an adult woman, sometimes it's nice to break away and have a coffee or go and have a hairdo but that can't always happen when there's no one for Kahu.

Furthermore, despite a higher rate of disability compared with non-Māori (Ministry of Health, 2004) Māori participation and representation in the disability sector is low. Elizabeth found this when she attended a disability forum. Not participating in such forums means decisions are being made for Māori rather than by Māori. This presents a challenge. On the one hand participation is low because services do not reflect Māori aspirations, values and practices, yet on the other it is not the responsibility of Māori to change services through their participation. Rather, it is up to the Crown as the partner to the Treaty of Waitangi to ensure that services are accessible and outcomes are equitable.

In only two instances did participants consider that health services provided appropriate care. First Kahu and his parents recognised the valuable care that he has received since he came into the world as a very premature baby. Over the years, Sara's experience of health services had at first not been positive one. She had been made to feel like a freak because of her eye condition, yet had never had a diagnosis. However, when she took her sons to a paediatric ophthalmologist, it was then that she and her whānau learned that she was seriously kāpo. It was her positive relationship with her sons' ophthalmologist that enabled her to be formally diagnosed.

Sara: It wasn't until my sons were born and [the ophthalmologist] was saying, "Well what's your vision like?" And I said, "Oh my vision's really bad." And she tested me and she said, "Your vision is really bad, did you go to school at

Homai?” And I said, “No I didn’t, I went to my local high school.” And she was shocked and my Mum was really shocked to find out how bad my vision was.

Sara: One of the reasons why I love [my specialist] is because she doesn’t stand any of the bullshit, she tells you straight what’s happening. But one of the things I really liked about her is that you actually felt like a person.

Visibility and invisibility

Woven through the narratives of the participants are their experiences of invisibility as Māori and/or as kāpo in both education and health settings. Two of the participants’ impairment was invisible to their whānau, in one instance because other members of the whānau were more obviously kāpo and, in the other, because whānau were not tuned into the issues that face kāpo Māori. However, being invisible is not necessarily a negative experience because some of the participants wanted to be invisible because they saw it as enabling their drive to be normal and lead normal lives. Markers of blindness such as using a white cane and reading Braille were resisted by some of the participants. Bruce refused to use a cane because he did not want to be identified as kāpo, while Elizabeth resisted using it because she wanted to be seen as normal. Elizabeth, purposefully hiding her difference (Cruz, 2007), also used to read Braille with her feet so she was not seen to be different to her class mates.

Elizabeth: I never used my cane ever. I would learn my way around everywhere without my cane ... I really wanted to be like everybody else ... I was a bit rebellious right through my life. But I didn’t want to learn Braille ... I even learnt how to write print ... I just learnt the letters. I got tactile like my mum helped me working on an alphabet board and I used to practice writing them. I learnt Braille too, so that first time it was cool that’s new, but when I went to primary school nobody had it and it was like I don’t need to do Braille any more. I ended up reading Braille with my feet so nobody would see that I had Braille.

Sara’s experience of invisibility cut across school and home. The extent of her vision impairment was not picked up by her whānau or the school. At home blindness was not discussed despite her brothers and sisters being kāpo. And at school, even with the tests that showed that she had vision loss, they did nothing to support her learning.

Sara: I mean I’d come home from school some days and I’d say: I can’t see the board. And mum would say, as parents do: well sit up the front of the class. You know and I’d do that. So I’d start every school year off saying: I can’t see the board. And I’d have to sit up the front of the class, but when you’re sitting at the front of the class and you can’t see the board it’s, you know, ‘where do I go from here?’

Sara: You always have those hearing test people and the vision test people that come through school, and I think they were fairly well aware that I couldn’t read the eye chart. I can remember one note going home to mum that said you know: Sara couldn’t read the eye chart. And mum said, “Well what letter did you get up to?” And it was like, “No I couldn’t even see the eye chart, I didn’t know where she was pointing.” (The tester’s) like “Read letter blah blah.” And I’m like, “Where am I reading?” And

they knew that, yeah, that I was obviously that bad but no one said, “Oh I think this child needs extra support or needs schooling through Homai.”

