MAORI CHILDREN WITH DISABILITIES: AN ANALYSIS FROM A CULTURAL PERSPECTIVE

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Janet Askew
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Abstract

This thesis explores a cultural perspective through the life stories told by the mothers of five Maori children who have a disability and relate with their tribal affiliations. The emphasis is on how culture, health, education and community support services have enabled Maori and disabilities to be addressed through a cultural perspective. From semi-structured interviews being carried out, the outcome recognises the importance of a strong whanau support system from the onset of the child's disability while adjustments were being put into place. Communication, trust, respect and personal power were important features within Maori culture that needed to be set in place between Maori and the services they were accessing to be more transparent in order to get the best care for their child who has a disability.

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CHAPTER ONE

INTRODUCTION

The government reflects the society we live in and as a result, groups that are misunderstood and that are deemed not to have economic value are pushed aside and minimal funding is allocated. Therefore, Maori and disability are two identities that are marginalised by society, even within their own community.

Mainstream services for health and education have been encouraged to provide services, which are likely to achieve good outcomes for Maori. In New Zealand, disability support services are funded under the umbrella of health. To access these services, people with disabilities have to be labelled under a medical model. Defining people with disabilities enables the assistance needed to access services and resources but it can also alienate and marginalised people with disabilities.

Maori identity has been socially constructed within whanau, and it has been socially constructed within the dominant society through social, economic and lifestyle characteristics, ecological and social influences. Such as, how people who have a disability are included and excluded differently within society than those people who do not have a disability.

Maori people have identified themselves primarily from within tribal structures, such as whanau, hapu, iwi, waka and mountain. Through these connections, the individual was able to maintain their sense of belonging through their whakapapa and cultural practices such as language, customs, whanau/tribal obligations and traditions.

My rationale for exploring life stories around Maori children who have a disability and a Maori culture perspective centres on my own identity as part Maori because of my ancestral ties to Ngati Porou and Ngati Kahungungu and my son's cognitive disability 'verbal dyspraxia'. However, my Maori identity and culture have only recently surfaced through educational studies around Maoritanga. I therefore wanted to explore the relationships, identity, culture, health and education services affecting families who have a child with a disability. Through my participants tribal affiliations, I wanted to explore the importance of culture around a child who had a disability. There were four aims I set out to achieve. Firstly, how did families interpret their child's disability and disability itself? In particular was it a gift or an obstacle, and if so, to whom and to what. Secondly, how proactive are families within culture and with managing special needs? Thirdly, what role do families perceive the community has towards supporting the wellbeing of children who have a disability? Lastly, how important is culture, when implementing programmes/incentives for children who have a disability?

Outline of Chapters

Chapter two begins by looking at the theories used to discuss Maori and disabilities, in particular Maori and child disabilities. Maori concepts of disability, wellness, spirituality and individual levels of personality, as well as children as 'taonga' are seen from a Maori perspective. This is followed by how Maori children who have a disability are supported through community services, such as through social policies levels, extended whanau role, funding, resources and service providers that ensure Maori cultural safety and how children who have a disability can get better access within the communities, health and education environments.

Chapter three focuses on the methodology of my research. This covers aspects such as ethics, confidentiality, procedure, participants, data analysis and qualitative research. It is important to note that the use of qualitative research has its value in the analysis of people's thoughts and feelings. While it is also interesting to note statistics, the importance of the statistical comparisons in this qualitative research is limited, and is outweighed by the importance of individual thought and feeling. There are two appendices: (1) identifies the research proposal, and (2) the Ethics Approval document

Chapter four presents the life stories of five whanau told by their mothers who participated in this research. The names of the children who have a disability have been given pseudonyms, to protect the whanau from identification. All references to other members within the whanau and extended whanau are referred to as their role they play within the child's life.

Both negative and positive effects will be explored in this chapter. Issues that will be considered include how a child who has a disability is supported within the whanau, culture and social services. Areas of discourse or discovery will be covered with the micro and macro environments through health, education and communities.

Chapter five discusses themes that that have been drawn out of my interviews by comparing and contrasting particular events around culture and disability. As a result, four themes emerged from the findings; culture, health and disabilities, education and disabilities and communities and support themes have been outlined, discussed, and analysed.

Chapter six covers what has been achieved through listening to the stories centred on Maori children who have a disability, aged between 7-14 years of aged who live within the Christchurch suburbs. It then summarises this and concludes the thesis. It draws attention to the findings and the subsequent results, which define the purpose of the work.

There is also a glossary at the end of the document. This outlines terms and abbreviated symbols. Terms that are included in the glossary are Maori vocabulary, Support Services, types of disabilities identified in this research and Special Education Services funding and their meaning.

The purpose of the thesis is to develop an argument that culture is very important when addressing children who have a disability.

CHAPTER TWO

LITERATURE REVIEW

Maori and Disability

Throughout my literature review research, I have found very little literature specifically referring to *Maori* children who have a disability. The research I found on the topic relates to health and education, in particular, special education for Maori children, which has appeared recently or during the last twenty years. Reasons for the lack of information about Maori children and education may be due to how Maori are placed within New Zealand society, and the social policies that are in place. These factors affect Maori and Maori children with a disability, within health services, education and within the community in which they live.

Defining Maori Historically

Prior to the 1840s, Maori were considered 'normal' and the colonisers were considered 'different'. This is reflected in te reo (language) where Maori means ordinary or normal in contrast to the Pakeha as different (Williams, 1971:179). History shows, after the signing of the Treaty of Waitangi and the declining population of Maori through health, diseases and through land wars, Maori became a minority and were termed 'different' by the colonisers who became the dominant society (Durie, 1994). Furthermore, Maori went through an assimilation process that saw Maori displaced from their land, culture and language. As well as Maori socio-economic status changes, alcohol, drugs and tobacco were introduced (Kingi, 2000:11). Over time, Maori identity changed from tribal traditions because of environmental, economic and social influences and due to migration from rural areas into urban areas for economic, social and lifestyle changes. The latter affected their demographic patterns, cultural beliefs and technological advancement (Durie, Black, Christensen, Durie, Taiapa, Potaka, Fitzgerald, 1995:1-6)

For statistical purposes in the 1986 census, self-identification was the method used to determine ethnic identity. By 1991, the census related Maori identity through tribal links. For example, 579,714 reported descent from a Maori while 523,371 identified as ethnically Maori. According to Durie, (1994) vital statistics remained based on the biological concept of race, such as data gathering by the health sector and funeral directors, which resulted in under-reporting of Maori. The difficulty may be in the methods of reporting data, as well as self-identification. There is no single Maori defining characteristic, and statistics do differ due to errors in data collecting in which Maori are under-reported within the health, education, social, political and economic sectors. (Durie, 1994:124-125)

The New Zealand Disability Strategy

The Treaty of Waitangi is New Zealand's founding document and the Government is committed to fulfilling its obligations as a Treaty partner to Maori. The New Zealand Disability Strategy enabled Maori to play an active part in defining and providing information regarding what Maori identify as important to their communities (Ministry of Health, 2001:5). Research carried out by Ratima, et al (1995) identified a framework for the delivery of Disability Support Services for Maori within mainstream disability services. It elaborates the service implication and provides measurable indicators. That framework has been created from Maori sources and may be implemented for use by other Crown agencies.

Maori and Social Policies

Maori are often under-represented at government level when policies are being made that affect Maori. Treaty based obligations or rights throughout government agencies have not been effective at empowering Maori within social policy decision-making according to the National Health Committee (Ministry of Health, 2002). A step towards promoting health and wellbeing among Maori would be the acknowledgement of, and referral to, the Treaty of Waitangi as the founding document of New Zealand. There should be encouragement for Maori and non-Maori in key positions to work together in partnership, promoting and improving Maori health (Ratima et al, 1995:60).

The three Treaty principles identified by the Royal Commission on Social Policy and cited by the National Health Committee (Ministry of Health, 2002) are, partnership, participation and active protection. These have been discussed and acknowledged in policy documents, but they have not been implemented as a formal framework. The National Health Committee believes that the Treaty principles will be an effective framework for improving Maori health policy (Ministry of Health, 2002:22).

The Government's commitment to the Treaty of Waitangi and to fulfilling its obligations as a Treaty partner, have recently resulted in research addressing culturally appropriate services for Maori within the social services. The Maori Disability Action Plan (MDAP) aims to meet the needs and objectives of Maori who have a disability, by means of planning, developing and funding, through Disability Support Services (DSS) (Ministry of Health, 2002:31).

Disability Support Services to Maori

Disability Support Services (DSS) take a long-term view of supporting a person who has a disability by meeting practical needs through support structures, processes and resources organised around the individual. These needs are met by Government funding, and within the child's local community, through the work of family, friends and other unpaid supports (District Health Boards, 2002:24).

According to the District Health Boards (2002:24.) report, Disability Support Services for Maori who have a disability gave limited access to health care. The funding that is split between Maori and non-Maori for health was not adequate for Maori because it did not take into account the Maori holistic view towards health. Therefore, Maori need more control over funding to meet their needs.

Even though the cost of disability is high for Maori, Ratima, et al., argue that 'cultural alienation' should not inhibit Maori accessing disability support services. Instead, working in partnership, providers of services to Maori should be equipped to meet the needs of Maori within the mainstream, but, also Maori be allowed the opportunity to participate in Maori society, belong to Maori institutions and to remain Maori (Ratima et al, 1995:72).

The principle of 'normalisation' argues that people with disabilities have the right to live normal lives. According to this view, normalisation demands that people who have a disability will develop skills and opportunities like anyone else. Meanwhile, the 'social role valorisation' theory has further argued that people with disabilities should have social roles that are seen positively by the public. It encourages organisations for people with disabilities to focus on enhancing both the image and skills of the group it serves, so they can be equal and participating members of their own communities (Fitzgerald, 1996:148).

Definitions of Disability

The definition of disability given by the Ministry of Health and cited in Fitzgerald (1996:148) has been stated as:

> *"...an intellectual, psychiatric, physical, sensory or age related disability which is likely to last longer than six months and results in a loss of independent function to the extent that ongoing support is required".*

Durie (1994:78) presents a Maori definition for health and disability as:

> *"The Maori definition of health is essentially holistic. The wellbeing of an individual is dependent not only upon the absence of illness, but also historical, social, cultural, economic, political and environmental circumstance".*

Moreover, the wellbeing of Maori is based on the four walls of a house: identified by Durie as,

> *'taha wairua – the spiritual side; taha hinengaro – thoughts and feelings; taha tinana – the physical side; and taha whanau – the family'. Each of the walls is necessary to ensure strength and stability within the individual (Durie, 1994:70).*

Maori holistic views concerning health give importance to culture, respect and the spiritual dimensions.

Cultural Definition

Members who belong to a cultural group define culture through social construction by interpretations, beliefs, the meaning given to things, and judgements made towards what is important and right, "Manners, traditions, customs, language, history and art all define culture" (Fitzgerald, 1996:147).

It is important to recognise the role of cultural identity in exploring the experiences of disability. Hine Tihi and Ruth Gerzon (1994), argue the importance of acknowledging the way that Maori people have been constructed when dealing with disabilities among Maori. "Not recognising the importance of whanau [family], whenua [land], wairua [spirituality] and te reo [language] marginalised Maori" (Tihi and Gerzon (1994) cited in Ballard, 1994:117).

Definition of Respect

The definition of respect identified by Ratima, et al., really gives meaning to how Maori culture and self-identification can be supported by non-Maori professionals who are willing to work in partnership with Maori while respecting the cultural differences.

> *"... respect is expanded to include the provision of opportunity for clients to develop abilities related to being Maori, a community focused approach emphasises the importance of developing links with Maori institutions such as marae and the Maori Women's Welfare League, and, workforce profiles acknowledge the importance of cultural qualified health workers who have a sound knowledge and practical understanding of tikanga Maori and te reo Maori" (Ratima, et al., 1995:61).*

The Importance of the Spiritual Dimension

Spirituality has always played an important function in Maori life and is a connected part of Maori society. Bevan-Brown cited in Rymarczyk Hyde (2001:3) identifies the two strands to spirituality as "service to others" (manaakitanga) and "Mana Tangata" through self-esteem and being valued by others.

In a Maori contextual framework, 'Maoritanga' spirituality is incorporated and is manifested through whanau and within Maori communities through manaaki, tiaki, awhi, and aroha. This coupled with Webber (1996) 'Poutama' (staircase design) inherent in the woven tukutuku panels which represents the six levels of personality that can be achievement by knowledge and the challenges faced at each stage of a person's journey to gain intellectual, physical, emotional, social, spiritual and cultural meaning. Raising a child who has a disability definitely challenges the six steps of ones personality, and in most cases in a positive light.

Whanau

Kaupapa Maori research draws from the strength of whanaungatanga, or networking through whanau, hapu and iwi relationships. From a holistic, Maori perspective, a sense of identity for Maori is not about the self-alone. As Durie (1986) suggests, "you are not healthy if you are alone; the whanau or the family of origin, the hapu or sub tribe, the iwi or tribe and the waka or canoe must be present for real health" (Durie, 1986:57). According to Durie cited in Davis (2001), Maori individuals have a range of cultural characteristics, and exist in a number of cultural and socio-economic realities, in that, traditional values are not the same for all Maori, nor do Maori define their ethnic identity according to traditional constructs (Davis, 2001:34). Within Maori culture, ties of aroha and a sense of commitment, bind whanau members to each other, providing financial and moral support to each other (Davis, 2001:24)

According to Davis (2001), Maori children are valued as "taonga" and are valued as unique individuals who belong to the whanau and therefore manaaki (cared for) by the whanau (Davis, 2001:24). When it comes to caring for Maori children in hospital, or during a crisis, patients and families look towards nurses to support them. Cultural safety in nursing education emerged during 1986, and in 1988, a model was negotiated towards an equal partnership in nursing education in matters of cultural safety (Durie, 1994:115). The aim of cultural safety was to educate nurses to examine their own cultural realities in order to be flexible and open to other cultures. For example, in order to assist Maori, nurses needed hands on experiences and learning within a Maori environment. The outcome of this would ensure nurses had a better understanding of Maori rights and knowledge, and the appropriate introduction to Maoritanga would make certain that values and actions were in line with Treaty obligations (Durie, 1994:185).

There has been little information available to professionals, on how whanau who have a child with a disability interact with helping services and agencies or on how to understand the concept on which the whanau is grounded. The word whanau means extended families across several generations and configurations. It is grounded within the hapu and the iwi.

The traditional concept of whanau and the place of the individual is the starting point for the research of Wilkie, et al (2001). The parents and extended whanau were approached to speak on behalf of the children who were not able to speak for themselves. The findings identified whanau as being the main pillar supporting children with special educational needs. It identified the difficulties faced by whanau trying to find and access help and support, such as specialist services and appropriate specialist or mainstream schools. Whanau who were supported within their community (Tangata Whenua) were more likely than those whanau living away, to have better access to support networks and services (Wilkie, et al, 2001:6).

Ballard (1994) highlights the importance of hearing the stories of people with disabilities in order to understand how their daily-lived experiences are constructed by information and controls within a society.

Extended Family Role

Researchers Mirfin-Veitch, Bray and Watson (1996) studied grandparents as informal support sources for families of children who have a disability, and found grandparents' support was frequent and highly valued by most families, except for parent-grandparent relationships that were hindered by past influences or conflict. The child's disability proved to be irrelevant to the issue of practical and emotional support that grandparents gave to families of children with disabilities (Mirfin-Veitch, Bray and Watson, 1996:136).

Shared Care Programmes

Researchers Riley & O'Brien (1998) recognised the importance of matching the natural and care giving families with lifestyle expectations, family values and social interests, during shared care programmes (Riley & O'Brien, 1998:99). These programmes, ensure that parents are able to have 'time out' from their family while a care giver looks after the child who has a disability and gives them the opportunity to interact with others outside their home environment. In some cases, the family caregiver may be someone from the extended family or an older sibling. In other cases, extended family and older siblings may also take on the role of respite care.

Maori Perspective of Health and Disability

The focus of research by Kingi et al., (2000) into Maori disability within the health sector, was to establish whether Maori viewed disability, or the concept of disability, differently. The research identified that Tangata Whenua needs were met inadequately because Maori concepts were different from those of non-Maori culture. Maori concepts of disability are not recognised or given any priority. For example, if the on-going effects of colonisation and its effects on the health, economic and social status of Tangata Whenua were to change, then Tangata Whenua would manage their own initiatives, and develop their own services by choosing from mainstream or kaupapa Tangata Whenua services for support to people with disabilities and their whanau (Kingi, et al., 2000:26).

A research carried out by Ratima, et al., (1995) looked at a draft framework and philosophy for disability support services for Maori. They argued service providers need to take into consideration the diverse realities of Maori people, and that this be reflected in the service options available, such as an option to use mainstream or Maori alternatives according to their needs. In order for Maori to feel comfortable and have better outcomes to services that operate with a Maori cultural content, they should be, "friendly, maintaining strong links to Maori institutions, informal Maori networks, conversant in tikanga Maori and Te Reo Maori" (Ratima et al, 1995:73).

There is a broad range of Maori health providers operating from both Iwi and community perspectives. Individuals who identify as Maori can access Maori networks and provide suitable individual services to Maori, which may not have been supplied within the mainstream health regime. In particular, Durie notes that primary health care and disability support should be consistent in regards to "well-child care, whanau services including preventative care, primary medical care, early intervention, rehabilitation and community care" (1994:185).

Health Barriers

Some of the main reasons why Maori who have a disability do not access Disability Support Services (DSS) as much as non-Maori, is that Maori view health and disability in a holistic way, and that there are barriers preventing DSS providers meeting their cultural needs, and also Maori expectations of DSS not being effective (Ministry of Health, 2002:31). The National Heath Committee identified five barriers that hinder the achievement of positive outcomes for Maori health. Firstly, limited Treaty based obligations or rights to ensure positive Maori health outcomes. Secondly, no clear framework to benefit Maori. Thirdly, having an all-inclusive strategy did not include health policies effective to Maori. Fourthly, lack of consistent openness and management between government and the service agencies did not help outcomes for Maori health. Lastly, some geographic regions constrained Maori health development because of unclear minimum expectations (Ministry of Health, 2002:16).

The Ministry of Health (2001:7) describes a perspective on people who have a disability, and the barriers they face daily as,

> *"Disability is not something individuals have. What individuals have are impairments. Disability is the process which happens when one group of people create barriers by exclusion from their way of living, where no allowance is made for impairments. Disability relates to the interaction between the person with the impairment and their social environment" (Ministry of Health, 2001:7).*

In general, one in five people in New Zealand have a long-term impairment. Society is comprised of people from diverse backgrounds, who hold different beliefs and have many different needs, and so too among people who have impairments, there is great diversity. Certain types of attitudes are major barriers that operate at all levels. Judgemental and stereotyping attitudes and ignorance are revealed as stigma, prejudice and discrimination. In June 1999, disability discrimination was the largest category of complaints to the Human Rights Commission (Health Funding Authority, 1999:10).

These attitudes are the cause of why barriers are put into place. Identifying as Maori and having a disability is a double burden when dealing with the 'system'.

Durie, (1998:29) argues that Maori people have the right to be Maori, which means not only choosing to identify as Maori, but also having access to the Maori world. Maori are as diverse as any other group and live in a variety of situations. Therefore stereotyping them will not see Maori as staying fixed, because Maori are always changing between Maori and non-Maori mediums.

Government agencies provide a range of services; however, accesses to these services are not flexible enough to meet individual needs. There is some difficulty in establishing a personal relationship with key agencies when the turnover of staff is quite frequent. Parents and caregivers always feel they are battling a system, rather than coordinating as members of a partnership who have the common goal of ensuring that the needs of a child who has a disability are met. For example, difficulties can arise when accessing a benefit or trying to obtain a piece of equipment; a story may have to be told many times (Ministry of Health, 2001:12).

People in higher socio-economic areas are more likely to successfully access and receive support services than people in low socio-economic areas. This pattern is reflected by the fact that Maori are typically low users of support services. The majority of support for everyday activities comes from families. As a group, disabled people are likely to have lower incomes and fewer financial and family resources than the general population. This economic disadvantage is compounded by the financial cost of a disability. The earning potential of families with children who have a disability can be restricted by their need to provide support for their children or to live and work in areas where they have access to family or professional support (Ministry of Health, 2001:11).

In April 2001, government initiatives towards the New Zealand Disability Strategy under the New Zealand Public Health and Disability Act

2000 identified fifteen objectives to ensure the removal of barriers faced by disabled people so that they would be able to participate in an inclusive society. Objectives 11, 13 and 15 are directed at promoting opportunities for Maori to participate in their communities and to accessing disability services. This will enable children and youth who have a disability to recognise their emerging identities as individuals and to reinforce their sense of self, to enable self-reliance, towards important links within family, friends and school. Opportunities for active participation within the community and acknowledgement through ongoing support towards the values of families and whanau must be provided (Ministry of Health, 2001:21 and 23).

Maori and Disability Research

Major works on disability specifically concerning Maori disability in general are rare in New Zealand. Two studies that focus on Maori participants and their intimate stories of families who care for children who have a disability have been covered by Ballard (1994); and Wilkie, Berryman, Himona and Paul (2001). Ballard covered first and second-hand accounts of the thoughts and experiences of caregivers of children with intellectual disabilities. Meanwhile, Wilkie, et al explored Special Education for Maori (Matauranga Motuhake), the experiences of Maori families with children who have special needs, and their ability to be supported by the social systems and people within their community.

Disability, Family, Whanau and Society

Ballard's (1994) research on disability, family, whanau and society covered both Maori and non-Maori experiences of having a child with a disability that focused on infants or young children and issues between parents and 'the system'.

Sonntag's theme (1994, cited in Ballard, 1994:185) was based on women involved in unpaid twenty-four hour, seven-days-a-week care giving. She discusses the experiences of fourteen other such mothers and their problems with a mix of her own experiences as an isolated mother of a child who is intellectually disabled. Their experiences spanned sixty years from the 1920s to the 1980s. She examined historical accounts of organised networks and pressure groups during the 1940s and 1950s that were requesting more funding for state support for home caregivers.

This resulted in children who were intellectually disabled being taken into residential institutions and segregated from their parents. Today most people with an intellectual disability reside within their community. However, caregivers face the same problems. They fight for respite care, for suitable education, for community acceptance, for sound professional advice, and support and adequate information from government departments that are responsible for children with intellectual disabilities, but the claims for these children are not well accepted. She also brings to light that all these women whom were care givers, were unpaid-round-the-clock carers (Sonntag, 1994, cited in Ballard, 1994:185).

Meanwhile, Brown (1994) cited in Ballard (1994:231) discusses the ethics of inclusion and organised parent advocacy that was required to pressure the educational system into accepting children who have a disability into mainstream schools. She states that

> *"the use of the word 'special' limits the inclusion of children who have a disability, and the word can have negative affects on their families. 'Special' is seen as negative, whereas all children should be considered special, with particular needs and with those needs being addressed creatively".*

In addition, Brown criticised the parent-professional partnership within special education, where some professionals acted as gatekeepers. By cutting parents down and not listening to them, they did not validate the experience and advice that full time carers had to offer (1994:222-223).

Munford (1994) cited in Ballard 1994:265) identified the experience of female caregivers. In particular, she explored the caregivers' experience within structures of power at the micro, interpersonal level and at the macro level, where cultural definitions of normality are forged and welfare policies are put together and executed. The links between networks of power are a necessary part of the empowerment process, or in opposing needless intrusions upon the bodies and emotions of people who have disabilities.

Ballard (1994) concludes that people with disabilities and their caregivers, like women, Maori and gays, are the victims of discrimination and oppression. Using 'the social model', he regards disability as a form of oppression, focusing on disabling social structures and attitudes rather than the personal deficits of those who are impaired (Ballard, 1994:313).

Therefore, he suggests research into disability must be social action aimed at emancipation of the disabled. Caregivers, and people who have a disability, must set the agenda for such action to manage their resources, and to formulate policy for people who have a disability, rather than to allow 'able-bodied professional experts and politicians' to form policies for people with a disability (Ballard, 1994:313).

Education and Disability

People who have a disability in New Zealand are falling through the gaps because the existing services have 'vertical and horizontal gaps' according to Rab and Mako (1996:161) and because there is no national rehabilitation policy, people are being left without treatment or intervention; (Rab and Mako, 1996:167). Conductive Education is one such organisation that falls outside the gaps because the Heath Funding Board does not fund it. Conductive education is a successful organisation for the people who do attend.

Conductive Education is based on a philosophy that motor disabilities are a learning difficulty that can be overcome by teaching and it challenges traditional approaches to rehabilitation (Rab and Mako, 1996:161). The aim of Conductive Education is for each child to achieve the ability to function as members of society and to participate in normal social settings appropriate to their age by becoming physically independent. Groups of children, who have similar motor-disorders, learn together under the instruction of one conductor. The group is used as a teaching tool in which school education is an integral part of the whole conductive process (Mintram, 1988:45 and 47).

Conductive Education is holistic in that it follows two principles; the professionals are holistic, and the programmes are designed to promote the development of the whole person through the recognition of the spirit (taha wairua), the thoughts, feelings, attitudes (taha hinengaro), the family (taha whanau) and the physical body (taha tinana) all being inseparably linked (Rab and Mako, 1996:167).

Special Education

Maori are the indigenous people of New Zealand. They make up approximately 15 percent of the New Zealand population and are over-represented amongst learners receiving Special Education according to Bevan-Brown (2000), who identifies some of the barriers to providing culturally appropriate, effective special education services to Maori. Maori children are unduly represented in low decile schools (that is, those situated in poorer areas), which have limited resources to provide specialised equipment and programmes.

In recent years, research with information on Maori and special needs have become known. Reports with ethnicity data and statistics appear to show a disparity between Maori and other ethnic groups within New Zealand. The Ministry of Health disability survey shows a clear over-representation of Maori children. When socio-demographic variables were adjusted, Maori were over-represented by a factor of 35 percent among children with a disability (Ministry of Health, 1999b cited in Wilkie, et al., 2000).

Statistics show that within education, Maori are over-represented in indicators of special educational needs. Policy-making processes in New Zealand have not generally been inclusive of Maori, so that, while policy may claim to be based on a philosophy of inclusion, it is more likely to have been developed outside a kaupapa Maori and without due regard to the Treaty of Waitangi.

The research by Wilkie, et al., (2000) on special education identified the lack of any substantial research in areas of importance to Maori, for example, special education, as part of the Ministry of Education's ongoing evaluation and development of Special Education 2000 policy, in a report in 1999 entitled, "So – What's So Special about Special Education for Maori?" Wilkie suggests from the title, Maori were not included in policy development, because the Maori concept of whanau playing a vital role in supporting special needs children was not included.

Two findings emerged out of their research that identified the holistic perspective towards individual and education: Maori perceive all children to be special, not just those requiring special education funding and Maori resisted labelling children in order to get funds because of the negative implications of labelling (Wilkie, et al., 2000:7-8).

Within the whanau, the children are accepted and naturally integrated into their schools and communities. Finding access to services and support that enabled their children to be mainstreamed relied mainly on word of mouth and the general knowledge within whanau networks. If the information about resources and support around special educational needs were easily accessible to whanau, it would ensure everyone was on an even keel to achieve the best outcomes for their child (Wilkie, et al., 2000:7-8.).

An estimated 7 percent of children with a disability aged five years and over reported that they had not always been able to enrol at the school of their choice. Reasons for this included, zoning restrictions, the school being unwelcoming, special services or equipment not being available and financial reasons (Statistics New Zealand, 2002:3).

Barriers for Maori within Education

With the introduction of the 1996 Special Education Policy (SE2000) Bevan-Brown, has been investigating the sufficiency of special educational services offered to Maori learners who have special needs, for the past three years. The top five barriers identified by principals, teachers and teacher aides were:

> *"... financial hardship of parents and whanau (extended family); low parental expectations; lack of parental support and involvement; shortage of teachers and special educational professionals with Maori language and cultural knowledge; and insufficient funding from Government" (Bevan-Brown, 2001:148-149).*

Meanwhile, the analysis that emerged out of the research revealed another five barriers, which she identified:

> *"... negative and stereotypical attitudes towards Maori children, their parents and families; low teacher expectations of Maori children; school personnel not recognising the importance of culture in the provisions of programmes and services for Maori children; Principals believing culturally appropriate services need only be provided where there are large number of Maori students; and school personnel blaming parents for their children's special needs" (Bevan-Brown, 2001:148-149.).*

Bevan-Brown then presents the 15 more barriers that hinder effective, culturally appropriate special education services for Maori as:

> *"... differing cultural concepts of special needs; differing cultural concepts, beliefs and worldviews in general; differing cultural values, attitudes, norms, customs, experiences, skills, knowledge and practise; differing language and cognitive structures including differing dialects, language patterns and body language; unequal power relationships; use of ethnocentric assessment measures and procedures; programmes and services based on majority culture values; differing learning styles not being accommodated; cultural practices that affect school attendance; cultural practices that mitigate against school learning; shortage of culturally appropriate teaching resources; shortage of culturally appropriate role models and mentors; unreliable ethnic identifications, culturally inappropriate methods of communication; and transience and absenteeism" (Bevan-Brown, 2001:148-149).*

According to Durie (1995 cited in Bevan-Brown, 1999:1), if Special Education 2000 policy and initiatives are to address Maori SES needs, the 'diverse Maori realities' need to be considered because Maori learners with special needs are not a homogeneous group. They come from different geographical areas, socio-economic circumstances, hapu and iwi. In addition, Maori learners are scattered throughout all educational settings.

Statistics of Children Who Have a Disability

According to a published report by Statistics New Zealand (2002), which discussed the 2001 Statistics report on disability, identified 11 percent of all children (0 to 14 years) had a disability and were living in private households. For this age group, boys were more likely (13 percent) than girls (9 percent) to have a disability. Of the children identified as disabled in this survey, 41 percent had a disability that existed from birth, whereas, 33 percent reported a disability caused by a disease or illness, 3 percent by an accident or injury and 19 percent by 'other' causes (Statistics New Zealand, 2002:1).

The 'other' category, indicated that 58 percent of disabled children (52,000) may have more than one disability, such as a speech impairment, learning and developmental difficulties, which needed special education intervention. Moreover, 17 percent of children who have a disability had an unsatisfied need for some type of health service. Chronic health problems and sensory disabilities (30,000) were identified as common types of disability for children (Statistics New Zealand, 2002:2).

Within each age group, the disability rates for Maori were higher than the national rates. The disability rate for Maori children was 15 percent, which was higher than the national rate for all children (11 percent) (Statistics New Zealand, 2002:2).

One of the difficulties of collecting data on Maori within the health sector, who have a disability, according to Pomare et al (cited in Ratima et al 1995:63), was that data collected from hospital admissions does not classify ethnicity. In addition, statistics do not show a breakdown of the number, nor type of disability, which Maori children have been identified as having. The statistics from the screening of school new entrants in 1991-1992 identified 15.2% of the Maori children had hearing problems compared to 10% of non-Maori children.

Meanwhile, Statistics New Zealand (2001:1) identified 3,700 (4 percent) of physically disabled children (0-14 years) living in households, had the use of special equipment for their physical disability. Approximately 1,100 children with physical disabilities had an unsatisfied need for equipment to help with standing or moving around. One of the most common reasons for equipment needs not being met was that it was too costly or they could not afford it.

Summary

There is a limited amount of literature available on the subject of Maori children who have a disability that explores how concepts of disability are seen by Maori, or by mothers who care for a child with a disability and who have tribal affiliations to Maori.

Maori concept of disability extends beyond individual disability, but is also historically associated back to the signing of the Treaty of Waitangi where Maori were disabled through colonisation and by such things as concepts of socio-economic status, and the introduction of alcohol, drugs and tobacco. Furthermore, the social changes saw Maori displaced from their land, culture and language. The dismantling of tribal traditions and whanau due to migration, from rural areas into urban areas for economic, social and lifestyle reasons were disabling for Maori communities.

Literature discussion concerning cultural alienation and normalisation tries to address the matter of individual choice regarding accessing disability support services within Maori or non-Maori mediums. It shows that individuals, in choosing the way they want to live normal lives differed according to Maori and non-Maori perspectives of Health and Disability. Maori concepts of disability were not recognised, or given any priority to have them addressed holistically. Non-Maori use the 'medical model' that looks at the illness and the methodology of treating the impairment. On the other hand, Maori have a holistic view of disability. Maori holistic views of health include the important factors of culture, respect and the spiritual dimensions.

Maori frameworks of discussion about health considered holistic, spiritual, whanau and individual personality viewpoints. Firstly, the holistic approach for Maori health was dependant upon historical, social, cultural, economic, political and environmental circumstances being acknowledged, and was focused upon the cultural aspirations and needs of Maori. Examples were shown of attempts to implement culturally sensitive policies.

Secondly, using a Maori contextual framework, 'Maoritanga' incorporates spirituality. Spirituality comprises two strands, "service to others" (manaakitanga), and self-esteem and being valued by others (mana tangata). This is manifested within whanau and Maori communities by manaaki, tiaki, awhi and aroha. Within Maori culture, ties of aroha and a sense of commitment, bind whanau through financial and moral support.

Lastly, 'Poutama' (staircase design), inherent in the woven tukutuku panels represents the six levels of personality that can be achieved by knowledge, and the challenges faced at each stage of a person's journey, to gain intellectual, physical, emotional, social, spiritual and cultural meaning. All Maori children are seen and valued as 'taonga', whereby they are valued as unique individuals, and cared for by whanau. Education and resocialisation within a Maori setting, has enabled people from non-Maori mediums (such as health providers) to have a better understanding of cultural safety consistent with Treaty obligations.

Whanau, Extended Whanau and 'shared care' were seen as important pillars supporting a child who has a disability. Better access to support networks and services were easier to access if whanau lived within the community. Those living away from their whanau and extended whanau took longer to access support networks.

Some efforts have been made to incorporate Maori concepts of disability within social policies, but they have not been enough to raise Maori in to key positions to work in partnership with non-Maori. However, attempts to incorporate the three Treaty principles; partnership, participation and active protection, has seen research being done to address the need for culturally appropriate services for Maori within social services, through Disability Support Services. The funding within Disability Support Services is divided equally between Maori and Non-Maori, but it does not adequately meet Maori needs because it does not accommodate Maori holistic views regarding health.

Options of whether to use non-Maori health services (mainstream) or Maori service providers (Iwi and community based), was left to individual choice because of the diverse realities of Maori.

Statistics gathered on Maori in general are difficult to interpret because of the way data are collected, and because of variable methods of ethnic and tribal identification. Therefore, it has been argued, that, Maori were under-reported within health, education, social, political and economic statistics.

The difficulty for Maori accessing health services for their child's disability is that there are health barriers preventing Disability Support Services providers meeting Maori needs and therefore, they are less effective in meeting Maori expectations. This occurs at policy level because of several factors, including people's attitudes, the diversity of Maori and high turnover of support staff. There are further problems because of fragmented and inflexible systems, differences in individual ethnic identification, and difficulty of access to resources and limited choices of health services.

Maori and disability research have been discussed through the thoughts and experiences caregivers faced when dealing with Disability Support Services and Mental Health in regards to differing conflicts such as caregivers and funding; residential institutions and communities homes; parent advocacy; parent-professional partnership within special education; and experiences of female caregivers. Furthermore, the two theories 'social model' and 'social action' have been identified. Under the 'social model', Maori who have a disability are victims of discrimination and oppression whereas the 'social action' model is aimed at emancipation of the disabled.

Studies in the areas of education and disability have identified how some Maori people, who have a disability, were missing out in assistance and not accessing treatment or intervention for their child. Conductive Education is an example of a service that is not funded under the Health Funding Authority, even though it has proven to be a successful organisation for the people who attend this facility.

The literature shows that within Special education, Maori are over represented as learners receiving special education. Barriers to learning have been identified and a lack of research in areas that Maori identify as being important, contribute to the problem.

CHAPTER THREE

METHODOLOGY

This chapter discusses how I went about my research, the people I met, the process I went through and the participants, who volunteered their time in order to tell their stories of raising a child who has a disability.

The First Development

My initial contact at the start of my research was made via an e-mail referring me to the Whanau Worker who organised the Whanau Support Group at CCS. CCS has a database of 50 whanau members whose children have a disability. I telephoned the Whanau Worker at CCS, and discussed my research and stated the requirements of my study. Because of my initial contact with the Whanau Worker, he suggested that he knew a few families who might consider participating in my research. First, he had to ask his immediate supervisor for approval to access volunteers. I received a response through an email from the Whanau Worker who informed me that CCS would not be involved in my research, but was happy for the Whanau Worker to send my Information Statement out with other CCS material prior to a pending monthly whanau meeting.

Later, I received an invitation to attend a whanau meeting at the CCS meeting room, in order to introduce my proposed research and myself. Prior to this meeting, the CCS Whanau Worker had sent a copy of my Information Sheet out to whanau members with other information.

Even though there was a small turn out (only one whanau and five members), the experience was beneficial. The meeting room was very large to cater for a number of people and people in wheel chairs. The Whanau support worker introduced me to the coordinator of the whanau support group, (who has a physical disability) and two kaumatua representing the CCS whanau group (a woman and her husband, a minister, who both belong to the Ratana Church).

The Whanau Worker opened the meeting at approximately 6.45 pm and invited the minister (whanau kaumatua) to say a karakia. This was followed by a group waiata. The whanau worker then went through the panui, and asked if I wanted to speak. I said to the group that perhaps I did not need to speak directly about my research proposal because the family in attendance was not in the age group of my research (their child being two and a half years of age) but I was happy to give my mihi. After all the mihi were said, the meeting went into general business. The minister said a closing karakia, and then a group waiata quickly followed at the closure of the meeting. The group then moved into the kitchen area for supper.

After the meeting, I was able to speak with both whanau kaumatua and was given their blessing and support towards carrying out my research. There were three outcomes from this meeting. Firstly, this meeting gave me the opportunity to meet the whanau group organisers, the two Kaumatua and whanau members. Secondly, the experience I gained at first hand within a setting outside my own familiar environment (the disability), speaking on my feet, carrying out a limited mihi in English; and lastly, I had the opportunity to introduce my research, by means of the mailed information, and myself, in person.

Attempts to Get More Participants

Part way through my research I was feeling concerned with only having three participant transcriptions done, and I considered that was not enough to fulfil my intended number of six participants. I decided to make school visits in search of students who would meet my criteria, in the hope of passing on an Information Sheet to the parents.

I contacted another participant through an introduction by a mutual friend. I rang my friend (whose work involved Kohanga Reo) asking her for a possible contact for my research. She gave me the name of a parent whom we thought might have been interested in participating. This participant initially agreed, but later withdrew after the initial meeting.

I visited a Secondary High school looking for potential participants and spoke to a receptionist who then contacted the Special Education Resource person, but there were no students who met my requirements.

I then decided to search for suitable candidates for my research using the telephone I contacted another four Secondary schools and spoke to people from various departments, receptionists, Assistant Principals, Principals and the Resource Education people. There was no one fitting my criteria but I received some suggestions that directed me towards the Mental Health System.

In an effort to contact more participants, I decided to take my Information Sheet and visit places where I knew children who have a disability would attend for education programmes. I spoke to the appropriate people to whom I was directed by reception or by the Special Unit itself. The following are the places I searched for further participants:

a. **Hospital for Children with a Disability**. I went to a hospital for children with a disability and spoke to a health professional about accessing their database for children who would meet my criteria. She identified a possible two children, but I was informed that this would have to be discussed first at their monthly meeting, and arranged to contact me after that. I left her with two Information Sheets to pass on, should approval be granted. She later informed me that approval had been given, and that two children met my criteria. She sent my Information Sheet out with a covering letter to the parents. Once again, I was unsuccessful at acquiring a research participant.

b. **Visual Impairment Centre**. I spoke to the teacher in charge of the unit, she suggested that there were a possible four people who may have met my criteria and so she agreed to pass the Information Sheets on to the parents. However, no parents volunteered to participate.

c. **School for the Hearing Impaired**. Reception put me in touch with the Resource teacher, who informed me that my Information Sheet was not quite correct. For deafness was not a physical or a cognitive problem, but rather, a sensory problem, the same as the blind and that I would have to revise the Information Sheet to reflect this before it went to the head Principal (who was presently away). She was very informative about the school, its history and that the children came from both the North Island and areas within the South Island, and she believed that some of these children's parents (eight families) might be interested in participating, subject to prior approval. I returned with the revised Information Statement and I eventually gained permission for the Resource teacher to send the information out. The outcome was that I did not gain any volunteers.

d. **Primary School**. Spoke to an Assistant Principal about possible access to participants for my research. She identified two families who met my criteria, so I gave her two Information Sheets for the children to take home. The outcome once again, was that there was no response from the parents.

e. **Primary School with a Special Unit Attached**. I spoke to the School Principal about my research and asked whether any children met my requirements. He identified a possible two families, so I gave him two Information Sheets that he said he would send home with the children. As a result, I received a phone call from one participant.

Because of all my attempts to gather further participants to take part in my research, I had three volunteers come forward. However, one of those withdrew prior to our second meeting.

Interviews

The interviews were recorded in the participants' home settings, at a time and for a duration that suited each participant. Permission to use their information for research purposes was given by all my participants before the interview began. In addition, permission to use a tape recorder to record the interview was consented in all cases. It was explained to them that they were under no obligation to answer any particular question or part of a question if they so chose. In most cases, the semi-structured questionnaire was used as a guide only, the preference being to allow my participants to choose what matters they were prepared to discuss. Interviews were tape recorded and transcribed for analysis.

Confidentiality

An important ethical consideration relates to the publication of the research findings. Tolich and Davidson's (1998) notion of New Zealand being a 'small town' is valuable. They assert that the researcher should acknowledge that New Zealand is a small place and so the identities of participants could be easily, accidentally revealed if appropriate measures are not taken. Therefore, the use of pseudonyms and the disguising of places and events should be used to ensure confidentiality. Therefore, they suggest ethical issues need to be thoroughly thought through before the research begins (Tolich and Davidson, 1990:79).

Each parent and the names of their children have been changed into pseudonyms. The names of institutions and places have been changed and written in the Maori language using overseas countries for places, months, body parts are used for the names of schools and colours have been used for hospital names, to ensure the privacy and wellbeing of the research participants.

Ethical considerations require that when accessing and selecting participants, informed consent must be obtained before the interview takes place. It is the researcher's responsibility to inform their potential informants as fully as possible, what the research is about, why it is being undertaken and what happens to the research after it is completed. All participants were informed and consented to take part in this thesis.

