



Disabled Maori and Disability Support Options

A report prepared for the
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Preface

This study was conducted over the 2002 – 2004. Data gathering occurred in 2003 with the report being written in 2004. During this period major restructuring occurred in the health sector in particular the devolution of funding to District Health Boards (DHB's). Some service funding was retained by the Disability Services Directorate (DSD) of the Ministry of Health. We have included at Appendix 8 of this report a copy of the Disability Services Supplement (Sept 2003) which details disability qualification criteria, exceptions, and a summary of services allocations (DSD or DHB). The reader should note that participants engaged in this study under the pre-Sept, 2003 funding and service regime, not that presently in place.

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E te hunga haua, nga kaumatua, nga kaimahi e tautoko ana i tenei mahi rangahau, tena koutou.

He maimai aroha,

Paimarire

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Overview

The goal of this research project was to provide information to enhance the development and implementation of an effective model of disability support service provision to Maori with disabilities. This was done by identifying and documenting the needs expressed by disabled Maori and their carers living in the Midland area, and by considering the experiences and observations of a key informant group. From our reading of the literature and the feedback we received from participants, a proposed model of disability support service provision has been proposed.

In five sections, this report begins by defining disability, and also by defining the act of caring for the disabled. Focussing on the Maori experience, obstacles, access to existing support services, cultural barriers, and health policies are discussed. In the second chapter, the research methodology is described, along with how the information was gathered. Following this is the third section which presents the opinions and reflections of Maori with disabilities. It concludes strategically with a view of the ideal community, suggesting possible resolutions, by exposing current flaws and inadequacies. Chapter four records the views and perspectives of key informant/whanau carers who participated in the project. They offer an insightful account of the often unrecognised side of the disability experience. Considering the preceding discussions, the final section develops a model of service provision for Maori with disabilities, and proposes this for effective service delivery.

Chapter 1: Introduction

In 2002, the Ministry of Health (MoH) asked the MPRU to provide information to support the development and future implementation of a workable and successful model of disability support provision for Maori with disabilities, and for kaumatua who have an age related disability¹. The MPRU proposed the completion of two objectives to assist the MoH in the development of models for support provision to Maori with disabilities. We would identify and document the needs of disabled Maori living in the Midland area, and propose a model of disability support provision matched to their needs and preferences.

In this initial section we briefly highlight relevant literature surrounding disability including a review of relevant Government policies, legislation and models of disability.

Defining Disability

For the purposes of this study, we have taken the MoH's definition of disability, that is, 'a person with a disability is someone who has been assessed as having a physical, psychiatric, intellectual, sensory or age related disability (or a combination of these) which is likely to continue for minimum of six months and result in a reduction of independent function to the extent that ongoing support is required; and is not as a result of personal injury by accident for which eligibility for cover and entitlement has been confirmed under the Accident Insurance Act.' While this is the definition we have used to define participants into this study, it is not without its limitations which will be contexted below in relation to models of disability.

¹ For the purposes of this study, the term "Maori with a disability" or "disabled Maori" includes Maori whose disability is age related. Kaumatua are therefore a primary stakeholder in this study.

Balancing care

Long-term health care refers to a broad set of paid and unpaid services for persons who need assistance because of a chronic illness or physical, mental or age-related disability (Feder, Komisar, & Niefield, 2000, p. 42). Policies that define the provision of long-term care to the disabled and elderly across member nations of the Organisation for Economic Cooperation and Development (OECD) vary according to what each nation values, what they can afford and what they are prepared to sacrifice by way of competing priorities. Up until the 1970's many countries, like New Zealand, enjoyed a universal comprehensive welfare system that assured assistance for persons in need during all their lifespan (T. Ashton, 2000, p. 72). While ideal, the realities of slowing economies, aging populations, increased public debt, and a shift toward 'user pays' philosophies has seen many nations through the 1980-1990's reform their health and welfare systems. Health policy makers confront a number of fundamental issues that they must resolve in order to provide what is seen to be fair and efficient long-term health care. According to Iglehart (2000), to build successful health care policy, policy makers must efficiently harness three main sources of health care: the family, the marketplace, and the state.

Like other OECD member nations, the New Zealand health system has and will continue to be confronted by increasing resource demands from an aging population, rapidly expanding technological possibilities, better informed consumers, and rising expectations, not only with respect to service provision, but also in regard to inclusion and participation of the disabled and aged. In the next section, we examine models of disability that have informed health and social policy over time.

Present Day Experience of Disabled Maori

National Overview

In 2001, Statistics New Zealand conducted their second national survey on disability in New Zealand. Their report, titled *Disability Counts 2001* provides the most recent statistical information on the nature and extent of disability in New Zealand, and the circumstances of people with disabilities, including their use of and unmet need for services and support (Statistics New Zealand, 2002a).

Statistical highlights for Maori are as follows.

- One in five Maori have a disability, the same as for the total New Zealand population. The disability rate for Pacific peoples is 1 in 7.
- Maori boys (0 to 14 years) are more likely to have a disability than Maori girls
- Physical disabilities are the most common type of disability reported by Maori adults
- Disease or illness are the most common cause of disability for Maori
- Maori adults with disabilities are less likely to be in the labour force than Maori adults without disabilities
- There are few Maori with disabilities in residential care
- Most Maori with disabilities have mild (44%) to moderate (44%) disabilities, and 12% have a severe disability.

Those with 'moderate' disabilities use, or have an unmet need for, some type of assistive device, aid or equipment. Those with 'severe' disabilities receive daily assistance with tasks such as bathing, preparing meals, shopping, housework, personal finances and the like (Statistics New Zealand, 2002a, p133).

Maori not only have shorter life expectancies, but also experience more years in states of disability than non-Maori. Thus duration and quality of life is poorer for Maori (Waikato District Health Board, 2002).

At present, few Maori kaumatua (aged over sixty-five years) are in residential care (Statistics New Zealand, 2002a). This is in part attributable to whanau support and in part to their being fewer Maori elderly in the Maori and overall population. However, this is predicted to change. The Maori population is aging faster than the general population (Statistics New Zealand, 2004). Increases in age more often than not, bring increases in the occurrence of health related disabilities (stroke, amputation as a result of diabetes, hearing and visual impairment, dementia). There is therefore an urgent need to examine the service requirements and preferences of Maori people and to develop a style of service that best meets their needs (T. Ashton, 2000).

The Ministry of Health (2002a) identified that Maori and Pacific peoples access disability support services (DSS) less often than other population groups in New Zealand. They suggest that DSS providers have not addressed the cultural needs or expectations of Maori (Ministry of Health, 2001a, 2002a). Indeed, Maori health researcher Chris Cunningham reports that many providers simply “fall short of the mark in terms of cultural competence” (Cunningham, 1999). While these criticisms of DSS may be valid, criticism does not necessarily bring Maori any closer to accessing and benefiting from DSS’s. Practical steps need to be taken to make a difference.

Models of Disability

Numerous writers have models of disability as their subject (eg., Alaska Mental Health Consumer Web, 2004; Barnes, 2002; Beatson, 2004; Hans & Patri, 2003; Hartley & Wirz, 2002; Johnston & Pollard, 2001; Jones, 2001; Keefe & Valenzuela, 2001; Kirby, 2004; Kreider, 1999; Lawrence & Jette, 1996; Mooij, 1999; Morris, 2001; Potok, 2002; Rummery, 2002; Titchkosky, 2003; Vash, 2004). The Alaska Mental Health Consumer

Web (2004) in their paper titled *Models of Disability: keys to perspectives*, provide an efficient overview from which much of the descriptions of models below have been paraphrased.

Models are influenced by two fundamental philosophies. The first sees disabled people as dependent upon society often resulting in paternalism, segregation and discrimination. The second perceives disabled people as consumers of what society has to offer leading to choice, empowerment, equality of human rights, and integration. Each of the following models demonstrates the degree to which these two philosophies are applied.

The Medical Model

The Medical Model holds that disability results from an individual person's physical or mental limitations – a 'sickness' that is largely unconnected to their social or environmental context. The model places the source of the problem within the impaired person, and concludes that solutions are found by focusing on the individual. Inevitably, finding a cure is difficult because disabled people are not necessarily 'sick' or cannot be improved by remedial treatment. Policy makers are limited to a range of options such as rehabilitation, vocational training for employment, income maintenance programmes and the provision of aids and equipment.

The medical model has dominated the formulation of disability policy for years. Although its therapeutic aspects can be extremely beneficial, the model has been criticised for abnormalising disabled people, and imposing a paternalistic approach to problem solving which, although well intentioned, concentrates on "care" and ultimately provides justification for institutionalisation and segregation. This restricts disabled people's opportunities to make choices, control their lives and develop their potential. The model has also been criticised for fostering existing prejudices in the minds of employers. Because the conditional is "medical", a disabled person is seen to be prone to ill health and sick leave, is likely to deteriorate, and will be less productive than work colleagues. It reinforces helplessness and dependence.

The Expert/Professional Model

The Expert/Professional Model has provided a traditional response to disability issues and can be seen as an offshoot of the Medical Model. Professionals play a 'gatekeeping role' and follow a process of identifying impairment and its limitations (using the Medical Model), and taking the necessary action to improve

the position of the disabled person. This has tended to produce a system where an authoritarian, over-active service provider can prescribe and act for a passive client, resulting in a 'fixer'/'fixee' power relationship that can limit choice, dignity and self-determination. Conversely, if the relationship is collaborative the interaction may well be experienced as empowering.