Hoani hid his increasing vision impairment by continuing to participate in activities that involved using vision such as playing rugby. As an adult he continued to strive to be normal in a society that perceived him as different and this had the effect of making his impairment invisible to his whānau. Hoani’s wife recounted his experience of being on the paepae and standing up to whaikōrero while his older brother was present. Transgressing the kawa of his iwi in which the mantle of whaikōrero is given to the eldest or tuakana, his brother stood up and berated Hoani for standing up to speak ahead of him. As his wife, Mirama, pointed out that Hoani had no way of knowing that his brother was on the paepae with him and it would have been simple for him to let Hoani know that he was there. It is nuances like this, in everyday situations, that continually remind kāpo Māori of their impairment and their difference.

Many kāpo Māori in this study have also been visible to health and education services. However, being visible did not necessarily mean having access to services that fulfilled their educational and health aspirations or overall cultural well-being. For some visibility meant heightened stigma and being easier targets for discrimination. Take for example Kapu Kore and her whānau. Kapua Kore was diagnosed as a baby with an eye condition which by the time she reached the age of two meant that she had complete vision loss. Because of this and other impairments, she required ongoing health and education services, and as a consequence of this was highly visible to practitioners and service providers. It is arguable in Kapu Kore’s case that being visible resulted in appropriate care. The issue for Kapua Kore was not that she lacked access to services rather that her care was overly medicalised.

By comparison Kapua Kore’s younger brother, Māui, who had the same eye condition, was invisible to educational and assessment services. His school attributed his disruptive behaviour in the classroom to his home life despite knowing that he had a vision impairment like his sister. In Māui’s case, his invisibility translated into him and his whānau being seen through ‘deficit oriented eyes’. The impact of his invisibility meant that he has had no special education assessment, which in turn meant that he was not eligible for teacher aide support in the classroom. Kapua Kore and her whānau’s experiences emphasised the tension that exists between visibility and invisibility. Neither can be considered binary opposites.

A number of the participants had multiple disabilities. These participants were both invisible and visible, and often at the same time. On the one hand they were highly visible because of their multiple disabilities, yet on the other hand experienced being invisible because their vision impairment was often overlooked in the face of more pressing needs. For example, when Kahu went to school it became obvious to his mother that they did not have enough support or information about his blindness. In hindsight, she would have liked to have had more information about his vision impairment earlier. Yet at the same time the services that Kahu has received have sometimes been overwhelming. So much so that his mother has begun to say no to them and be more active in deciding what happens to Kahu.

Kāpo Māori visibility/invisibility in their whānau, schools, and health services reflects a deep disjunction in Aotearoa/New Zealand’s social fabric. It impairs their positive identity and makes their full participation in society difficult (Frazer, 1995).

Transformation and change

Despite the struggle that the participants had in accessing appropriate and relevant services and the discrimination that they experienced as both Māori and kāpo, they, nevertheless, remained optimistic, expressing their desires to be Māori and their aspirations ‘to get on’ in the world. Their continued optimism can be understood using Jonathon Lear’s (2006) notion of radical hope in that when in the face of cultural devastation, they have been able to draw on traditional cultural values and ideals with which to lead meaningful lives as Māori who are kāpo.

The space in which this takes place is perhaps born out of a ‘gut refusal’ to be subordinated, and it is ironic that in living on the edges and experiencing marginalisation resistance is born. Kahu’s mother talked about having the strength and confidence of saying ‘no’ to services that she felt was not necessary. Mārama’s mother made sure that Mārama got what she needed, and that she was visible to educational and health providers because she, herself, was invisible ‘growing up’ kāpo.

Ngaio’s experience of racism and being teased because she was kāpo and Māori was a driving force for her working in kaupapa Māori organisations such as kōhanga reo and Ngāti Kāpo O Aotearoa. Similarly, Hoani expressed the need for kaupapa Māori service provision to ensure that Māori aspirations to be Māori are fulfilled. He maintained that blind and vision impairment services should have a strong bias towards kāpo Māori and prioritise Māori cultural values and practices, given that Māori rates of access to diagnosis, assessment, and rehabilitation health services lag behind those of Pākehā. At the center of his aspirations for kāpo Māori was the importance of developing a strong Māori identity first, then attending to living with their impairment. One participant said “to survive as Māori equals success.”