From a cultural perspective, this is a Maori-centred research thesis, which is guided by Kaupapa Maori protocols. These principles are firstly, Mana – empowerment of participation; secondly, Tapu – mauri – the sanctity of knowledge and thirdly, Maramatanga – clarity, understanding and demystifying of the process between the researcher and the participant. Therefore, I needed to find out whom, I should approach, to gain permission to carry out my research and whether such permission was, in fact, necessary. I first, approached Dr Evan Poata-Smith from University of Canterbury's Department of Sociology and Anthropology, who is the department's expert regarding Maori tikanga. I went to him to discuss cultural issues of how my research should be done in the best interests of Maori, and why it was necessary to do my research. It was suggested that Mental Health should be informed, along with a representative of Ngai Tahu, and a kaumatua from within the community.

I therefore approached a support person within the Maori Department at the University of Canterbury regarding my research and asked whether I would have to approach Ngai Tahu to seek approval. After discussion, it was decided approval was not required because my research was a small exploratory thesis, focusing on possibly six whanau, and because the research was orientated to whanau rather than to iwi. .

I contacted a person, who had been referred to me, in a Mental Health hospital who was responsible for queries relating to Maori issues. I did not speak to him in person, but I left a message outlining my research and asking if I need approval from Ngai Tahu to carry out my research. I left my number should I need to discuss the matter further. I did not hear back from him so I therefore assumed that there was no need for further action to be taken.

Contacting a community kaumatua was difficult because it was dependent on where the participants resided. In addition, not all participants would experience the same issues with disability, nor belong to the same support groups. Therefore, I concluded, that as not all my participants would be of Ngai Tahu descent and their circumstances would be dissimilar, there was not a single appropriate kaumatua who could be consulted. For those reasons, I made the decision following consultation and discussion, that because of the small number of participants involved, it was not necessary to seek formal permission.

Later, however, I was fortunate to gain approval from two Kaumatua at the CCS Whanau Support Group, which was most appropriate as four of my participants had affiliations to CCS. Two of the participants were very active in CCS, while the other three participants had participated, but had withdrawn because of other commitments.

Data Analysis

Tape interviews have formed the basis of my data collection procedure. Qualitative research provides the researcher with a vast quantity of data. Therefore the key task is to devise an effective way to code, sort and organise the data collected (Blaikie, 2000:31). After transcribing the interviews the next step is to search for interpretation by 'transforming qualitative data into quantitative data' (ibid) using a coding system such as themes and identifying patterns. The coding involves two stages; structuring and classification of the data before the connections are made to 'discover regularities, variations and singularities' (Blaikie, 2000:240) before theories can be constructed. Re-interviewing participants is then a possible strategy for further clarification and self-correction of in correct data in the transcription.

With discussions, tape recording and transcriptions, and the analysis of various literatures around Maori children and disability issues, I was able to develop main themes, patterns and trends. As a result, I have developed four themes for discussion, which are culture, health, education and communities. These themes are explored in detail in following chapters.

The Participants

In order to meet the objectives of this research, primary data was collected from five families who identified with their tribal affiliations from within the Christchurch region. In each of these families, there was a child with a disability. The children were given Maori tree names; Totara, Rimu, Matai, Kowhai and Kauri. Data was collected through interviewing their mothers and their voices are used in the quotes throughout the data.

I have used qualitative research methods in the form of semi-structured interviews. I have used key questions to initiate and direct the discussions (see Appendix 4). These questions established information in several key areas around raising a child who has a disability. These areas looked at background information; community interests and organisational or group membership; education, knowledge, learning interests and activities; and parents or caregivers as advocates.

Out of these four areas I was firstly, able to gauge the children's home life in the early years leading up to the children's current age, and what impacts the children's impairment had, on accessing facilities and services to meet the children's needs. Secondly, I was able to compare the quality of care the children received. Thirdly, how parents and caregivers experienced issues about accessing information, funding, educational needs and communications and how that was dependent on their personality, and the support, they had around them. Fourthly, I was able to gauge how culture identity, religion, spirituality, friendships, family activities and extended families supported the children's socialisation within their communities, as well as how the children were received within the education and health environments.

Next, the process of doing interviews will be described. All interviews occurred in the family homes in a space of their choosing. Settings ranged from being informal by sitting in easy chairs in the lounge settings with participants, to semi-informal by sitting at the dining room table in the kitchen living area. During most of the interviews, the children were present in the house, coming in and out of the room where the interview was taking place. I will now introduce my five participants and outline the steps in chronological order for each participant.

An Interview with Totara's Mother

Totara's mother was my first participant from the NZ CCS Whanau Support Group. I received an email from her offering to participate in my research. I emailed her back thanking her and I asked for a suitable time to meet and discuss my research, drop off the consent forms and semi-formal questionnaires and to answer any questions she may have had.

After a couple of days I decided to contact Totara's mother by telephone and left a message, asking for a suitable time to meet, not realising the information was in an email she had sent to me the same day, which I discovered when I read my email. My participant had left a suitable time to ring her (Wednesday evening between 8.45-9.30 am) due to her busy schedule.

The next day I accordingly rang her during the appointed time and we agreed to meet that evening for a meeting. When I arrived at Totara's home, I knocked on the door and waited, when someone from within the house yelled, "Come on in", I did not know at the time it was Totara. Thinking it was the mother inviting me in, I took off my shoes and proceeded to go through the door to find the mother was coming up the hallway to meet me. She informed me that he does that to everyone who knocks on the door. She led me in the lounge and offered refreshments.

While the mother was in the kitchen making refreshments, Totara came in the room and was very chatty discussing the television set and the channels that were on each channel (Sky network). When the mother returned, Totara went in the next room to play on the computer.

Using the Information statement as a guide, Totara's mother and I discussed, the procedure and what would be required, emphasising the confidentiality I was prepared to take in order to protect the family, by providing a pseudonym. We then discussed the semi-formal questionnaire and consent forms. Finally, I asked her if she had any questions she may wish to raise. At this stage, she was happy with the process. The meeting ended approximately one hour later. Leaving the information behind, we agreed on an interview time during the school holidays and I left the home.

When I arrived at my 9 am appointment to interview Totara's mother, the family were still sleeping. In order for Totara's mother to get ready, we agreed to start the meeting at 10 o'clock. I therefore left and came back at 10 o'clock. On arrival, I was offered a cup of coffee, followed by a quick chat. We then went into the formal part of the interview by firstly signing the consent forms and then we proceeded into the interview. The interview lasted three hours of recording with lots of interesting information coming out. The taped interviews were clear and articulate. I was able to transcribe it and present it into my findings using her voice, to tell her story. (See Chapter 4 Findings).

I returned to this participant for a final interview, so my participant could read the transcript, make amendments or clear up any areas of concern either my participant or myself may have had. I returned two days later to pick up the transcription and go through the comments she wanted changed.

Interviews with Rimu's Mother

Rimu's mother was my second participant from the NZ CCS Whanau Support Group. I received a telephone message at the Sociology Department from my second participant in response to the Information Statement that was sent out to whanau members from NZ CCS, to say that she was willing to participate in my research. I returned her call and we arranged a time to meet, drop off the semi-structured questionnaire, and the consent forms and to discuss the procedure of my research.

The next meeting was arranged for a 9 am appointment. I arrived at Rimu's home and was invited into the kitchen where the interview took place at the kitchen table. I thanked Rimu's mother for volunteering, and we made small talk to find some common ground between us. We then proceeded to the formal part of the meeting where I laid out what her involvement in my research would involve, and confidentiality issues. We also discussed the semi-structured questionnaire and the consent forms I was leaving for her to read and decide whether she wanted to continue. This meeting lasted one hour and a half before I left. This gave me a fair indication that these interviews were going to be at the longer end of the time I had predicted in my Information Statement.

The semi-structured interview was arranged for a 9 am appointment during the school holidays (April). We settled in the kitchen and after some small conversations, we then settled into the formal part of the interview. Rimu's mother handed me her signed consent form and I started recording the interview with a tape recorder and used the semi-formal questionnaire to prompt where necessary. Otherwise, the conversation went on to subjects that the mother was happy to discuss. Early in the recording, we were interrupted by a telephone call. I decided to pause the tape recorder and realised that the tape recorder batteries were not working properly, so I had to leave the house and drive to the nearest Dairy to get new batteries. A quarter of an hour later, we continued with the interview with two more interruptions (one telephone call and a visitor). The children came in and out of the kitchen and made small talk throughout the interview. The interview went over the time I had designated in my Information Statement, by thirty minutes or more. I was at her home for three hours and covered at lot of areas in the recording (see Chapter 4 Findings).

After transcribing the tapes, I arranged another meeting to clarify some of the data. This meeting lasted one hour and a half. She had a male friend (support person) at this interview. I had taken some biscuits with me that was happily received by the children who came in and out to eat them while the interview was taking place.

I made a returned visit to my participant once the transcript was completed, in order that she could read the final version and make the necessary changes, clarify any unclear data and approve the final transcription. She was happy with the transcription and did not want to change anything. She asked to keep the transcription because she was going to use the transcription to tell her side of the story of events around Rimu's disability with Accident Compensation Corporation (ACC).

Interviews with Matai's Mother

Matai was my third participant. A mutual friend approached Matai's mother to ask if she would be like to volunteer to participate in my research. After Matai's mother agreed, I was given her telephone number to call her. I telephoned Matai's mother and we arranged to meet and drop off the consent forms, Information Statement and the semi-formal questionnaire. After an initial postponement, I was able to deliver the forms.

Matai's mother was friendly and open when she invited me into her home and offered some refreshments, which I accepted. We then made small talk before we started discussing the consent forms and semi-formal questionnaires. My initial visit lasted two hours covering many details about Matai. Within this two-hour period of getting to know each other, I was able to meet Matai when he arrived home from high school.

Due to Matai's mother's university commitments we agreed to have the formal interview during the school holidays (April) confirming a time suitable to her.

The initial meeting took place at the beginning of April and I was unable to get an interview with Matai's mother until the beginning of July because of her commitments. After first getting lost arriving at her home, I took some biscuits with me as my koha, which was happily received. We had a cup of coffee and a 'catch-up' before we started the interview. The interview lasted four hours with plenty of data to analyse (See Chapter 4 Findings).

I returned to my participant with the final transcription for her to read, make changes and comment on aspects of the transcription. I returned two days later to pick up the transcription and go through the changes together. One of the comments that came out of this meeting was even though I had changed the names, places, schools and hospital in the transcription, if her whanau was to read Matai's transcription they would be able to identify Matai because the whanau is close and they have been involved at the beginning of Matai's care.

Interviews with Kowhai's Mother

Kowhai's mother was my fourth participant. The same mutual friend gave me Kowhai's mother's telephone number after she had approached her to see if she would be like to volunteer to participate in my research. After Kowhai's mother agreed, I was given her telephone number to call her. I telephoned Kowhai's mother and we arranged to meet and drop off the consent forms, Information Statement and the semi-formal questionnaire.

The meeting was held at 9.30 am at my participant's home. Two of her children were sick at home and unable to attend school on that day. They were in the lounge watching television, while we were at the kitchen table in their open plan living room. I was offered refreshments and made small talk getting to know each other before we settled into discussing the procedures of her involvement.

We discussed the Information Statement covering confidentiality and the option to withdraw at any time. The semi-formal questionnaire and the consent forms followed this. Finally, I asked her if she had any questions she wanted to raise. At that stage, she was happy with the process. I then gave her the choice of whether she wanted to set up another time for the next interview or to carry out the interview on the same day. She agreed to have the interview on the same day. After signing the consent forms, we proceeded with the formal interview. With only a few small interruptions from the children and the telephone, we managed to complete the interview. The meeting and the interview took just over three hours to complete.

When it came to transcribing Kowhai's interview it became clear to me that I had lost quite a lot of data and in some places the quality was poor because the tape recorder was on voice activation when the interview took place. I therefore transcribed what I could from the tape and set up another appointment with Kowhai's mother to clarify the bits I had missed and to add any other information that came to mind.

I arrived at Kowhai's house and presented a packet of biscuits for the family and an apology for my faulty tape recording. Her eldest daughter, who was sick at home, came in and out of the kitchen while the interview was taking place. We had refreshments before we started recording again. I covered the material that I managed to get from the previous recordings and then continued on, elaborating on the parts that were unclear and uncovered new information.

Returning for another interview also helped my participant, in that she was able to retrace some of her first interview and add more detail and some things she had forgotten to mention after reflecting back on the first interview. This interview lasted one hour and thirty minutes. There were no further problems with the recording of the second interview and all material had been successfully recorded (See Chapter 4 Findings).

I returned to my participant for a fourth meeting to drop off the final transcription so she could read, comment and change any information that need clarification. My participant then returned the transcription to me, with the changes she wanted changed. I then made a telephone call to my participant to confirm the changes she wanted changed.

Interview with Kauri's Mother

Kauri's mother was my fifth participant. I made my initial contact with Kauri at a primary school that Kauri attends when I was visiting the school principal. I was calling on the school Principal in search for more participants for my research. I left Information Statements with him to send home with two children for their parents. As a result, Kauri's mother left a message on my answer phone volunteering to participate. I returned the telephone call and this was my first contact with Kauri's mother. We then arranged to meet in order to deliver the consent form and semi-formal questionnaire.

I arrived at Kauri's mother home and was greeted with a friendly welcome from the family. I had taken some biscuits with me as a koha to give to the family, and I was offered refreshments. Kauri's mother was supported by the presence of her eldest sister. We decided to wait a while for her twin sister to arrive, (support for Kauri's mother) before starting the interview. After awhile we decided to forge ahead with the interview after she had not arrived. We then made small talk, in order to get to know one another, before we proceeded with the interview. We then discussed the procedures of my research, why I was carrying out my research, what her role was within the research and what would happen to the research once it was completed. I also discussed confidentiality issues when I spoke about the consent form, the semi-formal questionnaire and to answer any questions Kauri's mother might have.

Everything was all right, so she was happy to carry out the interview the same day after signing the consent form. The interview took place in the lounge where Kauri spends most of his time, when he is not in his room or at school. The interview lasted one and half hours and we were able to cover all areas from the semi-structured questionnaire. I found the taped interview to be clear and articulate. I was able to transcribe it and present it in my findings.

I made my final interview with my participant when I returned with the final transcription for her to read and make comments where necessary, of changes she wanted to the final transcription. I returned two days later to pick up the transcription and we went through it together and discussed the changes to be made.

CHAPTER FOUR: FINDINGS

TOTARA'S JOURNEY

During the week, Totara's mother is mainly involved with the care of Totara within the home, attending to his bathing, feeding and dressing needs. Any social activities that Totara's mother is involved in will also be attended by Totara. Totara has an older sister, aged fourteen years. Her role when not attending school or socialising is to act as a caregiver to Totara's needs and supervision.

Totara is a very social 10-year-old boy, whose physical disability is Cerebral Palsy and hydrocephalus (fluid on his brain). He also has a shunt in the head to drain the fluid to reduce pressure. He has Asperger's Syndrome that comes into the autistic spectrum. According to his mother, *"he is very bright, intelligent and into numbers …."* Totara has visual impairment in both eyes. In the right eye, he is blind and the left eye has astigmatism and has problems with long distance vision as well as near vision.

Totara was a premature baby and his vital signs were not considered good, so he was given the palliative care for a baby not considered likely to live long. However, Totara's mother believes that because of Totara's will to live, his vital signs improved until he was well enough to leave the hospital.

> *"Totara's disability was picked early, at six weeks the shunts went in. He was born three month premature. When he was three days old they gave him a scan and could see there was damage, but they didn't take any notice of it because they didn't expect him to live, so it wasn't an issue. At six weeks they told me to walk out of the hospital and leave him because he would be 95 percent of nothing."*
>
> *"With his vision they are suppose to be checked once a week – he didn't get checked until six months. That could have been picked up earlier if they thought he was worthwhile, they would have done it. It didn't matter because he wasn't coming out of there."*

Because of Totara's determination to live he was allowed to leave the hospital after a minor set back.

> *"After three months we had to fight to get him out. They had him in a corner with no attendance; he had pneumonia and needed a blood transfusion. His health had been up and down. Usually there was a set back, and then he would strive forward. It's as though his body shuts down before it moves ahead."*
>
> *"With 6 weeks fighting the hospital system, with family support, we were lucky enough to find a man on the board of trustees for the hospital, which my grandmother looked after through the family."*

This person was able to advocate for the family to have the child released from hospital and taken home.

Home Life

Once Totara was taken home, health professionals came to the home, and operations were arranged to care for Totara's health problems and his disability.

> *"... Physio, the house opened to all sorts of people coming. We spent at least 3-5 days at the hospital for test, for the eyes, this and that. Because of the different operations, most of them were done in the first year - with the eyes and shunt - we were in there for 10 days after that. The eyes had two operations for retina tension in the right eye; they also had to burn off to stop it overlapping. He's got glaucoma in the blind eye; he has to have eye drops for the irritation."*
>
> *"The shunt was broken 10 months after it was fitted. Two weeks after the repair it broke again, so they removed the shunt and replaced it with a new one. The breakages are due to the amount of head movements Totara is able to do."*
>
> *"The osteotomy operation because of his hip, they have to break his leg and rejoin the bone. By cutting the ligaments in the legs to stop them crossing over did not work, so we went for the osteotomy. Now he has a very painful leg and it's very short."*

Totara is able to walk four steps using the parallel bars. He does a lot of crawling, which is a bit crooked because cerebral palsy has affected his left side. His physical side on the right is fine. He has a built up shoe for his short leg.

In the mornings, his mother or older sister dresses Totara. In the evenings, someone from home help comes to bathe and dress him (this has been the same male person for sometime).

Totara returns home from school at 4 o'clock. Totara seldom takes naps, he is active for the whole day and talks continuously once awake so this can tire him out. He is usually in bed at 7.30 pm because he is tired from all the physical work he has done throughout the day. Some nights he may stay up until 8 o'clock but this is very seldom, as he will *'start flagging and grizzling'*. Totara is up at 7 o'clock most mornings.

TOTARA'S PERSONALITY

Special Attributes

Totara's mother identifies Totara's special attributes, which include many things:

> *"He's a hard case, he doesn't understand the concepts of jokes, but he does actually tell them, and then he looks at you and says "all I said was ... ", so he hasn't got the concept figured out."*

Totara's personality changes and attitudes are more noticeable by other people not directly involved in Totara's care

> *"More likely people tell me; because I'm with him all the time I don't take notice of his changes and his attitudes. It's when people haven't been here and they come in, he'll just talk, and they say he's made such a difference. Like I said, when he does them it goes so fast and I miss lots of milestones and that. Its other people that tell me, and other times I can actually pick up, he sort of does an overnight change in personality, which is quite freaky sometimes. This can be his difference in speech or his difference in interests. He'll set his mind on certain things and all of a sudden he'll make a change to something else. People and neighbours will notice a big change in him and*

> *point them out, while we are used to him, so he takes these big leaps."*

Interests

Totara's interests centre on electrical equipment and electronic technology:

a. Sports.

Totara does not belong to any Sports club, however through his contact with his caregiver; he has taken an interest in watching and listening to rugby on the Television.

b. Computer.

Another interest of Totara's is the computer, which he spends at great deal of time.

c. Television.

Totara knows all the television and Sky channels and is happy to demonstrate the channels.

Social Settings

The places of interest, which his family identify as ideal for meeting Totara's needs and social interaction, include:

a. Parks.

Occasionally Totara will frequent the park close to home, but this is subject to the condition of the pathways around the park. There have been occasions when uneven ground prevents a wheel chair being able to proceed and this has hindered his activities.

> *"The track at the park is close to home. He likes the trees over there, which have the bits fall off the tree, these nutty things on them, and the make a crunching sound when he runs over them. They make a mess of the wheel chair, but he likes that. He does the obstacle course and things like that. The Christchurch paths are really shocking because they are on a lean; he's got the one arm drive"* [on his wheel chair]. *"*

b. Shopping Malls.

Initially shopping Malls were convenient to take Totara shopping because of the bright lights. It was a place hyped with activities, noise and movement and that was very distracting because Totara could not block that out. The family had difficulty spending time in the Malls with him.

> *"We can sit outside MacDonald's now, we used to buy and take it away before. You have to buy a little bit, because when he's had enough he'll say he's going home now.* [Palms, Northland]. *Had to go into a shop very fast with him, buy something and get him out. But now we can do our shopping, sit down, eat and then bolt."*

There are two places of interest that Totara likes to visit on the occasions when he is in a shopping Mall, and which help him to relieve his stress.

> *"... he likes going into the washing machine part and the supermarket part. The guys down there don't really mind when he does the sale pitch, come in and look at the washing machine. He's always had a fascination for washing machines when he was little. When he was stressed, you had to go find a washing machine. In earlier days, even when Totara's sister was stressed you would put on a dryer or the hoover. It seems to be the washing machine for Totara. He knows the cycles and the different notes."*

Supermarkets are another place of interest and he likes grocery shopping.

> *"He likes grocery shopping. I didn't use to take him until he got his male carer and he would take him just gradually, and*

> *Totara realised this is a neat place, where he can go saying, ' I want this', 'I want this', or sneak things into the trolleys."*

Special Talents

One of Totara's special talents is his ability with numbers. He is able to amuse himself with numbers while he is in the Malls.

> *"Because he only gets to the shop on occasions like in the holidays and the occasional other time, (the fact there is so much variety) he can calculate how many items you have in your trolley. For instance, at a checkout counter the operator asked him how many items, he said 59 no 60, and sure enough there was 60 items."*

Pocket Money and Life Skills

Totara does not receive pocket money that he can budget and spend himself. Instead, money will be placed in a cup for him at the time of purchase, so that he can interact and participate in the transaction. The family is currently helping Totara with the learning of life skills and the value of money.

> *"We give him money in a cup, plus he's just got one hand* [he can use] *up to the counter, chucks it at them, grabs the ice cream and forgets about the change."*

Attempts have been made to socialise Totara into his community.

> *"In the weekends, from 9-3 pm on a Saturday when he goes out with his caregiver, he has his own wallet; his caregiver has to take it out and pay for what they want. His caregiver has been getting Totara into everyday living, so he's been taking him out grocery shopping lately. So I've got to make a list for them on Saturday so Totara can bring our groceries home."*

Security

Totara's mother is a parent on a solo benefit and so budgeting is an important matter in order to ensure that the basic needs of food, shelter and clothing, and other essential needs are met. Occasionally, money can become a concern to a child who has a disability because it affects their concept of themselves and how other people see them and their situation.

> *"He has his wants; sometimes I've said I haven't got enough money. I did a course last year, when Totara was concerned I didn't have enough money and queried what is going to happen. He said, 'If you die Mum, what's going to happen to* [his sister] *and me? I explained to him that when you get older you would have your own money. He said, "Oh that's all right then". He wasn't concerned with me dying but his own money."*

Future Aspirations

All children have dreams and desires of what they want to do or be when they grow up and Totara is no exception:

> *"He wants to be an ambulance driver. That was an issue for a long time."*

CULTURE

Maori Land Issues

In most cases, Maori still have historical issues relating to Maori land shares and property sales.

> *"Well we have got land all over the place. Now the 99-150 year lease on land is starting to come in from my Dad who died years ago. It's been split between the four of us, so I think there's an issue of 0.609 of an acre in Kanata."*
>
> *"We keep getting the paper work on it, I've written back to them to sell it, to see if someone wants to buy it. I think people who are working the land are entitled to it. If you want your land and you are going to work it, well that's fine, you can hold on to it or buy it. I think because the rentals were not worth much. It's the paper work and its costing money basically and I don't think I would like to go up there and live on it."*
>
> *"Mum had land in the Hiri Islands, and she wasn't getting any benefits because it would have affected her benefit and stuff. We have got aunties and nieces fighting over that land so we*

> *said to her, "We don't want you to keep the land, because when you die, the land will be split into four and we will be in the same position. We don't personally want to go back to the Hiri Islands to live, and if we did we would have to have the money to buy the land, because it is always coming up."*

Culture Values and Norms

Prior to Totara's mother's interest in educational studies regarding Maori, her cultural base and Maoritanga was located in the centre of the whanau:

> *"The values, and whanau to me, I suppose is the way we were brought up by Mum. It was just her and us kids. We had cousins and relations staying, you didn't ask them for help."*

However, since her studies on the subject of Maoritanga, her views have broadened and now she relates to it with greater depth of thought.

> *"Learning the Maori culture and stuff, I've learnt it's not just us, it's the bigger us. They are also there, you can help and they can help sort of thing. The little Whanau is good but you still need the extended the different aspects and things."*

Totara's mother sees culture and whanau as encompassing a wider field that view:

> *" ... not just Maori based, but Support Whanau group as well."*

Whakapapa

The sense of belonging comes from the stories that are told by the elders to their children and grandchildren, whether they are oral, written or acted out. Totara comes from tribal affiliations connected to Purukeria. Totara and Totara's mother have never lived in Purukeria, nor have they been involved in seriously studying the history and language. Totara's mother believes when the time is right, the language and the stories will be told.

> *"Both my Mum and Dad have tribal affiliations, but from different tribes and iwi. They are both from Purukeria; Ngati*

> *Mautanga and Ngati Awa. I can't get the information I want, - every time I've asked my mother, she will give me one or the other because she basically does not know. But in time, I will take an interest, its still there but I haven't gone in that direction."*

For Maori, a feeling of loss of identity can affect self-esteem and the sense of connection to home and family, whether this is through a loss of language, culture or land.

> *"Just learning the language, where we come from and some of the stories that connect with us growing up which Mum was trying to say. I'd go back and ask Mum and she would say no that didn't happen. It's good to know where you came from."*

Loss of Language

Totara's maternal grandmother came through an education system that, as part of an assimilation process of phasing out Maori language, banned Maori from speaking their language in school. Because of Totara's mother learning about colonisation of Maori and non-Maori within New Zealand, she has been able to give her mother another viewpoint.

> *"She always disliked the Maoris because of what happened in her life and getting a hiding for speaking it. But she is just realising now, when I talk about things. She said "I've just realised it wasn't the Maori that did it to us"; I said, "No Mum, that's what I've been trying to tell you."*

Colonisation and assimilation have seriously affected the identity of the minority group. The sense of belonging is diminished when you are isolated from the cultural capital of your origins, from such things as the culture and language, and the retelling of the histories of ancestors, or walking upon the land that has been part of the family for generations. In the case of Totara's grandmother, her choices have isolated her family from that cultural capital.

> *"My mother's brothers all speak the Reo and taught their children. Whereas, my mother's way of thinking was "The Maoris did it, I don't like them", and that's why she brought us*

> *away from the Hiri Islands and she took us away from everything there."*

Language

Totara and his family are exposed to a small amount of Maori language through CCS, school and the occasions they spend with their extended whanau.

> *"The Whanau group at CCS ran a 10 week Te Reo language session which was family orientated. Totara would be going in and out of the session, but was able to give the answers. He picks up the language really easy. He does it at school; they have it as part of the curriculum."*

Totara's mother has had little opportunity to learn te reo Maori, due to her mother not speaking the language within the home. However, she has attempted to find avenues for learning te reo Maori.

> *"I did do a Maori language class for the city Haina library, where you had to interact with numbers. I was coming home practising the saying, and Totara would correct my pronunciation by saying, "Mum you are not doing it right, you can't say those words probably and he proceeded to pronounce them correctly."*

Learning/Teaching Maori Knowledge

Through self-learning and educational courses, Totara's mother has come to believe that Maori culture and ethnicity are important issues regarding self-identity, self-esteem and a sense of belonging for herself and her family.

> *"It's really important. You learn something and it changes your views, you have a broader line."*

Identity

Throughout Totara's mother own high school experience in Christchurch she did not identify with Maori, because,

> *"... mainly European groups because it was right through the school. I was thinking of* [Totara's sister] *she's the same, but you still have your Maori friends and* [Pacific] *Island friends because you have that little association."*

> *"Like inside of school Totara's sister will stick with the European ones for the academic part, which I* [Totara's mother] *am really happy about because the Maori and Pacific Islanders are going down the back for the drugs. But outside of school that's the social bit..."*

> *"It's quite hard for her as well because of her* [pale] *complexion that people are taken back. Totara's sister just happened to mention she has a disabled brother and a mother who is a little short Maori woman and the reaction from the boy when he found out...."*

On another occasion, Totara's sister set up her friend, who was giving her a hard time about Maori in general, and she invited him home, and with one look at Totara's mother, he realised Totara's sister was part Maori, like himself.

Food

Totara's mother has fond memories of the type of food they ate on the Hiri Islands and sees it as being a part of her culture and heritage of life in the Islands.

> *"In the Hiri Islands you made your own bread, different foods like wekas, albatross, swan eggs and stuff like that, and another seafood like kaio (sea tulips). You eat what is on the island."*

Return To Home Roots

Totara's Mother left the Hiri Islands at the age of six.

> *"In the holidays, because I was in the education system, in the school holiday's I used to go back to the Hiri Islands and live, until I left school and then I had to pay for it."*

Totara's mother returned to the Hiri Islands fourteen years ago for a holiday, and has not been back since. However, when people from the Island come to stay in Christchurch, Totara's mother is happy to accommodate them.

> *"Every time someone comes up* [from the Hiri Islands] *they bring with them, the food, the swan eggs, swans, crayfish and so forth to us."*

Mixed Cultures

Totara's mother was raised within mixed cultures when her mother moved away from the Hiri Islands because her mother's employment was involved in the accommodation of people from different cultures, who had immigrated to New Zealand.

> *"The culture side, we were bought up with a Fijian family who lived in our house and we lived in their house and ate the same meal. The same thing happened when we had the Nuian family in our area. We learnt all about their cultures as part of our family upbringing."*

Totara's grandmother accommodated not only the people who were trying to settle in Christchurch, but also children, mainly boys, from the Hiri Islands, who were here for their educational schooling.

> *"We use to live near to St Korokoro, so Mum used to have all the boarding kids in the weekend stay with us."*

WHANAU

Totara's Grandmother

Totara's mother understands the decisions her mother made concerning decisions around culture and raising her children on her own.

> *"Mum brought us up on her own. She took us away from the culture; I can understand why she did it. It sort of affected us, by taking us away from it."*

As part of an assimilation process, Totara's grandmother has made limited contact with her cultural background regarding tribal links and her Maoritanga.

> *"She won't go on the Marae because of her background. When they stand up and say the mihi, she won't, she knows alright but she won't come out and say it."*

When the Whanau group first started, Totara's mother encouraged Totara's grandmother to attend.

> *"She came once, and when we came home she said, "I'm not standing up and saying that". All you had to do was say your name. We attended a Maori medicine seminar; run by a pakeha priest from up North who spoke te reo, and I took Mum because she was interested in that. He came up and did a hongi to her. Later she said, "What the bloody hell did he do that for", I said, "It's a sign of respect". She said, "What do you mean?" I said, "You're an elder". She said, "Oh I don't like it."*

On the occasions when Totara's grandmother has had exposure to her family upbringing, by returning to her grass roots for a funeral or a special occasions, she is able to indulge in the culture, language, and the sense of belonging, for the time she is there, only to switch roles when she returns back home to Christchurch.

> *"She will go to funerals and stuff up North, and she comes back speaking the Reo, but after a time she will shut it down again."*

Totara's mother may have limited exposure to learning te reo Maori, the historical elements of her ancestry, her ancestors, her extended whanau and childhood, but she is still able to take advantage of special occasions.

> *"I like to take* her [Totara's grandmother] *to her brother's; sometimes he's here, or they come here because I really ear flap when they come, especially when they get on that roll, you've just got to really listen. When she is with her brothers, I can talk to them about it* [the past]. *If my mother is there she will interact but if I asked that question there would be no interaction."*

Totara's Grandfather

Totara has not had any contact with his grandfathers.

> *"He* [maternal grandfather] *died when I was six months old. Meanwhile there is no contact with his natural father grandfather either."*

Extended Whanau

Occasionally Totara's relatives from the Hiri Islands will come and visit. Traditionally they used to stay at Totara's grandmother's place, but over time as people's lifestyle changes so does their circumstances. In the case of Totara's grandmother, she has since moved to a two-bedroom house and can no longer accommodate the larger families in her home. Totara's mother now takes on the responsibility of looking after extended whanau visitors.

> *"They will come out quite often when the fishing season is over. So we can get inundated with people and food."*

Aunties and Uncles

Totara's mother has one sister and two brothers. The eldest brother lives in Koromopia while another brother and sister live in Christchurch. They have not been involved or supportive in assisting Totara's mother in the care of Totara or his upbringing.

Her sister, who is working in the field of disabilities in a day centre for disabled people, relates it to working with Totara. However, Totara's mother feels that her time, if she really wanted to help, could be spent with Totara as her children have all left home. She has four children, all grown up, the youngest one now twenty-one.

Totara does not spend much time with his cousins within Christchurch because there is at least, a five-year age gap, and they have not been involved in Totara's upbringing at all. However, Totara does see his cousins on social occasions.

Mother's Profile

Totara's mother had no involvement with children or adults who had a disability prior to Totara's birth. It was something that was completely unknown to her.

"I was thrown into the deep end".

To better her understanding of Totara's disability, Totara's mother had to train and educate herself.

> "[I] *learnt by attending group meetings and reading books; depending on the issue at the time."*

Spirituality

Totara's mother has not only relied upon the mainstream health professionals for her child's growth and development, but she has also made use of also alternative methods and beliefs to aid and guide her in her role.

> *"I received insight from a physic reading about getting into learning and studying, otherwise your son would leave you behind. Because of Totara's spiritual knowledge and mentally he's going to leave me behind. So I've got to be up there with him to help him otherwise we will be poles apart."*

Even though she has sought different alternatives to enable her in understanding Totara's strengths and weaknesses, most of her learning has come from her child.

> *"The teaching I have learnt, is teaching from Totara. He's asked me some impossible questions and I have had to go to direct extremes to find the impossible answers because there are always answers out there."*

Voluntary Work

Over the years, because of Totara's disability and her connection to CCS and the associated Whanau Support Group, Totara's mother has volunteered to assist various services.

> *"Rata from CCS was our case manager when we first went there* [to the Whanau Support Group]. *She would ring up and say something was on, to come along. So with her help and assistance, my involvement has grown from there, that I am basically living there and doing CCS stuff."*

Social Connections

Totara's mother has formed many flourishing relationships that have resulted from her involvement with the voluntary services and support groups centred on Totara's disability. A network of supportive people has been built up and this has led to the creation of long-term friendships. Over a period, this group of friends have developed, and many of them were personal carers for Totara.

> *"They still come around for cups and tea and stuff. They have either given up caring for Totara because of health reason or moved on. They are the ex-carers group."*

The support systems that support a child with a physical disability require a large number of people over time, which come and go from the child's day-to-day care. From these connections, friendships develop between the child and the caregiver, as well as to other members of the family. Most of Totara's mother friendships have developed this way.

> *"They have lived in their house for seven years. Bringing her network from Kango as well as the Kuki Airani group come from Haiperu to Tenemaka, so that's 22 people in-between. Then the Whanau group is sort of another version again and the church group. So they come from miles."*

Future Career

Totara's mother is in her first year of study at the University of Canterbury, working towards a certificate in Social Work. She intends to move her focus away from disabilities and map a career in some other field within social work.

> *"Like I am in the disabilities field for this course but I know it, from the back of my hand because I see the intellectual, I see the physical and I'm in a bit of both. So, it can go a long way, but I would like to do something out of the disability, because in this course I'm the only one knowing about the disability. But, everyone else is in his or her different pockets. I've got disabilities covered I don't really have to learn too much more about that."*

Siblings

Totara's sister is the eldest in the family of two. Totara's sister is also Totara's caregiver and assists in Totara's daily care.

> *"She got her power as caregiver. They get on really well, but they do have their sibling rivalry on occasions."*

Totara and his sister have an uncanny connectedness both spiritually and mentally.

> *"His closeness with his sister is like a twin one. When one's sick, it's the other one who has got the problem. For example, Totara would be at school, crying and being sick, in the mean time, I will be going to get him and it would be his sister walking home with the actual illness, whereas he has had the symptoms. Once she was here and collapsed, but she went to school and Totara stayed home sick."*

Occasionally Totara may have his mother on about attending school.

> *"Sometimes he says he's sick to bunk school a lot, so it was very difficult to actually find out whether it was him or his sister, because nine times out of ten I've be picking him up, when nine times out of ten if would be his sister vomiting at school."*

At other times, there can be confusion, about which one of the two children actually has the sickness.

> *"Sometimes he won't say anything and it will be his sister saying, "I don't know what's wrong with me", next thing the school would ring up, I'll say don't worry its only Totara again. They understand that as well."*

RELIGION

Spirituality

Totara's family is not really strongly attached to the Catholic Church.

> *"We are sort of earth people more than anything. Earth and the trees, and when you die - no real big issue."*

One of the reasons for this attitude may be because of his mother's early memories of religion when in her early childhood years.

> *"When we left the Hiri Islands it was a Catholic priest that let the priest here know we were here. He used to come around and force us to Catholicism. They used to come around here in a van with these screaming kids and chuck us in. Mum would be half way through tea and all the doors would be locked and everyone hiding under the bed. So that was the basic religious structure we got. They realised we weren't coming out."*

However, the family will participate in some of the activities and venues supported by the Church, such as celebrating and attending Christmas midnight mass. Totara's mother views the Church and spirituality as catering two different needs. There are some aspects of the Church, which she does not agree with.

> *"The church has its place, but cannot replace 'the knowing', we keep it to ourselves and they do not need to know. It is part of culture and it is something we guard a lot. It's a case of having to, for safety. For instance, Totara, if he's doing some of the babblings they will tie him up because he's is a wheels.* [Totara's mother would prefer him to be able to say and speak

> to the let the messages coming through.] *But I don't want to stop him."*

Totara's ability to be able to feel and read other people's present and future wellbeing was more notable when he was younger, than it is today.

> *"He does future readings, he picks up on people's feelings and when somebody is sick. Especially when he was younger, we had a lot of people here for healing from Totara. They would come, and he would know whether they wanted a cuddle or to kiss. He would tell them what was wrong with them and where to go and the futuristic things."*

This is considered part of Totara's natural ability that the family see as normal. It depends on how busy their life style is, as to whether they will pay attention to his messages.

> *"Now, occasionally he'll say something. But you know you get busy and it does sink in and then later you'll think thanks I got you Totara. He sometimes come home from school and says, 'Mum you're not feeling well', and I'll say, 'No I'm alright', and then the next day I'm flat on my back. I should basically listen to him like that."*

The psychic connection between the two siblings is particularly notable.

> *"Both Totara and Totara's sister are very much in tune like that. The psychic ability is there. If he wants to see someone, he will go on and on. I would dismiss it, and then something happens. Now I have learnt to take notice when he is persistent."*
>
> *"When he says, 'What's Uncle doing?' I say, 'Come on then'. We have got to go, and sure enough there's something wrong basically in the household. Then Totara and his Uncle will go out to the garage, they have got the washing machine and dryer in the garage,* [calming down effect for Totara] *while I do the talking inside with the girl friend."*

Totara cannot turn his psychic ability on and off and when the messages come through; he has to say something. This sometimes happens when he is at school.

> *"He'll tell the school if one of the children is going to be sick. One boy in particular used to have very bad seizures; Totara would go and tell the teachers prior to the boy having them."*

It is necessary to look past the child's physical disability and to listen to what the child is saying. What may be seen as a trivial, general observation takes on a new level of importance when the child has a message with some personal relevance to the listener. A switch to attentive, active listening then occurs.

> *"It has taken the teachers years to accept what Totara says, until he has said something personal to them."*

Over time, these gifts seem to have diminished, or perhaps they have become superseded as new learning experiences and education has taken place. They may have had to become more grounded in day-to-day functionality so that psychic ability is not a strength that can be expanded within the child's learning environment.

> *"As he has gotten older, it's not so much now; but when he was younger it was terrible."*

Totara has had people convinced of his psychic ability on some occasions in the hospital setting and within the school.

> *"Such as mind reading, to some of the surgeons, their faces would drop. 'You're not happy at home' and his teacher aides understand."*

Telepathy

This family believes that telepathy is a naturally occurring thing with them concerning their connectedness to each other.

> *"I am telepathic as well to both of them* [her children]. *Totara's been in a situation where he is going to fall, and I'll get a flash and I'll stop it."*

Totara's sister as well has experienced flashes, or a 'knowing', about her brother before an event happens.

> *"So it's all intertwined at different times. But those two seem to be very close."*

Alternative healing

As part of working with Totara's physical, spiritual and emotional disability, Totara's mother tried alternative healing as part of healing the overall body of Totara as well as the family in general through reading and trying out suggested material.

> *"Basically, I haven't read anything for years and years. I had to find out about the auras and the chakras and crystals. We have been through the healing crystals, kinesiology for the left-brain and right brain. I have used colour therapy on Totara, harmonics the music and all those things. I learnt massage and reflexology through books, I'm not a professional, but I did it for Totara. The same with my family, each one has their different little interest in different body parts. It was all hands on."*

Spiritual Aspects of Healing

There was no specific Maori influence towards healing for Totara's well being, however Totara's mother understands the meaning of 'knowing' what is important for Totara and that it will be shown for her, the message will come from within.

> *"... because we don't really know that* [Maori healing]. *We already know knowledge and stuff is not in a book, but we know it is from somewhere. I think that is the Maori part."*

The search for alternative ways of healing and caring for a child, who has a physical disability, will require a study of the structures surrounding the child. These would include the health and education systems, the home and social environments that the child lives in. In a case such as Totara's, spiritual healing is seen as an alternative health remedy and Conductive Education is considered as an alternative to other, or mainstream, options of education.

> *"More alternative, like Conductive Education its not scientific way, there's no medical proof that it works, but if you actually look, it does. For example, the moon affects my mood being a*

> *cancer/moon thing. I can feel the ebbs and flows and different peaks when you can really do stuff and other days you can't do physically anything. I don't get really spiny but I get lots of energy and I can do heaps and heaps. So with Totara, you knew which steps to take and which things to refuse to do."*

On two occasions, Totara's family attended two spiritual healings within the Church that they occasionally attend.