The Tragedy/Charity Model

The Tragedy/Charity Model depicts disabled people as victims of circumstance, deserving of pity. Because disabled people are seen as tragic victims, it follows that they need care, are not capable of looking after themselves or managing their own affairs, and need charity in order to survive. From tragedy and pity stems a culture of "care". In many respects the model is highly praiseworthy but it carries certain dangers. Numerous charities exist to support and care for people with a particular type of disability, thereby medically classifying, segregating and often – as with the medical model – institutionalising many disabled people. Employers often view disabled people as charitable cases. Rather than address the real issues of creating a workplace conducive to the employment of people with disabilities, employers may conclude that making charitable donations meets social and economic obligations.

The Social Model / Minority-Group Model of Disability

The Social Model views disability as a consequence of environmental, social and attitudinal barriers that prevent people with impairments from maximum participation in society. Disability is seen to stem from the failure of society to adjust to meet the needs and aspirations of a disabled minority. If the problem lies with society and the environment, then society and environment must change. This model implies that the removal of attitudinal, physical and institutional barriers will improve the lives of disabled people, giving them the same opportunities as others on an equitable basis. The strength of this model lies in placing the onus upon society and not the individual. At the same time it focuses on the needs of the individual whereas the medical model uses diagnoses to produce categories of disability, and assumes that people with the same impairment have identical needs and abilities.

The model faces two challenges. Firstly, as the population gets older the numbers of people with impairments will rise making it harder for society to adjust. Secondly, its concepts can be difficult to understand, particularly by dedicated professionals in the fields of charities and rehabilitation. These have to be persuaded that their role must change from that of "cure or care" to a less obtrusive one of helping disabled people take control of their own lives.

Disable people from ethnic minorities face problems of both racial and disability discrimination within a system of service provision designed by dominant able-bodied people usually with dominant disabled people in mind.

The Social Adapted Model

This model builds upon the Social Model, but incorporates elements of the medical model. It accepts that impairments are significant, but stipulates that far more problems are created for disabled people by social and environmental causes. Not all problems of impairment can currently be addressed, but if we recognise our environment as discriminatory we can do much to change it. Unlike the social model, the social adapted model recognises that the inability of some disabled people to adapt to the demands of society may be a contributory factor to their condition. However, it still maintains that disability stems primarily from a social and environmental failure to account for the needs of disabled citizens. The advantage of this model is that it does not concentrate on individuals' limitations, but takes account of peoples' capabilities and potential.

The Customer/Empowering Model

This is the opposite of the Expert Model. Here, the professional is viewed as a service provider to the disabled client and his or her family. The client decides and selects what services they believe are appropriate whilst the service provider acts as consultant, coach and resource provider. Recent operations of this Model have placed financial resources into the control of the client, who may choose to purchase state or private care or both.

The Religious Model

The Religious Model views disability as a punishment inflicted upon an individual or family by an external force. It can be due to misdemeanours committed by the disabled person, someone in the family or community group, or forebears. Birth conditions can be due to actions committed in a previous reincarnation. Sometimes the presence of "evil spirits" is used to explain differences in behaviour, especially in conditions such as schizophrenia. Acts of exorcism or sacrifice may be performed to expel or placate the negative influence, or recourse made to persecution or even death of the individual who is "different". In some cases, the disability stigmatises a whole family, lowering their status or even leading to total social exclusion. Or it can be interpreted as an individual's inability to conform within a family structure. Conversely, it can be seen as a necessary affliction to be suffered before some future spiritual reward.

While these models may be useful in framing disability and service provision, they do lack an analysis of racism and minority culture status. Indeed, disabled Maori are in the

classic ‘double jeopardy’ position, that is, being a cultural minority with a disability in a Pakeha dominated society whose health system has been largely designed for and delivered by abled body Pakeha people.

Maori Views of Disability

Little is known about how disabled Maori in traditional society were perceived, treated, or responded to. While one might draw from references to impairment in both cosmological accounts², moteatea, and more recent Maori history to build an understanding of disability in traditional Maori society, the reality is that little investigation of this phenomena has been made.

We do know that the pre-colonial nature of Maori life and the physical environment were both demanding and harsh . Any reading of history will confirm this (see for example Belich, 1996; Best, 1924; King, 2003). While there may have been social controls in place to elevate the elderly to a higher and more protected social status and a general edict to extend care and protection to fellow members of social groups, the regard extended to the impaired is unclear. We suggest that when communities were peaceful, food bountiful, and leadership stable the impaired were probably well supported and valued within groups provided they themselves did not pose an uncontrollable or unpalatable threat to others. Of the latter, if sickness or impairment were seen to be caused by an infringement of *tapu* or an *atua* affliction, or *makutu*, then isolation or banishment of the individual and perhaps their family was not out of the question (for example, see Best, 1924). Indeed, during periods of unrest, war, in-group competition or food shortage, the need for individuals and the broader group to survive may well have been prioritised over the needs of impaired persons.

² The story of Maui and Murirangawhenua may infer that the blind and elderly, while still perceived as powerful, are there to be exploited by the younger and more ambitious.

While the historic research on this topic is desperately awaited, there is evidence to suggest that attitudes towards sickness and impairment as an infringement of *tapu* or an *atua* affliction, or *makutu* still persist today (Hills, Ngawaka-Nathan, Morrison, & Nikora, 2003; Simonsen, 1999). This can result in an attitude of whakama, sheltering and secrecy by Maori, their whanau and broader community. How prevalent this attitude and its related implications are in present Maori society remains unknown. However, the contemporary role and responsibilities that tohunga are presently enjoying may indicate two things. The first is a persistent Maori belief in illness and disability being caused by external forces as suggested by the Religious Model of Disability. A second and alternate explanation is the existence of a pluralistic and holistic approach to health and wellbeing that positions complementary approaches alongside that of the medical model. This infers a position described by the Adapted Social Model of Disability.

While a traditional view of disabled persons may persist in Maori whanau and communities, it needs to be viewed within the context of broader New Zealand societal attitudes towards the disabled. Many people reject the label “disabled” because they seek to avoid the harsh social reality that still exists within communities where identifying as disabled is a stigmatised position, one that many would rather avoid (Beatson, 2004). While disabled Maori, like their non-Maori counterparts, may benefit from being visible to services for them, they often choose not to identify because it helps them avoid that strong negative attitude attached to the label ‘disability’.

While social stigmatisation of the disabled person continues (T. Ashton, 2000; Beatson, 2004; Rua et al., 1998) models of providing disability support have not been helpful in dispelling many of the myths and resultant discrimination experienced. In this regard, it is hoped that the recent reforms to health policy, and particularly that relating to the disabled and the elderly will begin to more seriously address these issues.

Barriers to Accessing Disability Support Services

The previous research about Maori disabled access to disability support services (DSS) indicates that the barriers to be surmounted are numerous. While barriers may be easily identifiable, the dissolution of such barriers is not so easily achieved, as the solutions often lie in changing the dominant paradigm or model of disability. Alternatively, the solution may be as simple as installing a 'ramp' to enable easier access to a building. In either case, the challenge is to identify a 'way up' to more efficient and satisfying service provision. The first step in this process is to better understand the barriers facing disabled people generally and then examine those that may specifically inhibit Maori access. Our description of general barriers have been organised around four themes starting with a brief overview of those things that might prevent disability.

Poverty

The World Health Organisation (WHO) argues that many of the causes of disability are preventable. For example, many accidents that lead to disabling impairment can be avoided by promoting good work, home and driving practices. Vaccination against infectious diseases like polio and meningococcus can significantly reduce resultant disabilities, as can good nutrition. Attention to our environments can make a difference too. For example, reducing exposure to noisy environments can reduce the risk of hearing loss, and adequate winter heating can reduce respiratory disease. And early intervention can make a difference too. For example, addressing a 'learning difficulty' during childhood can significantly reduce the probability that a 'difficulty' will develop into a 'disability'. And some 'difficulties' experienced, for example, as a result of stroke or head injuries can be mitigated through speech, occupational and physio therapies.

While societies may be able to afford vaccination, education and rehabilitation programmes, as well as highly professionalized services, individuals still need to be in a position to benefit. Being poor often inhibits access to valuable services that the more

well off can afford. For this latter group, seeing a doctor for a vaccination may be a simple task and relatively cheap expense. However, for those whose budgets are heavily stretched, the cost of a doctor's visit may be prohibitive, thus preventing their being able to receive those benefits that others in a society have little difficulty accessing.

Poverty is both a cause and consequence of disability. Poverty and disability reinforce each other, contributing to increased vulnerability and exclusion. The majority of people with disabilities find their situation affects their chances of going to school, working for a living, enjoying family life, and participating as equals in social life (Department for International Development, 2002).

Statistically, Maori have fewer education qualifications and when employed feature more highly in manufacturing and service industries. Unemployment amongst Maori is typically higher than the general population and of other ethnic groups in New Zealand (Statistics New Zealand, 2002b). Furthermore, Maori adults with disabilities who are living in households are less likely to be in the labour force than Maori adults without disabilities. An estimated 48 percent of Maori adults with disabilities were not in the labour force. This means they were neither 'employed' nor 'unemployed and actively looking for work'. In contrast, 27 percent of Maori adults without disabilities were not in the labour force at the time of the 2001 Population Census. Sixty percent of disabled Maori adults had a total annual income of \$15,000 or less (38,200), compared with 44 percent of Maori adults without disabilities (95,100). This reflects the difference in the labour force situation of Maori adults with and without disabilities (Statistics New Zealand, 2002c).

These statistics can be interpreted in a number of ways. However, the point that we wish to make here is that Maori adults with a disability are less likely to enjoy employment and the benefits that increased incomes bring. Indeed, a weekly income of \$288 barely accounts for accommodation and food expenses let alone doctor and specialist visits, prescription medication, travel costs and the like.