Many of the participants saw the whānau as the vehicle for transformation and change. Bruce talked about being a role model for his four children in being independent and self sufficient, and in his retirement actively he worked to support the RNZFB. Sara considered that her brothers and sister were positive role models for her to be independent and able to ‘walk the talk’. She had aspirations to further her education in the disability area. Kahu’s parents were staunch advocates for him, ensuring that they were well informed of their rights. His mother lobbied to be able to be recognised and paid as his teacher aide when he went to school. As Kahu gets older they were focusing on supporting him to become independent. Mārama’s whānau talked about the way in which she was an inspiration to them and how they learned from her. They too have learned to stand up for her rights.

Given the centrality of whānau to the development of a positive identity as Māori and as a vehicle through which kāpo Māori aspirations can be realised, more should be done to support it. Respite care was given as one example where whānau should be able to be recognised and paid accordingly as carers for their kāpo whānau member.

The struggles that kāpo Māori and their whānau faced have led to many of them taking on advocacy and leadership roles in their whānau and communities and in the Māori world in general. Bruce, Ngaio, Hoani, Sara, Elizabeth, Tommy, and the whānau of Kahu, Cathy and Mārama in diverse ways worked to better the lives of kāpo Māori. Hoani and Kahu’s mother were strong advocates for Māori with impairments while others worked within their own communities and whānau to make change happen.

Many of the participants and their whānau considered their futures in the context of being Māori who happen to be blind. This did not mean being invisible to services rather it meant being able to access services and the resources on offer so that they could get on with living and being Māori.

In conclusion, we found that all of the kāpo Māori who participated in this research were strongly and culturally located in whānau. However, not all participants were connected into hapū and iwi networks and relationships. While for some this connection was not a priority, for others whakapapa was a dominant factor in their identity. Many of the participants were emphatic that they were first and foremost Māori, who happened to be blind or vision impaired.

However, it was apparent that the experience of being tangata kāpo impacted on their lives and identity as Māori. Equally, being Māori impacted on their experiences as tangata kāpo. In most instances, this was a negative impact with tangata kāpo and their whānau, being either invisible to services or visible for the wrong reasons. Many talked about their experiences of schooling and health services that did not take into account their disability or their identity as Māori, and in many instances both.

As a consequence kāpo Māori and their whānau in this study were marginalised in multiple ways in a society that perpetuated difference and disability despite a raft of policies and laws that have been put in place to eradicate discrimination and inequalities (Phillips, 2005; Petersen, 2006). Despite their experiences of being marginalised as both Māori and kāpo the participants in the study reflected a strong and positive identity as Māori who happen to be kāpo. It is clear that the kāpo Māori in this study were active agents in shaping a cohesive identity that enabled a way of seeing and understanding the world in positive and self determining ways (Ostrander, 2008).

Kāpo Māori and their whānau, who participated in this research, were highly resilient and resourceful in their everyday lives, expressing in a variety of ways their desire and rights to be self determining, and being able to live life being true to themselves (Hall & Bishop, 2000). That is: 'to be Māori who happen to be kāpo'.

Chapter Eleven

Concluding remarks about growing up kāpo Māori

This report is the result of two years of research, which was funded by the Health Research Council. The seed from the research came from Hine in Dr. Higgins' doctoral studies, and the research team would like to acknowledge her and her inspiration for this project. Ngāti Kāpo O Aotearoa Inc, which is a for kāpo Māori by kāpo Māori provider, initiated this project so that kāpo Māori lived experiences could be remembered and documented. The project privileged Māori ways of knowing and by doing this retrieved spaces for Māori voices and perspectives in which Māori realities are legitimate so that social transformation may occur (Smith, 1999), not the transformation of Māori but the transformation of policies and services to Māori.