> *"Through a Christian couple we know through the Church,* [they] *had a healer from overseas attend. Usually we can't make it* [to Church meetings], *but on this occasion we actually went. Initially Totara was apprehensive about it, but it worked for Totara, he liked it."*

> *"Another healer came from America, we went there and Totara didn't like him. The first one he said 'He liked been prayed at', whereas this one 'No I don't like it'. He liked the vision of the guy putting his hand up and praying rather than the guy putting his hand on him and praying. He said, 'I like been prayed at, not prayed on'."*

Spirit Guides

The ability to be able to carry out a two way or three way conversations while he is in a room by himself, can be confusing or even disturbing, for people listening outside the door, because they think there is someone else in the room. Totara's mother believes he has many guides and spirits that talk to Totara when he is on his own, because some of the things he questions or comments on are too advanced for his age.

> *"Even when he was two he'd say something and you would look at him and think you shouldn't know anything about that. Some of the things he comes out with is too advanced for his knowledge. He has a multitude of people in there. So depending on the situation and depending when he needs to speak. He can have conversations; sometimes he's just having 'his' conversation you don't hear the other."*

Some examples of Totara's conversations can be erratic in behaviour, as well as incoherent, which his mother suggests, can be coming from outside influences, as he is able to give future readings to others. His conversations can be,

> *"Sporadic really, you can hear him talking at night, you can ask him, 'you alright mate?' he will say, 'Yeah, I'm just having a yak'."*

> *"School has commented that Totara talks too much at times. But, it's a matter of listening because he has things to tell you. Sometimes he gets all mixed up. He comes out with this verbal. I say, 'What was that?' and he will say, 'don't worry I will rethink it'. Its not just 'earth' influence on Totara there's a lot there. He tells people that visit, their 'futures' just like that."*

> *"Some have come deliberately to get him to say something to them, so they will go out and do it in their life. That's when I say, "Cut that out, you are not allowed to do that to him. You ask his permission first."*

Other people with spiritual connections have from time to time been involved in Totara's care.

> *"One of the bath ladies came, and she could see auras and colours in people. She was trying to teach him a lot, but I think he actually taught her more. She was quite blown away with Totara."*

Spiritual Visions

Totara's mother gives some of the spiritual visions that she can recall of Totara's insights:

> *"Both his teacher aides* [lately] *they are really good on this thing, they listen to him and are aware he can do these things and he's done it to them. He has told them which kids are going to get sick, which ones are going to end up in hospital".*

> *"Passing a Cemetery aged two and a half calling out to stop the car 'I want to go to the playground', 'What playground?' 'There's people playing out there'."*

> *"Another time while driving passed the cemetery he mentions a girl from the unit, who had since died, saying she was happy now."*

Spiritual Gifts

Some of the old Maori traditions regarding noa and tapu and the superstition behind them are today still respected for what they represent. The meaning behind them can also enlighten the ways in which they are interpreted.

> *"Hiri Islands nasty things happen, good and bad omens. Mum's always has a bad thing about fantails bringing death. I tell her the fantail doesn't bring death it's only the messenger. You can't change it, and you are lucky you have a messenger ... it's time to get organised, and he hasn't brought death there and it's a change of attitude. It's only later you realise, and it's kind of groovy. The same thing with Totara, you think its crazy and you just carry on."*

EDUCATION

Early Childhood

There was no difficulty placing Totara into an early childhood centre that wanted him. His mother went to different centres, and explained Totara's situation and needs.

> *"... a lot of them* [early childhood centres] *said no thank you. They* [friends] *said you should push [to have their child placed in a centre]. I said no, I'm not having Totara in a situation where they have said no. However, the local one just around the corner, it was a breeze. I explained who he was and they said that's fine. They were absolutely wonderful."*

Totara enjoyed his time at kindergarten, making many friends.

> *"...they all knew him, and kids wanting to come over."*

Totara stayed at Kindergarten until the age of five. In hindsight, Totara's mother feels that another year at Kindergarten would have been good for him socially, because the primary school that caters for Conductive Education was away from his local community.

Primary School – Conductive Education

When the time came to make decisions about which primary school Totara would attend, his decision was straightforward; to carry on with Conductive Education.

> *"... because of the Conductive Education they had, the school was already up and running in Kuki Airani ... we followed on to the Conductive Education school. We have five other children older than Totara ... we didn't have to go through the process of looking. I knew where I was heading and that's where we went."*

Through a contact from IHC, one of Totara's friends suggested that Totara would benefit from Conductive Education.

> *"A lot of people were seeing Totara's future for me – oh well I'll give it a try. It worked for him and I have never looked back ...."*

Totara's mother describes her experience of the benefits of Conductive Education:

> *"Conductive Education is about teaching life skills, feeding themselves, toileting themselves and doing physical work on the child all the time, using all parts of the brain, training the brain to enable them to work."*
>
> *"We started off with early intervention. You went there, and everyone cried and went through all their problems and stuff. When you got to conductive, it was all on. It made a difference socially when we go out with Totara. For example, Christmas parties ... they had all the children at the back in wheel chairs. A lot of them* [parents] *don't have the vision, because they say at conductive if you cannot bring the stuff to your child,* [take the child to the stuff]. *We all* [The parents from Conductive Education] *picked up our children, took them up to the front, whereas, a lot of the other children just sat in their chairs."*
>
> *"One of the beliefs in Conductive Education is that chairs are for distance and they don't live in them. People were looking at us, saying these are strange people dragging their kids – a total different outlook we had compared to what they had through the normal system."*

When Totara was two and a half years of age, Totara's mother was involved in "Conductive Education", and this required a lot of physical work.

> "...[You] *learn how to handle your child ... what you were suppose to achieve was these sort of milestones. Had to rethink and train your child to do those things. It was pretty harsh because we sort of worked from 9am until 1 pm each day without a break as parents. We had to give them morning tea, had to feed themselves as a process of Conductive Education, but you as a parent never got the meals. You sometimes put in 9am to 3pm hour days – but the parents never got the break. It was really constructive and really, really hard."*
>
> *"It was a good enforcement on their part* [Conductive Education] *on how you behave because you became that much stronger. You couldn't fall down in class because it was not good for your child. So for two and a half years you were taught you don't worry about your care, but getting your child up and learning. Once they hit school you were lost because you didn't have full on attention, but you learnt to handle your child as they do [the Conductors] and how to teach them."*

HEALTH PROFESSIONALS

Hospital Care

Even though there are cultural and ethnic issues concerning support for Maori clients within the hospital system, these were not supported by a Maori social worker. In the case of Totara's care, there were no whanau facilities or provision of a place for them to stay to enable them to give support to Totara during his hospitalisation.

Totara's mother felt her needs and support were helped when Totara was hospitalised, by having a social worker assisting them.

> *"We have a social worker at the hospital... was a plus". The times I have taken a support person along, when I have had issues with the hospital, she's a really good lady, who has a strong personality. I've taken her and we have managed to get through the system because of her. She's not Maori, but she*

> *knows the system and she impatient. She likes things done now, so she just bowls into their office and chews them out."*
>
> *"For example, to get the metal plate it was meant to be out after a year, and they kept flagging us for three years. I had been to MPs but they were too busy, the GPs were writing letter."*
>
> *"The actual surgeon himself was a pain. When we finally got an appointment to see him, for support I took my girlfriend with her son and me. We were there for a 9 o'clock appointment and at 11 o'clock we still hadn't been seen, so she said (my girlfriend) point him out. So she went into his office and they had a whole group of people discussing something and she just ripped into him. He was out in a flash to see us."*
>
> *"Two seconds he was back in with us, we were kept up there for half an hour. He was explaining to my girlfriend what was happening with Totara, she said, "No use speaking to me, speak to the mother". We were in there* [hospital] *within the week and we also changed surgeon."*

Occupational Therapist

> *"We don't have an occupational therapist within the school, that's what the conductors do; they do all that intertwined with their learning."*
>
> *"The only thing is if we need equipment like wheel chairs, we have to go to the occupational therapist at Whero. We go through Life Links to Whero to get our equipment. They are supposed to have one chair for five years. He's gone through seven chairs. Mostly because they have not been suitable for him, basically you have to push them around and he wants to move, but he's stuck out nowhere yelling out for help. He's finally found one, but it needs to be fixed that he can turn corners and he can move by himself...."*

Health Politics

Access to the appropriate equipment to meet the child's physical needs is not being adequately addressed. Instead, these children with physical disabilities are being given the standard issue of equipment that is outdated but still stored at Whero Hospital.

> *"The conductors are not New Zealand qualified to sign a script for a wheel chair. So, what we are getting and what our*

> *children need are wrong. Our conductors can tell us what we need, we go through Life Links and are sent to Whero hospital and the hospital does not have that specific equipment, so you have to have this."*

> *"I have got a room full of x equipment up there [bedroom] that I have specifically asked for, even toileting and shower stuff but its not what I've got, because* [they say], *'This is all we have got, we don't have that sort of thing'."*

Totara's mother explains some of the difficulties that have occurred because there is a government funded mainstream medical ideology as opposed to a non-government funded educational ideology model.

> *"HFA* [Health Funding Authority] *don't accept the conductors to import it. Again, that's the basis of joining all these different groups because we haven't had the support. The medical* [HFA] *don't like Conductive Education either; you don't exist. When we actually changed over from CCS and we were basically told if you go there you will lose your support."*

> *"We lost the physiotherapist, we lost the occupational therapist but we gained more because it's more hands on, and this is what's happening at the school, because we are not covered under the health professional umbrella."*

> *"If the medical allowed us all to go through our kids would be all better. They gave him 75% of nothing; he would lie there and do nothing. We were there 6 months when he started sitting up on his own without support."*

> *"If I had listened to that I would have had him at home, he would be still lying on the couch doing nothing or health problem. So, Conductive Education has really helped Totara. We have a wee boy across the road that is a year older than Totara; I actually met him there. He was in a worse state than Totara a lot worse, but she gets really upset sometimes when she's here, to see the difference in Totara because her boy could have had that and more, an extension of life."*

> *"They had an assessor out and I think Mei School has the worse case of kids with cerebral palsy in the whole of New Zealand. But, some of the children, who are in the same position like the wee boy across the road, have got better from being in there. His mother has seen them and it is really hurtful to her. We look at Totara now and it's because of Conductive Ed, if my attitude changed I could say poor Totara pat, pat, it didn't happen and we are just going forward."*

COMMUNITIES

Most of the community activities have centred on the supportive role different support groups provide for a child's specific disability. In the case of Totara, the following groups have provided their services to Totara and his family:

Aspergers Support Group

This group supports parents/families with children and adolescents with Autism or Asperger's Syndrome. Activities include, Holiday programmes for children, community support, parent support, group meetings and telephone networks and social skills groups for those with Asperger Syndrome.

> *"We are in Aspersers Support Group, we haven't been to them because I haven't had time to fit it in, but I read a lot of their stuff. I have got a whole pile of stuff from the support groups I am in."*

IHC Incorporated

IHC provide support, advocacy, residential accommodation, vocational support and placements, for people with an intellectual disability. They also provide home support, shared care, and school holiday programmes for children with an intellectual disability. The 'brand name', IHC, is formed from the initials of its original name, the Intellectually Handicapped Children's Society but that name is no longer acceptable or appropriate because they now cater for all ages, not just children. It is also considered that the use of the word handicapped is disparaging and it is preferred to refer to their clientele as, people with an intellectual disability. Therefore, IHC Incorporated is the actual name of the organisation and not the initials.

> *"I use IHC mainly for the support on Saturday and Totara attended the holiday programmes, until their prices went up (extremely high), so I thought no stick it up your nose. They do*

> *a lot of workshops and different things as well. From their workshops I have got contacts for a lot of people I deal with."*

Parents of Vision Impaired Incorporation (PVI)

This is an organisation or network, which is active in the running conferences to ensure that relevant matters concerning social, economic and political aspects of visual impairment can be discussed. They deal with issues affecting people who are visually impaired and provide the means of expression, and insightful exchanges of information for families and caregivers.

> *"PVI have national conferences so it's everyone from New Zealand going to one place. So I have emails from those people if something comes up, and the friend thing, I'm going to be in town sort of thing."*

New Zealand CCS

Offer a range of support services, training and support for integration and recreational programmes for people with physical and multiple disabilities for all ages. They offer a multi-disciplinary team for Early Intervention Services for children from birth-5 years of age. Like IHC the organisation 'brand name' is derived from an earlier, out of date, use of words and CCS is now not the initials, but the name itself. The national organisation is New Zealand CCS. They provide a service, among others, which is referred to as the Whanau Group.

> *"The Whanau group the Marae meeting. I've been with them for five years now, so it's not just the parents, it's also the staff and different people under the umbrella of CCS. I keep in contact with those within the South Island, and people from Hamaika* [recent conference]*."*

RIMU'S JOURNEY

Rimu's disability occurred at the age of two, an event that cannot be identified for the protection of the child in this research. Because of the disability, Rimu was temporarily blinded and paralysed and left unable to walk and with a seizure disorder. Rimu was hospitalised for three months, with two weeks in intensive care.

The medical professionals who have been involved in Rimu's care since her 'incident' have been, an Orthopaedic Surgeon, Paediatrician, Hamaika Visual Centre, Occupational Therapy and Physiotherapy. Rimu has physical manifestations of cerebral palsy, with a slightly impaired gait and limpness on the right hand side. Rimu has a wheelchair for mobility for long outings, a Tripp Trapp chair to help with positioning and a bath board. At present, this equipment is not being used.

Rimu has impaired physical, cognitive and visual perceptual skills. She is able to walk run and jump, but unable to skip, but can ride a scooter and a bike; however, due to perceptual problems it is unsafe for her to ride her bike on the road. She uses her scooter to go to and from school.

Rimu has suffered developmental delay in visual perceptual skills that affect her learning ability in the areas of reading, writing and maths. At the stage of writing this research, Rimu is aged 11 but her cognitive age is between 7-8 years of age.

Rimu is orientated towards familiar people, places and routines. She gets confused with left and right, and has difficulty following instructions to get to a destination on her own. Rimu's mother insists `that either her older sister is with her; or that an adult or a designated caregiver is with Rimu for outside journeys if she is unable to do so. Rimu is self-motivated and able to initiate tasks such as doing her homework. For complex tasks requiring several steps, supervision is necessary to ensure the correct order of steps and the completion of the task.

Rimu's mother is the main caregiver for her. She is involved in her daughter's care twenty-four hours a day, seven days a week. Respite care has been available for school trips, organised camps and some outside activities.

Rimu belongs in a family of four siblings. Her stepsister does not live at home; she is aged 23, married and lives in Tiamana. Rimu is aged 11 years, her older sister (Child 1) is aged 12 years and her younger brother (Child 3) is aged 9 years. All three live with their mother.

Early Childhood and Home Life

Prior to the onset of Rimu's disability, Rimu's mother was a solo mother with very little family support. She had three children under the age of five years and her eldest daughter from a previous relationship aged fourteen living with her. When the incident happened, Rimu and her mother's hospital stay separated the family unit. Rimu's maternal grandparents took Rimu's stepsister to live with them in Tiamana and she stayed in Tiamana after the rest of the family came back together. Rimu's mother auntie looked after the second eldest daughter aged three years and her younger brother aged fourteen months.

Return Home

Rimu and her mother were reconnected with the other children after a three-month stay in hospital, and with the help of a supportive case worker who eased the way, changes in family life were made, adjusting to Rimu's physical and sensory disabilities and for Rimu's care.

> *"I had a wonderful social worker that gave plenty of information concerning places of support, the Blind Foundation and Hamaika Visual Centre, CCS and Work and Income* [Work and Income New Zealand (WINZ)]."

Coping with Rimu's Disability

Rimu's sensory disability was quite severe at the beginning and the mother was told that her child would be blind for life. However, four months after she returned home, Rimu slowly started getting her vision back.

> *"... when she was blind for those 6 months, we were with the Blind Foundation but she went to the Hamaika Visual Unit after that. Apart from co-ordination occupational therapy and living with her disability, there's not a hell of a lot you can do. She just has to learn in her own environment."*

Rimu used a walking frame for one year, having to relearn how to walk again. Rimu started remembering nursery songs.

> *"She came out as though she was another child, it's like having another child opposite to what she was ... she was a stranger to all the family. She wasn't walking, she wasn't talking and she used to cry out a lot saying 'no'."*

Support Group

Rimu attended a CCS Early Child Intervention support group every week, but she eventually discontinued that because of her mother's emotional state.

> *"I felt uncomfortable, families didn't ask for their children to be born like that, whereas I felt 'stupid' because no one really knew my story and I didn't want to say it. So I alienated myself from a lot of people."*

Homecare

A worker from Life Links assessed Rimu and initially they had homecare help with Rimu. However, this eventually stopped because the mother felt that.

> *"... it was my job as a mother to look after and care for my children."*

As part of the change over from Mental Health to Accident Compensation Corporation (ACC), Life Links has returned to assess Rimu's needs in order to plan for her immediate and long-term needs. The doorknobs in Rimu's bedroom, lounge and the bathroom have been changed, in order for Rimu to be more independent in her mobility as well as for her safety.

Rimu's mother identified particular areas of concern regarding Rimu's disability, such as, showering, physical education and a poor sense of direction in unfamiliar environments. Her mother has to lift Rimu into the shower, adjusting the taps, regulating the shower temperature and monitoring her time in the bath.

> *"You can leave her in the bath, then come back later to wash the soap off. I have to give her a little bit of shampoo; otherwise she would use the whole bottle."*

Physical Education

Rimu has physiotherapy for her legs and feet at home as well as at school. Last year she had, her feet operated on prior to wearing corrective boots.

> *"She's supposed to do it herself but I have to prompt her... She gets frustrated with the way she walks anyway, or writing a letter. She's frustrated and she's aware that she is different. I don't think she needs to be pushed into it, she's going on to 12* [years of age]*."*

RIMU'S PERSONALITY

Attributes

Rimu's attributes are:

> *"Rimu's mouth, "smart mouth" and "strong spirit" will get her through life. She'll soon tell you. She is honest, too honest sometimes."*

Examples of Rimu's spirit and determination being asserted have been evident this year since beginning attending a new school (Catholic). She no longer uses the wheel chair taxi services, or wears special corrective boots or needs to have assistance with changing in and out of her uniform during school hours for sport activities.

Rimu's Self Concept

Rimu's frustrations some days may consist of 'Why do I have to go there?" "Why do I have to do this or that", and, referring to CCS Independence Games, I don't want to run with a bunch of cripples". Her mother says, "... that at school, she thinks she is not popular", however, in reply to specific questioning, her mother indicated that she was the most popular student at her primary school, that she has a heap of friends from her old school and friends in the neighbourhood many of whom do not attend her present school.

Rimu is aware of her limitations.

> *"... cried when she couldn't write like everyone else,* [when writing a letter to the television programme, 'What Now'] *and Why can't I be like everyone else."*

Sporting Activities

Rimu has been involved with the CCS Independent Games over the years, which are designed to enable children who have physical disabilities to participate in sporting activities. Rimu has participated in the running and swimming events. Her mother would like further swimming lessons for Rimu to enable her to swim the length of the pool like her other children do, as well as being confident around water. Rimu has attempted Netball, but her visual perception limits her participation.

> *"... because around at Akuhata and at Huare Park, they run everyday and play netball which is compulsory. She is actually playing with the 9-10 year olds because she's never played netball before. She doesn't mind that, but she said, "it sucked"*

> *However, she has a go, but she really doesn't like netball. She knows herself, that she has limited coordination for playing sports as well as her bike riding."*

Future Sport Activities

Another activity Rimu's mother suggested she would like to see Rimu get involved in, was 'Riding for the Disabled'.

> *"She was assessed by a group of physiotherapists training out at Kirini who suggested Rimu was ideal ... She could be part of riding for the disabled because of her good coordination, but that probably won't happen until next year. We can't go out to Ferrymead. It's too much money to get her on the taxi and back."*

Animals

The family has two family pet cats, which Rimu is fond of, "she has a thing about animals and animals seem to love her."

Rimu's Finances

Rimu receives the disability allowance and the handicap allowance to ensure some of her needs are met financially. Rimu has a bank account that requires three different types of identification before she can withdraw any money because her signature is not consistent. These are a bank identification card, her total mobility card with photo identification and her community services card.

Revealing the Disability

The advice from a high profile person [name provided] who has a physical disability concerning when was a suitable time to reveal the cause of Rimu's disability and he thought,

> *"... a good time would be after she has gotten over the teenage years into an adult in order to comprehend it rather that blurt it out now. It would be like telling a teenager daughter, 'Oh*

> *you're adopted'. I don't think she needs it at the moment, when she dealing with* [adolescence] *her bra, discovering herself, rather than having that* [cause of disability] *landed on top of her."*

CULTURE

Tribal Connections

The children have tribal affiliations with Ngati Porou and Ngati Kahungungu from their father's whakapapa. Rimu's mother has taken the children to Whiti to visit some of their tribal whanau,

> *"I have been involved with extended whanau in Whiti, who were originally from Whinarana".... One was out, the other working and the grandfather had since passed away. So I took the kids to the cemetery and showed them because they had vague memories of him."*

I asked Rimu's mother whether the connection is still there for her children.

> *"Well it's not the same. I went out of my way to go to Whiti to see them and then there is the odd occasion the other auntie rings here. No, it's still there. They've got a sister* [father's side] *in Whiti and two brothers in Parani; they can go do all that. No it's all there for them."*

Tikanga

The children attended Kohanga Reo in early childhood. They are very aware of the protocol concerning behaviour in a Maori setting. They have continued with aspects of their Maori culture through Kapa Haka groups in their schools, and social activities around marae visits.

While the children attended Kohanga Reo, Rimu's mother was also involved by learning the karakia, doing a polytech course in Maori language and doing things the kaiako said without thinking. However, the mother has lost most of that knowledge now, because she no longer is involved in things Maori. However she also gained the benefits of the early childhood education while attending Kohanga Reo with the children, and there were social benefits as well.

> *"I knew it, but I didn't carry on with it. They were all there from the day they were born. Child 3 was there since the age of 2 days old. I'd stay there. You had your days where you stay there to help. It was my sanity... of getting out of the house."*

As well as trips away to other Kohanga Reo centres and marae visits, she supported the whanau.

> *"I'd attend the meetings but not the administration and that. Voted for this and that. I was involved in Kohanga for quite a bit."*

WHANAU

Extended Whanau

Rimu's relatives are scattered around New Zealand although no other relatives live in Christchurch.

Rimu's Grandparents

Her grandfather is her only surviving grandparent. He lives in Tiamana, Her mother's hometown, where she grew up. Her mother describes him as "A very hard workingman, often he was absent from the children and mother for long lengths at a time". When Rimu's Grandfather is in Christchurch she will see him, otherwise there is very little contact.

Aunts

Rimu's maternal Auntie assisted the family during Rimu's mother's time in prison by looking after the welfare of the children through budgeting, paying the outstanding accounts and the grocery shopping.

Uncles

There is very little contact with her uncle from either side of the family.

> *"The kid's Dad has only one brother and my brother is dead. So there's no other in the picture, only their Aunties. Oh, they have got Uncle Rod, which is my older daughters uncle. He's taken on the role of Uncle for these three children. Otherwise he's no relation to them."*

Father's Profile

Rimu's father has been in and out of institutions since the age of sixteen. At the time of Rimu's 'incident', he was separated from Rimu's mother and had been since the children were aged 2 days, 1 year and 2 years old and has not been involved in their upbringing. Rimu's father has six children to three different partners; however, Rimu has no contact with her stepbrothers or stepsisters from those families.

Emotional Issues

Due to Rimu's father having very little contact or influence with his children's well being, a lot of disappointment has been felt. When they were under five years of age, Rimu's mother use to take the children to visit their father in prison, but this stopped when the father became involved in another relationship. The children have not been back to the prison.

> *"He's got six children and he doesn't want them. I don't mean to be mean about him, but there's a lot of bitterness in there, because he's hurting a lot of people."*

The children are angry with their father after him sending them letters saying how sorry he was, and that he would make it up to them when he got out of prison, only to find one month later he had been re-arrested.

> *"He'll start writing letters soon saying sorry. Make up! Make up! Hell, we have just had all these letters, now we are going to get another lot of them". As a result, Rimu's brother has been*

> *having behavioural problems at school, but he has good support system around him. Rimu 'just cried', while Rimu's older sister took it in inwardly."*

> *"I've seen changes in her, she is not really dealing with it, she is in a bit of a daze, while her brother has switched right off. Their father sent them a letter and I think its still sitting in there* [lounge] *still unopened."*

The children also feel disappointment with their father's lack of involvement in their activities:

> *"He's never given them the time of day for 10 years and he just knows it. I think he's watched him* [Child 3] *play rugby league once in all the four years he has been playing rugby and I think he saw Child 1 play netball twice out of the five years. He's never been involved in any of her things, Brownies, Boy Brigades, nothing."*

Rimu's brother has felt the frustration of his father not showing up to any of his rugby games.

> *"He was an angry boy before his father got out* [of prison] *because there's no relationship, and broken promises."*

Mother's Profile

Rimu's mother has managed to raise her three children on her own, supporting herself on the Domestic Purpose Benefit with occasional, casual, part-time work. She and her family have had their fair share of tragedy, setbacks and hardship. The father to her three youngest children abandoned the family unit two days after the last child was born. She then had three children, less than five years of age, to support on her own with only the Domestic Purposes Benefit from Social Welfare and Income.

Rimu's 'incident' threw the whole family unit into turmoil with the family members being separated for three months. This was followed by the readjustments of being a family, getting to know each other again and dealing with a child who had a physical disability.

She looked after a friend's 3-month-old baby while the mother was in prison. After her release, Rimu's mother continued caring for the baby until the baby died of cot death at six months of age. Thus, alienated from her friend, her friend's family and her family, she was left to grieve on her own. No support or counselling was offered or taken.

As a result, she began drinking to console the pain, and to relieve the grieving and isolation she was experiencing. She was charged with a Drink and Driving offence and sentenced to six months prison and the loss of her driving licence for four years (she is due to get it back in February 2004). While in prison and separated from her other children, her eldest daughter (Rimu's stepsister) came up from Tiamana to care for the children, and her Auntie took care of the finances and budgeting for the family. Her auntie expressed to Rimu's mother that she was glad she was in prison because her children still had a mother. This was a wake up call for Rimu's mother.

While in prison, Rimu's mother attended some of the courses offered within the prison system and completed some educational courses. She had plenty of time to think and reflect about her life while in prison.

Rimu's mother explains what happened once she was released from prison:

> *" ... 12 months supervision when I left and I went to sentence centre because of my drinking problems and a straight thinking course, and a parenting course. I did three of them, all within a year because of 12 months supervision and I managed to stay dry for 6 months, then I got back into it again. I still battle with it."*

Over the years, Rimu's mother has resided in different suburbs within the Christchurch area and has been able to work part time while Rimu has been at school, on the proviso that it does not interfere with Rimu's care.

> *"I've moved over the years and I've had a few jobs here and there with the kids. One when I was in Kariki Road, working in mushrooms for awhile. I had a boarder living with me at that*

> *time. Maybe two and a half to three years ago the neighbour use to see the kids* [look after them*] after school when I had a part-time 9-2pm, which was only temporary doing a* [factory] *job. So, yeah I have worked over the years and anything that comes up, part-time."*

Counselling

Rimu's mother was first introduced to counsellors when she was released from prison. She went to a few sessions to help her learn better ways of coping emotionally. She found these sessions invasive and stopped going. Since then, the Accident Compensation Corporation's assessor has been in the home and she has started going back to her counsellor. She feels having the assessors in has opened old wounds and she explains why she has gone back to her counsellor.

> *"Well I had too. This stuff from ACC is dragging and bringing it all up. I sort of feel like even though they are transitioning Rimu into the* [ACC] *I feel not being allowed* [involved] *and talking over me. They've got big plans,* [I say to them] *don't assess Rimu, other people have done it for nine years. Don't come in too fast, because I get quite defensive. ... it's a wee bit painful because its bringing in a lot of memories, and its bringing up stuff."*

RELIGION

Rimu and her siblings have received Maori and Catholic teachings, initially through the family and social settings of their father's environment, followed by early childhood education. The children attended a Kohanga Reo where they learnt all aspects of Maori culture, religion and traditions. The children still have a strong connection to their Maori culture through Kapa Haka within the Catholic primary school that they currently attend. Rimu's grandmother was Catholic; however, her children were raised Anglican. Prior to her grandmother's death, her wish was for some of her grandchildren to attend a Catholic school. Rimu's mother has succeeded in fulfilling her mother's wish. All children now attend a Catholic primary school.

The children attend Catholic CD classes. Both Rimu's sister and brother have done their Holy Communion. Rimu will have extra lessons in order to comprehend the procedure so that she too can complete her Holy Communion.

Rimu's mother considers herself an Anglican.

> *"I believe in God, but I'm not an acting living fanatic believer.*
> *I'm an Anglican, but my children are baptised Catholic."*

However, she said that she truly believes that God gave Rimu back her eyesight and she believes in the power of prayer. The church prayer group linked up with North Island members for Rimu during the initial stages of her physical disabilities.

SUPPORT PEOPLE

Extended Family

Rimu's mother identified the main support people who have assisted her along the way with addressing the family needs and assistance she needs for coping with a child who has a disability.

The mother's daughter from her first relationship (Rimu's stepsister) looked after the children while she was in prison, and occasionally, during the school holidays, will still have her stepsisters or stepbrother stay with her family in Tominika.

Her maternal Auntie was receiving the benefit for the children while Rimu's mother was in prison and a little while after her release from prison in order for the household to function. She also taught Rimu's mother budgeting skills. As she explains:

> *"From that experience I have taken on being a budgeter ...*
> *keep something for emergency, keep something for next week,*

> *we're not broke ... we don't run out of bread, milk, toilet paper, because its going else where and you're not thinking about tomorrow anymore which is good."*

The mother's long time best friend has supported her prior to her having children, and has supported her emotionally throughout the years while she has been raising her children. Rimu's mother describes her relationship with her friend:

> *" She's taken on the support role, known her since 16* [years of age]. She *wasn't there when I had the incident – I didn't see anyone for those three months. Rimu's stepsister helped with the kids.* [Mother's friend, name provided] *came out once with my auntie to prison. It was difficult for her to come out, otherwise, because she didn't have a car. Rimu's stepsister used to go around to her place for support. She's a friend who has been there for me."*

Siblings

Rimu's mother has placed a lot of responsibility on Rimu's older sister, *Child 1*, for her to assist and protect Rimu's well being. Rimu's mother believes her daughter, *Child 1*,

> *"... takes on a lot ... might make her a better person ... she is her sister after all ... she might be a bit resentful ... not going to hurt her to help ... she has her own needs ... they communicate ok ... Rimu is closer to sister because of it.."*

Neighbour

Rimu is an outgoing social girl. She has a particular friend across from where she lives, who visits their place quite often. She and her grandmother support Rimu in her social outings because the grandchild is a friend of Rimu. Otherwise, there is no connection to the family, as Rimu's mother said:

> *"No, I don't know the family. Rimu just goes with her friend whose Nana looks after them while the mother works. Rimu just happens to be going swimming with her friend. ... her mother works full time, so her Nana comes in. I think I've spoken to the mother once."*

Advocacy

Rimu's mother believes everyone has a role to play to support Rimu's needs. The professionals are responsible for ensuring Rimu's physical and cognitive learning and support services are in place both in education and within her community.

> *"My role as mother is to look after Rimu's family home environment and well being, whereas the school is responsible for the children's education."*

Having Rimu's needs meet would enable Rimu's mother to pursue activities that are beneficial for herself and her family.

EDUCATION

Primary School

At the age of five, Rimu could not attend the Catholic primary school her older sister was attending because it was suggested her physical disabilities would be better catered for at a school that was equipped to meet the needs of children with a physical disability. Therefore, she attended a school that had a special needs unit within the school. Even though she was attached to the unit, she was mainstreamed into the school, attending classes and participating within the school environment.

With changes in school culture and the attitudes about catering for students with physical disabilities, and changes to education policies towards mainstreaming, the acceptance of Rimu into a Catholic school this year (2003) enabled the transition for Rimu to run smoothly. Rimu is now fully participating within her home environment; her school is in her local community, and she is among familiar friends from Kohanga Reo and children within her neighbourhood. As well as having friends from her old school and she is making new friends at her new school who come from within and outside her local community. To enable Rimu to participate fully within her school environment, it is very important that she be supported fully. Her mother has identified some of Rimu's limitations in learning.

> *"When she's at school she has full teacher aide. I just had an IEP done on her and they said she needs a one on one. ORS* [Ongoing Resource Services] *was there as well and saying the same thing."*
>
> *"She can't sit around in that classroom; she actually goes out of the classroom. She has her own programme; she doesn't do what everyone else does, because she can't comprehend it."*

Rimu's mother identified areas that need particular attention:

> *"She can't use a dictionary or tell the time. They are trying to get the education naturally in but its more about the life skill things, she's got to be able to get around in life you know, and with her visual perceptual is the hold up. She's safe in her own environment, but you can't put her in an unfamiliar environment and say I'll see you in half an hour at McDonalds or something she wouldn't have a clue where it is."*

Rimu's perceptual skills have been identified as a concern by her school and the medical professionals. She is presently being re-assessed after having been categorised under the heading of a medical physical disability for the last nine years, to now having the condition categorised under Accident Compensation Corporation (ACC):

> *"... the teachers and their concerns were the perceptual things but because she's transiting we have had all these interviews. The last lady psychologist is doing all these tests, to see where she's at. Then she's going back to ophthalmologists and the optometrist back for the tests again."*

Other concerns about Rimu's perceptual skills have been identified as reading, writing and geographical directions:

> *"As the teacher aide said she's like this* [crouched over her books with her head close to the table] *she's got to rule her lines because she can't see the lines on her book. She can't get the use of a dictionary. They are going to find a dictionary through Special Education with big print. She can't see when she does read and write, you don't know what she can see and not see."*

Individual Education Programme (IEP). Assessments are an important procedure to identify a child's progress or limitations whenever they change schools or if there is a change in the labelling due to the cause of the disability. The benefit of assessment is that it re-addresses the areas for improvement and the management of the child. However, for the parent this can sometimes cause anxiety concerning expectations, as well as raising doubts about the validity of previous assessments and reports, as true guides to gauging the child's progress.

> *"She has a fractural error from the brain and that's where she's delayed in her learning. I was a bit hacked off with them because last year she had a reading age of 7 ½* [year] *and that's what they said. They had one term with her this year and the lady said she said 6 year. How can they say that in one term? They've only had her for one term give her a chance. When they said Rimu's reading was back to a six year old, I said, "How did she go from seven and a half back to six in one term", maybe she's not reading enough. I'm going to keep an eye on that one. For the next IEP I will want to know why."*

Learning Difficulties

Rimu's school studies involving manual skills, telling the time and life skills are areas that are difficult for her on her own due to risk factors, as her mother explains:

> *"As the teacher aide said about her this year. She can't do manual – she can't do the sewing without helping her. You can't stand back and let her follow the instruction from the manual teacher. The teacher aide has to get in there; otherwise she would chop all her fingers off."*

Alternative and insightful teaching techniques can be helpful, and beneficial, but they can also add to the confusion of learning if the learning between home and school differ. Rimu's mother describes an example:

> *"At the moment Rimu is learning how to tell the time. The ORS* [On-going Resource Officer] *man said why is she learning quarter to and past, instead of 9.02 or 9.15, or 9.50? Oh, are you trying to tell us to start going another way around. I'm*

> *sticking to the past and to at the moment. You can buy watches with the past and to on them nowadays."*

The removal of funding and resources from a child's support framework to learning can also be stressful to a parent who knows their child's historical background, but has little input into the decision-making. Parents continually have to battle to keep support systems around their child.

> *"... they nearly cut her hours off the ORS. The input mainly came from the teacher aide that she has to do her own programme as a one on one. ... they tried to about three years ago; it was Huare Park* [old school] *that fought for it back. Nothing has changed from the last six months at Huare Park to this year. So don't take them away sort of thing. The physio at the school thought she wouldn't need physio because they run every morning. She thought she might cut down on the physio, I said "No, she's been running around for the last five years and still needed physio for that particular part of her body. So I'm questioning* [the main health professional that knows her care], *so I'll get it on paper, which will say she still needs physio. I will beat it. They are not going to take that away."*

Learning Technology

Learning aids, such as a computer, are vital tools that can assist children who have a physical disability.

> *"She does a lot of work on the computers at school. Part of her occupational therapy, they make it all really big, and she can take it at her own pace. A lot of her work comes out on paper so she can see it. Which is another way of doing it. That's always been part of her education."*

Selecting a Secondary School

Even though no definite plans have been finalised, her mother is aware of some of the choices she faces regarding the choice of secondary school for her children.

> *"Hepetema has got a Special Needs Unit but because she needs a teacher aide [all the time] she may go to the local school, which is either Oketopa or Nooema when each makes their mind up or when I make their mind up for her oldest daughter.*

> *I don't know whether they'll be going there because I say so or not. In the end I don't know which high school she will go. I want [Child 1] to go to Oketopa College, she doesn't want to go to Oketopa, and she wants to go to Nooema. I'll just see where she's going to get being around here first. It's a whole new ball game being down there* [Nooema]."

Rimu has one and a half years of schooling remaining at her present school before decisions about a secondary school can be addressed,

> *"She's nearly through this year. It will just depend on how she does this year."*

HEALTH PROFESSIONALS

Communication, Confidentiality and Trust

Rimu's mother identified some hurdles when talking to professionals, which may at times hinder constructive communications when confidentiality is not respected. Trust is fragile between health professional and parent when it comes to discussing a child who has a disability.

> *"It can become quite difficult at times and because I ask a lot of questions they almost think I'm confused.* [For instance] *I quite clearly said to her* [Occupational Therapist] *I'm not confused because I was querying why did she feel because she runs and exercises around there* [school], *should she not need her physio to her leg, because she's been running since that happened* [the cause of his disability]. *I'm going to check that out for her because if you take that away from her, it might be hard to get it back. I'm going to check that out and get it in black and white."*

Rimu's mother has sought the advice from Rimu's Paediatrician since Rimu's 'incident' and he has supported her when trying to understand the changes as they occur from time to time when Rimu's disability is due for assessment. He has also written letters supporting services needed to aid and support Rimu's disability.

Rimu's mother gave another example, where one health professional can make an assessment, which may not be in the interest of the child who has a disability, or for the parent who believes her child needs that particular support.

> *"If they say she doesn't need physio, that's only one physio lady that met with her one term this year and doesn't know Rimu from a bar of soap and has no background* [knowledge] *I will be checking with the people that know her background.* [Two] *public surgeons* [names supplied], *who are the two people who can overrule a physio can say in one term, because around at Akuhata and at Huare Park, they run everyday and play netball which is compulsory."*

COMMUNITY ENVIRONMENT

Safety and Familiarity

Rimu moves freely around her local neighbourhood, going to and from to school, but she needs supervised assistance elsewhere,

> *" ... watch her get around and you think there's nothing wrong with her until you get down to it and the teacher aide agreed with me. ... we have lived here for 6 years, so she will know her way around here. But, you couldn't do it in another area. If you said, wait over there by that tree; because all trees would look the same to her, that's what it is to her. Like I have a friend at Haiperu, she stayed there for a weekend. She was going to send her to the shop and I said you probably wouldn't see her again. So, she's got to be looked after in that way, and she's vulnerable not gullible. So she does need the extra protection."*

Public Transport

Rimu will use the public transport on the proviso that someone supervises her. She recently went to Tominika with her older sister during the school holidays to stay with their stepsister. She requires supervision for health appointments that require a visit to their offices and when using the public swimming pools.

Outdoor Activities

Rimu's physical limitations are hindered because she has a slightly impaired gait and limpness on the right hand side. This makes it difficult for her to walk for long distances; she uses her wheel chair to alleviate this problem.

> *"They* [school] *did a trip to Hanekari last year and she couldn't have done the walk and she didn't* [without her wheel chair]; and they took her chair to America with her [when she went to Disneyland with the Koru Club] *because she couldn't walk all day."*

Respite Care

Rimu is entitled to twenty-eight days a year of respite care. Rimu's respite care is used for school trips, camps and events away from home. Respite care can be paid for members of the family who assist in these events. For example, Rimu's stepsister, and her aunties are able to do the respite care when needed.

Rimu's mother has been tending to Rimu's needs for the last nine years and has not considered using the respite care for 'time out' for herself as she explains:

> *"... take one child away, I still have the other two to look after, so no real time out ... might as well have the lot."*

Social Services

Rimu receives the disability allowance and the handicap allowance to ensure some of her needs are met financially.

New Zealand CCS (CCS)

CCS has been involved since the onset of Rimu's disability. She attended the whanau support group, but drifted away quite early in the piece. However, she still attends a few meetings and still receives the whanau newsletter. Rimu participates in the CCS Independence Games, which is held yearly.

Accident Compensation Corporation (ACC)

For the past nine years, Rimu's disability was funded under the health system. Only this year has her disability been properly categorised and placed under the auspices of ACC because of the circumstances of Rimu's disability. Therefore, for the last four months or so, different ACC assessors and health professional services have been assessing Rimu's disability. This has caused some old issues to surface again, as well as anxieties for Rimu's mother.

> *"Where ACC is concerned they are still sorting their stuff out. They accepted her ACC claim thanks to Rimu's paediatrician. They have brought in all these independent assessors and they are going over the same things the Health Board does every year. Every year she's sees the paediatrician, the doctor, and a double check with the physio. ACC have to come in and get their own assessments on top of what she's always had with the government funding help. So at the moment I think they are invading the whole thing. I wished the hell that I never tried to go with ACC because they are upsetting and dragging you know* [past], *that's how I feel."*
>
> *"Well they... are going over the same ground, for example a Neuro-psychologist. I said what are you doing here; Rimu's never had one all of her life. She said," I see its confidential Rimu doesn't know any of this"* [cause of her disability], *I said yeah. So what does she do? Walks into the house and says, "Hi I'm so and so from ACC". I thought what part of confidential do you not understand. ... after me telling before meeting Rimu, she realised it was confidential."*
>
> *"Rimu is not stupid; she will soon work out what ACC ... mean. She might see a paper or something like that. I thought to myself "Oh you haven't told her". No, I'm crossing that bridge when it comes and I wondered if she was trying or deliberately say that, wanting Rimu to start to know. But, they better not go there with me. She knows she was sick as a baby* [Rimu], *but that's as far as we have gone. That woman knew I said confidential but she went ahead and said she was from ACC."*

She gave an example of people rushing in, not introducing themselves and dismissing the mother's concerns,

> *"The physio was talking about her* [Rimu] *and ACC and said don't be confused about all this sort of thing and I said "I'm not confused" because I was asking my questions. There were two other people there, I don't know who they were that were there* [she was not introduced to them]. *In the end I asked, "Who are you" sort of thing."*

I asked Rimu's mother what she thought of ACC taking over Rimu's long-term care:

> *"I don't know whether they can do anything better than the government has done to it. Apart from giving her an Independent Allowance, which I feel, she deserves, because any other person on ACC gets it, plus their care."*

Trust Fund

In Rimu's case, it is assumed she will get funds backdated to when the incident happened. This money will be put into a Trust fund; she is not entitled to a lump sum because of the severity of her physical and cognitive disability. When this happens, concerns about distribution and management of the Trust Fund will be raised:

> *"I know by law if she does get funds backdated, it goes into a Trust account for her. Which I can deal with that as it goes. But, somewhere along the line I'm going to give it* [nominate another caregiver] *if anything happens to me so someone is overseeing the Trust. That it's not as easy as that with Rimu being vulnerable. In years to come I wouldn't say oh give it to her when she's 18, I'm all right to say 25. She's more an eight-year old for her age and she's coming on twelve. So you couldn't really say at 18 because at 18 she maybe only 14 in her mind. I don't know that until she gets older. They won't know."*

Rimu's mother saw the benefits of ACC taking over Rimu's care because long-term care would be required around her disability.