While New Zealand is a relatively wealthy nation, people in lower socioeconomic groups and those on government benefits that include a large proportion of Maori and disabled continue to exist and we need to be cognizant of how poverty and disability interact.

Environmental and Access Barriers

Like other OECD countries, New Zealand has an increasing range of technologies that can be used to mediate environmental factors that inhibit access and participation for disabled people. While sophisticated technologies can make a difference, so too can a great deal of applied common sense. Simple examples that remove environmental barriers are, for example, ramps, accessible public transport, appropriately designed buildings, media in large print or talking books, headphones in movie theatres and the like. On a more individual note, access devices like artificial limbs, wheelchairs, hearing aids, Braille machines, txt capable phones, also facilitate the removal of access barriers.

While we may have the technology to improve the life circumstances of people with disabilities, almost 30 percent of Maori adults (22,400) in the *Disability Counts Survey* reported using some type of special equipment related to their disability. Seventeen percent of disabled Maori adults (13,000) reported an unmet need for some type of special equipment (Statistics New Zealand, 2002c).

Legal and Institutional Barriers

Legal and institutional barriers include government, local body, institutional and agency statutes, regulations, policies, and procedures. These are the tools that define disability, entitlement, employment and how to go about accessing services. More insidiously, such instruments can limit or enhance the capacity of disabled people, that is, what they can and cannot do, what should be provided for them, and how they should be viewed and treated by health professional, employers, educators and society at large. Furthermore, they are very powerful tools in that they provide the legal and institutional rationale for action or inaction as the case may be.

The Nurses Act 1977 gives a clear example of the power of the medical profession to define disability and capacity. For example, a nurse may be suspended from practice if deemed by a medical practitioner to have a mental or physical disability that prevents her from practicing satisfactorily the calling in respect of which she is registered or enrolled.

The same is true of entrance requirements into frontline police work with processes heavily reliant on ‘clearance’ by a medical practitioner. Yet amongst those career paths mentioned in police recruitment advertising it is clear that even people with severe physical disabilities are more than able to perform them (eg., information technology).

District Health Boards (DHBs) are required to have at least 2 Maori members, therefore allowing for high level advocacy, but nowhere in the New Zealand Public Health and Disabilities Act 2000 is there a requirement that disabled people be included in any board or advisory committee. While DHBs can establish and maintain processes to enable disabled people to participate in, and contribute to strategies for the improvement of their health, unlike Maori, their identification and inclusion is not specifically stated. The result is one of invisibility prompting us to recall the “out of sight, out of mind” imperative. Moreover, it is important to remember that...

There is an important and fundamental difference between disability and other forms of disadvantage. People with disabilities can only organise themselves to claim their rights when their additional practical needs, such as for mobility aids, have been met. People with disabilities have a right to be included in all aspects of life. In order to fight for the right to inclusion, people with disabilities need to live in an environment in which they are empowered (Department for International Development, 2002, p. 5).

Attitudinal Barriers

Attitudinal barriers are those that are usually expressed through fear and embarrassment on the part of an able-bodied person when confronted with a person with a disability. In addition, the attribution of low expectations of people with disabilities is discriminatory

and undermines the confidence and aspirations of people with disabilities themselves (Department for International Development, 2002). The negative attitudes of others can result in a 'self-fulfilling prophecy' with the disabled person pushed into a position of self-exclusion, avoidance, social isolation and non-participation. As found by Ratima et al (1995), attitudinal barriers can also lead to disabled Maori not wanting to access disability support services.

While the person with a disability may be the primary object of negative discrimination, family and friends are not immune to being discriminated against because of their association with a disabled person. Neither are they immune from negatively discriminating against disabled persons. Disability impacts not just the person with a disability but also the lives of those most closely associated with her or him. Indeed, those closest to a person with a disability can play a major role in facilitating or inhibiting access, participation and inclusion.

The Rural/Urban Divide

As a highly urbanised society, it is not surprising to find that the majority of disability support services, particularly specialist services are concentrated in major urban centres like Hamilton, Tauranga, and Rotorua. People in major urban centres are also more likely than those in minor urban centres like Gisborne, Whakatane, and Opoiki and rural communities like Murupara, Tirau, Ruatoki, Whatawhata, and Waimana to have a diversity of disability support services available to them, particularly community based services focused on specific disabilities like stroke, blindness, deafness, epilepsy, and on specific types of service delivery (eg., Kaupapa Maori). However, in rural areas, tasks like visiting a medical practitioner, having blood tests completed, or accessing day care facilities, or specialists are complicated by the need for and expense of transport.

Of research in progress at the time of our study, the preliminary results of one project³ indicate a clear difference between urban and rural Maori in that rural Maori communities tended to provide greater support to one another, whereas many Maori in urban settings reported feeling excluded and isolated from their Maori community. The support networks available to urban Maori may well be ‘thinner’, that is, containing less whanaunga, than those of rural Maori.

Cultural Barriers

While barriers that prevent access for disabled people might be artificially separated and examined, as they have been above, they remain dynamic systems that interact to produce a complexity of barriers that are often difficult to identify and change. For Maori, this complex of barriers is further complicated by the interaction of culture and ethnicity. Very little New Zealand research has focused on these interactions, with those few studies that exist examining Maori experiences of disability service provision.

In the study by Ratima, Durie, Allan, Morrison, Gillies and Waldon (1995), they surveyed a small sample of Maori and caregiver consumer perspectives of disability support services. Participants identified a number of cultural barriers to their accessing disability support services. They included:

- Few Maori staff in services
- Dominance of non-Maori staff
- Lack of provider awareness of Maori perspectives
- Inadequate cultural appropriateness of service delivery
- An underlying unfriendliness to Maori on the part of service providers

³ Direct quote from a MOE researcher reporting to the Ministry of Education Special Needs Reference group for children with physical disabilities meeting on 20 June 2003.

- Lack of acknowledgement of tikanga Maori
- Inadequate use of Te Reo Maori
- Lack of whanau involvement
- Lack of service integration

In addition to the above the Ratima et al (1995) study suggests that the overwhelming barriers to accessing disability support services were inadequate access to information, and poor communication between providers and consumers, often resulting in the use of services only in times of extreme need, rather than at an early stage.

‘Disabled’ as an identity

What cannot be emphasized enough is the need for adequate research into the experiences of Maori with disabilities that is published and widely accessible, rather than simply being research about Maori people generally. Of the limited research completed one might be lead to conclude that disabled Maori encounter the same difficulties that abled bodied Maori experience in accessing general health services. While this maybe true, there may be another possible explanation, for example, like that emerging from a project currently in progress at the time of this study. A researcher we spoke with noted:

When conducting research with Maori with disabilities and their whanau, not one of them used the terminology ‘disabled’ and I was very aware of this language being something not often used to describe the impairments their whanau member lives with.⁴

If we extrapolate on this observation, identifying as a ‘disabled Maori person’ or a ‘Maori person with a disability’ may have less meaning or carry greater stigma than identifying simply as a Maori person. Alternatively, identifying simply as Maori may carry more

⁴ Direct quote from a MOE researcher reporting to the Ministry of Education Special Needs Reference group for children with physical disabilities meeting on 20 June 2003.

value and social status than identifying as a disabled Maori. Whatever the rationale, failure to identify as having a disability may well have negative consequence as Swain, Finklestein, French and Olive (1993) point out

How a disabled person sees her or himself may not only affect the way problems that they face are identified, but also influence the way help offered by others is accepted or rejected. Seeing oneself as suffering because of an impaired body or function could lead to demands for assistance to become as `normal` as possible. On the other hand, if discrimination is seen as causing the difficulties, then help aimed at providing equal opportunities could be the preferred option. How disabled people identify themselves, then, can be very important in developing intervention strategies for services as well as helping them to help themselves (p. 9).

Once again, more research in this direction will help us to better understand the identification processes of Maori disabled people.

Health Policy and Direction

The New Zealand Health Strategy

The New Zealand Health Strategy (NZHS) was launched in 2000 following extensive public consultation (Ministry of Health, 2000). This strategy emphasises positive health outcomes for all New Zealanders, with particular attention to those groups in the lower socio-economic category. Underlying the strategy are seven fundamental principles the Government intends to have reflected across the health and disability sector.

1. Acknowledging the special relationship between Maori and the Crown under the Treaty of Waitangi
2. Good health and wellbeing for all New Zealanders throughout their lives
3. An improvement in health status of those currently disadvantaged

4. Collaborative health promotion and disease and injury prevention by all sectors
5. Timely and equitable access for all New Zealanders to a comprehensive range of health and disability services, regardless of ability to pay
6. A high-performing system in which people have confidence
7. Active involvement of consumers and communities at all levels.

In particular, the NZHS reflects a move towards decentralising decision-making to local representative District Health Boards (DHBs) rather government ministries. While the NZHS is quite a comprehensive policy strategy, the particular needs of Maori, Disabled and the Elderly are recognised in specific strategies of their own.

The New Zealand Maori Health Strategy

The New Zealand Maori Health Strategy – He Korowai Oranga, was launched in April 2001 (Ministry of Health, 2002b). This strategy recognises the Treaty of Waitangi and the special relationship between Crown and Tangata Whenua and aims to strengthen whanau health and well-being through reducing inequalities between different population groups, especially Maori and non-Maori, and building on the strengths of the whanau to achieve whanau ora. This strategy takes the goals, objectives and principles of the New Zealand Health Strategy further by providing detailed information on how Maori health objectives might be achieved. Woven into the strategy are three principles of the Treaty of Waitangi.