Throughout the project, the research team upheld the centrality of Te Tiriti o Waitangi with respect to research methodology and analysis, effective partnership building with non-Māori, social equity and justice, and most importantly to Māori aspirations to be Māori and self-determining. In total, 78 participants, five researchers, three Research Management Committee members, and a kaiawhina and two support staff from Ngāti Kāpo contributed to this project. In addition, hundreds of Ngāti Kāpo O Aotearoa members at two of their biennial hui provided us with inspiration as we shared our research journey, and the participants' stories. The research team would like to acknowledge all of these people who supported the research and the writing of this report.

Ranging over five generations, the ten case studies that have been presented in this report are narratives about what it is like to grow up kāpo Māori. The ten narratives highlighted the ways in which, despite their diverse lived realities, each of the ten kāpo Māori participants and their whānau, shared common experiences. In total, their stories covered 80 years of a society that has had difficulty in consistently providing culturally consonant health and education services that recognise and support kāpo Māori as being Māori and being kāpo. However, each of the participants was determined to 'get on with their normal life', and was resilient to encounters with health and education services that marginalised or 'othered' them. They resisted the identities that were prescribed to them through the collective support of whānau, including Ngāti Kāpo O Aotearoa. Indeed each of the participants strongly identified with, and located themselves, in whānau. We have used the phrase 'whānaucentric' to describe the way in which they all expressed their connectedness to, and embedment in, whānau, irrespective of whether those relationships were based on traditional genealogical ties or on those to whom they were close.

Bruce and Ngaio in the 1930s and 1940s lived in rural Māori coastal communities and had deep connections with their land and community. Without government support in that time, their whānau used what was available around them to survive. Bruce's mum collected pāua and mussels to feed her children and her father during the war, and Ngaio's whānau relied on the water that her brothers could carry in tins from the river. Both had a miserable time at schools in their local communities. Bruce's vision impairment was not acknowledged and he said that he subsequently failed at school. When he was at the Foundation of the Blind as a young adult, which could attend to his vision impairment, however, he only found solace with other Māori. The happiest part of his life was later when he got married, returned to his whānau and his community where he raised his own children. At school, Ngaio was

recognised as having a vision impairment, but no accommodation was made for her. She also encountered overt racism from her teacher at school. Ngaio left school at the age of 12, and throughout her life, like Bruce, worked hard to support herself and her whānau. Ngaio, who was a native speaker of te reo Māori, directly supported Māori through her caregiving and leadership work with Māori children, kōhanga reo, and, later, the local rōpū (branch) of Ngāti Kāpo O Aotearoa. Ngaio and Bruce were resilient to their circumstances and both had successful lives, albeit with some ‘bumps along the road’. They each had loving whānau and children in their life and were committed to improving the lives of kāpo Māori.

Hoani and Sara’s stories take place thirty years apart, and are quite different, but they had similar hereditary eye conditions, had children who were kāpo, and were extremely committed to their whānau’s well-being. They both wished to ‘be there’ for them. Sara, who had children who were kāpo, was determined to know more about the hereditary nature of her vision impairment so that through knowledge ‘the family curse would be done away with’. She was an educator, and a researcher in the area of her whānau’s vision impairment yet as a child she was invisible to health and education services in regards to her own impairment. Little consideration was given to her need for vision services because the rest of her whānau had more severe vision impairments. She thus ‘grew up’ with little of the educational support that was available at the time. She also said that she was primarily an urban Māori and not connected to her hapū or iwi. However, in her daily life, she was practicing tikanga in her work and at home; she felt that Ngāti Kāpo O Aotearoa was her whānau; and she belonged when she was with them.

Hoani was strongly connected to his hapū, his iwi, and kāpo Māori through Ngāti Kāpo. He was a native speaker of te reo Māori, and grew up in a small rural Māori community in which his identity was founded, and from which he gained strength and support. His mother was a spiritual person and took him to tohunga (priests/healers), one of whom told them that his sight would continue to deteriorate. When Hoani left to go to the special school because of his deteriorating vision, he sought out the Māori cooks and staff for friendship and support. He became a Māori field worker for the Foundation and, throughout his career worked for Māori and kāpo Māori. His aspiration was that kāpo Māori would be well grounded, have a strong identity, and accept being kāpo. He argued that being Māori was a primary identity, and being kāpo was a secondary identity for kāpo Māori.