> *"Yeah, it will be a continuous thing all her life and her paediatrician* [name supplied] *once said, she will end up in a chair by the time she is 30 because her hips are going to go in her back through her gait, weight and how her hips are. She's not eligible for a lump sum, because she's eligible to be with them for the rest of her life."*

FUTURE OUTLOOK

Looking into the future, Rimu's mother decisions are dependent on Rimu's care and therefore cannot project a life separated from Rimu at this stage. For example, regarding work or further education opportunities, Rimu's mother said:

> *"Well I could when she is in the hours of school or we had those Oscar programmes and that, I'd go."*

Rimu's mother believes that some aspects of Rimu's disability may hinder her full participation, or of having a normal life, but with the proper care and support, anything is possible.

> *"With Rimu, it's hard to say. There are a lot of things that are not going to happen for her in the future. I don't know, that's a hard one. But then she just independent, that she'll say she's going to do it. That's when CCS and those sorts of people will come in. They have people that work with young adults who want to go into the community, who want to do. They have people who do all that. They will show you the strategies."*
>
> *"She will always be with CCS and they will be her background if anything happens to me I suppose. They will be on board with her, if you know what I mean."*

MATAI'S JOURNEY

Matai is a fourteen-year-old adolescent boy who currently attends a Catholic High School in Christchurch. He is an only child, living at home with his maternal mother, and stepfather. The family lives on the outskirts of Christchurch in a township called Arapeninia. Matai catches the local school bus that takes the children into Poriwa daily to attend school. Matai's disability occurred at the time of birth. As a result, Matai suffered asphyxia and had scoliosis in the spine. Matai's medical professionals have involved doctors, specialists, paediatricians and occupational therapists.

Community Support Services have been provided through extended whanau and CCS New Zealand and Matai's social interests over the years have included Rugby League, Kapa Haka, and extended whanau activities in both the South and the North Island. Matai prefers familiar people, places and routines. Whanau and extended whanau members are important to Matai for his social and emotional needs.

At the age of five Matai and his family moved from Piritene to Christchurch, leaving behind a well supported family, networks from extended whanau and health services, so that his mother could be close to her whanau members (mother's side) in Christchurch, and because of her partner's move to Christchurch.

FAMILY PROFILE

Matai is a very sociable teenager who is happy to engage in conversation with others. Even though he is quite independent and is confident in communicating his views, Matai still has certain limitations due to his disability.

> *"... he's got to be supervised ... I can go to the shop, buy bread, come back and he's fine. It's constantly teaching safety*

> *and that sort of thing. But, apart from that he looks after himself, goes to the toilet and can shower himself. Matai's basic care requirement is, "He constantly needs his muscles massaged."*

Disability and Homecare

Matai's disability has not been identified.

> *"They have no label for him. He suffered asphyxia at birth. He had scoliosis in the spine that stems from lack of oxygen at birth. As a result he has out of rotation in his hips and severe tightening in the back, that causes him to lean forward and crunch over ... having scoliosis puts more pressure on his hips. He has night splints that he wears to straighten up his legs to stretch his legs. He can have operations later on but well that's something that you would have to seriously think about."*

Social Activities

Matai is adequately involved in his Maori culture when he is around whanau and external whanau, and at his Maori studies at school. For example,

> *"Hangs around with his cousins. Going on holidays with whanau. He isn't in anything specific that's specific Maori other than up North."*

MATAI'S PROFILE

Friends

Most of Matai's friends are his cousins. He has one school friend who spends time with Matai, either visiting or staying over at each other's place in the weekend. This friend attends the same school as Matai. He also has special needs but different from Matai's,

> *"They're both quite different, and they're both quite independent,* [but] *they're on a similar level."*

Transportation

Matai is unable to use the public transport provided by himself. However, he does use the public school bus to travel to and from school and home, and on school trips. Their location may hinder the use of public transport, however Matai's mother has considered a strategy for Matai to become more independent, but in the meantime, Matai is privately driven by whanau and extended whanau to most places. Matai is supported by his whanau or extended whanau when he is out in public, whether this is:

a. **School.** Matai will catch the school bus that arrives and leaves directly outside his school and return home on the same bus.

b. **Shopping Malls.** In shopping Malls,

> *"... he does his own thing; he and his cousins will go to the pictures. I won't let him go to the pictures by himself. But if he's got another cousin, they will go to the pictures together, and they will hang out at 'Time Out' and things like that."*

c. **Parks.** *"He'll roller blade up North and we roller blade down at the school, but I don't actually let him go wandering down to the school by himself unless his cousins are with him."*

d. **Social Activities.** Matai attends different concerts with the family when they arise, and this year, Matai recently attended a school social disco.

Special Attributes

Some of the special attributes identified are:

> *"... very sociable. Good sense of humour, very friendly, it came through in all of his reports. He's not cuddly, I mean he is to me, but he's very particular, he doesn't like some aunties. He's not a touchy-touchy type of person, but he's quite loving and friendly, which is probably good. In all his reports it's very clear that he fits in well, he's like a little mentor for other children, and even bigger children."*

Matai is very sensitive and receptive to other people's feelings and stresses,

> *"He's quite intuitive, he's very tuned into people and he remembers names."*

Characteristics

One of the strengths of Matai's character is his sense of humour,

> *"He can play games with you too. Like I've warned the school, to be very careful and don't take Matai for granted. He's not silly and I'm not saying that you think he is, but he will run around if he thinks you are, whatever. So be aware. I'm warning you now because he can be a character you know, there's a little, humour about him, it's a natural Maori gift but the way that he is, its still there. It's like; people don't see it as Matai deliberately doing things sometimes."*

Self Esteem

Humour is a vital tool for self-esteem and explaining social issues. Humour is used to explain how different perspectives and how people interpret meaning.

> *"I guess for Maori that's the way we heal. I even get them to laugh at themselves, they become stronger people and they become confident. I can laugh at myself and my whanau, and they know it's not intended to hurt."*

In order to make sense of his world, Matai needs structure and support around him. When there is a conflict around issues of how he sees things to be, this can cause anxieties especially about change. For instance, he would be inclined to think, why change something if it works, even if there is an easier way of doing it. Matai will see things as "black and white". For example,

> *"This poses to be a problem sometimes. He's black and white, if it's wrong, it will always be wrong, it won't be right tomorrow. He knows rules, he learns rules and systems well, "no you can't do that", "no, this."*

CULTURE

Maori culture has supported Matai's growth and development, as well as being a support mechanism for Matai's family identity.

> *"I don't know how I would have got on if I wasn't Maori, because I think as far as being Maori is concerned the support network was quite strong, so he has a lot of whanau that I'm quite comfortable with."*

Tribal Links

Matai's tribal links are:

> *"Matai's father is Te Arawa and I'm Ngati Whatua. Matai has got quite a strong sixth sense and I guess it's probably in his line as well. His great-grandfather was a faith healer, his grandfather as well, so all special needs children have gifts, so I guess he gets a bit of a double dose and he can be probably freaking the average person out sometimes."*

Home Marae

Matai spent a lot of time with his grandfather (father's side) whenever he visited his homestead, which was close to the marae. Matai spent a lot of time, 13 years, with his Koro;

> *"... they were very close from when he was a baby. He was quite close to his grandfather, so when he died a year ago, it hit him quite hard. It was so sad."*

He never knew his paternal kuia (grandmother). His kuia died when Matai's father was three years of age.

The Maori Language

Matai's maternal grandmother and grandfather did not speak te reo Maori, however Matai's mother was introduced to te reo Maori at secondary school. Matai's mother would not describe herself as a fluent speaker; however, she is aware of the Maoritanga and tikanga.

> *"My mother didn't speak, so she didn't help me much at school* [Maehe High, Ararata] *where te reo was strong."*

Food

Maori ethnicity and culture are very important to Matai's mother and her whanau. She is involved in creating cultural food and attending cultural dances and festivities.

> *"I make rewana bread, and I learnt a couple of years ago, how to actually make the rewana bug myself, which I couldn't do. Because I didn't have any resources out here, no aunties to go and knock on the door and say, "Can I have a bit of a bug?" So I had to learn it myself."*

Kapa Haka

Matai's stepfather is also very much involved in the Maori culture.

> *"He does Kapa Haka at a national level. His mother was a judge at Kapa Haka as well, so he's always done National Kapa Haka."*

Te Reo

Matai is at the age where he is learning about his culture as part of his school education, through language and protocols.

> *"Matai attends te reo classes at Pepuere's and he is doing quite well. I went to see a pouwhiri* [that Matai was participating in] *... he was up the front and doing his thing, so he's enjoying it."*

Faith Healers

Faith healers are a natural part of Maori culture that Matai's family participate in, namely, in healing, blessings and spiritual guidance.

> *"We participate in a lot* [in faith healing], *probably not as much down here as we would up North, but that's because we're not in our area. We were invited to go to Arapia, to speak about our child's progress because Matai always been under his care since he was 6-7 months old."*

Social Activities

Matai will accompany his family to culture festivals and indigenous conferences, as well as to sporting activities.

Understanding or Sensitivity towards things Maori

Matai's mother believes that aspects of Maori culture are not encouraged when dealing with disabilities.

> *"We had a Maori girl who helped us out at Mangu not specific to Matai though, but she was there. We had no Maori teachers in Aperira. But, there's a need for it. ... There's not enough sensitivity, support or understanding of Maori culture. For example, I've dealt with special education and CCS, health system and we have never encountered nor had a Maori in any of those places, except CCS. There's no Maori in Special Education. There are a lot of issues that need to be dealt with when dealing with Maori, especially spirituality aspects."*

The visibility of Maori in key positions is important, especially for Maori to be understood when it comes to complementing medical health with traditions.

> *"My sister is the tikanga advisor for Peretiama Health Board ... my friend and I from Uni attended one of my sisters' seminars when she came to Christchurch. An awesome seminar, she spoke about the wairua spirit, understanding Maori concept, individual wairua, whanau, hapu, the iwi."*

Ethnicity and Culture within the Health System

Matai's mother explains her experience of ethnicity and culture within the health system.

> *"In Piritene, I guess because of the population you have more Maori there, more Maori nurse. But, you know with the health system because it changes so often, they haven't got anything specific* [to Maori]. *No one specifically said to me, to give me the notion that they are sensitive towards Maori or culturally sensitive. So, I've never had anything like that put in front of me and said, 'Would you be more comfortable with a* Maori [social worker etc.]."

Regarding aspects of Maori and cultural values, Matai's mother explains how these are being learnt within the home environment.

> *"We tell Maori stories and Matai exposure to University, he comes to University with me and keeps up with the play [Maori studies] in lecture rooms."*

Different Approaches for Better Understanding

As Matai's mother explains Maori- non-Maori differences:

> *" ... as such non-Maori think they know everything. They think their way is right and that's it. We like that interaction of getting to know each other, "Oh, where are you from?" That's what we are good at. Like for mihi and powhiri that is the ultimate way of stranger-to-stranger, ultimate way of meeting people, it's more "Oh Kia Ora", "Oh hika". It's the same thing but it's not on the marae, instead of straight into business, and very matter of fact like."*

WHANAU

Extended Whanau

Matai's family is well supported by both parents and his stepfather's whanau,

> *"I'm proud that as far as our whanau is concerned, that the support has always been there. Regardless that we've parted [Matai's parents], both families have been there. Matai's really been like a ' taonga' to them, so even when we parted, we both get on with both families."*

Mother's Extended Family

Matai's mother comes from a large family.

> *"I'm in the middle. I'm the youngest of eight to my father. I'm the oldest of eight to my mother."*

Matai's mother was raised by her extended whanau. Her great aunt (mother's side) raised Matai's mother until she died; Matai's mother was aged seven years, when she went back to her mother to be raised.

Matai's Grandfather

Matai's grandfather (Mother's side), who he visits occasionally, is aged 92. He is a very active and important person within his community. His grandmother died when Matai's mother was seven years of age.

Mother's Profile

Pregnancy

Matai's mother describes her pregnancy and the ordeal of Matai's disability:

> *"I already knew 2 weeks prior that I would have a caesarean because he was going to be a breach baby. I actually went in the night before because I was having pains and I thought I was contracting, and I was showing stress signs. The doctor came in and said after calling for a second opinion, "Oh no, I'll operate tomorrow". They had a machine monitor the baby. Discussions with friends about the incident were sceptical about what happened, and I always wondered about whether Matai suffered asphyxia that night."*

When Matai was born in Piritene, he was placed in the hospital Szabo wing, where babies were monitored if they were showing signs of some disability.

> *"I didn't know I was a first time mother to Matai; I had nothing to judge it on. I didn't think there was anything wrong with him.*

> *However, I knew there was something wrong with him because we'd been in Szabo, but as far as I was concerned he was fine when we left for home. When he was 6-7 months we definitely knew there was something wrong with Matai."*

During a visit with the paediatrician, Matai's disability became clearer.

> *" ... he said "Oh ... there is something wrong with your baby" and*
>
> *I said, "ok" trying not to panic, "Do you know what is it?*
>
> *"We think he may have cerebral palsy" and*
>
> *I said, "Oh, ok", and*
>
> *he said, "What we'll do is send you a letter and we'll put you down in Mangu hospital", and*
>
> *I said, "Well ... no"*
>
> *I said, "You've just told me there's something wrong with my baby, don't expect me to go home and wait for a letter."*
>
> *I said, "You do it now!"*
>
> *I said, "You ring those people, and you get them to come up here. Not next week, not next month, NOW!"*
>
> *"So he rung them up and they came up."*
>
> *"Just go home and we'll send you a letter, I though that was so bizarre."*
>
> *"So they came up and so we go straight into Mangu. It was good because all four specialists, practitioners, and your therapists were there. They had little rooms where you could put your children in there for a weekend. It was set up to give parents a break especially those who didn't have support, but Matai never went there because he has so much whanau, so we didn't need to use that facility."*

Assessments

From the age of 6-7 months, the specialist monitored Matai's progress in order to identify a possible label that would define a majority of his symptoms and outcomes. However, the outcome from the test could not identify a specific condition, so to date Matai does not have a medical label.

> *"They get all these tests done and then they do the next set of tests 6 months down the track. It was test after test, where they monitored his progress as he has grown, that's why they haven't been able to put a label on him. For example, 'One moment he's cerebral palsy', then next, 'Well he could have this, but he hasn't got that'. 'Now because certain children don't do this and they don't read, so he's not that. They've sent his records around the world. He's not retarded; apparently it's quite common, that there are a lot unlabeled children out there."*

Parent's Separation

Matai's parents separated when Matai was three years old. Matai went to live with his mother.

> *"I was on the Domestic Purposes Benefit (DPB) when I first parted with Matai father, and I got a disability allowance for Matai. At the time when I was on the DPB, there was not the stigma of getting back to work. As a solo mum, I was on my own for three years. I was living on my own with my sister. I met my new partner prior to moving down to Christchurch."*

Work and Education

While living in the North Island Matai's mother was able to stay active through part time work and further education.

> *"I was quite active; I worked part time as well while being on the DPB for about 3 years and then studied computer office systems at Polytech."*

When she moved to Christchurch she did part time work before returning to further her education in Maori studies at Parahi University.

Matai's, mother's personality shows through when she recognises people in key position who can also hold gate-keeping position as well.

> *"I guess I'm an anti-system type person because I don't accept anything, unless I understand it totally, and I guess from being up North and the experience up North, they actually in a way trained me to look after my son. So when I came down here I knew exactly what to expect and what not to expect."*

Decision Making

Matai's mother describes the different stages in the decision making process when the family decided to move to Christchurch.

> *"We came down to Christchurch for a couple of visits before we moved. When you have a child with special needs it's not a matter of packing up and moving, you've actually got to set up a few things. I did things like; set up connections for his health such as specialist, getting transferred from the special education up there, making contact down here once we decided to go. So I already had things set up before we left. All the contacts I needed when I arrived here. They were pretty good in Piritene, pretty switched on, and I knew which specialist I was going to, where to go etc."*

RELIGION

Matai's parents come from two religious perspectives; however, there is no conflict between the two. The whanau religious view:

> *"I'm not Catholic, Matai's Catholic and I'm Ratana. For me, my fathers Yugoslavian, my mother's Ratana and my great grandmother was Ratana. Meanwhile Matai and his father are Catholics. Matai father's family are very staunch Catholics. But I let him* [Matai's father] *make the decision; Matai's his son ... the way I see it, he'll* [Matai] *find his own. For example, Matai said 'Oh Mum, religious studies is so boring', but he gets an awesome report for religious studies. I felt a little bit guilty when I had told him, 'Oh well just tell them you don't want to do religious study and do something else'. It's not a biggie to me (religion) at least he got some thing to judge [compare]. I think the more important thing to me is not religion; it's more about Maoritanga. I think there are only three mokapuna that*

> *are Catholic. That's through their father's line. My sister's husband is Catholic so her two children are Catholic as well."*

The Ratana Church to Matai's mother is strong and it's based also on Maoritanga. Matai's mother remembers when she was christened with 3,000 babies, *'I was living in Peretiama at that particular time and they were having a Ratana christening Day at Peretiama Square'.*

EDUCATION

Matai's educational background

Matai attended the following educational facilities: pre-school, kindergarten; Catholic primary school, Hanuere; and he currently attends a Catholic secondary school, Pepuere. Matai has had the support of school principals, teachers and teacher aides in the course of his education. Funding and Assistance have been provided for Matai's schooling through On-going Resource Services (ORS), and Special Education Services (SES). Academically, Matai is an average student. He has an Individual Education Programme (IEP) that identifies the areas where specific goals are to be achieved. He fully participates within class with the exception of violin lessons, which he attends at his old school, Hanuere.

Preschool

At Mangu Hospital, Piritene, they had an excellent preschool, specifically for children with physical disabilities. However, some children were too aggressive towards Matai.

> *"I left him there for a week. They actually paid you to take him. He got an allowance, they couldn't hold up his head until he was 4. His eyes used to roll around. At that time, he couldn't hold his head up; he used to shuffle."*

Preschool Education

Matai's mother weighed up what preschool education her son would attend, whether it would be kindergarten or Kohanga Reo.

> *"He went to kindergarten. We had a choice of* [attending] *kindergarten or Kohanga Reo because his father's aunties were all Kohanga Reo* whae [leaders, teachers]. *They would have looked after him, but I chose not to choose that path because I wanted him to stay within the system, and I didn't know what to expect. The stigma around Matai's time* [Kohanga Reo] *was a gloried baby-sitting outfit. I don't know what it was like down here, but up north it was pretty rough at that time. They did have a stigma attached to Kohanga Reo, however it has improved since Matai's time. They have something to look forward to now from Kohanga, to Kura and then to Wananga* [pre-school to school to college]."
>
> *"Whereas I actually targeted Matai towards the non-Maori system, to me the whanau was always there, I already had that, but I guess I needed to tap my way into this other world that I knew I had to deal with. I specifically wanted to start Matai learning te reo Maori at Form 3 so he can be well into it. Goodness me, could you imagine him special needs and he couldn't speak English. We would be more disadvantaged I mean later on."*

Selecting a Primary School

When deciding on the type of schooling for Matai, they first drove around the different Catholic schools in Christchurch before moving here, until they had selected the school they thought would be good for Matai, and then set up an appointment. Matai's mother describes the selection process.

> *"I brought the BIG file down and we turned up after making an appointment with the Principal. It was quite freaky really because he said yes, yes come in sit down. I said, "These are Matai's files" and I started talking about where he was at, and he said, "Oh that will be fine, put them down there and we will have to get together some other time". I started asking questions like, "Well I'm not quite satisfied with that, I need to know a little bit more", and he said," Oh yes, we will get into that, he'll be fine here" and that was it. I said, "Well thank you very much, but what I'll do is take these files and I'll bring them back when I come back and see you."*

At the end of the interview while in their vehicle, she said to her husband,

> *"He's not going there, if he can't give me the time of day". We were about to head out to Arapeninia when I saw 'Hanuere', so we decided to see if the Principal was in, because it was during the holidays. Sure enough he was."*
>
> *"He said, "Kia Ora, come in". We sat down. (He's from Purukeria, but I didn't know that, because when you looked at him you wouldn't know he had Maori in him). But I was quite impressed that he had said "Kia Ora". He gave us 2 1/2 –3 hours and that was without an appointment. The other one gave us five minutes with an appointment and brushed us off. So when the holidays finished we moved Matai here and Matai went to that school. He was really interested in where we were from."*

Matai's Involvement and Participation in the Selection Process

> *"I never took him on the trips, visiting the schools except when I had made a decision. I didn't take him because I didn't want him saying, 'Oh no I'll go to this one, oh no I'll go to this one', 'Oh yeah this ones good'. I couldn't cope with all that."*

High School Selection

The process of choosing a secondary school:

> *"With the help of the school's special needs teacher and my caseworker from CCS, we sat together and discussed the options of high schools within Christchurch suitable for Matai. "I did the big search thing again. We sat down and looked at his Individual Education Programme (IEP) then we made appointments with Poriwa, Parahi and Pepuere."*
>
> *"We went to Parahi; the reason why I chose Parahi was because of their Maori department. They've got a Whare out there and it's really choice. They've got something like decile 9 for the whole school. There was no one there at the Whare on the day to speak to so I wasn't too concerned, I said to them* [the support team], *if I'm more interested I'll come back."*
>
> *"The three of us felt he* [Matai] *was beyond where they were at in the special unit at Poriwa. We felt he would lose confidence*

> *because he had been so involved in mainstream and plus some of them were a lot bigger and some could be a bit aggressive. That's how the teachers weighed it up, I didn't go along with them, I just knew when I walked through the door we wouldn't be going there. But we went through the motions."*

> *"We then went to Pepuere, and I guess probably I was in two minds Pepuere and Parahi, but like I said it was familiarity on the same bus etc. The education resource teacher apparently was excellent. We actually found out a lot from another special needs boy from Hanuere who had gone to Pepuere. So we already had reports back on what was happening to him and the improvements he had made through correspondence for maths, whatever, and they go at their own level and things like that and then they also go into the class etc. There's not much difference in population from Hanuere, 400 plus. You have got Hanuere there and Pepuere right next door and their field is joined with just a set of trees in-between. So you can see Hanuere school from Pepuere school."*

> *"I looked at putting him into co-education ... at Parahi because I'm over that way [studying] and I looked at Poriwa because they have a Special Unit there and of course Pepuere because it's a Catholic school and it's smaller. I think what made me decide was the fact he would go on the same bus, with the same kids, geographically he's close by and most of the children from Hanuere are at Pepuere and he's familiar with the school in a sense that they went to dances and stuff like that."*

Academic Reports

This is Matai's first year at High School; any initial problems that occurred were sorted out promptly to ensure Matai made the transition smoothly.

> *"I rang up the school, two weeks after Matai started high school. Matai's has had mainstream education for the last nine and a half years. His progress for this year's education at high school, "his first term was 98%, his second term was 85% just gone. So his attitude and social skills have actually pulled him up quite a bit, its pretty much high marks for all of them."*

Subject Choices

A couple of Matai's subject choices (violin and Maori) at the start of his high school year conflicted with each other, until Matai and Matai's mother confronted the school about the clash.

> *"Matai still takes up violin at his old school. He walks across the field and he goes to the same violin group and his violin teacher, who is in the New Zealand orchestra They* [teachers] *put his violin lesson in place of Maori studies as opposed to replacing religious studies or some other subject."*
>
> *"I didn't know that until I went to a meeting. Matai was quite cunning, he brought it up at the meeting when I said, "I've got your violin in the car," and he said,*
>
> *"Oh no, I don't want it".*
>
> *"Well don't you do violin today?"*
>
> *"Well I have to go on my Maori class and I don't want to miss my Maori class"*
>
> *and then I realised "Why".*
>
> *His violin lesson was booked the same time as Maori studies. I said, "Maori is important I don't want him to miss his Maori class. You take him out of something else; you don't take him out of Maori."*
>
> *" I could see the look on his face* [Matai], *then I knew he instigated it, he knew I was coming and deliberately left his violin behind."*

Transportation

When Matai's family lived in the North Island, Matai had taxi chits to pick him up and deliver him to and from home and school. Moving to Christchurch, Matai used the local school bus, which was paid for, by the school until last year. The school has since contracted out the bus service. Otherwise, Matai's whanau and extended whanau will transport Matai around Christchurch.

Cultural Sensitivity

Within education, the experiences of feeling culturally connected to other Maori teachers and supporters are limited because they are few in numbers. However, when you do get a good support person, who relates to you as though of the same ethnicity, then that dialogue and support is appreciated.

> *"I guess with the system at school seems to be working well, but I would say they are not Maori sensitive. Everything that I have encountered apart from my caseworker from CCS, who is truly for Maori, has been non-Maori. My caseworker is really out there. If she didn't have a white face and you just spoke to her you would think she was Maori. She's real asset and knows all the little tricks, she's awesome and I'm glad we ended up with her."*

Assessments for Children who have a Disability

When a child has, a physical disability, Matai's mother is concerned with how they assess the child. Whether it is a general assessment or the same for everyone or is his disability taken into account.

> *"I have an issue with the school. Matai got a B for school uniform – because Matai is very particular that's one area where he wears the proper uniform, shoes and so forth. He doesn't like to be out ... he likes everything the same. When he leaves home, he is tidied and I wonder if he got a B because he can't reach at the back to tuck his clothes in* [for example, changing for sports activities]. *If he redresses he can be a bit untidy and if it's that, then he should get an A. What we can do* [reach behind our backs] *he can't do that. He couldn't reach behind his back, to me its part of his disability."*

Maori Education, knowledge and experience

Matai's mother is pleased that there are aspects of Te Reo Maori being taught within the school, but is unsure whether the school is the best medium for tikanga Maori, especially if the meaning is watered down. Matai's mother discusses learning things Maori:

> *"Hanuere incorporated a Maori karakia, which I thought was rather impressive and karakia for kai, so you learnt that at your first level. At Matai's school, I don't know whether all the school learnt it or just the Maori children. Matai learnt the vowels, parts of the body and that was a good thing. However I have a problem with non-Maori teachers teaching the language, but I guess I didn't mind because it was the vowels, and body parts."*
>
> *"I have a problem with it* [nuances and body language]. *You can see the difference between Maori teachers and non-Maori. For example, I went to the pouwhiri my son asked me to come along because he was right up the front it was so cool! Because I sat down, they must have been wondering what I was doing there, and one of the ladies said,*
>
> *"Did you help to put out the ... ?". I said,*
>
> *"No I'm actually Matai mother,*
>
> *"Oh how wonderful"*
>
> *I said, "He asked me to come down and have a look." She said,*
>
> *" Oh how lovely."*
>
> *"I think because they were all sitting on that side actually the manuhiri side and I was on the Tangata Whenua side they were probably wondering where I fitted in. But I guess for Maori that's not an issue." "Its like, oh well I didn't know anyone I know what's its for, I'll keep quiet, I know the procedures, I'll sit there, and as long as Matai saw my face, I'm happy."*

Overall, the differences between the cultures are acceptable, when they implement Maori into the school curriculum, and accept the teachers designated to teach the Maori component. If their heart and soul is in to teaching Te Reo and they think and act on that enthusiasm, then Maori accept and support them.

> *"The Maori teacher* [non-Maori] *at Pepuere are very different with the children that other non- Maori, she's very hands on, "Oh take your shoes off". We all are; we deal with things like we would in our own whanau. There's no distinction between, you're not special your exactly the same as the one next to you, so we have a gift, we have a special gift."*

Special Education

Cultural Aspects to Special Education

From Matai's mother's experience, she did not observe any Maori specialist in Special Education and was not aware of any attempts to incorporate a cultural element of getting to know the person before getting down to business.

> *"Well I wouldn't say they are really interested. I don't think they have anything special in there* [for Maori] *they seem to not understand Maori very well. I guess there's a need for Maori workers in those areas because Maori won't open up naturally to non-Maori. You'll open up naturally to Maori but not to non-Maori. When you look into the Maori education system, there is not a lot of Maori that specialise. For instance, teacher aides, I don't know whether it's a deliberate thing or whether Maori are not interested in that area. I've never come across a teacher aide that is Maori."*

Funding and Allocation

The early intervention funding for children who have a disability is high and necessary to build support around the child until the age of seven years. However, having an age cut off does not allow for a child whose cognitive age may be younger, nor does it allow for a gradual reduction of hours. Instead, the funding and assistance comes to an abrupt halt if the child is not classified as having high needs. Another example, the hours of funding was always decreased and if a review was requested, the hours were never increased to the original amount; rather, it was a compromise between the two. The funding hours never extended beyond the original funding.

> *"I thought the strangest thing ever was that when he first went to school, he had 30 hours. They knew he would never last being at school for 30 hours, he was only going to have mornings and that. So, they started him off at 30 hours when he didn't need it. Now that he needs it, as he needs it, they take it away. I think it's very important when they reach Form 1 and 2* [Year 7 and 8] *where it is very vital when you are stepping into high school, and high school is where it's the make or break I reckon Form 3 is either going to make them or break them."*

Funding

Matai receives a disability allowance, respite care and two and a half hours of teacher aide assistance daily because of his physical disabilities.

On-going Resource Funding (ORS)

Considerable importance is placed upon the procedure of filling out forms prior to ORS funding. The form must be filled out correctly and exactly, answering all relevant questions, and getting the key people to support and sign your form, or otherwise the outcome could mean a loss of funding for a child with a disability.

> *"Before ORS funding came in, we had to fill in these documents to get funding. The teacher that was in charge of special education resources gave all the mothers who had children with special needs these papers and forms to fill in. Well mine was the last one in. She rings up informing me everyone has handed their forms in."*
>
> *"I said, "Well actually I'm a bit concerned and I know its got to be in by Friday but I'm waiting for an appointment with the paediatrician which I'm having trouble getting because they are so busy."*
>
> *"Oh what do you need that for?"*
>
> *I said "Well I see on the last page that there are comments you need from a paediatrician".*
>
> *"Oh no you don't need to fill out that"*
>
> *I said "Well why is it there then?"*
>
> *"No you just get it signed by your doctor, your normal GP".*
>
> *I said, but it says "Specialist here",*
>
> *She said "Well no one else has done it; you don't have to worry about that* [mother's name]".
>
> *"I left it at that. Then the next day I was able to get an appointment – they said they would fit me in because I had to have it signed. All these applications were meant to be in on the Monday. On the Friday I hadn't handed my form in, but I had*

> *my appointment Friday morning. I went to the school first to inform them I was off to the hospital to get the form signed, then I would come back, she* [the teacher] *said,*
>
> *"Oh we have to wait for you; we will have to now send this on a courier so it can get there by Monday."*
>
> *I said "You do what you have to lady, and I'll do what I want to do, end of story."*
>
> *"So off I went, got all my papers signed, came back, handed it in".*
>
> *"We waited to find out our results. We got all our result back. I went to see the Principal and asked how Matai got on, he said, "Yes, he's been accepted, he's got a number of hours and it will be ongoing right through his schooling."*
>
> *"Oh excellent" I said, "So did we have a good result for everyone?"*
>
> *"Oh no" he said, "Matai was the only one".*
>
> *"So I guess in a way, you need people in those key positions for the parent. I almost felt embarrassed because I know all those other mothers would know that I had it. At the end of the day I knew why."*

Teachers and Teacher Aides

Matai's mother explains the caution she applied to support people when dealing with her son's disability,

> *"I think you have to be careful with special needs children concerning key figures like special education teachers and teacher aides. They are inclined to make decision for you and they slip into that role quite easily when they start making decisions for you. I had two incidents where the special needs teacher who was also a qualified teacher over stepped the mark. One incident, she told me to keep my son home one day because they were playing sports and thought Matai would get in the way."*
>
> *"Another incident, the teacher-aide decided Matai would not go to this Success Maker Computer Programme because she didn't feel he was up to it. Taking the choice away, Matai came home and he kept saying "I don't go to Success Maker all the time like other children. I only go if someone else doesn't go/is away." First I kept saying to him "Oh don't worry Matai,*

> *you'll have your turn. ' But I go sometimes but only when someone is away'. Then I realised ... so off I go down to the school."*
>
> *"Before I got to that meeting I rung my caseworker at CCS, and it just so happened, they came to check Matai leg. The young girl who came with my caseworker had helped set up the programme* [Success Maker Computer] *for special needs, and she said "Oh no that is an excellent programme for special education children."*
>
> *I said "Is that right". So I was armed up when I went to that meeting.*
>
> *I said "Well I actually know the person who set up that programme blah blah and she's willing to come down here, and second of all I'm Matai's mother, I'm the only one who makes decisions for him, you are not his mother."*
>
> *"I went straight into the Principals office and informed him of the situation, and that I wanted my son back on the programme."*

Empowering the Parent

It is important that parents stay empowered when it comes to advocating for their child, who has a disability, as she explains,

> *"They can over step the mark. Non-Maori are use to that, Maori can't tolerate that. You are coming into my territory and taking over my responsibility I guess that's a part of being colonised I guess. You don't want them in your space, but you get the odd one who wanting to help, or knows that something is not right or they are trying to put something across you."*

Systems to Support Matai's Disability Needs

When it came to Matai's needs being met at school, a good working relationship between the parents and the Principal is necessary at both primary and secondary school. The working relationship was set-up from the onset of enrolling Matai with the school [primary], and through their partnership, they took the journey together, to ensure Matai's educational needs were being meet within a school environment.

> *"There was none where I had to create it myself. In actual fact the school was behind, I don't think they knew what they were supposed to be doing. For the Principal, at that stage, and me I think was a journey together. He didn't quite understand as much as I did, in some things, and so I would do things like "yes, well we need to get the Ministry of Education down here."*

> *"I wouldn't mess around; I would ring the Special Education and say, "I'm waiting for someone to see my child, when they are coming?" I guess, it was quite natural for me to do that because I did it in the North Island. But, down here it was like, well the Principal did that; the roles were turned. But I guess I took a more active role and we went along together."*

Individual Education Programmes and Education Funding

Other partnerships that are in the best interest of everyone involved the parents, teachers, teacher aides, the child and the school Principal.

> *"You have to work close with others, otherwise you can muck it up for the teachers, because at the end of the day the teachers wants more hours and the principals want more funding. But it's not something you can openly discuss because it's quite cunning in around about way."*

> *"I had to get quite cagey. We would go over a lot of things before we actually had meetings with the third party. Just to go over 'Now is this clear'. It's never ever spoken, 'Ok we are going to say this'. It's more like, 'Ok, are you clear', 'Are you happy that is the way this is?' I'd go, 'Well maybe not', 'Well if you look at it this way', and then we move on."*

It is important to have your ideas rehearsed about the direction and the needs for your child, otherwise funding may be taken away. Once the funding is taken away, it is difficult to get that funding back.

> *"It's quite sad that's got to happen. To me I think, if you're special needs that's it. It should not be discriminated."*

It is important also to have key people accountable for their performance when working around a child with a disability:

> *"I even question the money that they get. Because you get a copy of what the Special Education, Ministry of Education give*

> *to the school for your child. So, I'm saying so where's the 1-2 hours. I always add up the dollars and coins, they are answerable to me, whether they or I like it or not."*

Documentation for Funding Assistance

This requires key people with the knowledge, to assist with the documentation for funding assistance. In Matai's situation, Matai's CCS caseworker has been very helpful because of her experience and knowledge about documentation, and funding assistance for children with a disability.

> *"I would ring her for specific reasons, or I needed her for wording. With special needs you've got to word everything correctly, you can't put down things about too much improvement."*

So with the help of CCS caseworker and one person from Special Education to assist, Matai's mother filled in the appropriate forms to ensure the proper wording and understanding are understood in order to access the appropriate funding.

According to Matai's mother, a leap of faith and trust is required when bringing in key players because they have the power to give or take funding away.

> *"There is a fine line as to, whom do you trust? Although I never trust the ones at Special Education because there's a fine line, you've got to. In order to try and coax them ... you've got to come across as being quite naive at times, so you are asking very sensitive questions but dumbly ... you've got to. So you've got to be careful with them, you don't want to tell them too much. Only what they need to know."*

Calling on the experience of another organisation, which deals with disabilities, in order to gain from their knowledge and assistance is also helpful.

> *"With the help from my caseworker at CCS, I can ask her what do they need to know. 'They need to know this and don't tell them this' and she'll give me a big run down what works and what doesn't."*

Shifting and Accessing the Appropriate Services

The comparison between services in the North Island compared to the South Island reveals distinct differences:

> *"It was very difficult to tap into this system here; it's not as close knit as Piritene. I guess area wise, it's all broken up into areas whereas, Piritene was one centre. It was central, there were suburbs but there was no suburb centres. So I guess that was to be expected."*

In some instances, the services and assistance were disjointed in some places.

> *"Sometimes I thought half of them didn't know what they were doing or suppose that I knew what they should be doing, I don't know. It was pretty weird; it was quite hard to get a system going, because it was like one thing after another. Fight that first and then get in. But whichever way you had to turn, you had to go through someone else again. So it was like now you have to go and see this person before you even get seen."*

Overall, the general observation was that accessing the appropriate services was not problematic specifically to being Maori but a general problem for any parent trying to access appropriate services,

> *"I think in general, I don't think that's specific to Maori. I think overall that special needs mothers; I don't think they are being looked after as well or parents and fathers as well as they could be."*

HEALTH PROFESSIONALS

Health System

In the experience of Matai's mother, there was little acknowledgement of Maori ethnicity and culture by the health system and the availability of assistance to Maori clients was not apparent. Most of her initial contact with the hospital happened not long after Matai was born.

> *"In Piritene, I guess because of the* [Maori] *population you have more Maori nurses; they had a whanau room* [suite] *down by the Szabo* [at Mangu hospital]. *It was different for me because I had a caesarean, I had to stay in bed ...* [otherwise*], I would have been in that room and stayed by him."*

> *"But you know with the health system because it changes so often, they haven't got anything specific* [to Maori]. *No one specifically said to me, or gave me the notion that they are sensitive towards Maori or culturally sensitive. So I've never had anything like that put in front of me and said, "Would you be more comfortable with a Maori* [social worker] *etc."*

Professional Services

The medical professionals who have supported Matai's health needs have been Paediatrics, Occupational Therapy, Physiotherapy, a Throat Specialist and podiatry.

Making Choices to Operate or not

One of Matai's physical disabilities, were his eyes. His eyes would roll in different directions, which his father related to extended whanau, "You're like your Uncle Boy, because one eye goes that way, one eye goes that way". When he was at preschool, Matai and another girl about the same age were offered the operation to correct their eyes. Even though Matai's father was in favour of the operation, Matai's mother was not. Matai's mother describes her decision whether to operate or not.

> *"Well her mother [the little girl's] decided to operate ... and I said, "No, he's not even 3 years old yet, let his own healing do that". And I said, "No, I'm not doing that, end of story."*

As an alternative to having an operation, Matai's mother found other ways to strengthen Matai's eye movement, such as using the car wipers.

> *"We were sitting in the car and turned the wipers on. He'd sit there because he couldn't move his head. Many a day we sat out in the driveway in the rain with the wipers going."*

Another alternative to strengthen the eyes was the use of Balloons,

> *"Balloons were good because they were light and you could blow them. Just walk into a room and blow them around."*

The decisions parents or caregivers have to make in regards to whether or not to operate will be an individual or a collective decision for the benefit of the child. These decisions will depend on the amount of information received, the support given to the family, the social pressures surrounding the family and the knowledge that whatever the outcome, the child with the disability will have to live with the final outcome. For example, the results of the other girls operation;

> *"The girl who had the operation ended up a year or so down the track, where her eyes were permanently slightly off ... it will never heal itself now because they've operated and put it in a particular way. So even though I was quite sad for her and for the mother, because she was quite stressed over it, I'm pleased I'd never made the decision. I thought, "Oh man you're not cutting my baby just for the sake of it."*

Misunderstanding the Body's Natural Healing

Healing and the ability to let time, environment, and the child's natural healing to take place, could eliminate the need to operate to correct a physical problem,

> *"Right through his schooling, right through preschool, right from the beginning, from when he was diagnosed, people had a tendency to not understand natural healing and I think that's where Maori are able to use it and feel a lot more comfortable and secure in letting your body heal itself. So we* [Maori] *have a lot more faith, and that's from experience (faith in our body and ourselves)."*

A parent with a young child who has a disability sometimes requires a very strong personality with a high sense of self-esteem and self worth, to be able to continue in their beliefs as to what is best for them and their child.

> *"It was constant fighting all the time."*

> *It was like, "You do realise that your child won't be doing this and your child won't be doing that."*
>
> *I'd say, "Says who?" "Excuse me! Can you tell me how you know that?"*
>
> *"Well I'm experienced in this field and that field and that field".*
>
> *And I said, "Well maybe you can be experienced wherever you want to be, but don't be telling me what my child may be not doing and doing."*

Physiotherapy

Due to Matai's physical disabilities, he required physiotherapy, while in the North Island these needs were being met, however Matai's mother noticed the difference when they moved to Christchurch.