1. **Partnership:** Working together with iwi, hapu, whanau and Maori communities to develop strategies to improve the health status of Maori,
2. **Participation:** Involving Maori at all levels of the health sector in planning, development and delivery of health and disability services that are put in place to improve Maori health status, and
3. **Protection:** Ensuring Maori wellbeing is protected and improved as well as safeguarding Maori cultural concepts, values and practices.

While a number of earlier policy frameworks for the delivery of services to Maori have been proposed (eg., He Anga Whakamana by Ratima et al., 1995) the Ministry lacked

effective articulation on an over-arching framework within which these smaller frameworks could be applied (National Health Committee, 2002). Indeed, the recent changes to health policy in New Zealand have been heralded as more integrated and focussed than “those ad hoc reforms of the preceding decades” (Beatson, 2004, p.v).

New Zealand Disability Strategy

To understand its significance, it is important to recognise the context in which the New Zealand Disability Strategy was introduced. A brief chronology of important policy changes that have ‘made a difference’ for disabled people and New Zealanders generally follows.

Accident Compensation Act 1972 – established a generous, no fault, state system of compensation and rehabilitation for people impaired by accidents.

Royal Commission on Services for Intellectually Handicapped Children 1972 – recommends deinstitutionalisation out of large, segregated psychopaedic hospitals into community based facilities.

Disabled Persons Community Welfare Act 1975 – disability support services operated by the Department of Social Welfare for those whose impairments were not caused by accidents.

International Year of Disabled Persons 1981 – results in raising the national profile of disability and mobilises disabled persons themselves. A Telethon fund raising appeal supports the launching of various projects for the disabled.

Disabled Persons Assembly 1983 – a pan-disabled advocacy organisation established

Education Act of 1989 – establishes a policy of inclusion making it mandatory for mainstream schools to admit disabled students into regular classes.

Human Rights Act 1993 – makes it illegal to discriminate unreasonably against people on the grounds of disability

Minister of Disability Issues 1999 – The disability sector becomes a whole portfolio in its own right rather than an accessory to others (eg.,

Health), and makes it on to the government's policy agenda. In 2001, the New Zealand Disability Strategy is launched

By noting these events, it is clear to see that each represents a significant step in the journey from exclusion, stigmatisation and discrimination to inclusion, participation, and acceptance. These steps and changes have been hard won and certainly represent an improved policy position for disabled people.

The New Zealand Disability Strategy (NZDS) sets out to address the inclusion and participation of disabled people in New Zealand society and to improve the opportunities afforded to them. The strategy has been described as a "total package encompassing all (or just about all) facets of disability" (Beatson, 2004, p.viii). The strategy consists of 15 objectives each with accompanying action points. The objectives are:

- Objective 1. Encourage and educate the community and society to understand, respect and support disabled people.
- Objective 2. Ensure disabled people's rights are understood and promoted.
- Objective 3. Provide the best education for disabled people.
- Objective 4. Provide opportunities in employment and make sure disabled people have an adequate income.
- Objective 5. Strengthen the leadership of disabled people.
- Objective 6. Make sure that government organisations, and organisations that get money from the Government, know about and respond to disabled people.
- Objective 7. Have services for disabled people that work for disabled people and are easy to get.
- Objective 8. Support disabled people to have a good life in the community and to have the opportunity to live in their own homes.
- Objective 9. Support disabled people to have choices and help them to have access to recreation and cultural opportunities.
- Objective 10. Collect information about disabled people to help with planning and understanding what disabled people want and need.
- Objective 11. Promote the involvement of disabled Maori so their culture is understood and recognised.
- Objective 12. Promote the involvement of disabled Pacific peoples so their cultures are understood and recognised.
- Objective 13. Help disabled children and young people to have good lives that prepare them to be adults.
- Objective 14. Assist disabled women to improve their lives and be a part of their communities.
- Objective 15. Recognise the importance of families, whanau and people who provide support for disabled people.

Sociologist Peter Beatson (2004, pp viii-xxxii) provides an insightful critique of the NZDS and for that reason we have chosen to repeat parts of his criticism here.

Of all the objectives in the NZDS, Beatson identifies the first as probably the most important as the objective targets those things, namely negative attitudes towards impairment, that produce barriers that prevent disabled people from leading fulfilling lives. He suggests that if society were truly committed to being a ‘non-disabling society’ then the remaining 14 objectives would achieve themselves. He warns that while objective one is admirable it is probably more easily said than done, hence the need for 14 further objectives.

One glaring omission from the NZDS, something Beatson refers to as a ‘peculiarity’, is that no mention is made of the elderly disabled. The strategy remains silent in this regard.

Because impairments of mind and body accompany the ageing process, the majority of the disabled lie in the ‘elderly’ category – that is, 65 and over. In purely quantitative terms, the bulk of the health and disability support needs accumulate in this age group. Furthermore, this is the age group in which the risk of social isolation is at its highest (Beatson, 2004, p. xiii).

If one was unaware of the existence of others strategies, the NZDS would appear to send the message that the NZDS is primarily for children and those under the age of 65 years and that the needs of the elderly are ignored. On the contrary, the disabled elderly are the subject of the *Health of Older People Strategy* (HOPS) (Ministry of Health, 2002), with the needs of the elderly generally addressed by the *New Zealand Positive Ageing Strategy* (NZPAS) (Ministry of Social Policy, 2001).

Beatson (2004) further described the NZDS as a social contract based on the social model of conceiving of disability and of disability support. He likens it to a ‘treaty’, similar to the Treaty of Waitangi, inferring that it is a useful advocacy tool, as well as one that establishes a partnership between the government and disabled communities. It is a tool

which recognises the distinct identity and right to self-determination of people with diverse impairments. The same might be said of the HOPS and NZPAS. However, he warns that for there to be useful and meaningful partnerships it is necessary “for leaders to emerge within the disabled community to represent its needs, interests and identity” (Beatson, 2004, p. xiv), something that is recognised by the NZDS’s fifth objective, that is, ‘to foster leadership by disabled people’. Beatson (2004) points out that while a small number of dedicated disabled activists have undertaken to speak and act on behalf of disabled people generally, he is aware of the need for representativeness, being cognisant of the immense diversity within the disability community. While consumer views are important to hear, the views, opinions and experiences of others impacted by disability, such as families and service providers, are just as legitimate. This highlights that disability does not occur in a vacuum, but rather in a context that is important to recognise, understand and respond to.

Beatson (2004) welcomes the NZDS and the principles that it brings. However, like us, he is frustrated by the ‘lack of detail’. The strategy is strong on principles but weak on measurable action oriented ideas, that is, the concrete steps and pathways to realising the strategies’ objectives. Associated with such pathways should be indicators that monitor and demonstrate progress towards the overall goal of a non-disabling society.

Yet more fundamental to the NZDS itself, are the financial costs of the strategy. Disability is expensive and Beatson (2004) is aware of this pointing to the combined costs of benefits, assistive equipment, accommodation, subsidies for disability agencies, the employment of service workers, medical and pharmaceutical bills and the like, amounting to billions of dollars to simply maintain the pre-strategy system. If the government is serious about making the NZDS work, then a great deal more funding will be required. It must make the financial commitment.

On the question of funding, Beatson (2004) raises the issue of accident related impairment versus hereditary, congenital or medical impairment, highlighting the invidious situation where two people have identical impairments, and therefore identical

needs, but receive markedly different treatment. One will be entitled to cash compensation for lack of earnings, lump sum payments for pain and suffering, and will benefit from the mobilisation of multi-disciplinary teams to get them back to work. However, the other whose impairments are not accident related will be offered a subsistence income, they will not be compensated for loss of enjoyment of life, pain or suffering, and they will often have to fight to obtain the goods and services readily on offer from the Accident Compensation Commission. Indeed, the NZDS simply fails to address this anomaly.

While financial costs and anomalies may exist, Beatson (2004) is heavily critical of how disability services are delivered and the fragmentation that plagues the sector which in turn baffles consumers on the ground. He puts this down to “institutional gormlessness” that might well be solved with a modicum of managerial common sense. He calls for specific action plans to eliminate the administrative chaos that so often prevents consumers from leading full and meaningful lives.

Beatson (2004) does not comment on objective 11 of the NZDS, - *promote the involvement of disabled Maori so their culture is understood and recognise* - nor does he comment on objective 12 – *promote the involvement of disabled Pacific peoples so their cultures are understood and recognised*. There are two comments that we wish to make here. The first is on the ambiguous wording of the objectives, particularly the use of the term “their culture(s)”. While one can read a reference to Maori culture or Pacific cultures, it is equally valid to read a reference to the culture of disability. The objectives are confusing in this regard.

The second point is, while both objectives are relatively the same, the action points that accompanying them vary significantly. For example, under objective 12, the fourth action point contracts to get Pacific communities to talk and think about disability issues. The fact that a similar type action point fails to appear under objective 11 infers that Maori communities have already done their talking and no longer need to engage in such action! We would argue that the Maori community needs to engage in a lot more

dialogue about disabilities for the NZDS to make a difference to the lives of disabled Maori. Another example relates to improving services for disabled Pacific peoples, their families and communities. The same action is not extended to Maori whanau or their communities. Indeed, while actions under objective 11 seek to involve Maori in planning services and leadership roles, it is not clear as to whether this means any Maori, or disabled Maori. Moreover, the same action is not extended to Pacific peoples. These aforementioned examples suggest to the reader that the strategy in respect to Maori and Pacific peoples was either hastily conceived, or simply not well thought through.