Tommy and Elizabeth, even though significantly younger, expressed like Hoani that they were Māori first, who happened to be kāpo. Tommy and Elizabeth both attended kōhanga reo and kura kaupapa Māori in their communities. While Tommy lived in a rural area Elizabeth lived in the city. In their community and whānau, they were accepted and loved. However, both were required to reside at Homai, the special school, for their secondary education. They then encountered educational services that were culturally dissonant. Tommy didn’t have the right to have private discussions with his whānau and Elizabeth stated that Homai was Pākehā and that Māori lost their mana (status/power). Tommy was eventually expelled because of suspected drug and alcohol use, and did not return to school. He felt unsupported at Homai, and said that, academically, he was succeeding but that he had reacted to the restrictions of the special boarding school.

Elizabeth resided at Homai because of her behaviour and not because of the need for vision support services. She was achieving at school and had been receiving vision support services, but she felt different from her peers at the local English speaking intermediate, which she attended after kura kaupapa. The Pākehā culture and the limitations at Homai were thought to

be of more benefit to her than the local school near her whānau and in her own community. Elizabeth's story and other stories, such as Ngaio's fifty years earlier, in this study speak about cultural assimilation at school, and not about the Treaty of Waitangi, social equity and justice, and Māori aspirations to be Māori and self-determining. Elizabeth received support from Ngāti Kāpo O Aotearoa for a successful adjustment to university, and she loved the way that they provided services because they "only catered for Māori". She strongly advocated for kāpo Māori to be able to speak up for themselves and their rights. She noted that she was only blind in one sense, and that her spirit was not and she could see in other ways.

Kahu and Kapua Kore were kāpo youth with additional impairments. Both were attending their local school, and both were firmly grounded in their whānau and culture. Kahu's parents wanted te reo Māori to be his first language but this was difficult because he was in hospital for several months after his birth and the nurses and doctors spoke to him in English. His whānau only spoke Māori to him though and he did become bilingual. His health remained fragile and the whānau had twenty-seven different health and education providers visit them over the years, and most were Pākehā service providers or professionals. Members of his large whānau purposely became his education support workers and teacher aides. Kahu's whānau were determined that his cultural well-being, and his whole being, was always considered by health and education services. This included his kura kaupapa, where he was invisible as being kāpo. His mother, in the end, withdrew him from the kura because they would not accept English-speaking teachers at the school and there were no vision education support teachers who spoke Māori. However, the next school he attended was inclusive. Kahu's principal was Māori, the school was flexible, support services were available and his mother was able to choose his teacher aide. Overall, though, Kahu's mother felt that there has not been enough educational support for Kahu because of his other impairments, which instead become the focus. For example, presently, the whānau and health services are focusing on enabling Kahu to walk. Kahu's whānau hope, like other whānau, that given his tenacity and spirit, that he will be able to do anything that he chooses to do in his life.

Kapua Kore's future aspirations were linked to her whānau. She wanted to do mirimiri (massage) for a living because of her desire to please and nurture her whānau, and especially her grandfather, and she had musical talent like her father. Other members of her whānau were also kāpo, and she accepted this whakapapa. She received education support services and attended her local secondary school, which had a 'special needs' unit. Her education was thus not always inclusive. She was worried that her teacher aide did not know Braille and subsequently would be unable to support her in class. She was hit and bullied at school, and said that her teachers did not support her. Her whānau was also struggling to have her brother's learning needs met as a kāpo Māori child. It was difficult for the sighted members of Kapua Kore's whānau to accept her difficulties. However, recently Kapua Kore's whānau have become members of Ngāti Kāpo and have benefited from sharing their experiences with other kāpo Māori and their whānau.