> *"He actually went backwards when he came to Christchurch. One of the disadvantages of coming to Christchurch is that his physical side has gone backwards because this system in Christchurch just hasn't got what it takes."*
>
> *"I've had this on-going battle with health special needs system putting us on 6-week stints for 1-hour sessions once a week for six weeks each year. From what I gather it's not about whether it's enough, it's what they can or are willing to provide. In Piritene Matai went every Friday morning."*

For the amount of time spent travelling from Arapeninia to the city, car parking and the associated fees, getting time off work, and taking Matai out of school, in order have physiotherapy was more an inconvenience than a benefit for six one-hour sessions per year.

> *"I had to drive all the way from Arapeninia, take time off work, pull my son out of school, and come here* [into the city] *spend* [time] *looking for a car park, for an hour's therapy. Then to do the return trip back to school, home and work. So I was thinking, you disrupt my life for six one-hour sessions I don't think so. I said, "I'm not wasting my time for 6 hours therapy, and then I can't get in until a years time. You might as well forget it because if that's all you've got to offer, it's not worth it". If they said, "You've got one hour physio every week, I would be wrapped for the rest of the year."*

Matai's mother identified two other frustrations to having only six one-hour sessions a year of physiotherapy, it did not meet Matai's needs and putting the responsibility onto the schools was not a solution.

> *"I need somebody, where I can have ongoing physio or on-going massaging. ... They do have physiotherapist go visit the school and who write little programmes for the teachers to do, which they don't do them."*

COMMUNITY SERVICES

New Zealand CCS (CCS)

CCS supports families who have children with physical disabilities. After moving to Christchurch and having Matai settled in school, it took nearly a year before Matai, his family were involved in CCS and a caseworker assigned to his family. That caseworker still supports Matai and his family.

> *"She was assigned to us when we first arrived but we actually went through one whole year without seeing anyone. It took us that long to get everything set up. She's been our only caseworker at CCS."*

CCS has a whanau support group, to which Matai's family still belong and receive the monthly newsletters, which are sent out to update members about current and future events.

> *"I still get that, but I never get to reply to anything, I just have a look at them and keep up to date with them, but I'm too busy."*

Rugby League

Rugby League is one of Matai's interests; I queried how culture and disability were supported.

> *"Very supported. Sports like rugby league or rugby are a culture in itself. So I guess you are not looking at needs specifically, it's a culture in itself, nothing else is taken into account except the fact can you kick a ball, and it's based on ability."*

> *"Poriwa League cup they gave him a trophy in his first year. Someone donated it and it stays at the Poriwa Club now, the 'Kai Kaha' trophy – it's like the top award. Matai got it the first two years, he shared it the third year and he didn't get it the next year.* [Laughter while speaking] *He was a bit annoyed about that. I think he resigned himself to the fact that he was going to have it every year. But he shared it with one boy who got injured and came back and played awesome rugby, he was quite a senior boy. Matai was quite happy sharing it."*

> *"I think not so much as 'Maori' but as far as 'special needs' there are clubs out there that are very supportive. Actually, they did very well with him because he was chosen as the ball boy for Boughs League one night when they played Aussies as well. But, then also all the referees were very supportive of Matai as well. I can't say it's because he was Maori or he's special need. I would say it's more because he was special needs and the only one at the time who participated in rugby league more than Maori ethnicity."*

Health Services

Matai's needs for health is met through non-Maori systems as opposed to his Maori needs. His Maori needs are met by Matai's whanau and extended whanau.

Parenting

It is important that people who share the same culture, identity and values support the parents, whanau and the child who has a disability.

> *"I think there is a need for a lot more support. I'm lucky being Maori, but I could say non-Maori may think the same."*

Parents as Advocates

Matai's mother has been an active participant in the processes to ensure her son's needs are being met within the education, health and social systems. Advocating for a child who has a disability may be forced upon the parents in the end; forcing them to take an active role:

> *"I don't think, you can afford not to ... if you are not active you become active. It won't take too long; unless you are introverted you certainly become an extrovert."*

KOWHAI'S JOURNEY

Kowhai's mother explains how Kowhai's disability eventually was identified. The cause of her disability was possibly the result of lead poisoning from the soil around their family home in Inia. All the children were tested for lead poisoning; only Kowhai was affected.

> *"Her Plunket Nurse picked up Kowhai's disability when she was three years old. She asked if the boys (twins) were sleeping okay, I said yes, but Kowhai wasn't. So we went to a Social Worker at the hospital and put her into a sleep program for her, who then sent us to a Paediatrician to see if there was anything else, and he picked up that she had lead poisoning from eating soil. After that was treated the Paediatrician noticed other things, so she sent us over to the Child Development Centre at Kowhai Hospital in Pahia and they diagnosed her straight away."*

Kowhai does not have a physical disability accompanying her cognitive disability. She has been diagnosed as having Autistic High functioning Asperger Syndrome. The telltale signs of her cognitive disability are apparent through her behavioural patterns.

> *" ... her communication, you can understand her but it is not clear, she is behind in her learning by two years, and her social skills are not up with the rest of her peers. Although she is getting better, she would rather sit inside than interact with others. You know* [slight pause] *she's not like the others, however she's not like some autistic children who don't like to be touched. She loves to be touched, held and have her back tickled, and ... she will interact when she wants to. She can see the injustices in things like for example; "He cheated" in a running race. As well as the funny side when she runs, she looks over her shoulder at the others running and if they pass her, "he cheated."*

Understanding Disabilities

Kowhai's mother has not relied heavily on Support Groups for Kowhai's cognitive problems. Instead she has limited the amount of her own reading and research on Autism because she does not want to feel or treat Kowhai differently in any way from her other children, She wants to rely on just the information and what she has picked up from Kowhai.

The family has attempted at understanding the different perspectives of autism. However, they feel that too much information can leave the parent feeling overwhelmed by the disability and its prognosis and it can be difficult to comprehend, understand or accept.

> *"Before she started school she had a session with a specialist from Ekuatoa who outlines the hopes and expectations for your child. We bought a book off him, but I have never been able to bring myself to read it, I've got this sort of mental block still, I know that she is Autistic and I know there's all this stuff, but its just a matter of reading. But when ever I've read something, for example on the Internet information about Autism, I think oh she's not that bad* [people telling their stories about their child's Autism]. *"*

KOWHAI'S PROFILE

Identity

Kowhai's ethnic identity and education concerning Maori activities are very limited within the family home and at school.

> *"They know they are part Maori".* [At school] *"They don't have a Kapa Haka group, but they have spoken about one. At the moment they are learning about doing a 'mihi'. This is a basic Mihi identifying the parents, and grandparents. A sample of the Mihi came home, and they had the dialect for grandmother and grandfather as Kuia and Koro, whereas I was brought up with Nannie and Poua. So Kowhai wrote Poua down for her grandfather. It will be interesting if anything comes back from it."*

Friends

Kowhai's self-esteem is high when she is around familiar faces. She is confident and able to participate in social activities.

> *"She's written a letter to one of her friends asking her friend to stay in the holidays. She has a group of three really good friends. They come here, and she will go to their homes and occasionally they will have a sleepover."*

Pets, Animals

Kowhai has a great affection for animals,

> *"We use to have a cat which she loved patting". Down at the Bush Inn, there is a pet shop where they have the pets on display for sale. Kowhai will always go and have a look at them; she will lean over and pat the puppies and other pet animals. Otherwise most animals living around the neighbourhood, Kowhai is, "... very wary, as are all my children are very wary around dogs. But, she will go up to cats."*

Favourite Toys

Kowhai finds solace in her stuffed toys, dolls and mermaids in order to act out events.

> *a.* *"We had a big chest full of stuff toys, and she use to* [at the age of four] *strip off and dive in and have them all around her, and sometimes you wouldn't know she was in there unless she moved.*
>
> *b.* *The mermaids she liked acting out was when she was little she would come home from her Day Care and it was her undressing thing, and*
>
> *c.* *Now it's to get into a bath and spend ages in the bath. It's been the bath for a long time. After a haircut, she will jump into a bath. When the bath is full she loves lying there."*

Acting Out

Kowhai was not in any outside activity after school or in the weekends, however, Kowhai loves to act out in pretend play.

> *"At the moment she likes to be a mermaid. How she would go on stage, I don't know. But she does like debating, having her views aired."*

Since our first interview, Kowhai has been an active player in touch rugby on a Thursday afternoon after school and cricket on a Saturday.

Swimming

Kowhai loves the water. She has had swimming lessons to ensure safety and confidence around the swimming pools and water in general.

> *"She used to do swimming lessons, a couple of years of that. She loves the water. Right from an early age when she was a tot standing on the side, she would throw herself at you."*

Pocket Money

Kowhai's understands the concept of money and she has the ability to budget her pocket money.

> *"She has her own pocket money, she has saved her money and has bought things with it and she knows. She said, 'When I get my next $20, could I buy a doll I want?' I said, 'Sure, it's your money'. She has bought some nice things with her money."*

Safety Issues

There is a safety issue involved in supporting Kowhai in her social environment. She requires adequate security in order to make her environment safe. Kowhai is not allowed to go to shopping malls by herself.

> *"... to the Malls with members of her family; she does not go on her own."*

However, she will go by herself to the corner shops, which are within walking distance from their house. Kowhai is never left on her own for safety reasons. She will walk to school with her siblings.

> *"... or with friends who will drop her off. It's more of a safety issue rather than independent. If the friends lived closer, I probably would let her go."*

Socialisation

Kowhai's socialising centres mainly on her siblings, her extended family, and with her school friends. For example, the family all get involved in activities as a group, watching siblings playing sports, watching televised rugby games together, or occasionally the children will have sleepovers.

Personality

Kowhai's mother has identified aspects of Kowhai's personality through the interests Kowhai has as being,

> *"She honest and very social. At the moment she's learning how to behave socially. If she could she would sit in front of the computer or television all day, but we don't have it on through the week. On the computer she plays children games and with the television it is children game shows. She gets really upset if the team she picks loses."*

Emotion

The two ways Kowhai expresses her emotions, are through verbally expressing them, and through her drawing. When Kowhai is troubled or upset about something, she will sit down and draw a picture. For example, Kowhai's mother showed a picture where Kowhai has just come back from the shops and is locked out, meanwhile the rest of the family are in two spas. All the family has a smile of their faces while Kowhai's face is sad. In one case, Mum, Dad and her older sister are in the spa, and her twin brothers are in the other spa.

Books

One characteristic of Kowhai's autism is her interest in large volumes of information.

> *"She likes looking through books. Really enjoys encyclopaedias. She has had stages in her life of looking through the yellow pages, looking*

> *at the ads". On other occasions Kowhai utilises the public libraries, "She will go into the library, mainly books lots of pictures and few words rather than chapter books."*

Patterns

When she was little, she used to have a problem with changing from set patterns or routines. For example,

> *"It often helped to change the routine* [before it became entrenched] *because she used to get upset when driving somewhere. How we got around the problem is we would take different routes to come home."*

Part of Kowhai's cognitive disability is the difficulty of learning to be flexible. In order to ensure an emotional outburst does not occur, strategies are put into place:

> *a.* *"If Kowhai's does not want to do something, it is best to listen otherwise she will perform."*
>
> *b.* *"She can get overwhelmed when things get on top of her. She has a really good memory; she can recall things that have happened in her past in great detail. Day to day events, like a drive in the van, the mother has to ensure she makes enough stops in order that all the children get a ride in the front seat."*

Home Life

Kowhai is very much integrated within her family and is expected to take personal responsibilities for certain tasks.

> *"The chores are shared among the children on a rotating basis. She gets upset when the other children interfere with her chores, for example getting the playing times from the sports page in the newspaper for Saturday's rugby game."*

Siblings

Kowhai shares a bedroom with her sister. They have the same disagreements as other siblings, who do not have a cognitive disability,

> *"... she is a tidy sister, and sometimes she takes her things from her older sister."*

Appearances

Another aspect of Kowhai's autism is the tendency to wander off without telling the people she came with where she is going.

> *" ... at the Mall she may disappear (without telling anyone), but you know she will be in toys or the books."*

As no physical disability is visible with Kowhai's cognitive disability, it is very difficult for other people to comprehend that she has a disability.

> *"She looks normal but sometimes acts differently."*

CULTURE

Tribal Links

Kowhai's lineage is Ngai Tahu; her maternal grandmother was a Taro from Taro Heads. Kowhai's paternal great grandfather had tribal links to Nga Puhi.

By virtue of their descent on the mother's side, Kowhai, her siblings and her mother are registered for their tribal affiliations with Ngai Tahu. However, at this stage the family has little involvement in activities related to Maori culture.

> *"We are all registered, originally by Poua* [Kowhai's grandfather], *but with database changes we had to register again."*

Some of Kowhai's extended families have begun researching their Maori links.

> *"... they are all looking into it, especially my sister in Ekuatoa."*

Even though the family is not actively involved in any aspects of Maori culture, Kowhai's mother recently received a package for children, for learning the dialect and waiata for Ngai Tahu people. Kowhai's mother has learnt how to make Maori kete through a course held at the local polytechnic.

> *"I did about three out of the five sessions. It was really interesting listening to their stories and learning skills."*

Tribal Support

> *"My mother died when I was aged 13. My younger sister was only six. My father raised us. We had support from my mother's side* [Maori], *her two sisters came down for a month each, helped us out, to sort things out and get organised. Not so much my father's side. His side wanted us to be fostered out. But my mother's side said no. So they sorted us out and got us all going, (It's horrible to think how our lives could have changed)."*

Kowhai's grandmother's other siblings have all been involved in Maori culture;

> *"... one of them has passed away a couple of years ago. The other one, her husband is the chairman Ingarangi cultural organisation* [name given]*; they are both very involved in their culture."*

> *"My grandfather (Poua) was chairman of Ngai Tahu for years. We were not brought up with a great deal of Maori culture, but we always knew it was there. As we have got older, all of us are finding it again. For instance, a cousin from Itari came over and spent a day at Ngai Tahu. He brought his kids and family out and was getting all the information he could about their Maori culture."*

Cultural identity has become an acceptable part of society today, so that the stigma that was once identified with certain ethnic backgrounds is less apparent.

> *"It's starting to come out again. It's a society thing too really. It's more accepting as well."*

Te Reo Maori is centred on early childhood learning through waiata, karakia and cultural hui. A learning package had recently arrived from Ngai Tahu.

> *"That was for Te Reo; it was a separate registration, to see if you were interested in it. The other registration with Ngai Tahu, you get the quarter magazines that are free, a block of posters, tape of Ngai Tahu waiata, and merchandise for sale, centred around families with children. The magazine identifies family connections as well."*

WHANAU

Paternal Grandparents

Kowhai's paternal grandparents live in Mehopotamia and Kowhai's paternal uncles and auntie live in Ingarangi. Occasionally the families will visit each other. Kowhai's father is a third generation New Zealander with family ties to Airana and Iharaira. He came from a family of six; he is the third child of three boys and one girl.

Kowhai's relations (father's side) live in Mehopotamia and Ingarangi and her mother's family lived in Christchurch. In the early stages of Kowhai's growth and development both grandparents were involved helping the family out from time to time and since the death of her maternal grandmother, Kowhai's grandfather has been the main support for Kowhai's mother.

> *"... he's the main support* [father on mother's side], *only because he has always been in Christchurch. We moved in with him for six months when we arrived from Inia. He's always been a great support, even when the children were born, we would fly up, be with us, he would be there. He would come for holidays, help and pot around the house. The children call him Popie."*

Maternal Grandparents

Kowhai's maternal grandparents were married in Ingarangi, lived in Christchurch and raised their four children. Their children now live in

Christchurch with the exception of their eldest daughter (who has no children) who lives in Ekuatoa. Kowhai's uncle (mother's brother) has four children. Her younger sister has no children.

The lifestyle of extended families will also have an effect on how much support can be extended to other families.

> *"... it's only because of our lifestyles. My brother has got children ranging from university age to seven year olds. He knows and I know it's only a phone call away if we need each other. We talk on the phone, but he goes one direction with his children and we go the other". Occasionally the cousins will visit Kowhai's family, "We see them and the cousins. My father stays with us each week for three or four days."*

Parents Profile

Relocation

Due to her father's occupation, the family has relocated several times. The family has moved from Ingarangi, to Inia; and from Inia to Christchurch, over Kowhai's life span. Kowhai was born in Ingarangi and attended an early childhood in Inia. She started primary school at a Catholic school in Christchurch. The parents bought their family home in an area to be close to the Catholic school their children are attending.

There is always a possibility of moving again because of her father's employment. However, Kowhai's family are happy to be around extended family and see the benefits of staying in one place while the children are at school.

> *"There is a possibility, but at the moment because of their schooling, and to give them stability, we will stay here until the children are out of school."*

Mother

Kowhai's mother works part-time. One of her roles is teaching Kowhai coping strategies in and around her daily activities both within the home and in her social environment. Kowhai's mother is an active parent on the Parent Teachers' Association (PTA). While her children are at school, Kowhai's mother is occasionally involved in part time work, babysitting. She obtains the work through a babysitting service and she is currently looking after 5-month-old twin boys.

Father

Kowhai's father is a Catholic man who regularly attends Church services with the children. Kowhai's parents have been married for 12 years.

Siblings

Kowhai lives in a family of six. She lives with both parents, an older sister aged 10 years and her younger twin brothers aged eight years of age. Kowhai is nine years old. Kowhai and her older sister were born in Ingarangi, and the twin boys were born in Inia.

RELIGION

Church Group

Kowhai's mother is not a member of the Church, which her husband and children attend.

> *"I am not Catholic. Only my husband and the children are Catholic."*

Spirituality

Kowhai's mother does not recognise any special aspects concerning spiritual gifts Kowhai may, or may not have. However, she did identify one aspect, she said, *"If she is playing, she is playing with two dolls or with something ... she has a good memory recall"*.

EDUCATION

Early Childhood Centres

Kowhai attended a day care centre in Inia prior to attending primary school in Christchurch.

> *"We moved from Inia to Christchurch just before Kowhai started school, she had transitional funding until she was seven."*

Primary School

Kowhai attends a Catholic primary school with her other siblings within the Christchurch area. At the school Kowhai attends, there are approximately 270 children. She has thirty children in her class. Kowhai is very aware that she is the oldest in the class because she has been put back a year into Year 4. In order for Kowhai to participate fully in class, she requires one-on-one tuition.

Special Art Classes

Kowhai is a very quiet but caring young girl. One of her main interests is Art. She attends an art session (found out through the Autistic Newsletter) that is run every day for people with special needs. Kowhai attends for half a day, once a week on a Tuesday.

Teacher Aide

Since Kowhai turned nine years of age, she has had no funding from the Special Education Services (SES) for a teacher aide. However, funding has been made available through the school (Board of Trustees) from Resource Teacher Learning and Behaviour Resources (RTLB), for three hours of teacher aide every morning until 12.30 pm.

Individual Education Programme (IEP)

Kowhai has worked with IEP's from an early age; the last programme was done last year. Kowhai's mother is not aware of Kowhai's IEP being completed for this year.

Bullying and Teasing

Both parents and Kowhai's school are quick to act on any misappropriate behaviour, whether it is bullying, teasing or using inappropriate language. Kowhai has experienced being on the receiving end of bullying and teasing.

> *"She does, but not in a big way, she may come to me and say* "[somebody] *called me an idiot" so we will march down and tell them* [the school] *because we are careful about the words we use. When they are made aware it's sorted out."*

Behavioural Programmes within School

These programmes have been helpful in ensuring the safety and the awareness of safety to children at school.

> *"They ran a social skills or behaviour programmes for the girls last year. They brought it in mainly for the purpose of Kowhai's and a group of them in her class* [making them aware of the differences]. *"*

Lost Funding

Kowhai's mother believes that because of the glowing report from Kowhai's teacher, Kowhai lost her funding. The parents were devastated because they did not have a say in the overall process. It may have been beneficial if the school and the parents had worked out a strategy for achieving a consensus for Kowhai's funding before sending the report on to the Ministry of Disability and Health. Kowhai's mother explains:

> *"It was her* [Kowhai's teacher], *and when I went to question it with the Ministry they said, but you have signed it. I said we were given a form to sign with our comments, and I knew immediately when we got a copy of it, on the front page it had ethnic group and they had written European. I said I could look at that and know we hadn't done it because we will put New Zealander down. So we know we didn't see it."*

Kowhai's parents were anxious to have her funding returned and tried different avenues because they knew that without the funding and a teacher aide, Kowhai's education would suffer.

> *"We spent about a year and a half; just about every week, ringing somebody, I couldn't get anywhere. The people working with her day to day knew she needed help."*

The avenues that the family tried in order to gain their funding back for Kowhai were as follows:

> *"We tried Ngai Tahu, but they could only do a Kip McGrath after school programme, but she needed basic education help within school hours.*

Part of the reason for going to Ngai Tahu for assistance was that Kowhai had lost her ORS (On-going Resource Service) funding at the age of seven years even though her cognitive age was two years behind. Her mother thinks that the reason why Kowhai lost her funding was the glowing report that the teacher gave the SES (Special Education Services) evaluator about her. In desperation, the family and teacher aide tried using an unrelated physical injury from a childhood accident *("she has a physical injury on her* *right hand and an operation on a ligament has left her finger sticking out further than the others")* in an attempt to get Kowhai's funding back. That attempt was unsuccessful.

Other avenues Kowhai's parents approach to readdress Kowhai's removal of funding:

> *a.* *We went and petition the local Member of Parliament (MP) and*
>
> *b.* *we went to the Alliance MP* [name supplied], *she supported us and wrote a letter to MP* [name supplied] *the Ministry of Disability and Health,*
>
> *c.* *but because we were not in her* [MP, name supplied] *constituent we could not see her, and*
>
> *d.* *because she* [MP, name supplied] *was the Minister we would have to go to Ingarangi.*
>
> *e.* *we went to the Maori Mental Health out at Sunnyside, can could only be an advocate for us, they went down the same avenues as we did.*
>
> *f.* *My aunt in Ingarangi visited the CEO of Special Education and asked for a review pleading our case."*

There is an uneven playing field between the assessors and the one being assessed, this can have long or short-term consequences that can affect future funding.

> *"The Ministry agreed to do a review case* [on Kowhai] *and two people in suits came into the classroom and sat down, and she was a little angel that day even though the Principal about a month before had observed her in classroom, filled up a page and a half of disturbances."*

There is no set procedure outlined as to how these assessors will assess children when they come into the school to assess them. Therefore, the child is not being assessed in her natural environment. If you have adult assessors dressed in official attire (suits), the child may feel intimidated, and her performance will be affected and the outcome may not be appropriate for the child's usual pattern of behaviour. In Kowhai's situation:

> *"We didn't know whether to have the teacher aide with her or take the teacher aid out. So they decided to have it as an ordinary day, so the teacher aide stayed in there, which was calming for her. Their observations were for a couple of hours to judge a child."*

Kowhai's school currently does not have any children who have a physical disability. The children who mainly need help have a cognitive disability,

> *"There are no physical disabled children at the school. A recent report from the Board of Trustees, said that 3 or 4 people had funding. There are others that do reading recovery. I think there is only one child who gets funding but she maybe in the transitional phase."*

The amount of anxiety that arises from any slight change in your child's life can affect how decisions are made. As in this case, Kowhai lost her funding, and her parents had to decide what would be the best move for Kowhai.

> *"We even considered sending her to Tihema Special School, Maahunga Christian School or Kaki Waitaha as to whether it would be challenging or be with children her own age and learn from them, rather than being in other environments. They were all things we looked at when the funding was running out."*

School Involvement

Kowhai's parents are involved in all aspects of Kowhai's education and schooling.

> *"They will inform us, and they are very aware of Kowhai's feelings. We are involved. Unless if there is a decision that has to be made on the spot, for example the school had swimming sports, they informed us because she* [Kowhai] *was the only 9 year old they kept her back at school to play with the other children, I hope you didn't mind."*

Intervention

Right from the beginning of Kowhai's schooling, her learning disability was well supported by a speech language therapist and a teacher aide. Even though her funding from Special Services Education (SES) ended at the age of seven, Kowhai is receiving speech therapy through the School's Resource Teacher: Learning and Behaviour (RTLB) funding for the next two years, once every fortnight.

> *"Speech therapy and teacher aide time has been a godsend for Kowhai. Rather than keeping her at home, or if the teacher aide rings us see say she will be absence, Kowhai can cope at school when the teacher aide is away. Kowhai is able to settle in at school now, which is good, but she still needs the one-on-one."*

Future Schooling

Kowhai's mother does not see an academic career for Kowhai as being the most important thing regarding her education. Instead, she sees basic life skills as necessary.

> *"She doesn't need to speak Japanese really, and I think life skills are more important for her, such as being out in the community, having a social life and being independent."*

Kowhai is, at present, nine years old, and she has another four years before she attends high school. Future projections into further education will see Kowhai following in the footsteps of her eldest sister. At this stage Kowhai's education will focus more on learning life skills rather than pursuing an academic line,

> *"She will probably follow her older sister* [at the same school] *or perhaps an all girls' school. It depends, to me it wasn't important whether she got qualifications it was more important that she got life skills, but then I am still keeping my options open that reader/writer's will be there for exams, and that I shouldn't close my mind to it. Whatever happens she will get there, it just won't be a straight path to get there."*

HEALTH PROFESSIONALS

Kowhai has received health professional help with her cognitive disability over the years, through early childhood intervention services.

> *"She was assessed by a paediatrician, had speech therapy up in Inia, and when she was diagnosed she was assessed by an occupational therapist, psychiatrist, speech therapist who wrote one combined report on Kowhai's outcome. She has a speech impediment, slurring some sounds."*

Kowhai's cognitive disability was picked up early:

> *"Because Kowhai does not have a physical disability, the only reason I knew there was something wrong with Kowhai was she was not sleeping like the other children; she would nap and then be up and about."*

Speech Therapy and Teacher Aides Funding

Kowhai was fortunate enough to receive extended funding and was able to receive funding until she was nine. However, when the funding was withdrawn, the family was really left on their own to figure out how to access services that would meet their child's needs. Among the support groups which Kowhai's family attended in search of funding, Kowhai's mother identified that there were people worse off than her child and feels they needed more help than Kowhai.

> *"They don't give you any resources or backup. The difficulty is knowing how and what to say, how to access the different supports and services."*

The systemic structuring of mental health can be alienating to families who are unfamiliar with accessing services for their child and especially so if they have no support system within those departments. In Kowhai's family, everything took a long time to access and to process.

> *"Mental health issues, it really annoys me that I have to chase it up, I think no this is not how you treat people. Even when you leave*

messages you expect them to get back to you but they don't, it's a continuous struggle."

COMMUNITY SERVICES

Social activities

People who include Kowhai in their day-to-day activities support Kowhai and cognitive disability within her community:

a. School Sports.

Sports activities are not a major feature in Kowhai's social activities. However, at School she will attempt sports activities that are compulsory, *"Kowhai does get involved in Netball"*.

b. Catholic Church.

Kowhai's father and Kowhai's siblings are all involved in the Church. Kowhai's mother will participate, but she is not an active Catholic. Kowhai has done her first communion and reconciliation.

c. Family Activities.

These include any family outings and visiting friends or extended family. Family time within the home can centre on the computer; playstation, reading and playing board games.

e. Parks and School.

The children all ride their bikes around the park and to school (opposite their house, which leads to their primary school). For safety reasons:

> *"Kowhai comes home with her brother or sister; I don't want any of the children coming home by themselves."*

f. *Swimming Pool and Movie Theatres.*

Occasionally the family will visit the public swimming pool or the movie theatres as part of a 'special treat'. For safety, Kowhai is not left on her own. Other members of her family always accompany her. The parents will let the children sit together, while the parents sit somewhere else, to give them a sense of independence.

Local Shops

Kowhai can independently visit the local shops on the opposite side of the road from her home, 50 metres walking distance.

> *"... she goes to the corner shop by herself. She can freely go there because it is a safer community, the people down at the shops all know her.*

People outside her local environment would not be as understanding of Kowhai in some situations. For example, as Kowhai's mother put it:

> *"... this particular day* [at the checkout] *Kowhai had her mind set on having something and because she couldn't have it, she made a scene. The person at the checkout had no understanding about children with cognitive problems."*

Support Groups

The family did not seek any support from Kowhai's Maori culture because they have no contact with it.

> *"The culture has not played a big part in Kowhai's development. However, support has come from their Church, and Kowhai's school, as well as multi-birth support. Because my husband is Catholic, the Church were there to help and the School has been supportive, and as*

a result of having the twins a year later after Kowhai was born, we had home help from the multi-birth support group".

There has been support from other agencies as well.

a. Intellectually Handicapped Children's Society (IHC).

"Kowhai had help at a place called 'Hauraki Kids' through the Intellectual Handicapped Children's (IHC) up in Inia. They took her out for some respite care, took her out and did one on one to her during her preschool years ... because she was special needs. She hated it, screamed all the way. Because we were shifting she only went for about six months or so."

b. Autistic Association.

Kowhai's mother does not belong to any support group.

"I'm not with any group really. We are registered with the Autistic Association, however I told them last week to take our name off the list. We have never done anything with it, except get the newsletter. With the collection coming soon, they rang to see if I could help out for a couple of hours. I asked them what the money was going towards and they said administration costs, so I said no I'm not helping, cut your administration costs by taking me off your mailing list."

c. Parent Teachers Association (PTA).

"My main involvement is things like the children and with school. Doing the sausage sizzles and organising fundraising …."

d. Parents Support Group.

With her eldest child, Kowhai's mother went to antenatal coffee mornings. She continued with the antenatal coffee mornings until Kowhai was 13 months old when they left and the family moved to Christchurch.

"...[Support Groups] *nothing with Kowhai really because we shifted from Ingarangi to Inia. After that there was the multiple*

> *births coffee evenings ... it was helpful because it was a break away. ... also had 240 hours home help for the first year because I had multiple births, and* [two] *other pre-schoolers."*

KAURI'S JOURNEY

Kauri is an only child in his family. He is a ten-year-old boy who lives at home with his mother, his auntie and his cousin. Kauri's disability occurred at the age of two and a half years, through a medical mishap. Kauri suffered a hypoxic brain injury, and as a result, he has a diagnosed disability called spastic quadriplegia. The Accident Compensation Cooperation (ACC) is Kauri's main provider for his care and wellbeing. Prior to the accident Kauri was an outgoing toddler, meeting all his milestones at the appropriate stages and Kauri lived with both parents. Three months after the accident Kauri's parents separated.

Kauri requires twenty-four hour care. Caregivers have been selected by his mother to support Kauri within the home. Both Kauri's parents and their extended whanau are supportive, and his caregivers are whanau orientated as well, which has ensured that Kauri's wellbeing, is paramount.

Kauri attended an early childhood centre prior to attending primary school at Huare School, which has a special disability unit along with mainstream schooling. Kauri attends both. Kauri is able to communicate his needs using his eyes and verbal sounds.

Kauri's mother describes the events surrounding Kauri's medical accident when he had croup at two and a half years of age:

> *"He was having trouble with breathing, his air way were blocked. I took him into hospital and he stayed in overnight. Then we took him down to Tominika to see my mother. He got worse down there, so we took him into hospital, where he stayed for 3 or 4 days. He wasn't getting any better, so they had to incubate him. The tube fell out and they couldn't get it back in, so he suffered severe brain damage."*

Because of the accident, Kauri has a hypoxic brain injury. His case was accepted as a medical mishap and Accident Compensation Corporation (ACC) provided the main care for Kauri. Kauri is now a spastic quadriplegic with epilepsy. At the time following the accident, and over the years, some people who have met Kauri's mother have suggested that a lump sum payment may have been better for Kauri. However, Kauri's mother disagrees,

> *"ACC have spent so much money and if I had accepted about 2 million, how long would that last in his lifetime?"*

The Return Home

It took the family awhile to realise how severe was the brain damage that Kauri had suffered. Kauri was in a Tominika hospital at the time of the accident and he stayed there for approximately three to five weeks before the family brought him up to Christchurch hospital, where he stayed for three to four months before going home. Kauri's mother gives two examples of taking control of Kauri's wellbeing concerning his food and his eyesight problems.

a. Food.

Prior to the accident, Kauri had enjoyed his meals so when he had the accident he was given his own formula. Kauri's mother believed that just because he could not communicate well, there was nothing wrong with his memory.

> *"When he first came home, he was fed through a tube and that was a horrible formula. Every time we would sit down for dinner, he would get upset. I thought it was because he could smell the food we were eating, so we started feeding him little bits, like mashed potatoes and that. Now he eats what we eat, so we are lucky that way, I think we did the right thing there, getting him on to the right food."*

b. Eyesight.

> *"Right from the beginning they told me he was blind, but I didn't believe him. From the beginning, we built a big box with silver paper. His room is really built for sight for stimulation. Every time he gets a present it's either something he can touch or use. Some we made up, and others they would give us ideas. Otherwise the therapist was coming to the home they would bring toys or whatever with than."*

Health System

> *"When he was in hospital, we never leave him alone, ever, with anybody* [nurses, doctors and specialist]*."*

The hospital staff educated the family on how to look after Kauri's needs cares and medication,

> *"They had to, we insisted, and in the end we did everything."*

Kauri's mother feels Kauri's needs were met much quicker if the family attended to them, whereas if the hospital staff were attending to them, his needs would be prioritised among the needs of other patients.

> *"We were so grateful that he was alive, but after that all wore off we thought ok, and when we arrived back in Christchurch they were really good to us, but we wanted to do it ourselves. It was tiring and it was hard, we did a roster, where we had someone stay overnight, have someone go and relieve him six hours at a time, it was tough."*

Therapy

From 2 ½ -5 years of age, Kauri had home based therapy.

> *"It took quite awhile before the ACC came through. We went to CCS firstly and he had a bit of therapy there and when it did come through he had very intensive therapy, all here in the house, everyday."*

Homecare

Initially the return home from the hospital took a heavy toll on his parents. This was exacerbated by Kauri's sleep patterns:

> *"It was tough at first because he would hardly sleep at night, he would just cry all night and we were just wrecks."*

Kauri's homecare requires twenty-four hour supervision. Kauri's mother arranges for the sitters or caregivers to come into the home.

> *"I have one from ten until 7 am everyday. Tuesday and Fridays, I have one from 2-6 pm and 6-10 as well. She watches him, so sister and Kauri's mother can go out."*

In the last six months, the hours of homecare have been cut, due to Kauri's age.

> *"The assessors who came out are very good to me, they could see, so I got another seven extra hours back. I still lost about 13 hours".*

As part of a continuing process, Kauri's mother has resigned herself to the fact that not only does it have to do with Kauri's age, but, also, to cost cutting within the corporation.

> *"It's ok though, when they finish at six, he's basically mellow, and ready for bed."*

Exercise

> *"Most of Kauri's exercise is carried out at school. The carers are meant to do the basic maintenance exercises, but I find now when he gets home from school he's too tired. Although it has to be done."*

Home Life

Kauri is very much a part of his family in that he lives in the lounge most of the time, except when its time for showering and sleeping.

Renovations carried out by Housing Corporation New Zealand and ACC have improved accessibility both inside and outside the house. Kauri can hear what is going on around him; they have the television on for him showing children's programmes and sometimes videos. He can smell food cooking, and he has no special food. He eats what the rest of the family are eating,

> *"... just ordinary into bite sizes, he has whatever we have."*

His mother notes that the main signs of stress for Kauri are related to tummy pains, constipation and mouth sores.

KAURI'S PROFILE

Social Activities

Kauri occasionally participates in social activities within his community.

> *"He goes on school trips and his carers may take him out in the weekends."*

Some of the other activities Kauri has participated in exemplify some of the limitations and pleasures encountered:

a. Swimming.

> *"He loves being in the pool such as Jellie Park, Wharenui and QEII for swimming."*

b. Malls.

> *"Sometimes he enjoys it in there, while other times he's grizzly. At the beginning, the Malls would send him into seizures. We use to take him out a lot, but I hated it, you would be there for two minutes and then he would want to go."*

c. Parks.

> *"In the summer we will take him out to the parks and stuff, to feed the ducks."*

d. Movies.

> *"Kauri does not attend the movies at the Malls; however he loves the movies at home shown on television or videos. He has been to one movie at the theatre* [a school visit]*"*

e. Libraries.

> *"He was a member of the special toy library. He's been out to the library and being read to. Even at the pool he's been able to jump the queue."*

f. Carer's Home.

Occasionally Kauri may visit a carer's home, as part of whanau orientated environmental activity.
"... he may go to his carer's place."

Kauri's Attributes

Kauri's mother and caregivers can understand Kauri when he communicates his wishes,

> *"We know when he's grumpy through his eyes and with the sounds he makes. He laughs, he loves music and he will give signs to turn it up or down. It is a 'knowing', like when he was in hospital we would play songs, which he used to love, and I know he use to listen. He likes voices; he is very close to his* [paternal] *grandfather."*

> *"That is not really important to us; we are Anglican, but we don't go to church."*

CULTURE

Maori ethnicity and culture

Kauri's mother is very aware of the protocol in regards to doing things 'Maori':

> *"It is very important. Kauri got a new electric bed, and the little boy who had it before him had died, so we had a Maori priest to bless it. I believe in those sorts of things, and when we had Kauri baptised we had a Maori priest."*

Kauri's mother and her siblings have grown up within Maori culture, all the girls having a Maori education at Hune Maori Girls College.

Land and Tribal Links

> *"Land is important to us. Our iwi is Ngai Tahu, and our hapu is whaka tu mahi Hapana. ... Ngai Tahu have got 18 marae that make up the runganga from all around the South Island and that's just the ruling body. Ngai Tahu are a big organisation a multi million-dollar company, we are doing very well."*

Te Reo Maori

Kauri's mother does not speak fluent Te Reo Maori.

> *"I did it at school. I then lived in Ekuatoa for two years, Thomas was born there and I kind of moved away from my Maori culture. Now that we are back we are getting into it. It wasn't a major thing, Te Reo, at that time; it's only been over the last couple of year we have got into it."*

Maori Culture and Development around Kauri

Kauri's extended whanau have been supported by their employers,

> *"It is not the culture that much, it is more the awhi, my sister worked at Ngai Tahu and they really felt for our whanau* [at the time of Kauri's medical mishap], *they gave her time off, sending cards and things like that, later on they gave a $500 grant for some equipment."*

Disability Access

Ngai Tahu is still in the process of making the marae more disability friendly and improving the accessibility.

> *"Our own marae at home has disability facilities, for example ramps which is really new."*

WHANAU

Maternal Grandparents

Both of Kauri's grandparents (mother's side) have died, and her stepmother has raised Kauri's mother and siblings when Kauri's mother was nine years of age. Her stepmother is very much into her Maoritanga and Maori culture. They live in Tominika, a suburb called Hapana. Her stepmother was a great help at the time of Kauri's accident.

> *"From the time of the incident (because my mother is a kaumatua in Tominik) they organised a Whanau House for us across from the hospital, they checked up on us now and again. It wasn't a normal procedure, but because they knew Mum and they knew us, and there was so many of us also in our family."*

Paternal Grandparents

Kauri's paternal grandparents both live in Ihipa. His grandmother originally came from Ingarangi. Kauri's paternal aunties live in Ekuatoa. Kauri's mother met his father while living in Ihipa. Kauri and his mother occasionally visit Ihipa only to see Kauri's grandparents.

When Kauri first came out of hospital his [paternal] grandparents had separated and one was living in Ihipa and the other in Ingarangi. When the accident happened,

> *"Well they both moved in here* [family home] *for two years to help me with him. They adored him though; he will always be their favourite. They have known him right from birth, they got to hear him say, I love you grandma, granddad, too sad really."*

Because of their two-year stay with Kauri, his grandparents are still living together in Ihipa.

Aunties

At present, one of Kauri's aunties is living with him with his cousin aged 12 years. His auntie is helping with his daily care, supporting Kauri's mother mentally, socially and physically.

Father's Profile

Kauri's father is non-Maori and lives in Ekuatoa so there is limited contact with his father. However, when his father visits New Zealand to see family, he comes to stay and spend time with Kauri. However, his contact with Kauri is very seldom.

> *"He probably hasn't seen him since year-two years now because he has another family now. He's got two other children. But I did say to him next year, that I was hoping when he and his girlfriend move back, maybe they could move in here and I could have a life."*

Mother's Profile

Kauri's mother comes from a large family of one-brother and six sisters, having two sets of twins. Kauri's mother is a solo mother caring for Kauri with the support of her extended family. There have been no serious relationships in her life as Kauri's care occupies twenty-four hours a day. Kauri's mother says,

> *"I am involved in everything, he's at home, I'm with him all the time, or someone else* [caregiver] *is with him all the time."*

For Kauri's mother the emotional trauma which she suffered after having a perfectly healthy two and half year old boy one day, and the next day that same little boy with severe disabilities, was a big shock to the parents and extended whanau, each having to work through their own grieving stages.

Emotional Issues

> *"We had a social worker assigned to us, but she was useless, we ended up dealing with it ourselves, we dealt with the stresses ourselves. I refused to have psychologist in, what was the point. But, ACC sent me to a counsellor; I went for one session that was really good, and that was all I needed. There were so many people around me that I could talk to anyway. It took about a couple of years. Then I was so frighten when his grandparents moved out and I was on my own, but it actually worked out quite well."*

Looking back, Kauri's mother sees the outcomes for Kauri have been positive.

> *"You have to do what you have to. You see I have been lucky I haven't had to fight ACC too much really. Everything has fallen into place for us. People always go at us, why didn't you sue, why didn't you get millions of dollars and that. I chose ACC, because I wanted him to get therapy straight away rather than waiting years, go through court and then you have to prove who was negligent and we couldn't do that. I'm sick of people saying but why didn't you get any money."*

Support Person

Another facet of his mother's life is that she has been a support person for other families who are referred to her because they have a child with a severe disability.

> *"I did a few talks from a mother, parent's perspective looking after a child with multiple disabilities, with the head injury society, and sometimes ACC would ring me and say we have a mother who is interested in talking to another mother. So they will come around, I will meet them and have a chat. It was good for me, there was a couple that were referred to, that I saw some things that they did that I picked up and learnt about."*

Employment

Ngai Tahu Corporation has employed Kauri's mother because of family connections and tribal affiliations, in the communications unit as a part time reliever.

> *"I have only been working for three months filling in for someone who's been on maternity leave. I finish up in two weeks. I quite like working part time. I'm working in the communications unit. I handle media stuff. It's an easy job. Any articles at all about Maori that pertained to us, or that we were interested in I would get transcripts and copies like that, then I would distribute them to all relevant people."*

RELIGION

There is little emphasis placed on religion that may be due to the family and extended family being very supportive of each other. However, they do classify themselves as being Anglican.