Whakatataka – Maori Health Action Plan 2002-2005

While *He Korowai Oranga* (Ministry of Health, 2002b) sets out the strategy direction for Maori health and disability provision, *Whakatataka*, the Maori Health Action Plan 2002-2005 begins to address some of the gaps apparent and commented upon above in regard to the NZDS. It also begins to address some of the suggestions put forward by Cunningham (2000) in his paper to the National Health Committee in 2000. What we see being adopted in *Whakatataka* is what Cunningham (2000) describes as the ‘dual goals’ of Maori Development and Maori Advancement. These dual goals

represent a clear statement of philosophy which is based upon the union of the positive approach of development (Maori Development) and the problem-oriented approach of addressing disparity by advancing outcomes for Maori (Maori Advancement) (Cunningham, 2000, p.14).

Whakatataka harnesses the concept of ‘whanau ora’ to “achieve change at the level of systems and processes ...(in order to) to build on the strengths and assets within whanau and Maori communities” to realise health gains for Maori (Ministry of Health, 2002c, p.iii). *Whakatataka* details four pathways to achieving this outcome. They are:

- The development of whanau, hapu, iwi and Maori communities
- Maori participation in the health and disability sector
- Effective health and disability services
- Working across sectors

While the NZDS is clearly low on detail and action ideas, particularly for Maori, *Whakatataka* is not. It spells out milestones, measures and responsibilities. It provides specific steps to be taken by DHB's, service providers, the MoH, professional organisations, Maori communities, Maori providers and others across the health sector.

What we begin to see happening in this action plan is the potential merging of a combined Treaty of Waitangi and Maori health philosophy, with that of the social adapted model of disability. The result of this merger appears to be a greater contexting of the individual as being Maori and existing within a wider socio-political network of relationships. The action plan plainly acknowledges the inequities experienced by Maori but does not necessarily make an explicit link between 'Maori' as a social identity, and 'disabled Maori' as another. This, I think, is the action plan's greatest downfall. While Maori health and Maori social group involvement is prioritised, the specific involvement of disabled Maori appears absent, or hidden under the broad category "Maori". Again, the issue of visibility is raised.

He Anga Whakamana

He Anga Whakamana is a framework for the delivery of disability support services to Maori designed by Ratima et al in (1995). The framework reflects the social adapted model of disability and is organised around six principles that imply changes to service provision that can be evaluated according to a range of indicators. The principles are enablement, participation, safety, effectiveness, accessibility and integration. At the same time as presenting a clear guideline for the provision of mainstream services to Maori, it also provides flexibility for the development of Maori focussed or Kaupapa Maori health services. While the framework may go some way in addressing access barriers for Maori generally (which might be all that is required) the extent to which barriers for disabled Maori are removed still remains unknown, or untested.

Models of Maori health and service delivery to Maori have mushroomed over the past two decades (Durie, 1994, 1995). Most emphasize a holistic, integrated approach to health care with an emphasis not only on an individual need for wellness, but that also of the whanau and community. In effect, these models attempt to integrate the medical and social models of the causes of ill-health and disability.

Primary Health Organisations

Public health is commonly defined as ‘the art and science of preventing disease, promoting health, and prolonging life through organised efforts of society’ (United Kingdom Department of Health and Social Services, 1988). Public health is primarily concerned with altering the determinants of health, that is, those factors that protect and promote good health, in order to improve the health status of population (Crampton, 2004). A public health approach tends towards the social model yet is still influenced by the biomedical model.

According to the Ministry of Health (2004b), the concept of primary health care covers a broad range of out-of-hospital services, although not all of them are Government funded. It aims to improve the health of the people in communities by working with them through health improvement and preventative services. Primary health care includes first level services such as general practice services, mobile nursing services and community health services targeted especially for certain conditions, for example maternity, family planning and sexual health services, mental health services and dentistry, or those using particular therapies such as physiotherapy, chiropractic and osteopathy services.

Primary medical care is based on the biomedical model of health care and usually concerns those services provided by medical specialists in clinical settings.

Ashton (1990) has described primary health care as the 'meeting ground' for primary medical care and public health. In this sense, primary health care becomes not merely a level of care or just the gateway to health services, but the organising principle for the

country's health system (Crampton, 2004) as evident in the *Primary Health Care Strategy* (Ministry of Health, 2001b).

Crampton (2004) points out that there is conflict about where, on the continuum between medical health and public health, PHOs should be located. Crampton (2004) also raises further issues that include the need for PHOs to come to grips with issues of ownership, governance, size and geography, as well as reconciling philosophical tensions between personal and public health. Of importance to elderly and disabled Maori, is whether their philosophies of health and wellness are resolved within the philosophy and governance of their PHO.

While many disability support service providers (like GP's, Health Educators, Immunisation services, assessment services) in the health sector will merge into the new PHO structure, some will choose to remain independent. Looking at those PHO's already registered (Ministry of Health, 2004a), it appears that services for specific disabilities that have a strong advocacy role like the Foundation for the Blind and The Stroke Society and which disabled people themselves 'own', are choosing to remain independent. It is also significant that most Maori and Iwi health providers appear to prefer alliances with each other, rather than with mainstream agencies.

Chapter Two: Method

The overall purpose of this study was to provide information to support the development and future implementation of a workable and successful model of disability support provision for Maori with disabilities and kaumatua who have an age related disability⁵.

Two objectives were proposed to achieve the overall purpose of this study.

1. To identify and document the needs of Disabled Maori living in the Midland area.
2. To design a model of disability support provision matched to the needs and preferences of Disabled Maori living in the Midland area.

Two information gathering strategies were used. The first was to engage disabled Maori and their whanau, and the second, to invite contributions from key informants. These strategies and the general characteristics of those that participated in this study are described in turn below.

Strategy One: Gathering information from Disabled Maori and their Whanau

Recruiting participants

We initially set out to complete 110 interviews with Maori living with disabilities or with their whanau carers, or both, dependent upon the ability and on the comfort of people with us as researchers. We were keen to not lose the voice of the person with a disability by over sampling whanau carers, but to still include whanau carers as important contributors and informants.

⁵ For the purposes of this study, the term “Maori with a disability” or “disabled Maori” includes Maori whose disability is age related. Kaumatua are therefore a primary stakeholder in this study.

We were particularly interested in accessing those whanau reported to have not accessed Disability Support Services, or who had not had their needs assessed for service entitlement. To do this, we purposefully avoided recruitment through any of the known disability or health service providers. Instead, we publicised our study and search for participants through social networks that Maori with disabilities and their whanau may have been a part of. At the same time, we invited Maori with disabilities to assist us by volunteering as interviewers for the study.

We developed a panui (see Appendix 1), and information sheet (see Appendix 2) inviting people to participate in this study either as an interviewer or as an interviewee. Included in these panui were: a) a description of project objectives, b) information on what was required of interviewers and interviewees, and c) project team contact details. We sent this panui to Maori networks across the Midlands Region and asked people to distribute further. To ensure a wide range of Maori with disabilities were included in this study we publicised our study in a number of ways (written, electronic, by making phone calls to people who we anticipated would be helpful in our search, and having informal and often impromptu discussions with those involved with other research activities in the region). We then collected the names and contact details of all those who replied.

Information and interview packs were put together and distributed to those interested in being interviewers or in being interviewed. These packs contained a copy of both interview schedules, information sheet, panui, and consent form (see Appendix 3). Prior to the commencement of interviews, all interviewers were provided with information on the project and interviewing skills training.

We invested a significant amount of energy into recruiting participants however, we did not secure the anticipated 110 interviews. A number of barriers were encountered. A substantial number of potential participants whom were approached by the researchers or interviewers expressed reluctance or simply declined, their reasons reflecting a 'tiredness' of being acted upon by the 'system', accompanied by a sizeable and

understandable measure of cynicism as to the outcome and effect of our study.

Recruiting men into the study was particularly difficult. We have no exact explanation for this other than the possibility that the psychological risk associated with discussing a condition that threatens masculinity (that is, ‘ability’ or ‘being able-bodied’) and male role expectations was simply too high. Also, the interviewers were all women and this may have inhibited participation by men.

Sample Characteristics

We contacted 49 Maori living with a disability, and 18 whanau carers who resided in the Midlands Region. There were substantially more women than men living with a disability, and more women featured as carers than men.

Table 1: Gender of Participants

(n=67)

Gender	Number	Population
Male	Carer (3)	4 %
(n = 22)	Client (20)	30 %
Female	Carer (15)	23 %
(n = 45)	Client (30)	43 %
Total	67	100%

Our sample is reasonably representative of a wide range of age groups from teenagers to the elderly. The majority of participants (49%) tended to be aged between 30 to 50 years old. Most of the participants resided in urban centres (81%).

Table 2: Age range of Participants

(n=67)

Age	Client	Carer	Percentage
10-20	4	0	6%
21-30	6	3	13%
31-40	14	6	30%
41-50	10	3	19%
51-60	7	3	15%
60 +	9	2	17%
Total	50	17	100%

Table 3: Geographic location of Participants according to Urban and Rural sectors

(n=58)

Geographic Location	Client	Carer	Total
Urban (n=54)	42	12	81%
Rural (n=13)	7	6	19%
Total	49	18	100%

Of the 67 participants interviewed, 15 were fully employed, 16 worked part-time, the remainder (35) reported being unemployed, in unpaid work, students, or retired⁶. Only twenty three (23) participants received some type of financial assistance, usually from ACC or WINZ.

⁶ One person did not respond to the question.

Table 4: Employment Status of Participants

(n=67)

Employment Status	Client	Carer	Total
Full-time	12	3	15
Part-time	12	4	16
*Unemployed	25	10	35
Not Answered	0	1	1
Total	49	18	67

* Also depicts unpaid work, students, and retirees

The disabilities that were part of these participants lives were spread across the spectrum of disabilities defined by the Ministry of Health. Most had physical disabilities, some neurological, with many experiencing multiple disabilities.