Marama and Cathy were the youngest participants in this study and were bright lights in their whānau. Their whānau hoped that they would have promising futures, and grow up strong and healthy in their own communities. Marama lived in the city and her parents had less contact with Māori culture, but her grandfather, whom she often visited, was a native speaker of te reo Māori and his Māori identity was very strong. Cathy was growing up in a Māori community and with her extended whānau, including great grandparents. There was always someone there to lend her, and her parents, a helping hand. They were involved in marae

activities and te reo Māori was spoken around Cathy. Her grandmother was also a kaiako (teacher) at the local kōhanga reo, and she wanted Māori to teach Cathy. Interestingly, her grandmother believed that Cathy would not get the support that she needed at the kōhanga because she was kāpo, so she taught Cathy, herself, at home.

Education and health services for Marama and Cathy were thus ‘variable’ in that they were not consistently available, accessible, timely, or relevant. Marama’s whānau needed to move from a rural area to better access health services because no one would respond to Marama’s call for help. Cathy’s whānau encountered a health service that was confusing and, at times, irrelevant. They rarely had their questions answered and did not feel welcomed or included. In regards to education, Marama was happily included at school. However, Cathy’s whānau were struggling with professionals who talked past them and the fact that Cathy and her parents may need to relocate in order to receive relevant educational support services. Like other whānau, they could not rely on a health and education system that would support their child in her own community and with her entire whānau.

The results of this project echo the academic literature that underpinned this study. Traditional Māori literature spoke about strong and knowledgeable kāpo Māori, but the most recent literature spoke about marginalisation, exclusion, invisibility, and ‘othering’ in that Māori and Māori with a disability are viewed as being deficient, different from others, and not ‘normal’. The statistical results of this study have indicated that kāpo Māori are not accessing ophthalmology services as they should, including children, and further attention to, or research on, this issue is necessary. The pro-active and positive policies of health and education services, which speak about the Treaty of Waitangi, human rights, and inclusion are not consistently being enacted. All members of New Zealand society, including Māori who happen to be kāpo, do not have equal access to health and education resources.

The stories in this study have indicated that kāpo Māori are ‘othered’ when there is little account taken of their culture or impairment when encountering health and education services. For our participants, this ‘othering’ caused pain, withdrawal, anger, despair, confusion, and also motivation to change such injustices through their involvement in Ngāti Kāpo O Aotearoa, where they could be firstly Māori, who then happen to be kāpo. Rangatahi told us that we should conclude our report with the statement that “it needs to change and be fixed.” Kaumātua have said that our findings are no surprise to them, and little has changed over our 80-year coverage of growing up kāpo Māori.

Certainly, health and education services need to become more culturally consonant so that Māori can maintain a strong identity as Māori. Also, vision health and education services need to be available. It is urgent that Māori health and education professionals (e.g. vision teachers, eye specialists, Māori researchers) be supported and encouraged to enter the field of disability, and that non-Māori professionals be committed to supporting the principles of the Treaty and Māori self-determination. They also need to be supported to become culturally aware and learn te reo Māori me ona tikanga. In general, timely and welcoming services that meet whānau needs should be available. However, this research has shown that whānau usually do get on with their lives even if there are barriers to accessing health and education services because of cultural dissonance, bureaucratic labyrinths, geographic location, or service unavailability.

We believe that in order for positive change to occur for kāpo Māori, there needs to be radical changes of systems, discourses, and beliefs, and not slow incremental changes, which

may be hardly noticeable and easy to reverse. Visionaries have challenged us to imagine a society where everyone is valued, and has opportunities to happily ‘grow up’ and reach their true and full potential. Poverty, racism, the immense gap between the rich and the poor, and the quality of life disparities between Pākehā and Māori as demonstrated in this report would not exist in such a society. Interestingly, each of us, no matter what political beliefs that we have, would probably aspire to such a society for our children, but the deep structures in our education and health services, economic system, traditions, history, and, perhaps, fear of difference seem to prevent these aspirations from becoming reality.

The vision that kāpo Māori have is that some day they will live in a society that includes, supports, and values them as Māori, who happen to be kāpo. Health and education services would be readily available, accessible, culturally consonant, and strengthen kāpo Māori identity and well-being. ‘Growing up kāpo Māori’ would be about growing up nurtured, and loved by whānau, who are in turn supported and valued by health and education services, and society in general.

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