EDUCATION

Early Childhood Preschool

Kauri's mother wanted him out in the community and learning socially at an early age, regardless of his disability. She was very active looking for the appropriate preschool for her son and she went to quite a few preschools before settling with the one Kauri attended.

> *"The preschool was close, I liked the people and they were willing to have him. They had a good mix of children; however, there were only a couple of Maori children who attended this preschool, which was not a problem. They did go out of their way to say "Kia Ora* [Kauri]*" when he came in the morning. He was their first disabled child, but they were very good. We enjoyed it there. He attended from the age of 3 years and left at the age of 5 years."*

Primary School

Kauri's mother was proactive in selecting a primary school that would cater for Kauri's needs and wellbeing.

> *"Kauri was four when I went there. I was looking for schools, I went quite early, well before he was due to start school, and then when I went to Huare I just liked it. I liked the idea it was mainstream, but they had a unit there and there was a kid there like Kauri."*

First impressions of potential schools are important indicators of whether or not a parent should select that school for their child's education. This can be an emotional time for the parents trying to make the right choices. How they interact with teachers and other staff, their observations within a classroom, of the learning programme and the layout of the school are some of the factors that they must take into consideration.

> *"I went to Kuki Airaru, and Etonia Road. I hated it there, the children would be lying on the floor and they weren't being stimulated at all. I don't know whether it was when the staff was having a break at the time, but it was awful. I went to the Puru Centre and they just made the kids cry, so I wasn't going there. It was probably going to be good for him, but I could not handle it."*

Kauri has settled into Huare School, and is well known by the children who attend there.

> *"All the kids know Kauri; I think they get taken to different classes and have a buddy and stuff."*

Kauri's mother was unsure how long he would be at primary school. , *"I don't know how long, but he just moves up with his peers."*

High School

The prospects of choosing a high school for Kauri are not being considered at this stage.

> *"I haven't really thought about it, I just don't know. I don't look too far ahead. It's something I will have to look at eventually."*

Kauri's mother will attend the meetings arranged by staff at Huare School if any adjustment to new equipment or changes to Kauri's education need to be considered. For instance, when Kauri was fitted with some new equipment:

> *"I went out to school on Monday because they want me to have a look at a new standing frame they are trailing for him, so they can get him upright."* [Meanwhile, Kauri's Independent Education Programme (IEP) at present is focusing on] *"Making choices.... with his eyes or gesturing towards something."*

While in the school setting Kauri's physical and cognitive needs are stimulated by exercise carried out by Occupational Therapists, physiotherapy and music therapy.

PROFESSIONAL SERVICES

Kauri has very little contact with health professionals within the hospital unless there is a problem with his stoma or any other health problem that may occur from time to time. If Kauri is required to return to the hospital for any reason, his mother and any support person she may take with her closely monitor his visit. There are no professional services required within the home, as his mother, extended whanau and his carers' meet all Kauri's needs.

Health System

Kauri's mother is very watchful when Kauri needs involve the health system,

> *"I am not a big fan of the health system", however from time to time Kauri's needs have to be met within the hospital setting."*
>
> *"I will keep him out of hospital as much as I can because I do not think his needs are met very well. He very seldom has to go in, if the thing on his tummy falls out, it is just a quick trip for five minutes and out again. However, the thing that is on his eye at the moment he will probably have to go into hospital for that. He will be in for one night and I will bring him home. It's just I don't like the way they care for him. Not only that, the waiting for appointments, or the in-between times, it has got nothing to do with him being Maori, it's more the procedure."*

Speech Therapist

> *"The speech and language person used to come and say to me you should really feed him in his chair, and I know I should, but I don't like to because he eats less and he doesn't eat well sitting up in his chair. So I feed him there* [lying on his back, head slightly up, propped by a pillow]."

Physiotherapy

It was difficult for Kauri's mother to watch or hear her son's cries when physiotherapy was carried out in the home because it was distressing for her.

> *"I had to leave, I couldn't watch or listen because I would cry, it made me angry, even though I knew it was helpful, he should do it, it was good for him, I hated it because he was crying. Even when I could hear him and he would go for so long I would come storming out and say ok that's enough, leave him alone. In some ways I kind of feel guilty I might have held him back physically because I thought they were hurting him."*

Alternative therapy

A Maori spiritual group from Etiopia came to Christchurch offering massages, which Kauri attended.

COMMUNITY SERVICES

Transportation

The family van and taxis equipped with the electric wheel chair elevator for access in and out of the vans are Kauri's main means of transport within his community environment, and to and from school.

> *"It's not a problem because I have a van to take him to Marae, shopping and whatever.... "*

Overall, Kauri is able to participate in social activities within his community; however, these can be limited due to his mother's perspective,

> *"It's probably my fault, we should be getting him out there more* [in the community], *and the carers do take him out a lot. I just feel he gets too uncomfortable in the chair; so I take him home."*

House Renovations

In order for Kauri to be cared for within the whanau environment, alterations were made to the family home that the family rent. Housing New Zealand owns the house where Kauri resides. Both Housing New Zealand and ACC assisted in the alterations to the property

> *"Housing New Zealand put the front ramp up before we moved in and before we received the funding,. The front part of the house is made for Kauri's wellbeing – with open plan living areas. The new lounge/dining room and kitchen is open and spacious, and ruled by Kauri. What used to be the old lounge is now Kauri's bedroom and bathroom. ACC paid for the renovations. When ACC started work on the renovations, they consulted with me. The coordinator was marvellous right down to measurements for wheelchairs, this ramp and the ramp out the front. They knew what they were doing; I just discussed it with them."*

Getting Access to Resources and Information

Soon after Kauri's accident, the whanau had access to information relevant and helpful to Kauri's care and wellbeing. The whanau felt well supported.

> *"The Social Worker at the hospital told me a few things, and when we went to CCS they told me another few things. All the people I needed around me, came to me, I didn't have to go out and look for them."*

New Zealand CCS (CCS)

Since Kauri's accident, he and his family have been involved with the CCS Whanau support group, but as Kauri grew older, the family slowly moved away. Their main source of information from CCS Whanau support group is a monthly newsletter sent to past and present members of up, coming events, and any other panui (notices) relevant to the group.

> *"Since he's at school now, we haven't actually been to CCS for quite awhile. However, I still like to get the newsletter. If they say there is something on, and we have to go away I don't really like taking Kauri with me. It's so much easier to keep him at home. Lazy of me probably, but you need 2 or 3 of you to look after him. Well you just have to take so much. Trying to bath him at someone else house is the 'too hard box'. He is just getting too big to bathe in a non-disabled environment."*

Ngai Tahu Corporation

Having tribal affiliation to Ngai Tahu Corporation, the whanau is kept up to date,

> *"Well we are members; we get updated monthly on panui and things like that."*

FUTURE ASPIRATIONS

Relationships

As Kauri gets older, his mother will still manage his twenty-four hour care, with support from extended whanau and caregivers. This has enabled Kauri's mother to work part time, and she is looking to broaden her horizons.

> *"Well I haven't had a date in seven years ... I'm on a dating site. I've met a few but there's been no sparks. ... But I want to do a bit of travelling, and do stuff."*

Education

His mother's education aspirations have centred on meeting the needs of Kauri as opposed to her own needs.

> *"There's nothing special. I did a First Aid course and a CPR course.* [However] *I've often used to think if anything happened to him I would probably go into this field, either be a carer or something similar."*

Aspirations

The possibility of Kauri's mother having time out to do the things she wants to achieve will be hindered without the support from extended whanau. The possibility of Kauri's father and his partner sharing in Kauri's support is very unlikely because they live in Ekuatoa.

> *"Well she's very nice and very young; she's a good mother. But, it's up to her, if she can't handle it. ... but I would like to have a few months off."*

Kauri's Prospects

Kauri's disability will always require 24-hour care, however Kauri's future looks very positive in that he is well supported within his immediate family and extended whanau. Whanau and his care workers are also meeting his daily care and wellbeing. All funding and resources are provided through ACC, along with his health care. Kauri's education and socialisation with children are being catered for within his school and his extended whanau. His mother's view on the future for Kauri is pragmatic,

"I don't think about it. He's healthy, so we are very lucky."

CHAPTER FIVE: DISCUSSION AND ANALYSIS

SECTION 1: CULTURE

Introduction

In this section, I will identify how my participants have given meaning and linkages to their own identity in relation to culture, customs and values. Secondly, I want to identify the differences and similarities among my participants in connection with whanau and extended whanau concepts. I will argue that cultural identity is socially constructed, and depending on the parents' upbringing, will determine the kind of support extended to a family who has a child with a disability, immediately after the prognosis.

Cultural Identity

Culture plays an important part in any ethnic group because of the different views and expectations held within a specific group. Maori as an ethnic group is made up of many iwi (tribes) and hapu (sub-tribes). Within each iwi, the cultural identity may differ, through language, dialect, customs and protocol (tikanga). There are differences in the tribal affiliations of all my participants: Matai, Te Arawa and Ngati Whatua; Totara, Ngati Mutunga and Ngati Awa; Kauri and Kowhai, Ngai Tahu; and Rimu, Ngati Porou and Ngati Kahungungu.

In order to understand Maori (as a people) it is necessary to understand their holistic view of the world. Stories about traditional Maori societies are told in mythology, legends and history. For contemporary Maori, identity is about unity of tinana (body), hinengaro (heart) and wairua (spirit). The entities are interlinked; it is about understanding the Maori concepts of individual wairua, whanau, hapu and iwi.

To be Maori, cultural identity is expressed through, and actioned by, the individual within conceptual structures of land, religion, spirituality, cultural values, language and customs. Maori cultural identity has been a salient feature in the lives of my participants and their mothers.

Land

Tribal identity around kinship, collective development and whanaungatanga (loyalty) has enabled Maori to survive in spite of the assimilation practices of previous governments. Land is a very important factor in the formation of identity for Maori, as it links them to their whakapapa (genealogy) and a sense of belonging to their iwi and hapu, even when they are no longer resident in the area. Matai, Kauri and Kowhai, have strong ties to their land. There are complications around land issues, and particularly those caused by the dwindling value of land shares over the course of several generations because of ownership being divided among growing numbers. This was shown in the case of Totara's grandmother who sold her land interests to her extended family.

Religion

Religion is an aspect of cultural identity. When we explore the meaning of religion, and what it has to offer, we find that it has to do with the ideas of transcendence, the supernatural, and the sacred, through language and cultural practice (Elsmore, 1998). Religion can also be divided into two distinct categories, one being the material aspect and the other being the spiritual aspect. The material aspect is defined in the religious establishments, the social groups, and social movements associated with religion. On the other hand, the spiritual aspects of religion centre upon worship, and social and individual behaviour that help believers to organise their everyday lives.

Historically the Christian Church, Catholic and Protestant, was the main religion in New Zealand around the early 1800s. By 1840, a majority of Maori were Christians. Today, large proportions of Maori belong to the

Anglican, Catholic and Mormon Churches but there is a strong following of Maori, who belong to their own religious groups, for example the Ringatu and the Ratana Churches. This helped to address the spiritual and social conflicts that Maori were suffering and it gave Maori a voice in politics. The religious following of the mothers of my participants are diverse. Matai's mother and her extended family belong to the Ratana Church, both Rimu's and Kauri's mothers are Anglican, and Kowhai's mother did not identify a particular religion.

Church attendance varied among my participants; Rimu, Totara, Matai and Kowhai belong to the Catholic Church, but only Kowhai and her family attend Church on a regular basis. Both Rimu and Matai attend Catholic schools where they participate in religious studies. Totara seldom attends Church, except for special occasions such as Christmas midnight mass. Kauri and his family is Anglican, but they do not attend Church on a regular basis.

Even though Rimu, Matai and Kowhai belong to the Catholic Church, there is no conflict between the mothers' choice of religion and their children's Catholic faith. These mothers believe children will be able to decide for themselves later on, as to how important a part religion will play in their lives. In the mean time they believe the benefits for their children's wellbeing, and education, through the Church are paramount.

The severity of the child's disability, coupled with the enthusiasm of the support people around the child, will determine the practicability and the benefits of attending Church. For example, Kauri's mother would not entertain the idea of having Kauri sit in his wheelchair, when he is used to lying on his side, but, Totara's mother would occasionally attend Church services. However when they started tying Totara's arm to his wheelchair to stop him lashing out with his good arm, Totara's mother's wondered whose safety was being protected; Totara or the congregation.

Spirituality

Historically, the conversion of some Maori to Christianity was seen as predominantly instrumental in order for Maori to acquire education and jobs within a growing European society. However, for some Maori, this did not mean severing their ties with their traditional beliefs and spirituality in order to adopt European religious beliefs. Instead, aspects of each one complemented the other.

The views about religion and spirituality among my participants' mothers differed. Totara, Kauri and Mata's mothers viewed the Church and spirituality as offering means to fulfil different needs. They saw the Church as having a place in society, but it could not replace 'the knowing', the spiritual intuition and the wairua, which is seen as sacred to Maori. This is a part of Maori, which they believe is something that is within the self and it provides protection and safety. From the mothers of Kauri, Totara and Matai, I learned that all have tried alternative healing for their families. Both Kauri and Matai's families are well supported by extended whanau and have a strong belief in spirituality.

Another part of Maori spirituality is concerned with healing. A spiritual healer is usually a tohunga (a priest) who removes curses or sickness from the person or family seeking help. Occasionally, a person or family may attend a healing for their mental and spiritual health. The healers can be either male or female. Kauri, Matai and Totara have all received hands-on healing, and Rimu received a Christian prayer group healing.

One of my participants described using other alternatives to help with mental and spiritual healing. Totara's mother explored crystal-healing, kinesiology, colour therapy, harmonics with music, massage and reflexology. In the cases of both Rimu and Kauri, healers were called upon to bless furniture, houses, clothing and other things for which they felt a healing was needed.

Cultural Values

The meaning of Maoritanga is another word to mean Maori culture and identity. We learn the values and meanings of culture through the processes of socialisation and cultural transmission. For Maori, the personality of the child does not grow in isolation, and the family is not the only environment in which learning takes place. Therefore, the child is socialised in cultural values by immersion in the language and in social interactions.

The cultural values Mana Atua, Mana Tangata, Mana Whenua, Mana Reo, and Mana To Ao Turoa are the foundations of tikanga Maori. These five Maori values maybe understood as values to ensure personal well being, self-esteem, a sense of belonging, communication, and lastly, the development of knowledge in the world we live in, and the universe as a whole.

Maori culture has supported Matai's growth and development, as well as being a major support mechanism for Matai's identity. When Matai lived in the North Island, he was supported by the extended whanau, their hapu and their iwi, and the marae environment was important. His grandfather was an important man on their home marae; Matai would follow him everywhere, so when he died, he was sorely missed. When Matai moved to the South Island, he had the support of the small-extended whanau in Christchurch. However, during the school holidays Matai spends some of his holidays staying with extended whanau in the North Island.

Kauri has limited cognitive and physical mobility. However, Kauri has been raised around the Maori concept of tikanga within his family environment, so that extended whanau have supported Kauri's mother to enable her to make the best choices available for Kauri's care and well-being. For example, Kauri's paid caregivers have been employed on the proviso that they support tikanga Maori, and support Kauri socially through interaction and touching.

Even though Totara's mother has not raised her children in an environment based upon Maoritanga, she still links to Maoritanga through her extended family, and the CCS Whanau support group, and through further education, she is gaining in knowledge of her culture enabled a better understanding of the losses Maori have suffered.

Kowhai's family has not been raised within the culture of Maoritanga, but the family has tribal affiliations to Ngai Tahu. Rimu's mother introduced her children to their father's Maoritanga at an early age through Kohanga Reo. However, the only exposure the children have to Maoritanga now is through their school.

Language

Some Maori grandparents retained the memory of the hardships of their families and their extended families and in which Maori, in general, suffered because of the assimilation process, in which Maori culture was identified as being inferior. For example, the use of Maori language was banned in a majority of schools. As a result, Kauri, Totara, Kowhai and Matai's mothers have limited language to enable them to speak te reo fluently, as well as limited cultural knowledge. However, these mothers are attempting to learn more about their Maoritanga through further education at polytechnics, universities, in their work environments, books, and through self-interest courses.

Maori Customs

Maori customs are expressed using different media and practised by Maori and non-Maori through the exposure that is dependent of the environments in which they live. The participants of this research have expressed a variety of observations concerning Maoritanga, that:

a. Maori have been able to retain their Maoritanga and express it fully on their marae or any place where an organised hui (meeting) is held and where usually a large proportion attending are Maori.

b. Cultural festivals and cultural groups focused on Kapa Haka have been clearly identified by Matai and Kauri's mothers as an important part of their culture.

c. Food plays a significant part in linking people to traditions passed from one generation to another. The social element of a shared meal and a friendly conversation allows connections to be made before settling in to talking business.

d. Maori art (carving, tattooing and weaving) identifies with where cultural knowledge is and where it is practised. Most of the learning now can be taught within the polytechnics and universities today.

e. Prayer. The power of prayer within a group was beneficial for Rimu's mother, who believes this helped Rimu to regain her eyesight.

f. Education plays a vital role in learning tikanga, both past and present, as well as providing mental and spiritual health. This will ensure the individual has a sense of belonging through high self-esteem, self-motivation and the skills to communicate and socialise within their community.

Extended Whanau

Within Maori societies, each iwi has its own history, myths, proverbs, waiata, dialects, customs and practices that make up their cultural identity. An iwi consists of groups of families who belong to a hapu. The word 'whanau' contains five different meanings. The first relates to siblings born to the same parents. The second relates to all descendants of an ancestor traced through both male and female links. The third identifies all those who participate within the group. Fourthly, the descent or connection by marriage or adoption within a group, and lastly, it is the aspect of whakapapa (genealogy) that relates the group to a hapu and their iwi.

Both Kauri and Matai's mothers were raised by extended whanau. Her stepmother raised Kauri's mother and her grandmother raised Matai's mother. Kowhai's mother had the support of her extended maternal whanau initially when her mother died. Her father was then the main caregiver. Solely her mother raised Totara's mother after her father died. Both parents raised Rimu's mother, although the father was absent a lot.

Matai's family is well supported by both sets of parents and his stepfather's whanau and are all very much involved in Maoritanga. The same applies to Kauri's family who is supported from his mother's extended family and his grandparents (father's side).

Kowhai's great aunties, on her mother's side, are involved in Maoritanga. Kowhai's mother identifies with her iwi, and acknowledges aspects of her heritage but it only plays a small part in her family. They receive information through the Ngai Tahu quarterly magazine and other relevant newsletters from Ngai Tahu.

The lifestyle of extended families, and their location, will dictate how much involvement they will have, and their ability to support and connect with the extended families. For example, Rimu's relatives are scattered around New Zealand with no relatives living in Christchurch. Occasionally, Totara's relatives from the Hiri will come and visit and Totara's mother takes on the responsibility of looking after extended whanau visitors.

Grandparents

Recently, Matai made contact with his maternal Grandfather who is a very fit 92 years old, living in his own home in the North Island. Matai was really close to his grandfather. He followed him everywhere, and especially liked the marae setting. His grandfather recently died, and Totara was very upset.

Kowhai's paternal grandparents live in Mehopotamia, and her maternal grandfather who lives in Christchurch has been the main support for Kowhai's family. Rimu's maternal grandfather lives in Tiamana. When Rimu's grandfather is in Christchurch, he will visit; otherwise, there is very little contact.

Kauri's paternal grandparents knew Kauri prior to the accident when his parents separated. After the accident, both grandparents who had previously separated came to live with Kauri's mother to help support Kauri, and are still together today. Both of Kauri's maternal grandparents were deceased prior to Kauri's birth. The stepmother of Kauri's mother has been involved in Kauri's care from time to time although she lives in Tominika.

Neither Totara nor his mother has any association with his natural father or his extended family. However, his maternal grandmother lives in Christchurch and is able to support Totara and his family. Totara's grandmother did not teach her own children the culture, language and protocols to do with Maori, and nor does she encourage Totara to learn his Maori culture.

Uncles

Uncles can play an important role for males and females if their paternal parent is absent from the child's upbringing. They may become good role models, and can give disciplinary and knowledgeable support for the child socially. Matai has plenty of support from his uncles, both in Christchurch and in the North Island. Kauri has the same support from his uncle within the South Island on his mother's side. Meanwhile, Totara has no contact with his uncles; instead, he has plenty of contact with his great-uncles. Rimu has no contact with uncles from either side of the family. However, the uncle of Rimu's stepsister has taken on the role of uncle for Rimu's family. As for Kowhai, there is very little contact with her uncles from either side of the family because two uncles live overseas, and, the one uncle who lives in Christchurch has much older children and so there is seldom contact.

Aunties

More often than not in extended families, it is usually the aunties who do most of the child sharing and is actively involved in their nephew's and niece's development and welfare, but this is not always the case. Kauri's aunties have fully supported him and his mother, both within the home, through employment and funding. At present, one of Kauri's aunties is living with him, along with his cousin aged 12 years. His auntie is helping with his daily care, supporting Kauri's mother mentally, socially and physically. Meanwhile, Matai has plenty of contact with his aunties from his mother, father's and stepfather's side. He has one auntie in Christchurch, who he stays with on some weekends so that he can be with his cousins, and at other times, the cousins will stay at Matai's home. During the school holidays, Matai will travel to the North Island to be with his aunties.

Rimu has no contact with aunties from either side of the family. However, her maternal great aunt assisted the family during Rimu's mother's time in prison by looking after the welfare of her children through budgeting and paying the outstanding accounts and the grocery shopping. Kowhai's aunties (mother and father's side) have limited contact with Kowhai's family. Kowhai's paternal aunty lives in Ingarangi. Totara's maternal aunt lives in Christchurch, and even though her children have grown up and left the home, she has little contact with Totara and his family.

Parents

The 'ideal type' of a happy family is a mother, a father and their child or children. This is not always possible because many things can interfere with that picture, especially when social, economic and political environments are not favourable. Having a child with a physical disability may be the cause of a double handicap, which some parents find hard to accept. Kowhai's parents have both been active in Kowhai's care and well being, in that, Kowhai's disability is not considered an issue, instead she has been included in all activities centred in the family, whether it be household chores or personal responsibilities. Matai's parents separated when Matai was three years old and Matai's mother took sole care of Matai for three years, until she married again. Matai now lives with his stepfather and his mother. Matai has the support from the three whanau; mother, father and stepfather.

Meanwhile, Kauri's parents lived in Ekuatoa at the time of Kauri's birth. They moved back to New Zealand to be with whanau. After the accident, the parents separated and Kauri's mother took sole responsibility for Kauri, while Kauri's father went back to Ekuatoa. Rimu's parents separated when Rimu was one year old. Over the years, Rimu has had occasions to visit her father; otherwise, she has had very little support from her father. Both of her parents have spent time in prison. In the case of Rimu's mother who was raising the children on her own, this was a warning for her and alerted her to think about who would look after her children, and the immanent possibility of the state taking over the care of her children. Totara does not know his birth father. His carers have been his mother, his older sister and on occasions his maternal grandmother.

Siblings

Siblings can be a source of socialisation for children who suffer from a cognitive, sensory or a physical condition that often hinders the child from fitting into society. These children do not feel excluded or ostracised when surrounded by children about the same age as them. Kowhai lives in a family of six. Her older sister aged 10 years and her two younger twin brothers aged eight years. Kowhai is nine years old and she is not treated differently from her other siblings. Her oldest sister's responsibility is to make sure Kowhai is safe when going to and from school or on any social outing. The same responsibility is given to Rimu's oldest sister aged 12 years. Rimu also has a younger brother aged 10 years and an older stepsister aged 35 years. As for Totara, his older sister aged 15 years is also his main caregiver in addition to his mother. Meanwhile, both Matai and Kauri is an only child within their families, however they are well cared for and supported by their cousins.

Conclusion

Cultural identity is not only embedded in the individual, but within their community. History links them to their ancestral past, their iwi and hapu and come forward to the present day. Land, religion, spirituality, cultural values, language and Maori customs have a historical beginning; they have been recreated in order to give certain aspects, relevancy to this day. Family and extended family have played an important part to ensure their Maori cultural identity is maintained, while others have created their adopted family around the support groups that support their child's disability or their immediate family, while still acknowledging to the history of their culture.

SECTION 2: HEALTH AND DISABILITIES

Introduction

The themes that emerged out of my findings identified different approaches to the health system prior to, during and after, hospital care. It also identified an element of trust or distrust in regards to hospital care, which was dependent upon each individual case and the disability. Whether the cause of the child's disability was hereditary, a medical mishap or accidental, each case was affected by the care and sensitivity they received.

Pre-Health Care

Early pre-health care revealed no problems and none of my participants had ever experienced having, or being around children, who had a physical disability. All of the pregnancies were going well; Kauri and Matai were first-born children, while Totara and Kowhai had an older sister, and Rimu had two older sisters, one being a stepsister. All was going well, until late into the pregnancies when difficulties arose for the mothers of Matai and Totara. Matai exhibited signs of stress. Two weeks prior to giving birth, Matai's mother knew she was going to have a breach baby that would be delivered by caesarean section. The day before the due date, the baby was showing signs of stress, so both Matai's mother and the baby were monitored. After a second opinion, it was agreed to operate as scheduled. Totara was born four-months premature, with lots of complications. It was thought that the baby would die. Rimu, Kowhai` and Kauri had no complications prior to, and after parturition.

Delivery

After delivery, Rimu, Kauri, Matai and Kowhai were healthy babies and went home early after their births. A Plunket Nurse discovered Kowhai's disability early, and through a sleep programme organised by a paediatrician, they were able to diagnose her autism. Matai's disability was not identified until six or seven months later after a consultation with a paediatrician. The cause of Rimu's disability (at the age of two years) cannot be identified within this thesis because of a confidentiality agreement between participant and researcher. Kauri's disability was caused by a medical mishap at the age of two years. Totara had the most severe disability at birth, firstly by being born three months premature with a minimal life expectancy. Overall these children who had a disability ranged from mild to severe, with all children requiring twenty four hour care, seven days a week.

Culture and Health Care

A lack of cultural sensitivity was also noted when dealing with health professionals and in the processes of the frequent changes within the health system at that time. There was very little sensitivity shown towards being Maori or to the culture of Maori. For example, there was no information provided about the availability of choice of health professionals from their own ethnic background.

Some of my participants identified cultural and ethnic issues that supported them as Maori clients within a hospital setting. The parents and families of Matai and Kauri believed it was important. Totara's and Rimu's parents thought that having a strong social worker or support worker who was able to be your 'ears and eyes', while in a consultation or any other medical situation, helped them when they were under stress. They were able to help because they could fully take in all that was being said. In Kowhai's situation, the support of her partner helped when seeking understanding and advice about Kowhai's disability. With the support of both parents, they were able to blend her disability within a safe and secure family environment.

Hospital

Totara's hospital care was minimal at the beginning because of his limited life expectancy. Totara continued to fight for his life, while the family tried to get him released from hospital but it was not until one of the members from the Board of Trustees advocated for the family, was Totara able to be released into their care and allowed to go home. From the viewpoint of his family, it took six weeks from the day he was born before medical personnel actually looked at him seriously as a survivor. They then attended to his medical conditions, such as his eyes and putting the shunts in his head. He had an osteotomy operation because of a hip deformity, but now he has a very painful leg and it is very short. He has a built up shoe for his short leg.

Matai was admitted to a hospital in Piritene and had a full team of specialists available to attend to Matai's assessments and needs. Even after these tests and still today, specialists have not been able to label Matai's disability, only that he suffered asphyxia at birth and has scoliosis in the spine. Rimu's disability occurred at two years of age that required Rimu to be admitted to hospital for three months. The hospital stay required other members of the family to be shared among extended family, and staff members were very helpful for both mother and child while in hospital.

At the age of two years, Kauri was suffering from croup. At the time, he was being monitored in the hospital because his condition was not improving; a decision was made to incubate Kauri. During incubation, one of the tubes fell out and Kauri suffered a hypoxic brain injury, and as a result, he is now a spastic quadriplegic with epilepsy. Kauri's medical mishap happened at a Dunedin hospital where he was hospitalised for 3-5 weeks before being transferred to Christchurch Public Hospital and closer to home. He remained there for three to four months before coming home.

Kowhai was physically healthy as a baby; her sleeping patterns (lack of sleep) showed signs that things were not quite right. The Plunket Nurse was the first to recognise Kowhai was not meeting some of her milestones and a Social Worker at the Hospital was helpful, suggesting that the family put Kowhai into a sleep programme and have a paediatrician's assessment. At the Child Development Centre at a hospital in Pahia, she was diagnosed as having Autistic High functioning Asperser's Syndrome. The Paediatrician found that only Kowhai had lead poisoning from eating soil, but all the children in the family were tested.

Health Professionals

The health professionals play an important part in a child's long term and short-term care. This care can be continuous from infancy through childhood, adolescence and adulthood until to old age. This will require both health professionals and family and carers working together to ensure the best interests of a person who has a physical or cognitive disability. Another important aspect for long-term or short-term care centres on culture. Attention should be paid to maintaining interaction with professionals who have tribal links to their cultural background and who are proud to promote it through their practices, language and education. It is also believed that a physical, 'hands-on' approach will ensure a better rapport between carers and health professionals. Any barriers that may have previously arisen, through judgement, guilt or anxiety, will be put to rest, and thus enable better communication in which questions can be raised and adequately answered, clarified and understood. The environments in which these health professionals participate in their fields are in general practice, hospital settings, marae-based health centres, within schools and commercial and private homes of clients.

Access

Barriers can impede access to adequate care for a child who has a physical or cognitive disability, if a carer does not have adequate support. These barriers may hinder the amount of care, or the type care that could be beneficial for the child with a disability. Often, the carers or parents have to overcome their own ignorance, or problematic attitudes towards disabilities, before they can gain access to help, for their child.

Communication

When limited support is coupled with uncertainty of what different medical and government departments can offer to assist with a child's disability it can be an intimidating and frustrating experience. This can be exacerbated if a parent or carer is not acknowledged on arrival and attended to at the appointed time, or if concerns are not addressed and followed through with a telephone call.

A lack of communication caused when accessing services for resources or assistance, either deliberate or through miscommunication will hinder full entitlement or understanding of the necessary steps that are needed in order to get the best possible outcomes for a child who has a disability. Having a whanau support system that caters for Maori needs under one hierarchy, would ensure a whanau concept of Maori needs and culture. This could facilitate the flow of information about all aspects of disabilities and the better sharing of resources, equipment, services and educational resources.

Trust

Stigma, prejudice and discriminatory attitudes can affect how people behave towards others. These attitudes can cause insurmountable barriers that make it difficult to create and maintain trust. People see themselves as part of Maori culture, being a woman on a benefit, raising children on their own, having and raising a child who has a disability, living in a low socio-economic area, and are unemployed are examples of situations from which discriminatory attitudes can arise. They may be socially constructed within society, but they are real in their effects.

Respect

Parents want themselves and their children to be treated respectfully by health professionals. Therefore, if people are shown respect they will react differently by being more open to sharing information and receiving information if they know that their health specialist cares for them and their child, they will be inclined to reciprocate that respect, as will the child. For example, the experience faced by Kauri's mother, *"When he was in hospital, we never leave him alone, ever, with anybody nurses, doctors, and specialist."* The hospital staff educated the family on how to look after Kauri's needs cares and medication, *"They had too, we insisted, and in the end we did everything".* Kauri's mother feels Kauri's needs were met much quicker if the family attended to them, whereas if the hospital staff were attending to them, his needs would have been prioritised, of necessity, among the needs of other patients.

Paediatrician

Paediatrics is that branch of medicine that specialise in children's diseases and health. It is also concerned with genetics, obstetrics and psychological development, the management of people who have a disability living at home and within the school environment, and the effects of social conditions on a child's health. A paediatrician was involved at an early phase in the diagnosis and treatment of Kowhai, Matai and Rimu. Kowhai's Paediatrician identified lead poisoning as the cause of her disability, and Matai's Paediatrician was called upon as part of an overall assessment to identify his disabilities. Rimu's mother has two supportive paediatricians who give her support when pressured by other specialists who suggested to her other strategies to have her involved in. They also supported Rimu in having her case and funding reclassified from Mental Health to the Accident Compensation Corporation (ACC).

Orthopaedics

Orthopaedics helps to correct deformities through surgery, manipulation, traction or special apparatus. Matai, Kauri and Totara have had various operations. Kauri now has very little contact with the health professional within the hospital unless there is a problem with his stoma or any other health problem that may occur from time to time. At present, he has a problem with a lump on his eyelid.

Totara had an osteotomy operation because of his cerebral palsy and he had two operations for retina tension in the right eye. He had operations to put shunts in his head; ten months later, he had two more operations to replace the broken shunts, and one operation to remove them. The breakages are due to the amount of head movements Totara is able to do. In the end, the family wanted the plates removed. They had difficulty with Totara's specialist to remove a metal plate from his head after a year. It took three years, after requesting Members of Parliament to intervene and letters from General Practitioners for support to have the metal plate removed. After this incident, Totara changed her specialist and had the metal plate removed.

Occupational Therapy

Occupational therapy helps with the physical and psychiatric conditions to encourage a maximum level of function and independences in all aspects of daily life at the capacity of the individual. Rimu, Matai and Totara all had occupational therapy. However, Totara's occupational therapy was carried out within Conductive Education treatment. Today, Matai has no occupational therapy, Totara still has therapy at the conductive education school he attends; and Rimu is at the stage of being reassessed under Accident Compensation Corporation (ACC). Her mother has concerns about services and funding being stopped, as well as assessments made about Rimu without the full history and personality of Rimu taken into account.

Physiotherapy

Physiotherapy employs physical methods to promote healing, such as massage, manipulation and remedial exercise. Matai, Rimu and Kauri, Totara have all been involved in physiotherapy. Matai had therapy for his shoulder, hips and feet Kauri for his whole body; and Rimu still has physiotherapy within the home by her mother, and at school for her leg. Even though they no longer attend physiotherapy sessions, the mothers of Matai, Rimu and Kauri still carry out the physiotherapy exercises with their child within the home.

Therapy was stopped for different reasons, in the case of Matai and Kauri when their mothers stopped the treatment. In Matai's case, it was stopped due to the distance for travel to their appointments, car parking problems and the inconvenience of getting time off work. Also the disruption of taking Matai out of school to meet his appointments, and the amount of therapy he was entitled to was only a one-hour session once a week for six weeks per year. This was not productive enough to be continued. Matai's mother identifies Matai's needs as ongoing, requiring regular massaging, and feels that having a physiotherapist visit the schools would be less disruptive.

Kauri's treatment was stopped because the therapy was carried out within the home, and although Kauri's mother would go to another room to enable therapy to be carried out, the cries from her son over a period were too much to ignore. It was not a choice for his mother to leave the property while therapy was carried out, because of her mistrust of medical professions. She has always been on hand to observe and participate in Kauri's care.

In Rimu's situation, an assessment was carried out as to whether further therapy was required early this year, as Rimu had transferred to a new school to be closer to home and to attend the same school as her siblings. This coupled with adjusting her care and funding from mental health to ACC; resulted in a physiotherapy assessment that decreed that Rimu no longer needed physiotherapy because her needs were being met within the school. However, Rimu's mother is requesting a second opinion.

Totara lost funding and access to a physiotherapist and an occupational therapist when his mother put him into a Conductive Education programme that is not recognised or funded under the Health Funding Authority. However, the benefits were gained much more quickly with intense hands on therapy.

Speech Therapy

Speech therapy assists people who are unable to speak coherently because of congenital causes, accidents or illness. Both Kowhai and Kauri had early childhood speech therapy.

Visual Centre

The Visual Resource Centre's purpose is to meet the special educational needs of visually impaired pupils in Canterbury and Westland, serving children between birth and the age of twenty-one years in the state school system. Only Rimu attended the Visual Centre in the early stages of Rimu's disability recuperation, when she was blind, until she regained her eyesight. However, Kauri and Matai had eye problems. Kauri was told after the accident that he would be permanently blind, but the mother did not accept that he was, and set about to stimulate his vision. Matai also had problems with his eyes rolling so an operation was suggested. Instead, Matai's mother opted to strengthen Matai's eye movement using the movement of car wipers.

Podiatry

Rimu, Kauri and Matai have had the podiatrist involved in meeting their needs in regards to the care of their feet and the fitting of special shoes.

Throat specialist

As part of Matai's early assessment, he attended a throat specialist.

Alternative therapy

Rimu's family have used the 'power of prayer' to help assist Rimu's Hiri Islands; Kauri, Matai and Totara have all attended a spiritual group for the purpose of healing and massage.

Natural Healing

In some instances, operations are necessary to correct a deformity or to improve the quality of movement and wellbeing. On the other hand, not all situations need to be fixed by having an operation. The option to let time, environment and the child's natural healing to take place is another possibility to consider. In the cases of Matai, Kauri and Totara, they all opted to letting the body heal itself and had faith in themselves to find alternative ways to strengthen their child's eyesight.

Parents advocating for a children who have physical disabilities, sometimes require very strong personalities, with high self-esteem and concepts of self worth to be able to continue in the belief of what is best for them and their children. For instance, there is a considerable difference in a health professional's perspective compared to a parent's perspective. Health professionals have their qualifications that identify their specific skills and knowledge, whereas the parent has the close and personal experience and the knowledge of the child's personality. Health professionals' may see the physical benefits for surgery, such as mobility and greater independence, whereas a parent looks at the internal spiritual, emotional and social aspects, of what is best for their child in the long term.

Home Based Therapy Compared to Hospital Based Therapy

Of all of my participants, Kauri is the most severely, physically disabled child, with limited mobility and independence. Health professionals see limitations in meeting the needs of the child within both a home and a hospital setting. In order to be an active parent in the daily care of Kauri, his mother learnt the therapy procedures to pass on to her carers.

From the age of two and a half years to when Kauri was five years old, he had home based therapy that was very intensive. Today Kauri has no need of professional services within the home, as his mother, extended whanau and his carers meet all of his needs. Any physiotherapy for Kauri is carried out within his school environment. If Kauri is required to return to the hospital for any reason, his mother and any support person she may take with her closely monitor his visit. This is because Kauri's mother feels hospital procedures apportion the amount of care given to patients.

Home Care

Rimu, Totara and Kauri all require twenty four hours home care to ensure their needs and safety are paramount. Over the years, their homes have had visits by health professionals, assessors and therapists, as well as carers from different organisations, to support their child and the family in their everyday care.

For instance, Rimu's mother looks after her daughter's care at home, and she has respite care available. Totara's mother and his older sister attend to his needs in the morning and most of his home care and in the evenings, a carer comes into the home to shower and dress him. Home care for Kauri requires twenty-four hour care. His mother has selected the caregivers who support Kauri within the home, on the proviso that they are whanau orientated.

Respite Care

What was identified from my research about respite care is limited. The purpose of respite care is to allow the child with the disability to have a break from their family environment and in order for the family to have a break from a child's daily care. However, there is inadequate rest if there are other children in the family and one parent is caring for the family. In most cases, it is the mother providing for her children. The respite care is not long enough to provide an adequate break from the normal routine.

Funding for Services

In order to have adequate care, there must be funding for services such as health care, transport, education, respite care, home maintenance and home help to ensure an adequate amount of mobility and social activity. As most of my participants would be considered to be living in low socio-economic areas, their resources for providing adequate services is very limited compared to people living in higher socio-economic areas, who may have the means financially to access better services.

Recipients of a social welfare benefit, or those employed in the lower income bracket, will have fewer financial or family resources to enable adequate care for a family. This is especially so if only one parent supports the family and there is more than one child, and the difficulties are greatly increased if a child has a physical disability.

Any changes to services, funding, expenses or access will have an additional, adverse effect on resources and the stress within the family unit, because the family will spend a lot of time fighting the system, in order to get access to the same opportunities that other people have who have better resources to do so. For instance, Kauri's home care hours have been reduced from twenty-four hour care to eleven hours home care. The reasoning for the cut in home care was Kauri's age and funding.

Some of the difficulties for funding for Conductive Education lie in Health Funding Agencies not recognising Conductive Education as an alternative model of health care. Parents who decide to put their physically disabled into the Conductive Education programme are told they will lose their access to some health services, for example, Occupational Therapy and Physiotherapy. Therefore, resources for equipment and health services are not funded for Conductive Education. Instead, other support groups resource these.

Support

For one reason or another, support is not fixed; it is negotiated and renegotiated as changes occur within the family. Initially, extended families assist in the readjustments that have to be made. However, this is not always possible due to extended families lifestyles and distant locations, to fully, or adequately, support the family. Another area of concern that arises is that when there is inadequate support externally for family, problems may arise internally within the family. For instance, a parent may withdraw from the situation, or they may focus on the child with the disability and neglect other members within the family.

Counselling is an important element for putting life back into perspective in order to maintain a healthy environment. Kauri, Rimu and Totara's mothers have had specific counselling at different times. Kauri's mother had counselling soon after the accident, after Rimu's mother came out of prison and for Totara's mother, counselling was provided through Conductive Education. The support of the extended family has helped the parents of Kauri, Matai, Totara and Kowhai.

Social Activity

Physical disability is not a determining factor as to whether a child can fully participate within their community. Rather, it is how they are received within the wider community, may determine where their child will socialise. Access to places of interest; have to be 'user friendly' and to allow easy access to people who have disabilities, such as ramps, and lifts. Their equipment is there to aid them in their mobility, however, if their equipment is inadequate, there are limitations placed on where they can go. For example, Matai enjoyed playing rugby league and was acknowledged for his ability, while Totara's wheelchair limited his mobility within the park close to where he resides. This is due to uneven footpaths in need of some attention. Rimu has achieved recognitions for her efforts when she competes in the CCS Games, which takes place annually. Meanwhile, access to bathing equipment limited the amount of trips away from the home

Equipment

Access to the appropriate equipment to meet the child's physical needs was identified as not being adequately supplied. In the opinion of some participants, children with physical disabilities are given the standard issue of outdated equipment that is in a storage department for new and used equipment at Whero Hospital. Whether equipment is suitable or not will depend on how the degree of mobility that the child has and what benefits it will have for the individual, such as for toileting, showering and wheel chair equipment. For example, a wheel chair is designed to last a person five years, but Totara has gone through seven chairs because they have been unsuitable for him to manoeuvre independently. Rimu has a wheel chair for long distance journeys, as she cannot walk long distances because she tires easily. She also requires another person to aid in the pushing because she cannot push herself for long distances. These parents do not have the resources to purchase the appropriate equipment needed for their child, so they have to accept what is available.