Table 5: Type of disability

	Whanau member	Whanau carer	Total
Physical	30	6	36
Sensory	5	2	7
Neurological	10	8	18
Intellectual	4	5	9
Psychiatric	3	1	4
Age-related	6		6
Multiple Disabilities	15	6	21

*Responses in this table do not total to 67 as 21 participants reported having more than one disability

Most (67%) had lived with their disability, or had cared for their whanau member for over 10 years. Others (5%) were new to living with a disability. Of this latter group, one had recently experienced a stroke, another was a toddler with a congenital disability, the other had encountered learning difficulties. There was little reported difference between how whanau members and carers described their disability to the description used by their health professional.

Table 6: How long person has had disability

(n=67)

	Whanau member	Whanau carer	Total
Up to 2 years	2	1	3 (5%)
2 – 10 years	14	6	20 (30%)
Over 10 years	33	11	44 (67%)
Total	49	18	100%

Interview schedules

We developed and piloted two schedules, one for use with disabled Maori, the other for whanau carers. Both schedules were very similar to each other and are described below (see Appendix 4).

Section A (Questions 1-5) of both interview schedules included demographic questions. These questions helped us to assess and identify any relevant patterns across a number of demographic areas (i.e. by age, geographic location, gender, and employment status).

Section B (Questions 6-7) of both schedules included questions that sought background information on the persons disability so that we could gain an understanding of the types

of disabilities that people were living with and whether these descriptions were synonymous with that of primary health providers.

Section C (Questions 8–14) of both interview schedules canvassed information around the types of carer support available and experienced by participants. From these questions, we wanted to see what proportion of participants accessed and used other sources of support. Secondly, we wanted to explore which groups of people/agencies Maori tended to access as their likely key support person (i.e. whanau, friends, health and disability workers etc). In addition, we assessed the frequency of support provided (i.e. how often) and looked at the period of time that support was provided (e.g. up to 2 years, 2-10 years, or over 10 years). Finally, we asked participants whether they receive any type of financial assistance to assist them or their carer in meeting their needs.

Section D (Questions 15–25) of both interview schedules investigated the types and level of support available to participants from Health and Disability Support Services. We wanted to assess the nature and degree of support provided by Health and Disability Support Services; which support groups Maori tended to access; and which support groups were preferred by Maori and why.

Section E (Questions 26–40) of both interview schedules included questions aimed at eliciting information around the needs of both client and carer who are living or caring for someone with a disability. We targeted our questions around emotional, informational, financial, practical (e.g. home help), and other types of support needed by clients and carers.

Strategy Two: Key Informant contributions

For this purposes of this study, key informants were people who were aware of or had experienced the challenges faced by whanau carers, and who also had ideas about how the role and contribution of whanau carers could be better supported.

Seven key informants were selected by the researchers to participate in a one day hui in August 2003. The informants were or had been carers, or were living with a disability, or were involved in providing disability support services, or were critical of them. The important pre-requisites for being selected were that key informants came with an open-mind, with ideas around how whanau carers could be better supported irrespective of the key informants' interests or persuasions, and that they were not afraid of making a contribution and speaking their minds (See Appendix 5 for a list of key informants).

The informants were asked to participate in a number of activities focussed around the following questions.

1. Whanau Care – What is it?
2. Who are whanau carers?
3. What do they do?
4. What do carers go through?
5. How can carers be better supported?

As researchers, we choose to pursue an approach to the key informant hui focussed on whanau care rather than the broader and more tangled issue of 'disability support provision'. Our rationale for this rests upon the current transitional nature of disability support provision, and proposed policy and infrastructure changes that are presently confronting the disability sector. We wanted to avoid a fixated focus by key informants on what currently is, in favour of a focus on what could be. By prioritising the person with a disability and their whanau, we felt better assured of a whanau oriented outcome, rather than one that was institutionally entangled.

Chapter Three: What Disabled Maori told us

In this section we present a summary of what participants in our survey told us, followed by what our key informants discussed with us. The major findings are highlighted in the headings that we have used below. Each heading is followed with a brief elaboration. We have chosen to append detailed tables and data as, in our view, this tends to detract from what we see as the essential findings (see Appendix 6).

The nature of support

The main provider of support to Maori with a disability is a whanau member

The majority of participants (79%) had a key support person available, or were whanau carers (refer to Table 7 for more information). Most (89%) had received or given support for more than 2 years and usually on a daily basis (75%) (refer to Tables 8 & 9 for more information). Most carers were whanau members (79%) who lived in the same household (60%) and were usually a spouse, child or parent. Some participants received support from agency care workers (15%) and friends (2%) (refer to Table 9).

Support is also received from sources other than whanau

Sixty four percent (n=43) of participants reported also receiving support from sources other than their whanau. These were usually professionals or specialists, for example GP's, hospital out patients, physiotherapists and the like. Maori providers were also mentioned but infrequently. They were usually accessed on an 'as needed' basis. Most of the time, the person with the disability (n=32) made contact with these other sources of support directly (refer to Table 11).

Most were satisfied with receiving support from other sources but some dissatisfaction was expressed

Of those who had contact with other sources of support, most were satisfied with that contact (48%), some were dissatisfied (13%) and a few were unsure (2%). Of those who had no contact with other sources of support, 15% were satisfied with this arrangement but 15% were dissatisfied (refer to Table 12).

What participants say...

“I have approached a number of support services but was told that [I] failed to meet the criteria”.

“[I] was not blind enough to meet the criteria which would allow [me] access to resources’. [I] would like to learn Braille now in order to ready [myself] for the possibility of blindness”.

“[I] don’t think it meets everything I need”

“The system is set up to meet the needs of health professionals rather than my needs as a consumer”.

“We need help but don’t know who to turn to for it”.

“Contact with support networks [were] too far away”.

Of those who were dissatisfied with sources of support outside of their whanau, two areas of concern were evident: a) participants felt their needs were not adequately met, and b) information on availability of services was insufficient.

Health & Disability Support Services

Maori living with a disability and their whanau, use a range of HDSS's

Mainstream services were the most frequently (70%) accessed HDSS. Some participants (22%) accessed both mainstream and Maori HDSS's. Six percent only accessed Maori providers (refer to Table 13).

What participants say about mainstream HDSS's...

“Very helpful”

“Prompt”

“Provided most of the things we need”.

“Only ones available for this disability in our area”

“Its all we have for most needs”.

“Not a lot, find them to be unhelpful with support”.

Given the option most would access a MHDSS's

Ten participants told us of their experiences with Maori HDSS's. Most felt 'comfortable with Maori HDSS's as they connected with the person or agency because they were Maori and Maori oriented.

“I relate to them... they are Maori”

“Whanau member is Maori this helps her stay connected”.

“They do regular home visits”.

Of those that had not accessed a MHDSS, we asked them if they would use MHDSS's if they were available. The majority said that they would (82% n=55). Their reasons for doing so converged on three points: a) comfort of whanau with service provider; b)

relatedness of whanau to service provider workers; and c) availability and accessibility of MHDSS.

Only seven participants stated that they would not use a Maori provider if available, as they “*feel comfortable with mainstream services*”, and “*happy with current [service provider]*”. Another participant felt that “*they don’t think they can get the help they needed*” while another felt that Maori needs were too diverse and could not be met by having a “*one stop shop for Maori*”. Some indicated that they would use a MHDSS’s only if they could provide the same expertise, knowledge and resources as mainstream services.

Improving the way services are delivered to Maori and their whanau

The most frequently commented upon areas for improvements to HDSS’s were the perceived need for more culturally sensitive staff and providers and that these staff/providers are more accessible. Access to more Maori healing/activities for whanau along with increased contact and discussion with support networks for the whanau member and carer were also perceived as areas for improvement (refer to Table 14).

“Does not know what happened to the eye that she lost, she was never asked if she wanted it or what was to happen to it, she would have liked to have done something with that part of her body and to do what was appropriate for her”.

“Mainstream [needs to] become more culturally sensitive and caring”.

“I also care for my adult IHC son. More support for the whole whanau and pay for husband to care for son to help me”.

“Like to access more financial support as there are many things she feels are available to help her child’s development, e.g. employing a tutor to assist in child’s development at home”.

“A better financial support base, e.g. not all mothers of children with disabilities work”.

Dealing with crises...

GP's are more likely, than others, to be contacted for advice about accessing health/disability care

Most participants (50, n=67) contacted their doctor when they needed advice about accessing health/disability care. Whanau and other people who provide care to people with similar disabilities were the next most frequently mentioned information source. Less frequently accessed were Maori HDSS's, the hospital and nurses (refer to Table 15).

GP's are more likely, than others, to be contacted when there is a crisis

The majority of participants (46, n=67) contacted their doctor when they faced a crisis. Not surprisingly, the second most frequented group contacted were whanau. Twenty six would access the Hospital while 18 would make contact with other people who provide care to people with similar disabilities. Only 8 participants said that they would contact a Maori health/disability provider (refer to Table 16).

Overall satisfaction with the Health system

Many were dissatisfied with the Health System

Many participants (61%) reported being dissatisfied with the way the health system is currently configured. This dissatisfaction derived from frustrations around participants not accessing support. Issues around waiting times, service fragmentation, cost, systems rather than a consumer focus, and cultural barriers were highlighted as areas needing to be addressed. Those who were satisfied reported open contact between participant and provider, and accessing services in a timely and coherent manner (refer to Table 17).

“It’s frustrating...a time wasting setup, I spend more time waiting to access the system than actually accessing it only to be bumped back on waiting lists or just ignored”

“It takes so long to get the support you need. They have you on computer yet you have to go through the same slow process every time..... Time consuming”

It’s a lot of hassle; they don’t seem to talk to each other, lots of appointments, takes up a lot of time and money...”

“For assistance with her problem she has to firstly see her ACC Case Manager, then her doctor (which is expensive), and then her Case Manager again, who then requires her to get an Occupational Therapist and a Wounds Manager to come in. This process often includes a lot of delays and is intrusive to her life and whanau”.

“Dissatisfied, bloody hassle, time wasting lots of different departments, waste heaps of time going”.

Needs and suggestions

More financial assistance and Maori HDSS’s were seen as important to accessing the right support

The majority of participants (25, n=49) indicated the need for disabled Maori to have more ‘Maori health/disability/social worker or support/liaison person for whanau carers to talk to’. Additionally, most participants (25, n=49) indicated that ‘more financial support/support for themselves or their whanau members who provide care for them’ was important to accessing the right support. Issues around not getting all their needs met with mainstream services and not having an income which catered to all their needs while living or caring for someone with a disability were highlighted as being important to accessing the right support (refer to Table 18).

“Maori services for disability not available in our town”

“Suitable Maori based respite”,

“Maori for Maori with same understandings of issues”

“It cost a lot of money to travel for health, need help financially”
“Many Maori have unfulfilled needs because they don’t have the money to cover them”.
“Many disabled persons are on benefits and its difficult finding money and many struggle to make ends meet”.
“I work but I get paid just enough to survive so I need supplementary assistance to meet medical and disability needs”.

More emotional support when really stressed

Many of the participants who responded to this question (21, n=35) indicated that they would like more contact with Maori HDSS’s/worker and support when really stressed. Seventeen participants indicated that they would like their family and staff to be more understanding. Thirteen participants stated needing support systems to be more reflective of their situation. A further 25 participants stated that they do not need more understanding or emotional support. The main reasons provided were that the whanau member or their key support person had adequate support available to them in this area. Eight participants did not respond to this question (refer to Table 19).

“We don’t ask for much different than everyone else but there are a couple of things [like realising for big meetings the whole family wants to be there and that the whole family includes cousins, nieces and nephews] that we need them [hospital staff] to understand”

“More information as disability progresses”
“More support as disability creates new stresses”

More financial assistance to help Maori and their whanau living with a disability

Forty eight participants responded ‘yes’ to needing more financial assistance to help them or their key support person better meet their needs as a Maori living with a disability. Thirty seven participants reported needing more money for travel and holidays for themselves and/or their key support person. The main reason provided here was that most participants felt that they did not having an income which catered to all their needs

while living or caring for someone with a disability. Additionally, 30 participants stated that they would like more knowledge of what is available financially. A further 23 participants reported that they would like to see more money put into MHDSS's and more support given to whanau (refer to Table 20).

“It cost a lot of money to travel for health, need help financially”

“Many Maori have unfulfilled needs because they don't have the money to cover them. Many disabled persons are on benefits and its difficult finding money and many struggle to make ends meet”.

“WINZ is always changing their criteria or policies or who administers certain allowances and you end up getting sent to a person who doesn't know what to do with you”

“Help for my whanau to come more often. They can't afford it”

“Transport, koha to whanau who provide respite out of town”

More practical assistance to help around the home and time-out from carer duties

Twenty four participants indicated that they would like to have more help around the home. Types of help mentioned by participants centred mostly on needing help with household tasks and time-out from 'carer' duties. This was particularly evident when the carer was related to the person who had the disability. For those participants that responded 'no' to needing practical assistance or extra time-out, they indicated that they had good whanau support available to them and/or they were managing adequately (refer to Table 21 & 22).

“Home help would be wonderful as it's the small things e.g. bringing the washing in before it gets dark and dew sets in that get away from me”.

“Some help around the home (for washing and ironing maybe) would be good because it's just 'M' and I. When M is very poorly or when I'm sick the house work can pile up and it's hard to catch up again sometimes”.

“Me and my whanau need more time out...28 days per year is not enough”

“I need someone to help me do the things I want to do, my whanau are busy and can't be running after me all the time”

Enhancing support services

More Maori HDSS's/workers, facilities and finances to enhance service delivery to Maori and their whanau

The majority of participants (26, n=48) indicated the need to have more Maori workers and HDSS's available to them and their whanau as a way of increasing their chances of getting their needs met. Twenty three participants indicated needing more financial assistance, knowledge of who to contact and better facilities available in order to enhance their positions as Maori living with a disability. Furthermore, the need for whanau carers to be recognised by the health and disability system was viewed by some participants as important to getting their needs met as a whanau (refer to Table 24).

Making a positive difference to Maori living with a disability

Many participants (32, n=67) indicated that having more Maori health and disability workers would make a positive difference to their current situation. Additionally, 25 participants indicated that they need to 'know where to go for information' on what services and supports are available to them and their whanau while living with a disability. A further 20 participants stated the need to have adequate financial support available to both them and their whanau carers, adequate social support and adequate equipment and information specific to the persons disability (refer to Table 25).

Whanau are more likely to be contacted for support, guidance and a listening ear

Fifty-two (n=67) participants indicated that whanau provided support, guidance or a listening ear in times of need. Forty-three participants stated close friends as the group they access when needing this type of support. In many instances, participants tended to utilise both whanau and friends. Which of these groups are accessed by the whanau member was generally dependent on the nature of contact. For those who responded negatively, their comments tended to fall into two categories; ‘dissatisfaction with the lack of support provided by service providers’ and a general feeling by some participants that “*this was life*” (refer to Table 26).

Whanau are more likely to monitor how their whanau member is coping

Fifty two participants responded to this question. Of these participants, whanau (34), friends (33) and the Doctor (26) were the three groups identified as having asked how participants were coping. Only 12 participants mentioned being asked by programme staff while another 15 participants identified ‘other’ sources of support in this area. The majority of these tended to be professional or agency support people.

Whanau as key carer support was viewed as integral

Fifty eight participants responded to this question. Of the 58 responses, 33 participants felt that having a key support person was ‘better for the whanau member/themselves as it enabled the person with a disability to be in their own home and/or with their whanau’. This outcome was further supported by responses made in the ‘Other’ category. One main theme to emerge was the need for whanau to be accessible and available to the person living with the disability. Comments such as “*always better to have whanau care for you*”, and “*always better if whanau can support us*”, were common from this group. This need further increased when consumers faced cultural and service barriers. Having someone there regularly meant that participants were able to experience a sense of security and stability. Emotional and physical support on an “*as needed basis*” was mentioned by some participants as being important to meeting their needs. This additional support would also serve to enhance whanau member companionship and

contact with their whanau carer/whanau (refer to Table 27). As described by the following participant

“Being able to listen to you emotionally, being there, supportive, doing household chores if I couldn’t finish the task”.

Ideal Community

At times of crisis...

Thirty five participants responded to this question. Of the 35, 19 participants indicated wanting ‘24 hour access’ to key health and disability service providers’, along with having support available to them on an ‘as needed basis’ in a time of crisis. Nine participants mentioned needing ‘financial support’ available during this time and for ‘whanau to be recognised’ and paid for the support they provide. A further 32 participants did not respond to this question.

When coming out of hospital...

The majority of participants (47, n=67) provided responses to this question. From these responses, 23 participants indicated that having ‘better follow-up services available by hospitals’ was important to getting the needs of supporters/whanau carers met. A further 23 participants stated that ‘having more rehabilitation day programmes and care’ would also be of benefit, while only 9 of those that responded indicated wanting ‘more rehab/halfway accommodation available’. Twenty four participants mentioned a variety of ‘Other’ types of support needed for the whanau member/whanau carer and/or whanau when the person first came out of hospital. Of these responses, 20 participants suggested having ‘support available to the whanau’, ‘improved and adequate service delivery’ e.g. *“mobile support”*, ‘personal support’ such as *“emotional support, someone to be there”*, and ‘increased accessibility to information and support’. Twenty four of the 67 participants did not provide any comments to this question (refer to Table 28).

Day to day living...

Twenty four (n=54) participants felt that ‘acceptance by the community’ was needed to enhance their current support situation, while just as many wanted to see ‘more jobs for whanau members made available’ as well as ‘more day rehab programmes’. Twenty nine participants provided ‘Other’ types of supports which they felt would enhance the needs of whanau carers/supporters. Of these responses, the majority of participants suggested having ‘support available to the whanau’, ‘improved and adequate service delivery’ e.g. having “*equipment*” and “*interpreters*” accessible to them, ‘extra home support’, ‘improved financial support’ on a ‘when needed basis’, and lastly ‘increased accessibility to information and support’. Fourteen participants from 67 did not answer this question (refer to Table 29).

Summary

Overall, Maori living with disabilities, and their carers, were dissatisfied, or barely satisfied, with the mainstream services provided. Given the options, most would prefer a Maori provider, and there was a clear consensus that greater financial provision was needed. This would enhance and facilitate whanau relationships and ensure an ideal situation.

Chapter Four: Views and Perspectives from Key Informants

The second objective of this study was to design a model of disability support provision matched to the needs and preferences of Disabled Maori living in the Midland area. The survey process provides information that takes us some way towards mapping a model of service provision, while the part that whanau play in supporting their member(s) with a disability required further examination.

To do this, we asked key informants to discuss with us their ideas about whanau care, whanau carers, the work they do, the challenges they face, and how whanau and whanau carers might be better supported.

Key informants came together in Hamilton for a day long hui. They were asked to participate in a number of activities focussed around the following questions.

1. Whanau Care – What is it?
2. Who are whanau carers?
3. What do they do?
4. What do carers go through?
5. How can carers be better supported?