Conclusion

All of the participants' experiences and outcomes were discussed under the theme of health. This theme ran in a chronological order, starting from pre-health care, delivery and their stay within a hospital setting, and depending on when the child's disability occurred. Cultural sensitivity, support and communications were considered vital when health professionals were interacting with whanau members. The effectiveness of these communications will depend of how whanau perceive trust and respect. Other aspects of health looked at the relationships with health specialists, the efficacy of hospital-based therapy and home based therapy, funding, support and the availability of equipment that has been found necessary to meet the needs of my participants. The research identified that some participants had a lack of trust with health professionals sometimes because of personal experience, and revealed the inflexibility to certain varieties of therapy, the lack of cultural sensitivity and confidentiality, and provision of inappropriate equipment. On the other hand, other participants' identified excellent support and trust from health professionals with effective communication leading to gaining access, funding and long term relationships between health professionals, parents and clients.

SECTION 3: EDUCATION AND DISABILITIES

Introduction

Under the theme of education, I want to emphasise that communication and social activity are vital when different cultures are involved, and more so, when another variable is added, such as a child having a disability, a behavioural problem, or when cultural values differ from the education being offered. In such circumstances, cultural factors, which may include spoken language, body and facial language and social interpretations, may be barriers to learning. Secondly, I will discuss the selection process of education facilities made by parents of a child who has a disability, to ensure their child's wellbeing. In addition, parents have to consider the relationships between parents and school, assessments, the availability of assistance, and access to funding. Thirdly, I will present six factors that are necessary for the wellbeing of a child who has a disability, before effective learning can take place. Finally, the future prospects that my participants foresee.

Improving Inter-Cultural Understanding

The communication and understanding of difference, whether of culture, language, or physical and cognitive disabilities, requires a place and time in which learning can take place. It also requires an infrastructure to support and aid in that learning. A Maori holistic perspective on education is based upon a belief that all children are special and have gifts that are inherent within them. It is the responsibility of the whanau, hapu and iwi to nurture, support and enhance these gifts. Education funding and resources are necessary to ensure the development of their gifts.

Selection Process

Choices are available during the selection process between a variety of schooling models, including alternative education, both in early childhood education and primary schooling. There are also options of public and private education, both of which are partially government funded. A child with a disability has four other options that will determine the type of education that best fits their needs; these are, geographic location (outside or within their community), type of school (co-ed, single sex, religious or secular), public or private education, and the school programmes offered.

When the parents in this research considered the type of schooling for their child who has a disability, they looked at all options before they made their final choice. Parents' decisions when selecting an education environment were made by their first impressions, the feeling of the place, interaction between staff and pupils, classroom layout; open spaces, organised and hygienic working areas and how their child would fit in. Another determining factor in the decision-making was how the school principals and staff reacted towards the child's history provided by the parent through documented files and verbal accounts, and what was said and done upon receiving this information.

The reality of choice when selecting a school for a child, who has a physical or cognitive disability, is very limited, because, in effect, early childhood centres and schools selected the child. Almost all parents experienced exclusion from different education domains within their local community while others .were accepting. Therefore, the parents' selected a facility that did not discriminate. For example, Rimu by choice attended a local Kohanga Reo early childhood centre. Kowhai attended a day care centre in Inia, while Kauri, Totara and Matai (in Piritene), attended a local kindergarten close to their residence. Throughout his life, Totara has been involved in Conductive Education that is a proactive programme for children who suffer from severe cerebral palsy. It is intensive, and actively 'hands on' form of training which includes the participation of parents and the child who has a disability. This ensures the child will become independent enough to feed, toilet, and learn life skills, by doing and making individual choices for themselves.

The accounts of the participants showed examples of exclusion and limitation of choice from primary and secondary schools. Totara was excluded and denied from most choices of primary and secondary schools except the two schools (primary and secondary) that supported Conductive Education. Rimu was excluded from attending a local Catholic school, which her older sister was attending, for seven years because of her disability. Instead Rimu attended Huare Primary School. It has a special education unit attached to the school, where children are integrated into mainstream education.

Schools and Parent's Participation

All of the parent participants have taken an active role in their child's education. They have been involved from the beginning, starting at the selection of school, and then with transportation and safety in going to and from school, and with activity programmes that support their child's interests. Some have participated on school committees and on other organisational activities. Kowhai's mother is a committee member of the Parent, Teachers' Association (PTA), and the other participants' parental involvement within the school is related to their own child's pursuits. They will support activities that their child is involved in, and manage any conflicts that may arise for the child, as well as attending meetings and organising equipment or services that might support the child in the school environment. For example, Matai's mother attended a cultural concert that Matai was participating in; and Kauri's mother attended school to talk about a new piece of equipment that the unit was introducing to help Kauri stand upright. Totara's mother is now no longer so involved with Totara's schooling at Conductive Education. Rimu's mother attends meetings when required. Otherwise, Rimu's mother views school education and home education are separate, in that, she believes that the school is responsible for Rimu's school education, while her role as a mother is to teach life skills within the home environment.

The pattern of communications between home and school is quite fluid, so that the parents are informed when events are scheduled by means of school newsletters. If there is a school camp, plenty of notice is given, and respite care is organised by the parents, in order to meet the needs of the child. If a teacher aide is going to be absent, she will inform them individually. The child's teacher notifies the parents if there are any changes to programmes affecting their child or if there are impending meetings concerned with their child's progress.

The parents also usually ring the school to arrange meetings with the appropriate teacher, Principal, teacher aide or the resource teacher, when there are any concerns that need addressing, or issues to be clarified concerning their child. In Matai's case, there were three examples of conflict regarding subject clashes when, his violin lessons were scheduled at the same time as his Maori studies, and secondly, when his teacher aide, removed him from a computer programme course that was specifically designed for children who are physically or cognitively challenged. The third matter related to how Matai's funding was being distributed among his subjects.

Funding and Assistance

To gain funding a child has to be recognised as having a disability (physical, cognitive or sensory) and assigned to a taxonomic category for their disability, before access to funding can be processed. This requires that the child be labelled and categorised to become eligible to receive the target funding. For instance, people, who have a physical disability, depending on the severity of their disability, will be graded high, low or mild. People with a physical disability, have better chance to accessing funding because it can be physically assessed and easily accepted as requiring assistance. On the other hand, cognitive disability on its own can be excluded from the same sort of funding, because the measurement is gauged on physical disablement.

However, if they have both a physical and a cognitive disability, they have a better chance of accessing funding.

The sharing of knowledge is dependent on the severity of the disability. Funding agencies within organisations that best fit the child's disability are informed and information is given to the parents to ensure they are informed on what organisations can do to help them through their transition and to the entitlements that best fit their child's needs. For example, Totara and Matai disabilities occurred around the time of birth. Totara's funding comes from IHC, whereas Matai's disability is not clearly categorised so he does not have a taxonomic title, however, he is able to receive a disability allowance and funding for his physical disability.

In the case of a medical mishap or accident, because of which a child suffers a physical or cognitive disability, funding is obtained through the Accident Compensation Corporation (ACC). This ensures the child a lifetime of health care within their social environment, for such things as health, education and community care. Kauri and Rimu fit into this category. Kauri has received funding since shortly after the accident, while for Rimu, funding came from Disability Support Services instead of ACC. Only this year was the error picked up and his case transferred to ACC. Kowhai's disability was caused through an accident but she is not covered by ACC.

Once funding has been approved, Special Education Services (SES) provides funding that be attached to the individual's case record to enable long term planning centred on the child's disability. All participants received Ongoing Resource Services (ORS) assistance at the onset of their disability until the age of seven years. At that time, all children with a disability are reassessed for further funding. There are three possible outcomes from this assessment. A child will be classified as having high or low functioning needs, or no longer needing funding because they are integrated within mainstream education. Those with high functioning needs, will receive more teacher aide hours, than low functioning needs. Both Kauri and Totara have high functioning needs, while Matai has low functioning needs. Rimu's ORS funding continued until she was nine years of age. Kowhai lost her funding at seven years of age, but managed to have speech therapy and teacher aide funding until the age of nine.

The difficulty that is experienced with this system is that once their funding has been scaled down or removed, it is difficult to get the funding back. It is left up to the individual to push for another review or pursue other avenues for funding or assistance. All my participants have experienced funding losses and have sought other avenues for support, such as mental health, Ministry for Disability, local politicians, the Ministry of Education (MoD), and tribal affiliations. In Rimu and Kowhai's situation, although Rimu's physical disability does not hinder the specific physical activities in which she participates and Kowhai has no physical disability, both children required one-on-one teacher aide assistance with their schoolwork. After all avenues were exhausted to no avail, their schools gave them funding from Resource Teacher: Learning and Behaviour (RTLB) for teacher aide time.

Assessments

Another difficulty that was uncovered by my findings was the amount of trust and faith a parent has to give to other support people, such as school principals, teachers, teacher aides and education resource teachers to ensure the best possible outcomes for their child.

Another aspect to assessment where trust and faith was a concerned was how assessors or researchers came from the Ministry of Education, Special Education Services, and entered the school environment to observe a child with physical or cognitive disabilities. Parents are informed and give their permission for their child to be observed. Nevertheless, parents often feel that this is an unfair system, in that both parents and teachers are unsure whether to have the child supported by a teacher aide for the assessment, or have the child unaided. Another concern was how a child reacts to being assessed and whether it is a fair assessment when the child knows that someone unfamiliar is sitting in his or her class. When these officials are dressed in suits, a child may believe them to be a very important person, and therefore their behaviour within classroom may change dramatically, so that they appear as uncharacteristically compliant.

The affects of these assessments can have devastating results for the child, the school and parents, if funding and services are removed. The conflict occurs when glowing reports identify areas of success a child has achieved, not by themselves, but with the help and support of a teacher aide, and this coupled with the official assessment can justify the removal of funding. However, this process does not take into consideration the child's case history, nor informal observations made by other staff members and teacher aides within a classroom setting. Once funding is lost, other avenues have to be explored to help aid a child's progress.

Strategising for Funding and Resources

In order to unravel the unfamiliar, such as funding for disabilities, requires the experience and knowledge of people who specialise in accessing funding for others. These key people belong to mental health institutions; they are health providers, disability agencies and social caseworkers. They can also be experienced people in support groups and can be educational providers within Special Education Services, and school resource teachers. It is important that reports have the appropriate wording, and that all parts of the report are filled in where appropriate. If it requires a specialist comment, it is better to pay the consultation fee and have it available in order to support their child's needs. The experience of the parents involved in this research has shown that it is better to undervalue the child's progress than to exaggerate it.

Six Factors that Reinforce Learning and Wellbeing of Students

1. Communication.

Good communication between the school and the home were important in regards to school events, activities, and parent-teacher interviews, and IEP meetings. Communication is very important for the parents whether by means of a newsletter, a note or telephone conversation as this helped the parent support their child within the school environment. Communications that kept parents involved, and informed in decision-making about the strategies to ensure funding for their child, and the provision of resources for their school, are necessary for good parent involvement. It is also important to be kept up to date with new technology and equipment that can be used to support their child's learning. Good communication ensures a partnership for the benefit of the child who has a disability.

2. Individual Education Programmes (IEPs).

The IEPs for each participant are designed to meet his or her individual needs within the school environment. Assessments are important tools to identify the needs and requirements for the child, as well as for monitoring the child's progress, limitations and achievements. The IEP assessments are done every six months. Teacher aides, classroom teachers, Education Resource teachers and the parents and support people attend meetings to discuss the child's learning and progress. Teachers who are unable to attend write a report for the meeting, usually identifying positive factors and areas of concern. In some of the cases in my thesis, it was the parent who followed up on IEP meetings to ensure that their child's needs were being met, and in dealing with concerns as to how funding hours were spent, and whether these hours were spent on the child's strengths or weaknesses. As parents, they were also interested in having a say on funding resources should be dispersed.

3. Classroom size.

Alternative types of education, and class size, were determining factors when choosing a school for children with a disability. Many children who have a disability are raised in an environment in which structures and functions are centred on routines to ensure that safety measures are in place. Therefore, the important factors to ensure a suitable learning environment for their child were seen to be, smaller class sizes, how well focused the school was, and how structured and organised it was in regards to routines.

4. Behaviour.

In order that children feel safe at school and within their classroom, safety measures have to be put into place with programmes that monitor inappropriate behaviour and support desired behaviour. Empowering children to support each other, and report incidents early will ensure a safe environment. Children with a disability rely on others to make them safe if they are unable to do so themselves.

5. Friendships.

Friendships for children develop from the people who support them in their learning whether they are disabled or not. They come to rely on familiar faces, familiar surroundings and familiar routines. If they have siblings, they will be their main support for safety and socialisation. If they have no siblings, then extended families and children within their neighbourhood, or classroom friends are needed to ensure a child's wellbeing. Another factor is the extent of their mobility and the limitations imposed by their disability and that will determine how peers will interact with them and the friendships that develop.

6. Support and Inclusion with 'hands on' Learning.

Firstly, for a child who has a disability (physically or cognitive), it is important that routine structures are in place, and that they are well supported by teacher aides, resources and funding. Their safety is paramount before learning can begin. Secondly, social interaction is an important ingredient for wellbeing. The child should be actively involved in classroom settings, and integrated into mainstream classrooms. Thirdly, learning programmes about life skills are necessary to ensure real life experience relevant to their school, home and community environments. Lastly, once the above have been achieved, then learning programmes centred on their strengths can be pursued in earnest.

Future Prospects

As the child moves through the different milestones throughout their lives, the process of selection, assessment and monitoring of learning is always taking place. Therefore, at the end of their child's primary school education, the parents have to repeat, once again, the same process they followed during early childhood education and primary school selection. Matai is currently in his first year at a secondary Catholic school next to his old primary school, so the transition went smoothly. As part of his school programme, he visits his primary school for violin lessons. While Totara is in his final primary school year, his mother has to decide whether to place him at a local school that has a special support unit, or to continue with Conductive Education, outside his local community again. Meanwhile, Kowhai, Rimu and Kauri have two more years, before a decision will be made about secondary school. At this stage Kowhai and Rimu may attend the same school as their older sisters. There is a lot of uncertainty as to what Kauri needs will be.

Conclusion

I therefore conclude that education is important for social needs, for not only children who have a disability, but able-bodied children as well. Working in partnership, and effective communication, enables parents and schools to work successfully. Mainstreaming the child who has a disability within their community has a positive effect for children, both disabled and able-bodied, whether the interaction is passive or active. Effective communication among school educators and the parents' to work together in partnership will enhance the opportunities of children with disabilities to achieve well within a learning environment. Whether the funding and adequate resources came from government funding (e.g. ACC, or Special Education Services), outside or inside the school (Board of Trustees, or Resource Teacher for Learning and Behaviour funding), funding and adequate resources were important to ensure that a child was well supported so that learning could take place. The six factors of Communication, Individual Education Programmes, Classroom sizes, Behaviour, Friendships, Support and Inclusion, and experiential learning, are the foundations for safety, wellbeing and learning in an education environment.

SECTION 4: COMMUNITIES AND SUPPORT

Introduction

This final theme refers to the importance of community support for people who have a disability in order that they may experience a normal lifestyle and community integration. Parents' first experience of finding what support is available is when they first learn about their child's disability. I want to identify the importance of having sufficient and appropriate information and support services that will enhance a child's well being and provide adequate mobility and transportation to assist them in gaining independence and accessibility. By means of housing alterations, access can be provided for equipment and resources for a child who has a disability and enable them to socialise and join in social activities both in their public and private environments.

The Flow of Information

Initially, at the time of the disability being identified, the first contact that parents have for relevant information about understanding their child's needs and development, will be from a health professional, followed by referral to the appropriate services and support groups.

Dependent on how the disability occurred, whether it is from a genetic, medical mishap, accidental or 'other' cause, information may vary in quality and availability. This was dependent on whether the parents are able to acknowledge and absorb the information on a particular disability relevant to their child's disability. In the cases of both Kowhai and Rimu, the parents decided that their child was not as severely affected as others who had the same disability, and they found that the information that they read was overwhelming. Kauri's disability was caused by medical mishap and the parents were eager to learn what they could, in order to take their child home and take charge of his care, with the help of whanau. Matai's disability was not identified, although plenty of tests have been done. The category of his disability is not known so information has been borrowed from the classification of other disabilities. Totara's mother has been active in seeking the available information at each stage of her child's progress, even to the point of gathering information in advance before the child faces those changes. For example, she has attended conferences concerning the obstacles, which adolescents that have a disability face, regarding sexuality, relationships and body awareness.

Support Services

In order to support people who have a disability, support groups are the first step to getting in touch with communities outside the home. Under the auspices of Disability Services, services that may support a child are divided into specific support groups relevant to the child's disabilities. Over time, the family, and the child with the disability, may outgrow one or more services dependent on the child's progress and the severity of their disability. The more integrated the child is within their community the more they may be able to participate in social events. For example, in my thesis the following support groups have assisted some of my participants:

- Intellectual Handicap Children (IHC)
- Autistic Association
- NZ CCS
- Aspersers Support Group
- Parents of Vision Impaired Inc (PVI) conferences
- Accident Compensation Cooperation (ACC)
- Parent Teachers Association (PTA)
- Parent coffee mornings Support Groups

Support groups, conferences, Ngai Tahu quarterly magazine, NZCCS newsletters, Church meetings, family and friends, have all assisted in distributing the knowledge regarding the availability of services. Support has also come from the experiences and stories shared by others who support, care or have, a disability. The mothers of Kauri, Totara and Matai have spoken to other parents, attended conferences and advocated for their child within the health and education environments in order to share their experiences and to raise the awareness of others dealing or coping with disabilities. Totara, Rimu, Matai and Kauri also participated in research carried out by various researchers in the field of disabilities.

Mobility and Transportation

The main means of transport for children who have a disability will depend on the severity of their disability. Both Totara and Kauri have limited mobility, in that they need a wheel chair to move from one destination to another. More often than not, the family van is their main source of transport, and the taxi vans that are used to transport them, to and from their school.

When the child's mobility is less restricted, they are able to participate more freely within their community. Rimu, Kowhai and Matai are able to use public transport for school trips and on social occasions, the family or friends' vehicles adequately meet their needs. Rimu's family has to use public transport or rely on the generosity of friends to move about in Christchurch.

Housing Alterations

Totara, Kauri and Rimu are renting Housing New Zealand homes that have been altered to enable them better access for the child who has a disability and to allow independence, safety and mobility. Both Housing New Zealand and Accident Compensation Corporation (ACC) carried out alterations to Kauri's home. Ramps around the house were provided by Housing New Zealand and Kauri's bedroom, shower and changing room and extensions to the living area were built on to the house by ACC so that Kauri and his equipment could be in the main living area with his mother, care givers, and extended family.

Access

In some instances, access to parks or public places was a problem. For example, Totara was hindered from being able to freely enjoy the park close to his home and in using his wheelchair, because of the uneven pathways. In Kauri's case, he has limited access to public places partly due to the severity of his disability, and partly because his mother feels that Kauri is more comfortable lying on his side or back than sitting upright in his wheelchair.

Resources

Sometimes due to the lack of personal income, limitations are placed on the kind of activities, such as leisure activities and community groups that are accessible in the community, for the children to participate in. This can be more difficult if the child has a visible disability and there are other siblings within the family. For example, Kowhai, Totara and Rimu have other siblings, so their resources are shared and that allows them to participate within social settings such as the Church, school sports and organised activities, as well as family activities within the home. In addition, respite care was shared among other family members in the cases of Rimu, Totara and Kauri.

Socialisation

To ensure that the development and the wellbeing of a child who has a disability are being addressed, it is important for socialisation to take place so that norms and cultural values are acquired. Firstly, this process occurs within the home among other family members, and then secondly with extended family members or caregivers, thirdly, by the health, education and social services and lastly with their own peers. More often than not, siblings' or extended whanau assisted Matai, Kowhai, Totara and Rimu.

Social Activities

In most cases social activities involving the participation of children who have a disability is limited, partly due to the severity of the disability. For example, Kauri is very limited compared to Totara and Kowhai who can interact enough to participate in social activities. If a child's mobility and coordination are sufficient to allow them to participate, and the child is determined to partake in organised social events, then they can enjoy and experience satisfaction and personal achievement. In the case of Matai, he was able to play rugby league and gain recognition for himself. In Rimu's case, she has participated for several years in NZ CCS Games and has achieved recognition for herself through medals and certificates she has won.

Public Places

For safety reasons, children who have a disability are nearly always monitored to ensure their safety. The amount of monitoring needed is dependent on the severity of the disability. The level of access to public places, such as, to shopping malls, swimming pool complexes, and the amount of independence given to the child who has a disability when among her peers, will differ. In all cases, Kauri, Rimu, Totara, Matai and Kowhai have 24-hour care, seven days a week. They are allowed more independence around their neighbourhood than in public places outside of their neighbourhood, because of their directional confusion and their poor sense of geographical location. They are also disturbed by the noise created by large crowds that may hinder the enjoyment of attending certain venues.

Home Entertainment

In most cases, social activity takes place within the home because the child who has a disability can be monitored and they have the support of people around them, and have the security of familiar things. For instance, having visual equipment available where interaction can take place among peers, such as play stations, computers, certain television programmes, videos and board games have all been found useful as learning aids in the fields of communication, coordination and learning about social interaction.

Conclusion

I have identified some of the themes that help support a child who has a disability to interact successfully within their communities, and that this will be subject to the amount of support surrounding the child. Enabling a child, who has a disability to be an active participant within society, requires that he or she be given the means to gaining the appropriate access, resources, and information. This will enable the child to lead a normal lifestyle and to gain community integration within their home community.

CHAPTER SIX

CONCLUSION

For Maori to be able to tell their story in relation to raising and caring for a child who has a disability, they must do so by explaining their situation and their personal experiences. In this thesis, stories told through the voices of the mothers about the complications and impacts of their child's disability are seen as a valid reality for a child who has a disability. In most cases, these mothers care for children who have more than one type of disability, and these children will usually require twenty-four hour care, seven days a week.

Four of my participants are proactive (in some form or another), not only for their child, but, in sharing their knowledge in the wider community by telling their stories to groups that support their child's disability. They have become speakers on behalf of other parents, and advocates for alternative healing, and have participated in research in different academic fields on topics relating to children and disabilities.

Telling their stories may also help others who are in similar situations, to confront the obstacles, and to look forward to the successes, which they could encounter in the process of raising a child who has a disability. Therefore, as researchers we are able to give a voice to the voiceless, to people who have not been listened to. These carers are the experts when identifying the processes of dealing with a disability on a day-to-day basis. So, retelling their story, places autonomy back with the parents and the caregivers who face discrimination, marginalisation and institutional racism.

Culture and Language

The stories that came out of this research identify historical barriers to Maori culture, their language has been identified and efforts have been made to address them within health, education and social services. Connections were made between culture and language, looking at two generations, the participants' and their parents' tribal affiliations. Their parents came from an era that saw the migration of rural Maori into urban areas for employment and for better opportunities within the service and production areas. This in effect broke down the whanau and the support that extended whanau gave within their communities. In earlier generations, as part of the assimilation process, Maori language was banned within most schools. As a result, my participants did not speak fluent Maori, and some of their parents chose not to speak Maori at all, while others only spoke Maori if they were attending certain Maori celebrations. More often than not, Maori language was not spoken. My participants today are all involved in some aspect of education relating to Maori concepts that centre on learning part of their Maori culture. They are learning such things as language, cooking, weaving, kapa haka and other cultural activities. They are also reading historical material and monthly information from support groups and Maori organisations. Those who identify with their Maori side, or decide to learn about their culture and language will grasp their knowledge and learning at an individual level they feel meets their needs.

Immediately after the prognosis, the kind of support that was extended to a family whose child had a disability was dependent on the parents' upbringing. Long-term support from the whanau was dependent on whether they lived within close proximity. In other cases, those who had ease of mobility found support within the communities in which they resided.

Therefore, cultural identity is not only embedded in the individual, but within their community. Family and extended family played an important part in ensuring that their Maori cultural identity was maintained, and others who lacked a local family, created an adopted family among the groups that supported their child's disability and their immediate family.

Elements of trust or distrust became evident when dealing with health professionals within the health system. In addition, there were differences in the performance of the health system that were dependent upon the circumstances of each individual case and the type of disability. Whether the cause of the child's disability was hereditary, a medical mishap, an accident or some other cause, each case history was affected by variations in the care and cultural sensitivity that was delivered. When there was a partnership between parents and the health professionals, the results have been excellent, and have led to high levels of support and trust, both to, and from, health professionals that result in effective communication leading to the gaining of access to funding and the development of efficacious long-term relationships.

Communication and social interaction are vital when different cultures are involved in the care of children with disabilities. This is especially so when cultural values differ within the community. These differences may include spoken language, body, facial language and social interpretations. Within the field of education, it has been shown that there were many unique barriers that Maori faced, which needed to be addressed. The participants in this thesis all had Individual Education Programmes that were being used within the different schools they attended. In most cases, they all needed additional assistance with their schoolwork. The parents were quick to respond if there were any problems about their child's needs not being met. Parents' devised strategies to ensure that assessments, the availability of assistance, and access to funding were provided, and in the best interests of children who have a disability. Having glowing progress reports about a child who had the help of a teacher aide, may be impressive reading and give assurance to a parent, but having that same report seen by an assessor can result in devastating effects for the child if funding is withdrawn for a teacher aide of other assistance. It can cause considerable stress to the family who become involved in a struggle to have the funding or assistance re-instated.

Education is important for social needs, not only for children who have a disability, but for able-bodied children as well. Having a working relationship, with effective communication, enables parents and schools to work successfully together. Mainstreaming within their community has a positive effect for children, both disabled and able-bodied, whether the interaction is passive or active. Adequate funding and resources are important contributors to safety within a classroom setting, in order to foster good communication, behaviour and friendships. Individual Education Programmes and small class sizes also help to ensure that a child was well supported so that learning could take place.

It is important that community support be available for people who have a disability to ensure that they experience a normal lifestyle and community integration. The provision of access to the appropriate equipment and resources to a child, who has a disability, enables them to socialise and join in social activities both, in their public, and private environments.

Disability and Gifts

There were four aims I set out to explore. The first aim was to identify how families interpret their child who has a disability and the concept of disability itself, and whether a disability was a gift or an obstacle, and if so, to whom or to what. What I found was that the Maori concept of disability extended beyond the individual disability to historical events that disabled Maori.

Through socially constructed discourses that include or exclude people from fully participating within society, Maori have been disadvantaged. The stigmatisation that is shown historically, places Maori as a minority that is over represented within the lower socio-economic grouping. As an ethnic group, and the indigenous people of New Zealand, they have limited economic power. More Maori men and women are unemployed, are poorly paid and supported by Social Welfare Services than any other ethnic group in New Zealand. Disability is another discourse that places the majority of people who have a disability, and their caregivers, within the lower socio-economic grouping with minimum benefits or wages. Those who had access to resources could afford better intervention for their child's health, education and social activities than those who did not have the resources.

Maori are not homogeneous because of their diverse characteristics. They live in different geographical areas, may belong to different iwi, and hapu, and they may have different belief systems that are dependent on their socio-economic status, education and health. Therefore, Maori or non-Maori services alone do not meet their needs. In most cases, the individual finds that the two mediums can complement one another, and the individual can interchange between the mediums. This may be facilitated or inhibited by the amount of mobility to which a family has access or their ability to relocate depending on what best 'fits' the child's needs at that time.

Maori Contextual Frameworks

Maori contextual frameworks were identified with a 'holistic approach', through whanau and 'Maoritanga' (culture) and the six steps towards Maori health and wellbeing. The 'holistic approach' for Maori health was dependent upon historical, social, cultural, economic, political and environmental circumstances being acknowledged and the absence of illness was focused on the cultural aspirations and needs of Maori. Attempts have been made to incorporate and implement these concepts of cultural sensitivity at a policy level.

Whanau and culture is represented through 'Maoritanga', which encompasses spirituality within whanau and Maori communities by means of manaaki, tiaki, awhi and aroha. All participants experienced aspects of 'Maoritanga' through their immediate or extended whanau at the onset of the child's disability, and some still have ongoing contact with whanau and extended whanau. Some have also found support through Kohanga Reo and support groups.

Meanwhile, the six steps Maori identify as working towards an 'individual's personality' is achieved through knowledge gained and the challenges that are faced along one's life journey. I would argue that these challenges are increased many times when raising a child who has a disability, as it certainly challenges the intellectual, physical, emotional, social, spiritual and cultural meaning of one's personality.

Disability and the Gift concept

A Maori holistic perspective on education is based upon a belief that all children are special, and have gifts that are inherent within them. It is the responsibility of the whanau, hapu and iwi to nurture, support and enhance these gifts. Education funding and resources are necessary to ensure the development of their gifts.

These gifts can be extended to whanau, extended whanau and any support people that work with these children because they, also, will gain knowledge and understanding. These can be seen in triangulation between the mother and child and the social services that support them. Appropriate attitudes and open minds allow these gifts to develop. These gifts are what parents, carers and support people give meaning to. These gifts start as minute, but grow with each interaction that takes place between the child, their disability and what they give out to others.

For instance, the children in this research had a variety of gifts attributed to them. Such as, children having spiritual insight, their determination and perseverance to work with their disability, their friendliness and openness to interaction with people, their trust in others, only telling the truth because they cannot lie and a lack of fear or awareness of the consequences for some of their actions.

The gifts given to parents were the ability to focus on a particular disability and use research skills to enable them to become expert in their child's disability. Parents' became proactive, even becoming spokespersons for support groups, and they sought further education to stay active participants in their child's education and disability. Some parents returned to their Maori culture for further education, while others hope to be employed in social services that address Maori and disability issues. Denying Maori children the right to share their gifts with others because of discourse structures hinders them being fully accepted to participate within their community. This will result in Maori children, who have a disability, having low self-esteem, being withdrawn, and compliant to the demands of the established structures.

An Active Partnership

The second aim looked at, to what extent parents were proactive within a working partnership with support people when managing the needs of the child's disability. Communication, trust and respect were the three main identifiable outcomes, which parents wanted for their whanau, their culture and for their child's disability when interacting with government, health, education and community services.

In the initial stages when parents are first aware of their child having a disability, they must go through a grieving stage. While health professionals are taking care of the child's problems, the parents are also trying to grasp what information they can absorb about the symptoms, causes and short-term and long-term consequences. The personalities of the parents will determine whether they become proactive or passive parents in dealing with their child's disability and in their interactions with others involved in the wellbeing of their child. In most cases, those people who were passive parents became proactive once they experienced barriers to funding, and denied access to resources.

Trust and respect were important when accessing funding and resources. The difficulty arises when funding, resources are of limited supply and the ideology of user pays for services, excluding those who cannot pay. Some services may exclude whanau because of their financial situation. This will determine the availability of choice for the care and education that their child will receive. Being proactive parents, four of my participants used alternative 'healing' for their child who has a disability, to complement the health services that their child was receiving.

Being able to trust the flow of information was another important matter when assessments and reviews focused on their child's disability, and in particular, the correct entering and filing of the appropriate paper work. It would be desirable to have a standard procedure that was known to all people who support a child with a disability within the social, education and health services when funding and resources are to be assessed. Whatever funding, or hours, a family receives for their child's disability, the funding and hours of care or instruction never went up past the previously allotted amount. What usually happened when assessments were done was that whanau lost funding or the hours allocated. When they appealed that revised amount, most families gained some funding and hours but not to the same level existing prior to the assessment.

The wishes of whanau about whether to reveal a child's disability, or how information should be collected concerning their child's disability, were not always respected when caregivers invited support services to their home. In addition, they were not always shown the appropriate courtesy when communicating with officials within social services. Respect should also be given by understanding and accepting the stage of a parent's grieving process, and being able to work within those stages to support the family and the child who has a disability. This was noticed to have occurred in this study group when a caregiver was in denial concerning their child's disability and not able to accept many of the descriptions written under the label of the disability.

All participants were able to raise their personal power when issues around their child who has a disability arose. 'Personal power' is the ability to navigate around obstacles or discourses, whether they are identified as culture, health, institutions, education, social status, gender, age or employment and will be dependent on the individual's self-esteem, motivation, respect, education and life experience.

The power relationship of parents who advocated for their child's education and the selection of an early childhood centre and school often did not extend to them exercising their rights of insisting that their child attend the school of their choice. Instead caregivers took their time to get 'a feel' of a school, which depended on the reception they received, whether the administration personnel were willing to listen and were accommodating to the needs of their child within the teaching environment. Drawing up the education programme together ensured a good working relationship, and was one of the reasons parents chose a school because, they felt welcomed and listened to, which made the transition for their child into a new school environment easier.

Conductive education is not a recognised intervention programme run or funded by the Mental Health Board. Consideration should be given to alternative methods of child education, where funding should follow the child who has a disability, and a decision made by the parents to access an intervention programme that best fits the parent and the child, should be given more respect. Conductive Education has proven to be an effective programme of early childhood intervention. Two positive outcomes resulted from the intense therapy. It ensures that a bond is made between the parent and child, and between the child, the educator, and these children become more independent and self motivated through their own mobility. The parents who are proactive in Conductive Education become self-motivated and involved in supporting their child's disability by joining support groups, and becoming a support person to new families whose child has a similar disability.

Communities and Social Activities

The third aim was identifying the role that communities and whanau play in supporting a family whose child has a disability. Each participant's story tells about the level of disability that their child has and relates similar experiences of whanau and culture within their home environment. They also describe similar experiences in their community environment when accessing funding and resources from social, health and education services.

Caring for a child who has a disability calls upon a spectrum of areas that can help or hinder different outcomes, such as problems of isolation, lack of support, difficulties of access to funding for social, health and educational services and equipment. If they cannot be supported by whanau, a support group or support person, or a health professional, who can support their needs through the bureaucratic processes, will ensure whanau are not separated from their communities.

The power of social networking through support groups is the first link to avoiding isolation. The family caregiver may belong to a number of support groups relevant to the child's needs. The benefits of socialising with other parents and caregivers, who are facing similar experiences, can be valuable. Networking also helps in finding educational material relevant to their child's disability, accessing the services and dealing with the appropriate paperwork for financial assistance for the child and the child's family.

The outcome of belonging to specific support groups enables knowledge, expertise, conferences, education, resources and employment opportunities to be shared among people who are then better able to support the goals of understanding, independence and self-motivation.

Maori become anxious when funding, services or resources are withdrawn from their child who has a disability or from the child's family due to their socio-economic situation, because this disadvantages the whanau further. In order to meet the needs and problems that arise for Maori, knowledge and information about access, funding and procedures within health, education and social services that set out all that Maori were entitled to would help prevent barriers being put into place. Other information and knowledge regarding Maori whanau, kaupapa and tikanga to Maori health and wellbeing would ensure the ability of any service provider or school to respond appropriately.

Cultural Values and Norms

Finally, the fourth aim identified the importance of culture in relation to programmes for children who have a disability. The programmes focused mainly on safety and the cultural issues focused on whanau relationships, and extended whanau support.

In some cases, the nuclear whanau consisted of the mother alone raising a child who has a disability. The different milestones a child with a disability will attain or try to achieve can be taxing on any relationship, whether the cause of the child's disability was hereditary, medical mishap, an accident or through other causes. If the disability occurred during the two-year-old mark, sadness was often felt because of the memories of a 'normal' child held prior to their child's disability. Extended whanau were supportive in the initial stages of the disability until some normalcy came into place, where the child's needs were being supported by the health services and whanau.

If the child who has the disability is an only child, support from extended whanau and within their macro environment is more freely available, and so will enable the relationship between a solo mother and her child to be a healthy one. Solo parents are more likely to lead a more fulfilling life in forming intimate relationships, employment, gaining further education and getting a good support team around them than a solo parent raising a child who has a disability and other siblings around the same age group.

The difficulty that most families face when they have a child who has a disability is the question 'Why'. In most cases, they have never been exposed to other children or families who have a disability. They are thrown into the deep end, and have to grasp, as best they can, what steps need to be followed and implemented. The type of assistance they receive during their hospital stay will speed the process up if the parent is able to participate with staff in a culturally safe environment.

Whatever the cause of the disability, whether it is hereditary, medical mishap or accidental, a grieving process takes place. No two people will grieve at the same rate or pass through the different phases of denial, blaming, anger, guilt and acceptance. Some will move quickly through each stage, while others maybe stuck in one phase for a longer period. As a result, support persons can have a vital role to play by being their ‘eyes and ears’ to inform and guide them through their decision-making processes.

Relationships are tested, exposed and left vulnerable after the onset of the child’s disability. It is critical at the initial stage that whanau or support systems are put in place. If adequate time is allowed for parents to re-evaluate their relationship by having a strong whanau support base to help with the care of the child who has a disability, as well as the care for any other siblings, this assistance will help with the transitions and adjustment that is required to support a child with a disability.

From the data collected from my five participants, only one family relationship has survived the transition to having a child who has a disability. So I conclude that this family was able to do so because the severity of their daughter’s disability was mild compared to my other participants. This maybe a mitigating circumstance as to why some relationships survive a tragedy while others relationships are severed. Two of my participants have been in a long-term relationship (one remarried) while the other three were not and continued alone.

As the child who has disability ages, the scaffolding that has supported the funding and intervention programmes around the child (depending on the disability), most hours and resources are adjusted accordingly. In most cases, the resources for physiotherapy and allotted hours for home care dwindle away, leaving the parent to take care of most of their needs within the home and their social activities outside the school environment. Therefore, women can become confined within their homes, restricted to part time employment and their ambitions being controlled by micro and macro environments.

In most cases, women are the carers who look after children who have a disability. Usually they are overworked, not recognised for their expertise, nor are they acknowledged in monetary terms for what they do. Carers are more knowledgeable when it comes to their child’s behaviour or reactions within micro and macro environments. The child's social interactions will be dependent upon a safe environment before social, academic, personal and emotional situations can be explored and learnt. Sometimes carers' experiences and concerns are ignored when expressed during health assessments and within educational environments.

Caregivers' expertise can validate the type of health and educational programme that best suits the child's ability and competency. The care is individually assessed to meet the personality of the child and at the cognitive age level, which encourages self-motivation and adequate independence. Long-term relationships are formed through the interactions made with support people and their families, the parents and child, the child and their siblings, the child's involvement with their own disability and interaction with health and educational professionals.

Grandparents are another resource that should be recognised through monetary value as caregivers. Instead, most of their time is given on a voluntary basis. The benefits grandparents provide, as caregivers are vital in providing support for young families, also for solo parents who often feel unsupported and judged. They assist in giving parents 'time out', spending quality time with their grandchildren, and giving special care to a child who has a disability. They also assist the parent to pursue other areas of learning, employment, socialising and networking away from their child who has a disability.

Future Prospects

Overall, the discussion in this thesis is based upon the assumption that the experiences of mothers, who are the main caregivers for a child with a disability, must be understood in the context of factors such as their economic positions, their culture and ethnicity, their gender, their environmental locations and lifestyle opportunities. Through their stories, we can gain an understanding of the ways in which these factors cross into the macro level such as the support systems surrounding a child with a disability.

The outcome of all my participants is that they are well supported within their whanau, schools and services. Through their stories, other parents who are caring for a child who has a disability are not alone. Sharing these stories with others can give us strength and courage to forge ahead knowing we can support and challenge those who think differently to what we believe to be beneficial for our child's disability.

I hope in some cases the isolation faced by a few parents can by eliminated by reading other peoples life experiences to understand their perspective on Maori children and disabilities. These stories maybe informative or supportive towards empowering parents to make decisions based on what they 'feel is right', challenging decisions they are not happy about, and to seek alternative care, rather than relying on what the professionals tell them at face value. For others, it maybe the acknowledgement that the choices we make to support our child's disability are made within aroha, whanau and tikanga even when resources are limited and access to services is denied.

GLOSSARY

Aroha	Love
Awhi	Assist, assistance, to help
Hapu	Sub-tribe
Hongi	Press noses
Hui	Gathering, usually on a marae, conducted according to Maori protocol
Iwi	Tribe
Kai	Food
Kaio	Sea turtles
Karakia	Prayers
Kaumatua	Respected tribal Elder
Kaupapa	Rule; basic idea; topic; plan; foundation; factors
Kaupapa Maori	Maori topic
Kawa	Ritual, protocol
Kete	A bag or basket usually made of flax.
Kohanga Reo	Literally 'language nest'; a preschool education centre using Maori language and run according to Maori Kaupapa and tikanga
Koroua	Old man
Kuia	Older respected woman
Kura	Primary school
Kura kaupapa	Total immersion, Maori-language primary school
Manaaki	Entertain; befriend
Manaakitanga	Service to others
Mana Tangata	Powerful, influential person
Maoritanga	Maori culture
Marae	Meeting ground
Matauranga Motuhake	Special Education

Mihi	Formal greetings especially to a group in which a person introduces him or her self and which includes important background information of genealogy (ancestors), tribal connections and place of birth and upbringing.
Mokapuna	Grandchild
Noa	Free from tapu
Panui	News
Poaora	Fried bread
Pouwhiri	Welcome
Rata	Leavened (bread)
Rewana (Bread)	
Runganga	Thoughts and feelings
Taha hinengaro	The physical side
Taha Tinana	The spiritual side
Taha wairua	The family
Taha whanau	People of the land, of that place, local people
Tangata whenua	Treasures, cultural artefacts, property
Tapu	Sacred, forbidden
Te reo Maori	The Maori language
Tikanga	Habit, custom, plan or method. Way of doing things. Custom; rule; principles; obligations; conditions (legal); provisions (legal).
Waiata	Song or singing. Especially in formal or ceremonial settings.
Wairua	Spirituality, spiritual development
Waka	Canoe
Wananga	Seminar, course, college
Whanau	Family member/s
Whanaungatanga	Relationship
Whanau Worker	Family supporter
Whare Kura	Secondary division of Kura Kaupapa Maori
Whenua	Land

Names of Countries

Arapeinia	Albania
Arapia	Arabia
Ararata	Armenia
Poriwia	Bolivia
Parahi	Brazil
Piritene	Britain
Peretiama	Belgium
Purukeria	Bulgaria
Kanata	Canada
Hiri	Chile
Haina	China
Koromopia	Colombia
Kango	Congo
Kuki Airani	Cook Islands
Haiperu	Cyprus
Tenemaka	Denmark
Tominika	Dominica
Ekuatoa	Ecuador
Ihipa	Egypt
Ingarangi	England
Etonia	Estonia
Etiopia	Ethiopia
Whiti	Fiji
Whinarana	Finland
Parani	France
Tiamana	Germany
Kariki	Greece
Hanckari	Hungary
Hapana	Japan
Inia	India
Pahia	Iran
Mehopotamia	Iraq
Airana	Ireland
Iharaira	Israel

Itari	Italy
Hamaika	Jamaica

Names of Months

Hanuere	January
Pepuere	February
Maehe	March
Aperira	April
Mei	May
Hune	June
Hurae	July
Akuhata	August
Hepetema	September
Oketopa	October
Noema	November
Tihema	December

Colours

Mangu	Black
Ma	White
Whero	Red
Puru	Blue
Kirini	Green
Kowhai	Yellow

Parts of the Body

Mahunga	Head
Kaki	Neck
Korokoro	Throat

Tribal Affiliations

Nga Puhi

Ngati Awa

Ngai Tahu
Ngati Kahungungu
Ngati Mutunga
Ngati Porou
Ngati Whatua
Te Arawa

Disability Services

CCS	A not-for-profit organisation devoted to the welfare of people with disabilities that advocates and provides support services. CCS is the name and not just initials. It derived from its previous and now obsolete name, The Crippled Children's Society.
New Zealand CCS	See CCS.
IHC	A non-profit organisation that advocates and provides support services for people who have an intellectual disability. IHC is now the name of the organisation and not the initials of its previous and obsolete name Intellectually Handicapped Children's (Society).
Aspergers Support Group	This group supports parents/families with children and adolescents with Autism or Asperger Syndrome. Activities include, Holiday programmes for children, community support, parent support, group meetings and telephone networks and social skills groups for those with Asperger Syndrome.
Parents of Vision Impaired Inc.	A parent's support group that is active in running conferences. They ensure the relevant information concerning social, economic and political aspects of vision impairments are discussed. They provide the means of expressions and share information with families and caregivers.

Special Education Services

BoT	Board of Trustees
Conductive Education	A form of intense physical therapy and applied exercise to stimulate the neurological processes of people who are affected by motor disabilities.
IEP's	Individual Education Programmes
MoE	Ministry of Education
ORS	On-Going Resource Funding

RTLB	Resource Teacher, Learning and Behaviour Resources
SES	Special Education Services

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Appendices

Appendix 1

NAME: JANET ASKEW

MASTER THESIS

SOCIOLOGY OF MAORI CHILDREN WITH PHYSICAL DISABILITIES: A CULTURAL PERSPECTIVE

RESEARCH PROPOSAL

DUE: 17 APRIL 2003

SOCIOLOGY OF MAORI CHILDREN WITH PHYSICAL DISABILITIES: A CULTURAL PERSPECTIVE

TABLE OF CONTENTS:

TOPIC: SOCIOLOGY OF MAORI CHILDREN WITH PHYSICAL DISABILITIES: A CULTURAL PERSPECTIVE

ABSTRACT: From a cultural perspective, the purpose of this research is to explore the life stories around Maori children who have a physical disability. The emphasis on culture within a Maori community will identify how relationships, identity, family and culture are supported around children with physical disabilities. This is a Maori-centred research project, which is guided by Kaupapa Maori protocols. These principles are firstly, Mana – empowerment of participation; secondly, Tapu – mauri – the sanctity of knowledge and thirdly, Maramatanga – clarity, understanding and demystifying of the process between the researcher and the participant. I want to address themes around culture, identity and self-esteem. I want to hear whanau/family views concerning their child's disability, education, and identify what support services have aided/or not aided in meeting their child's needs. My primary data will be collected using the qualitative social research method, with field notes from observations and tape-recorded in-depth semi-structured interviews. Participants for the interviews are from Christchurch. This research will be a case study of six Maori family networks that are members of a whanau support group.

RATIONALE:

My rationale for exploring life stories around physical disabilities and a Maori culture perspective centres on my own identity as part Maori because of my ancestral ties to Ngati Porou and Ngati Kahungungu and my son's cognitive disability 'verbal dyspraxia'. However, my Maori identity and culture have only recently surfaced through educational studies around Maoritanga. I want to explore the relationships, identity, culture, health and education services affecting families who have a child with a physical disability. I am interested in children with physical disabilities aged between seven and fourteen years of age, who attend primary and secondary schools and the attitudes of parents, caregivers, siblings and other key persons identified by parents/caregivers who support the child with physical disability.

Ballard's (1994) research on disability, family, whanau and society explored people's experiences of intellectual disability regarding their everyday life, and identifies what parents, whanau and the individual with intellectual disability want in terms of community recognition and support, in education, health and welfare services. Participants describe individual achievements, ongoing struggles for inclusion and ideas for a fairer society. Bevan-Brown (1994) cited in Ballard researched a Maori perspective on cultural differences towards intellectual disability and the attitudes around it, for example, whether Maori children receive or need services that are different to those provided for by non-Maori, and what parents wanted in regards to support for their child's intellectual disability. In my research, these issues will be explored from a Maori perspective with children who have physical disabilities within Maori communities. Stories around early childhood invention programmes, and Individual Education Programmes (IEP's) at primary and secondary schools will identify the relationships between school, home, community and culture.

Mainstream services for health and education have been encouraged to provide services, which are likely to achieve good outcomes for Maori. In New Zealand, disability support services are funded under the umbrella of health. To access these services, people with disabilities have to be □rganiz under a medical model. Defining people with disabilities enables the assistance needed to access services and resources for people with disabilities, but it can also alienate and □rganizatio people with disabilities.

LITERATURE REVIEW

In 2001, Statistics New Zealand carried out a survey regarding disability of people living in households and residential care facilities. The Survey consisted of nine sections that provide an overview of disability in New Zealand. In the findings, approximately 107,200 Maori reported having a disability; one in five people of Maori ethnicity have a disability. Maori boys (0-14 years) are more likely to have a disability than Maori girls are, and physical disabilities are the most common type of disability reported by Maori adults. They also identified disease or illness is the most common cause of disability for Maori. There are few Maori with disabilities in residential care (May 2001:1).

Fifteen percent of Maori children (0 to 14 years) reported a disability; sixteen percent of Maori boys (0-14 years) reported a disability, compared with 13 percent of Maori girls in the same age group. Nearly 60,000 disabled Maori (55 percent) reported having more than one disability, such as speaking, learning and developmental difficulties as well as special education intervention programmes. Approximately 10,000 Maori children had sensory disabilities and chronic health problems (June 2001:1).

Approximately 3,700 (4 percent) physically disabled children (0-14 years) living in households had the use of special equipment for their physical disability. Approximately 1,100 children with physical disabilities had an unmet need for equipment to help with standing or moving around. One of the most common reasons for equipment needs not being met was that it was too costly or they could not afford it (July 2001:1).

According to Durie (1995) cited in Bevin-Brown (1999:1), if Special Education 2000 policy and initiatives are to address Maori SES needs, the 'diverse Maori realities' need to be considered because Maori learners with special needs are not a homogeneous group. They come from different geographical areas, socio-economic circumstances, hapu and iwi. In addition, Maori learners are scattered throughout all educational settings.

Kaupapa Maori research draws from the strength of whanaungatanga, or networking through whanau, hapu and iwi relationships. From a holistic Maori perspective a sense of identity for Maori is not about the self-alone, as Durie (1986) suggests you are not healthy if you are alone; the whanau or family of origin, the hapu or sub tribe, the iwi or tribe and the waka or canoe must be present for real health (p. 57). According to Wilkie's (2000) research on special education for Maori, two findings concerning the holistic perspective towards individual and education: Maori perceive all children to be special, not just those requiring special education funding (p. 7) and Maori resisted labelling children in order to get funds because of the negative implications of labelling (p. 8). These two perspectives identified in intellectual disabilities will be explored with Maori children who have physical disabilities.

The focus of Kingi et al., (2000) is research into Maori disability within the health sector, they set out to establish whether Maori viewed disability, or the concept of disability differently. The research identified Tangata Whenua needs were met inadequately as Maori concepts were different from non-Maori culture. Maori concepts of disability are not recognised and considered a priority. For example, if the on-going effects of colonisation and its effects on the health, economic and social status of Tangata Whenua were to change, Tangata Whenua would manage their own initiatives and develop their own services by choosing from mainstream or kaupapa Tangata

Whenua services to support people with disabilities and their whanau (p.26).

In April 2001 government objectives towards the New Zealand Disability Strategy under the New Zealand Public Health and Disability Act 2000, identified fifteen objectives to ensure the removal of barriers faced by disabled people so that they can participate in an inclusive society. Objectives 11, 13, and 15 identify promoting opportunities for Maori to participate in their communities and access to disability services. Enabling disabled children and youth to recognise their emerging identities as individuals and reinforce their sense of self, promoting self-reliance, recognising their important links with family, friends and school, and opportunities for active participation within the community; acknowledging and giving ongoing support towards the values families, whanau and people provide (p.12-13). Issues around these three objectives in this case study will identify how needs are met for Maori children with a physical disability aged 7-14 years.

RESEARCH OBJECTIVES AND QUESTIONS:

The primary objective of this study is to explore the needs of Maori children with physical disabilities. Themes around the type of services required, gender, peer groups and socialisation will assist my observations to identify relationships, culture, identity and self-esteem. Accordingly, this project seeks answers to the following questions:

1. How do families interpret their child's disability and disability itself? Is it a gift? Do they see their disability as an obstacle? Is so, to whom and to what?
2. How pro-active are families within culture and with managing special needs?

3. What role do families perceive the community has towards supporting the wellbeing of children with physical disabilities?
4. How important is culture, when implementing programmes/incentives for children with physical disability needs?

Data Collection, Sampling and Analysis

In order to meet the objectives of this research, primary data will be collected from six family networks within a whanau support group for children with physical disabilities from the Christchurch area using in-depth semi-structured interviews and field notes. My interest is in Maori children, aged 7-14 years who have a physical disability and attend primary and secondary school. Contact has been made with the whanau worker who organizes the Whanau Support Group meetings in order to gain access to families willing to participate in my research thesis. At the outset of data collection, participants will be informed about the thesis and the intentions of the research via an information letter (See Appendix A). Even though interviews will consist of three-four different meetings, engagements with individuals who know the child will be many and varied, because participants involved in this case study will be members of families, extended families and people identified by parents who play a significant part in the child with physical disabilities well-being. The age group of siblings to be interviewed, will be limited to fives years and onwards. Information acquired through conversation with participants will be recorded using written field notes, observations, as well as in-depth semi-structured taped interviews.

My role as researcher will involve engaging with the process of "Narrative Inquiry" (Bishop, 1996:23) which views "social reality as the social construction" of Maori children with physical disabilities, a reality which does not exist independently of their shared activities

(Blaikie, 2000:115, 121). The epistemological assumptions are that the reality of Maori children with physical disabilities and the families can only be known from the social accounts provided by them (ibid. 115).

In order to understand the relationships around culture identity and self-esteem that assist Maori children with physical disabilities, research around the type of services available, and issues around gender, peer groups and socializations could identify inclusion and exclusion factors. Informal methods of observations using a semi-structured interview format with open-ended questions will be used. Bentzen (1993) suggests the openness of informal methods of observations enable you to gather large amounts of information that is unselected, which preserves the description of behaviours, the chronological sequences and contexts in their original form to enable further examination and analysis (p. 72).
Asking questions of my participants will encourage them to "consciously search for or construct meanings and interpretations" of their usually 'taken for granted' social world (ibid.). Concepts generated from a "bottom up manner" through the processes of "re-examination and reflection" will occur (ibid. 139).

Ethical Considerations

Ethics approval will be sought prior to commencement of fieldwork. To ensure cultural sensitivity and respect is adhered to regarding researching Maori I have approached Dr Evan Poata-Smith from University of Canterbury Sociology Department and the whanau worker for Maori Whanau Support Group who have children with physical disabilities.

An information statement will be provided to all participants. The information sheet contains details about the researcher and the project.

In addition, statements regarding the autonomy of the researcher, confidentiality and anonymity, have also been included, along with in-depth semi structured questionnaires and the option to withdraw from the research should the participant wish to do so. Concerns exist regarding anonymity within family networks, this may be only partial because of their relationships to the child with the physical disability. Also the six families will be known to each other, however secrecy will be discussed with participants. Each case study will use a pseudonym name.

Permission from parents or main caregiver will be obtained before interviews with children commence. Children aged between 5-9 years of age will give a verbal consent, while children aged 9-14 years will sign consent forms.

Limitations

Possible limitations to my research I foresee that could be problematic are:

- **Participants**. Whether participants want to continue telling their stories because of personal issues which may arise. Should a participant or participants no longer want to participate, my research will be adjusted from an in-depth research to a much broader research about children, disability and culture.
- **Time**. Being able to set up and carry out interviews suitable to participant and myself. The same would apply for follow-ups with transcripts.
- **The size of the study**. As my thesis will be completed over a 12-18 month period, only a small sample of six families will be involved.
- **Time**. Completing all eight stages of my thesis within a 12-18 month timeframe.

- **Age**. The age of the child (interviewee) may limit the amount of information gathered.

Key Assumptions

- Access to carry out my research through the whanau support worker has been given.
- People will volunteer to participate
- People will be willing to tell their story
- Enough time to complete my thesis within one year
- An avenue for further research; using the same model within other geographical areas looking at culture and disabilities for Maori

Resources

This is not a funded research project for any funding agencies or any Organization. Therefore, I have limited my research within the Christchurch area. As this research is a case study of six individual Maori families, their caregivers and any persons the family identify as assisting their child will incur travel costs, access and time for observations, interviews, and transcribing, redrafting, photocopying and any other incidentals to a minimum. It is estimated my cost to carry out this research to be $2500.00.

Xeroxing and Printing	$400.00
Book Binding	$200.00
Library Inter-loans	$100.00
Incidentals (paper, stationery, printer ink)	$500.00
Koha for Marae, support group meetings, seminars and whanau gatherings	$150.00
Travel Costs within Christchurch area (petrol, car maintenance, visiting six network families)	$150.00

Travel Costs away from Christchurch	
(Transportation and accommodation costs interviewing network participants and a conference concerning physical disabilities)	$1000.00
Total Costs	$2500.00

Provisional Timeline

The proposed research will follow the suggested time line below. It is expected that this thesis will be completed within the eight stages listed below and submitted within one year:

Stage 1	Review background literature Prepare and submit Proposal and ethics approval
Stage 2	Gain ethics approval
Stage 3	Secondary data gathering and analysis Establish potential participants and begin to make contact Preliminary field work
Stage 4	Field work and analysis Continue analysis of secondary data
Stage 5	Analysis
Stage 6	Thesis writing and continued literature reviewing
Stage 7	Thesis writing including proofing, refining and editing
Stage 8	Binding and submission

A WHANAU VIEW OF LIFE FOR CHILDREN WITH PHYSICAL DISABILITIES: AN INFORMATION STATEMENT

You are cordially invited to take part in a research project. The purpose of this research is to explore the life stories around Maori children aged 7-14 years who have a physical disability. The emphasis on culture within a Maori community will identify how relationships, identity, family and culture are supported around children with physical disabilities. This statement also outlines what the expectations will be should you agree to participate in this research.

I want to explore a cultural perspective regarding Maori children with physical disabilities. My primary data will be drawn from personal interviews with parents, caregivers, siblings and the child, as well as other people whom the parents or caregivers think would provide valuable information concerning their child. I am very interested in what your personal experiences are on this subject.

This is a Maori-centred research project, which is guided by Kaupapa Maori protocols. These are: Firstly, Mana – empowerment of participation; secondly, Tapu – mauri – the sanctity of knowledge and thirdly, Maramatanga – clarity, understanding and demystifying of the process between the researcher and the participant. I am of Ngati Porou and Ngati Kuhungungu descent and have a personal commitment to positive outcomes for Maori and disability issues because of my own child's disability.

A pseudonym for yourself and your whanau will be used throughout this thesis. Thus, confidentiality is assured. However, family networks will be made aware, they may be identifiable to others in the whanau networks as well as the support group they attend at New Zealand CCS. You can also withdraw from the project at any time, and if this happens, all information acquired during the interviews will be destroyed.

I expect to carry out three meetings. The first meeting will be a quick face-to-face call to introduce myself, leave copies of a consent form, and guideline questions to be used in a taped interview (a taped interview is at the discretion of the participant). Telephone contact will be made two days later after the initial meeting, in order to get from you and your child confirmation that you consent to participate in the research project, setting a time for an interview, and discuss any further queries you may have concerning your participation. The second meeting will be approximately a 30-45 minute or longer interview, around a semi-structured questionnaire, and any further comments you may want to make. Telephone contact will be made if there are any further questions relating to the interview.

After parents and caregivers interviews have been completed, interviews with the siblings 9 years and over will take place. The research will be concluded by interviewing the children with physical disabilities. I will give all children 9 years and over a written consent form to sign before I proceed with a 15-20 minute semi-structured interview. Verbal consent will be obtained from children aged 5-9 before I proceed with a 10-15 minute picture drawing session.

Your participation in this project would be appreciated. Please contact me if more information is needed or if you wish to volunteer to participate in my research thesis.

Janet Askew
Sociology Master's Student
11 Poynder Avenue, Fendalton, Christchurch.
Telephone: 355 4050 (home); email: askew.jb@xtra.co.nz

Supervisors:
Dr Arnold Parr, Sociology Department, University of Canterbury, Ilam, Christchurch.
Telephone 364 2185, email: a.parr@canterbury.ac.nz.

Dr Alison Loveridge, Sociology Department, University of Canterbury, Ilam, Christchurch,
Telephone 366 7001, Extension 6981, email:-a.loveridge@soci.canterbury.ac.nz

PARENTS AND CAREGIVERS

INTERVIEW QUESTIONS AND PROMPTS

Background Information

What is your relationship to the child with physical disabilities?

How much involvement do you have with the child?

Describe how you became involved in the child's development.

What were some of the steps you undertook to help, once you knew about the child's physical disability?

What special attributes stand out for you, concerning the child's personality and strengths?

How has Maori culture influence the child's growth and development?

How important is Maori ethnicity and culture to you? Please explain by giving examples of whanau, whenua and wairua.

Community Interests and organisational/group membership

In your experience how has Maori ethnicity and culture been supported in community services to assist children with physical disabilities? (e.g. Marae, sports clubs, social activities, transportation, shopping areas, parks and theatres).

From your experience, do you think Maori ethnicity and culture are sufficiently supported within the health system when dealing with Maori children with physical disabilities? Please explain.

How is Maori ethnicity and culture within education supporting your child's learning and assistance with physical disabilities?

In what ways is religion important to you, your whanau and extended whanau?

Education, knowledge, learning interests and Activities

Could you share some of the stories that describe (name of the child with physical disabilities) journey concerning their physical abilities within:

a. the home;
b. extended family;
c. early childhood;
d. primary school;
e. Marae setting;
f. professional services;
g. health;
h. education;
i. community services.

Parents/caregivers as Advocates

In what capacity have you participated in advocating for (child's name) physical disabilities?

Daily life issues
Emotional issues
Access issues
Training/education issues
Professional issues
Resource issues

PEOPLE OUTSIDE THE FAMILY NETWORK

INTERVIEW QUESTIONS AND PROMPTS

Background Information

What is your relationship to the child with physical disabilities?

Describe how you became involved in the child's development. How much involvement do you have with the child?

What are some of the steps you have undertaken to help the child?

What special attributes stand out for you, concerning the child's personality and strengths?

How has Maori culture influenced the child's growth and development?

How important is Maori ethnicity and culture to you? Please explain by giving examples of whanau, whenua and wairua.

Community Interests and organisational/group membership

In your experience how has Maori ethnicity and culture been supported in community services to assist children with physical disabilities? (e.g. Marae, sports clubs, social activities, transportation, shopping areas, parks and theatres).

From your experience, do you think Maori ethnicity and culture are sufficiently supported within health?

Is Maori ethnicity and culture important in education for supporting the child's learning and assistance with physical disabilities? In what way would you agree?

In your view, how is religion important to the family's networks?

Education, knowledge, learning interests and Activities

Could you share some of the stories that describe (name of the child with physical disabilities) journey concerning their physical abilities within:

a. the home;
b. extended family;
c. early childhood;
d. primary school;
e. Marae setting;
f. professional services;
g. health;
h. education;
i. community services.

Parents/caregivers as Advocates

In what capacity have you participated in advocating for (child's name) physical disabilities?

Daily life issues
Emotional issues
Access issues
Training/education issues
Professional issues
Resource issues

SIBLINGS AGED 9 YEARS AND OVER

INTERVIEW QUESTIONS AND PROMPTS

Background

What is your family placing among your siblings?

How have you supported your brother/sister's physical disabilities?

Initially how did your brother/sister's physical disability affect you?

How did you adjust to the changes? (Older children only)

How were your needs met when your parents were meeting your brother/sister's needs? What role if any did your extended family help to assist your family?

Do you see any differences as to how people treat your brother/sister's physical disability or not. If so, what would these be?

Education, knowledge, learning interests and Activities

Could you share with me some of the stories that describe your brother/sister's likes and dislikes within:

a. the home;
b. extended family;
c. early childhood;
d. primary school;
e. Marae setting;
f. professional services;
g. health;
h. education;
i. community services

Siblings as Advocates

In different social settings, how have you supported your brother/sister's (with physical disabilities)? (For example, culture, educating others, assistance at school, in social outings and so forth).

YOUTH AGED 9-14 YEARS

INTERVIEW QUESTIONS AND PROMPTS

Background

What is your family placing among your siblings?

How has your family supported you to ensure your needs have/are being meet?

Tell me a little bit about your disability?

How do you adjust to the changes when going into new settings? (Older children only)

What role if any, does your extended family help to assist you and your family?

Do you see any differences as to how people treat your physical disability or not. If so, what would these be?

Education, knowledge, learning interests and Activities

Could you share with me some of the stories that describe your likes and dislikes within:

a. the home;
b. extended family;
c. early childhood;
d. primary and/or secondary school;
e. Marae setting;
f. professional services;
g. health;
h. education;
i. community services

Speaking Out

In different social settings, how have you supported yourself when getting your point of view across? (For example, culture, educating others, assistance at school, in social outings and so forth).

SIBLINGS AGED 5-9 YEARS

DRAWING EXERCISE

B. With white and coloured drawing paper, crayons, colouring pencils and felt tip pens I will ask the child to select and draw:

1. a picture of her family (positioning of their brother/sister who has a physical disability and extended family);

2. a self portrait (self concept and self esteem);

3. a portrait of their brother/sister with physical disabilities (how they see their brother/sister to be).

C. Tell a funny story about your brother/sister (with physical disabilities). In regards to culture, what are some of their favourite foods, TV programmes, favourite saying (language) and games? What do you like about your brother/sister?

CHILD AGED 5-9 YEARS

DRAWING EXERCISE

D. With white and coloured drawing paper, crayons, colouring pencils and felt tip pens I will ask the child to select and draw:

2. a picture of your family;

3. a self portrait

4. a picture of your friends.

B. Tell a funny story about yourself. In regards to culture, what are some of your favourite foods, TV programmes, favourite saying (language) and games? What do you like about your family, relations, neighbours, teachers and friends?

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McKinley, S. (2000): **Maori Parents and Education: Ko Nga Matua Maori me to Matauranga**. Wellington: New Zealand Council for Educational Research

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Wilkie, M.A., (1999) **Special Education 2000 – "So – What's So Special about Special Education for Maori?"** Report to the Ministry of Education, Wellington: New Zealand Council for Educational Research.

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http://www.stats.govt.nz/domino/external/pasfull/pasfull.nsf/web/Media+Release+20 Statistics New Zealand (2001) **New Zealand Disability Survey Snapshot 2 (Maori) – Media Release (May).**

http://www.stats.govt.nz/domino/external/pasfull/pasfull.nsf/web/Media+Release+20 Statistics New Zealand (2001) **New Zealand Disability Survey Snapshot 5 (Children) – Media Release (June).**

http://www.stats.govt.nz/domino/external/pasfull/pasfull.nsf/web/Media+Release+20 Statistics New Zealand (2001) **New Zealand Disability Survey Snapshot 7 (Physical Disabilities) – Media Release (July).**

Appendix 2

UNIVERSITY OF CANTERBURY – HUMAN ETHICS COMMITTEE

APPLICATION FOR REVIEW AND APPROVAL

This form should be completed in the light of the Principles and Guidelines issued by the Human Ethics Commi
Applicants must read those before filling out the application form. The latest versions of both the Guidelines and the Application F
can be found on the website of the Research Office.

website: http://www.research.canterbury.ac.nz
email: admin@research.canterbury.ac.nz

NOTE:- **This electronic copy may not have sufficient space for completion of all parts of the form if downloaded as a blank c**
of the application form. It is intended as a template for use by those staff and students who have access to a word processor
separate expanded copy is available for downloading as a blank application form. When typing in please type where
paragraph marks start after each question, not in the actual boxes.

Staff members are reminded that the guidelines and the application form are subject to occasional amendment.

PLEASE SEND **ten** printed or typed copies of the completed form, duly signed by applicant and supervisor or Head of Department,
of the relevant documents referred to in questions 3, 7,8,9,10,12,16, to the Secretary.Human Ethics Committee, Old Maths Building.

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1. PROJECT NAME: **SOCIOLOGY OF MAORI CHILDREN WITH PHYSICAL DISABILITIES: A CULTUR**
PERSPECTIVE

2. NAME OF APPLICANT: **JANET ASKE**

Contact Telephone No: **(03) 355 4050**

UNIVERSITY DEPARTMENT (or other contact address): **SOCIOLOGY DEPARTMENT, PRIVATE BAG 4**
CHRISTCHURCH

email address (if available): **askew.jb@xtra.co.nz**

STATUS OF PROJECT (e.g., EDUC XYZ class project, M.A., M.Ed., M.Sc., Ph.D., Staff research study)
SOCIOLOGY M.A.
PRINCIPLE SUPERVISOR **DR ARNOLD PARR**
ASSISTANT SUPERVISOR: **DR ALISON LOVERIDGE**

OTHER INVESTIGATORS:

SIGNED BY: Applicant: .... Date:

HOD/Supervisor: .... Date:

A check page at the end of this application must also be signed by the applicant and, if the applicant is a student, by applicant's supervisor

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3 (a) WILL THE PROJECT REQUIRE ETHICAL APPROVAL FROM OTHER BODIES? e.g. Regional Heal Authority Ethics Committee
If Yes please explain how this approval has been or will be obtained, enclosing copies of releva correspondence.

(b) WILL THE PROJECT REQUIRE APPROVAL FOR ACCESS TO THE PARTICIPANTS FROM OTHE INDIVIDUALS OR BODIES?
(e.g., parents, guardians, school principals, teachers, boards, responsible authorities, etc.)
If Yes please explain how this approval has been or will be obtained, enclosing copies of relevant correspondenc
MIKE KOKERI, WHANAU WORKER FOR CRIPPLE CHILDREN SOCIETY (CCS) HAS MENTION MY

PROJECT TO WHANAU PARENTS.

4 (a) IS THE PROJECT BEING EXTERNALLY FUNDED?
If Yes, please identify the source of funds.

(b) IS THE PROJECT COMMISSIONED BY, OR CARRIED OUT ON BEHALF OF AN EXTERNAL BODY?
If Yes, please identify the body.

A. DESCRIPTION OF THE PROJECT

Answer the following questions in language which is, as far as possible, comprehensible to lay people.

5 AIM
(a) What is the objective of the project?
TO EXPLORE A CULTURAL PERSPECTIVE ON CHILDREN WHO HAVE PHYSICAL DISABILITIES AND WHO IDENTIFY WITH MAORI CULTURE.

(b) Describe the type of information sought. **THE CHILD WITH PHYSICAL DISABILITIES AND THE CHILD'S FAMILY NETWORK. INTERVIEWS WILL BE WITH ANY ADULT THE PARENT'S AND CAREGIVERS IDENTIFIES IMPORTANT TO THE CHILD'S WELFARE.**

(c) Give the specific hypothesis, if any, to be tested. **NONE**

6 PROCEDURE
Describe in practical terms how the participants will be treated, what tasks they will be asked to perform, etc. Indicate how much time is likely to be involved in carrying out the various tasks. **PARENT/S AND CAREGIVER/S PARTICIPANTS WILL BE REQUIRED FOR IN-DEPTH SEMI-STRUCTURED INTERVIEWS AND SUBSEQUENT TRANSCRIPT REVISIONS SPREADOVER THREE VISITS. THIS PROCESS WILL INVOLVE AN ESTIMATED THIRTY TO FORTY-FIVE MINUTES OR LONGER PER PARTICIPANT FOR EACH MEETING. SIBLINGS AGED 9 YEARS AND OLDER, SEMI-STRUCTURED INTERVIEWS FOR FIFTEEN MINUTES MAXIMUM, WHILE SIBLINGS AGED 5-7 YEARS INTERVIEWS ARE ESTIMATED TEN MINUTES MAXIMUM TO DRAW PICTURES. THE CHILD WITH PHYSICAL DISIBILITIES INTERVIEW DEPENDING ON AGE AND DISABILITY WILL BE THE SAME AS FOR SIBLING INTERVIEWS.**

7 DOES THE PROJECT INVOLVE A QUESTIONNAIRE?
If Yes, please attach a copy, if possible.
[Note:- The HEC does not normally approve a project which involves a questionnaire without seeing the questionnaire, although it may preview applications in some cases where the production of the questionnaire is delayed for good reason.]

8 (a) DOES THE PROJECT INVOLVE A STRUCTURED INTERVIEW?
If Yes, please list the topics to be covered and the questions to be used. **INTERVIEWS WILL BE IN-DEPT SEMI-STRUCTURED. See Attached.**

(b) DOES THE PROJECT INVOLVE AN UNSTRUCTURED INTERVIEW?
If Yes, please list the range of topics likely to be discussed.

(c) IF THE PROJECT INVOLVES AN INTERVIEW OF EITHER TYPE, WILL IT BE RECORDED B'
AUDIO-TAPE
OR VIDEO-TAPE?

(d) WILL THE PARTICIPANTS BE OFFERED THE OPPORTUNITY TO CHECK THE TRANSCRIPT OF THE INTERVIEW?

B. PARTICIPANTS

9 (a) WHO ARE THE PARTICIPANTS? **THE PARENT/S, CAREGIVER/S, SIBLING/S AGED BETWEEN YEARS AND OLDER, THE CHILD WITH PHYSICAL DISABILITY WHO IS AGED BETWEEN 7- YEARS OF AGE AND ANY OTHER PERSON THE PARENTS OR CAREGIVERS IDENTIFY A IMPORTANT TO THE CHILD.**

(b) HOW ARE THEY TO BE RECRUITED?
If recruitment is by advertisement or letter or notice, please attach a copy. **MIKE KOKERI WIL DISTRUBUTE INFORMATION SHEET TO EACH OF THE PARENT/S OR CAREGIVERS IN TH WHANAU GROUP. THEY WILL CONTACT ME IF THEY ARE INTERESTED IN PARTICIPATIN (See Attached).**

(c) WILL ANY FORM OF INDUCEMENT BE OFFERED?
If Yes, please give details and a brief justification.

(d) IF A SELECTION FROM A GROUP IS NECESSARY, HOW WILL IT BE MADE?
(e.g., randomly, by age, gender, ethnic origin, other - please give details.).
BY AGE, 7-14 YEARS; THE CHILD HAS A PHYSICAL DISABILITY; AND ETHNIC ORIGIN, AR OF MAORI DESCENT;

(e) HOW MANY PARTICIPANTS (OF EACH CATEGORY, WHERE RELEVANT) DO YOU INTEN RECRUITING? **UP TO SIX FAMILY NETWORKS CONSISTING OF THE CHILD WITH PHYSICA DISABILITIES, THEIR PARENT/S, SIBLING/S AND CAREGIVER/S WHO ARE CULTURALL INVOLVED WITH THE CHILD.**

10. WHAT INFORMATION IS BEING GIVEN TO PROSPECTIVE PARTICIPANTS?
Please attach a copy of the Information Sheet (or sheets if there are different categories of participant or if responsib persons, other than participants, need to be informed). **INFORMATION SHEET (See Attached).**

[NOTE:- Projects which involve only an anonymous questionnaire may not necessarily require a separate information sheet, provided that the rubric of the questionnaire includes your name and contact number as well as the other points contained in the model shown in the GUIDELINES. In general, however, the HEC recommends that participants be given an information sheet, which they may retain, unless there are good reasons against such a procedure.]

11. ARE THE PARTICIPANTS COMPETENT TO GIVE INFORMED CONSENT ON THEIR OWN BEHALF?
If No, please explain:
(a) why they are not competent to give informed consent on their own behalf. **THE CHILDREN UNDER 18 WILL NEED THEIR PARENT/S OR CAREGIVER/S CONSENT BEFORE CONSENTING THEMSELVES.**

(b) how consent will be obtained. **FOR ADULTS – WRITTEN CONSENT FORM. FOR CHILDREN AGED 9 YEARS AND OLDER, A WRITTEN CONSENT FORM. FOR CHILDREN AGED 5-9, VERBAL CONSENT.**

12. WILL CONSENT BE OBTAINED IN WRITING?
If Yes, please attach a copy of the Consent Form which will be used. **(See Attached).**

[Note:- Separate consent forms may be required if there are different categories of participant, or if consent is needed from responsible persons, other than participants.]

If No, give reasons for this.

13. HOW WILL THE ANONYMITY OF THE PARTICIPANTS BE ASSURED?

(a) If any identifying information about the participants is obtained at any stage of the project, how and where will such information be securely stored? **ALL INFORMATION WILL BE STORED IN A LOCKED FILING CABINET AT THE RESEARCHER'S OFFICE; EXCEPT FOR IDENTIFYING INFORMATION WILL BE STORED SEPARATELY IN A LOCKED FILING CABINET AT THE RESEARCHER'S HOME.**

(b) Who will have authorised access to such information? **THE RESEARCHER AND MY SUPERVISORS.**

(c) What will be done to ensure that the identities of the participants cannot be known by unauthorised persons? **IN REGARD TO DATA COLLECTION, CONFIDENTIALITY WILL BE GIVEN TO THE CHILD WITH THE LEARNING DISABILITY. CONFIDENTIALITY AND PSEUDONYMS WILL BE USED IN WRITTEN TRANSCRIPTS. ALL OTHER PARTICIPANTS WILL BE REFERRED TO BY THE ROLE THEY HAVE TO THE CHILD WITH LEARNING DISABILITIES. FOR EXAMPLE, KOWHAI'S MOTHER, GRANDMOTHER AND SO FORTH. HOWEVER, FAMILY NETWORKS WILL BE MADE AWARE, THEY MAY BE IDENTIFIABLE TO OTHERS IN THE WHANUA NETWORKS AS WELL AS THE SUPPORT GROUP THEY ATTEND AT THE CCS.**

C. OTHER PROJECT DETAILS

14. WHERE WILL THE PROJECT BE CONDUCTED? **AT THE PARTICIPANT'S PLACE OR AT A MUTUALLY AGREED VENUE.**

15. FORESEEABLE RISKS TO THE PARTICIPANTS

(a) Is there any risk to physical well-being?

(b) Could participation involve mental stress or emotional distress? **POSSIBLE EMOTIONAL DISTRESS MAYBE EXPERIENCED FROM RECALLING THEIR EXPERIENCES IN REGARDS TO THEIR CHILD'S DISABILITY AND DEVELOPMENT. I WILL STOP THE INTERVIEW AND OFFER OPTIONS AS TO HOW TO PROCEED BY GIVING INITIAL SUPPORT AND ASKING IF THEY WANT TO CONTINUE THE INTERVIEW, REBOOK ANOTHER TIME OR WITHDRAW FROM THE RESEARCH. .THEN I WOULD MAKE SURE SOMEONE IS AVAILABLE TO SUPPORT THE PARTICIPANT OR STAY WITH THEM UNTIL THINGS SETTLE.**

(c) Is there a possibility of giving moral or cultural offence? **I HAVE APPROACHED THE FOLLOWING: EVAN POATA-SMITH FROM THE SOCIOLOGY DEPARTMENT AT CANTERBURY UNIVERSITY, CCS WHANAU SUPPORT WORKER AND TWO KAUMATUA WHANAU WORKERS AT CCS FOR THEIR SUPPORT.**

If the answer to any of those questions is "Yes", please indicate briefly the nature of the risk and what actions you could take, or support mechanisms you could rely on, if a participant should become injured, distressed or offended while taking part in this project.

16. IS DECEPTION INVOLVED AT ANY STAGE OF THE PROJECT?

[NOTE: The use in the information sheet or consent form or questionnaire of a title which differs from the project title given in this application form, in order not to reveal the real aim of the project, is considered to be a form of deception - however mild.]

If Yes, please

(a) explain how and why it is to be used and how the participants will be 'debriefed' following their participation in the project.

(b) attach a copy of the debriefing sheet prepared for use by the researcher or for distribution to the participants after their participation in the project or after the completion of the project.

17. WILL INFORMATION ABOUT THE SUBJECTS BE OBTAINED FROM THIRD PARTIES?

If Yes, please state:

(a) the identity of the third party or parties. **PARENT/S, CAREGIVER/S AND SIBLING/S**

(b) why such information is needed. **FOR A WHANAU FOCUS, TO GET DIFFERENT VIEWPOINTS ABOUT THE CHILD'S LIFE AND WELL BEING.**

(c) whether appropriate consents for access to such information have been or will be obtained. **ACCESS WILL BE OBTAINED THROUGH PARENT/S. THE INFORMATION SHEET AND CONSENT FORM WILL MAKE IT CLEAR THAT MORE THAN ONE FAMILY MEMBER WILL BE INTERVIEWED. (See Attached)**

(d) whether the use of such data in your research project needs the consent of the participants. **CONSENT FORMS WILL BE GIVEN TO PARENT/S AND CAREGIVER/S. CONSENT FROM PARENTS/CAREGIVERS WILL BE SOUGHT FOR SIBLINGS AND CHILD WITH PHYSICAL DISABILITIES TO PARTICIPATE. IF THEY CHOOSE TO PARTICIPATE. THEN SIBLINGS AGED 9 YEARS AND OLDER WILL BE GIVEN A CONSENT FORM, WHILE ORAL CONSENT WITH SIBLING/S AGED 5-9 WILL BE OBTAINED. THE SAME APPLIES TO THE CHILD WITH PHYSICAL DISABILITIES AGE GROUPING. (See Attached)**

[NOTE: It may happen that by virtue of your job, you have right of access to information concerning the participants. Such information may have been given by the participants for a particular purpose or collated by yourself or colleagues in the normal course of your job. The use of such information for a quite different purpose (i.e., a research project culminating in some form of report) may well require that potential participants at least be informed that their agreement to participate may involve such use. The Information Privacy Principles should be consulted for guidance in this area.]

D. DATA

18. HOW WILL CONFIDENTIALITY OF THE DATA BE ASSURED?

(a) Where will the data be securely stored? **A LOCKED FILING CABINET DRAWER AT RESEARCHER'S OFFICE. HOWEVER, CONTACT AND PERSONAL DETAILS WILL BE HELD IN A LOCKED FILING CABINET AT THE RESEARCHER'S HOME.**

(b) Who will have authorised access to the data? **THE RESEARCHER AND MY SUPERVISORS.**

(c) What will be done to ensure that unauthorised persons do not have access to the data?

PASSWORD ACCESS ONLY TO DATA FILES ON MY COMPUTER; OTHER INFORMATION WILL BE LOCKED IN A FILING CABINET DRAWER AT MY OFFICE, AND PERSONAL DETAILS LOCKED IN A FILING CABINET AT MY HOME ADDRESS.

(d) What will happen to the raw data at the end of the project? **TAPES RECORDINGS WILL BE DELETED AND RESEARCHER WILL KEEP TRANSCRIPTS AND FIELDNOTES WITH ALL IDENTIFYING INFORMATION REMOVED.**

19. ARE THERE PLANS FOR FUTURE USE OF THE DATA BEYOND THOSE ALREADY DESCRIBED? If Yes, please describe the future use. NOT KNOWN AT THIS STAGE

[NOTE: It may be the case that such future use should properly involve the production at an appropriate later date of additional information sheets and/or consent forms prior to such use.
In that case, copies of those additional documents should be sent to the Human Ethics Committee, along with a covering letter referring to the present project, for HEC approval.]

Secretary, Human Ethics Committee

E CHECK LIST

Please check the following items before sending the completed form to the Committee. Circle N.A. i.e., Not Applicable, where appropriate.

All the necessary signatures on page 1 have been obtained.	**[Y]**
All the necessary approvals under Q 3 have been obtained or are the **subject of correspondence of which copies are attached.**	**[Y] or N.A.**
A copy of any questionnaire, with an appropriate rubric at the beginning or accompanied by an appropriate covering page, is attached.	**[Y] or N.A.**
A list of interview topics and, for a structured interview, a reasonably detailed list of questions, is attached.	**[Y] or N.A.**
A copy of any advertisement, or notice, or informative letter asking for volunteers is attached.	**[Y] or N.A.**
A copy of each information sheet required is attached.	**[Y] or N.A.**
A copy of each consent form required is attached.	**[Y] or N.A.**
A copy of the required debriefing sheet is attached.	**[Y] or N.A.**

Attention to the preceding checklist is intended to ensure that the application and its documentation have been thoroughly reviewed by the applicant and (where applicable) by the supervisor and that the preparation of the project is up to the standard expected of and by the University of Canterbury.

The signature of the applicant will be understood to imply that the applicant has designed the project and prepared the application with due regard to the principles and guidelines of the HEC, that all the questions in the application form have been duly answered and that the necessary documentation has been properly formulated and checked.

APPLICANT'S NAME: - JANET ASKEW
and SIGNATURE:-

The signature of the supervisor will be understood to imply in addition that, in the judgement of the supervisor, the design and documentation are of a standard appropriate for a research project carried out in the name of the University of Canterbury or for training in such research.

SUPERVISOR'S NAME: - DR ARNOLD PARR
and SIGNATURE:-

ASSISTANT SUPERVISOR'S NAME: - DR ALISON LOVERIDGE
and SIGNATURE:-

For HEC use.
Comments.

Recommended action

(1) Approve
(2) Approve subject to some action (SPECIFY)
(3) Defer approval until applicant and/or supervisor have responded to points raised.
(4) Withhold approval and return the application for redrafting and resubmission.
(5) Reject the application and return it to the applicant with reasons given.
(6) Refer the applicant to another authority, e.g., National HEC or Regional Health Authority Ethics Cttee.

Secretary, Human Ethics Committee