In posing the above questions, our intention was to conclude our hui with some clear ideas about the nature and scope of whanau care, and the challenges that whanau carers meet.

Defining 'whanau care'

Key informants were clear about the nature and scope of caring for a whanau member with a disability. Whanau care involved marshalling resources available to a whanau to meet the needs of a whanau member in such a way as to enhance the whanau as a whole.

Key informants defined whanau care in the following way:

Whanau care is diverse by nature and facilitates more than just practical care. Whanau care enhances the emotional well being of the whole whanau and is about ensuring a person with a disability maintains a sense of purpose, independence, dignity, health and connectedness with whanau, hapu and community across the persons lifespan.

Issues discussed included the need for a whanau member living with a disability to feel a sense of independence, purpose, mobility, dignity, connectedness and intimacy. Being valued and having a meaningful place within the whanau, irrespective of disability, was central to this discussion.

This definition of whanau care provided by key informants attempts to deal with a number of issues. Although a focus on the individual with a disability is an important perspective, so too is attention on the wellbeing of the whole whanau. Any definition of whanau care needs to be cognisant of both internal demands from other whanau members, as well as external demands upon the whole whanau (ie., economic demands). A holistic approach is therefore critical to positive outcomes for the individual.

As much as a person with a disability will move through lifespan changes and have varying needs, so too will other whanau members. Children will grow up, more children will be added to the whanau, and so too will spouses or partners. Parents will become grandparents, and inevitably will pass over. Attention to lifespan changes necessitates a flexible approach to care provision and to understanding the person with a disability and their whanau in context.

Who are whanau carers?

Key informants were asked to think about those people that they knew who fulfilled the role of providing care to a whanau member. Obvious whanau carers were children, spouses and parents. Not so obvious were the ways in which these people became carers. Key informant discussions revealed that many whanau carers may find their way into this role by default. For example, there is a perception within whanau, particularly with respect to caring for the elderly, that the care role should fall to the eldest daughter or eldest mokopuna (usually female), or to the child that is gay, or the one who is unmarried or unpartnered and seemingly without obligations. Whangai were also seen to be obligated into the care role purely out of their perceived need to reciprocate. Those on Work and Income benefits were seen to be more available, and young children of parents with a disability were said to be handed the responsibility whenever they demonstrated ability or circumstances became desperate. Parents of children with a life long disability became carers at the point of birth, others in the instant of a diagnosis. Grandparents were also sometimes seen to be handed the care role as they were perceived to have more time on their hands. And there are also those whanau members who have simply been pressured, manipulated, blackmailed and bullied into the role by other whanau members.

Who are whanau carers?

A whanau carer is a person who is linked to the person with a disability by whakapapa and who has inherited or assumed the role out of a sense of duty, obligation, and love. Occupying the role of whanau carer may be relative to their status or capacity as a tuakana, teina, mataamua, potiki, mokopuna, whangai, spouse, parent or grandparent.

One key factor in many of these pathways towards becoming a carer is the perception held by others of a potential carer having the time, energy and being relatively free, or 'free able' from commitments outside of the whanau. In this regard, little

mention was made of aunts, uncles, cousins or even siblings of older people. This may have something to do with how whanau in this instance is conceptualised with the main focus being on those that live within an immediate whanau, or within close proximity.

Those key informants who had also been whanau carers were quick to point out that irrespective of how they came into the role, “we do it for love”.

What do whanau carers do?

Whanau carers were seen to perform a number of tasks related to the whanau as a whole and to the independence, comfort, wellbeing and life goals of the whanau member with a disability. These include the following reported in note form from our discussions with key informants.

Whanau carers fulfil the role of or provide...

<p>Companionship and Personal Care</p> <ul style="list-style-type: none"> • For everything • They humour, amuse, occupy, distract, entertain and fill long days and nights • Home help • Cook, clean, toilet, bath, dress, groom, iron and wash 	<p>Advocacy</p> <ul style="list-style-type: none"> • Help advocate for person’s choice and mediate between the whanau member with a disability and others (i.e. whanau, doctors, specialists) • Interpret, assume, and anticipate individual needs and wants – this can be abused or manipulated by carer and caree
<p>Medical Provider/Administrator</p> <ul style="list-style-type: none"> • Become adept medical social workers and unregistered nurses • Form filler, paper worker, phone message taker, negotiator • Determine capacity of person needing care 	<p>Community Link</p> <ul style="list-style-type: none"> • Taxi driver and Courier • Means of independence • Companion
<p>Personal gatekeeper</p> <ul style="list-style-type: none"> • Consent giver (maybe controller or gatekeeper to visitors and providers) • Take the role of the parent (sometimes pushed into this role early) • Provide love, care, intimacy and affection (difference between whanau carer and paid carer) • Counsellor • Your dumping box (personal off loading) 	<p>Your eyes</p> <ul style="list-style-type: none"> • Cultural interpreter • Facilitate cultural obligations (they do or they don’t) • Interpreter of language (Maori/Pakeha) • Maintain spiritual sense of being and ensure wellness of wairua

In summary, whanau carers provide a range of services to a person with a disability. A whanau carer is expected to provide some cultural interpretation between Maori and non-Maori while acting as a personal gate keeper (i.e. parent, consent giver and counsellor). A whanau carer is also expected to provide a link between the person with a disability and their community. There are roles as a medical provider and administrator outside of that afforded by health professionals and health providers. A whanau caregiver is also an advocate and companion.

What do carers go through?

We asked key informants: What do whanau carers go through? The exercise was designed to elicit positive and negative experiences of being a whanau carer. To aid this exercise, we asked four key informants to each provide a case study reflective of their experiences either as carers, or as a Maori with a disability. Key informants were asked to take a broad approach to this exercise and to describe their strategies for the following:

- In dealing with Maori things (whanau, marae, associations i.e. MWWL, taurahere, extended whanau, church i.e. Paimarire, Ringatu)
- In dealing with non-Maori things (medical fraternities, institutions, GP's, social workers, assessment agencies, WINZ, banks, specialists, taxi drivers etc)
- In dealing with friends and associates of the carer (workmates, drinking mates, sports mates, people they may/or use to hang out with) – what do they go through with them?
- In dealing with spouses (loved ones)?
- Carer themselves (that aren't easily shared, contemplated, negative or positive outcomes...the carers themselves)

The responses made by key informants were organised into thematic areas and constructed as needs. These are presented and commented on below. The original unedited list of comments made by key informants is included in Appendix 7.

The need for information

Whanau carers were seen to have a need for information and knowledge to better understand their whanau member and their disability so as to provide support to them. Knowledge and information was seen to be available from a variety of sources. These included: all medical professions including GP's and specialists, all support staff such as assessors, social workers, service providers, voluntary organisations (eg., ADARDS, Epilepsy Association) and other whanau carers of whanau with similar disabilities. Pamphlets, booklets, the internet, libraries were also sources of information.

Being informed can, amongst other things, lead to: better decisions about care; being able to access resources and networks; being more understanding about a whanau member; being better able to provide advice and guidance to others, including the medical profession; and being better prepared to deal with crises and challenges. Lack of information often inhibits these abilities.

Key informants emphasized that accessing information and resources was often a very difficult exercise, particularly if a whanau carer had to negotiate a mass of systems and gatekeepers to access the information required. In this regard, whanau carers needed to be determined and assertive in their quest.

Moreover, some information, particularly medical, required that whanau carers had to engage a steep learning curve to understand the information that was being provided (directly or indirectly). Medical diagnoses, conditions, processes, and procedures engage, for the lay person, often highly technical language. Key informants felt that whanau carers became adept at understanding complex terminology and interpreting it in simple terms to others.

Information gain is empowering in positive and negative ways. Whanau carers, in acquiring information can also become gatekeepers to that same information. With increased information, whanau carers can begin to occupy quite powerful positions enabling them to broker support, resources and opportunities for their disabled whanau member, themselves and their whanau. While positive when exercised for the benefit of the disabled whanau member, when exercised otherwise, the outcome can have a disempowering effect. This can raise issues about power and control, and affect the dynamics of an already unsettled whanau.

Having knowledge and information can cause frustration. When whanau carers come to know that a particular service or resource is required yet are unable to access that service, frustration (at the least) is an outcome. For whanau situated in rural areas where services and resources are limited, finding the appropriate service or resource can be either an expensive (travel and time) or fruitless exercise.

Lastly, key informants discussed the impact of the Privacy Act upon whanau carers especially carers of children. It was noted that when children with congenital conditions or who have become disabled during their childhood transition to adulthood (an immediate and age related event), the integral role that whanau carers have and in many cases, will continue to perform is 'side lined' by the Privacy Act. Furthermore, the Privacy Act, when strictly applied, often inhibits the whanau from acquiring information that invariably is helpful to care and support of a their disabled whanau member in the whanau environment.

The need for practical support

Whanau carers need support too. Sometimes carers are faced with practical tasks that that can only be eased with assistance from others. Physical strength is sometimes a pre-requisite for providing care particularly when having to lift equipment or a whanau member. Some manage on their own, others need to seek support from others. For those

whose mobility is incapacitated access to private homes, public buildings and motorvehicles may well require assistance beyond that afforded by the carer. Key informants who were also caring for a disabled whanau member reported that “partners provide awesome support”, so can friends, and in some instances, total strangers.

Transportation was seen by key informants as a major need, particularly to travel to appointments. In some areas, free or reduced cost transport is available. However, this was not seen to be the case in all areas. When appointments with some medical professionals were very hard to make and often infrequently available or had long waiting lists, attending was seen as very important. Again, friends and extended whanau were helpful in this regard.

Key informants reflected on how participation in informal community, hapu and iwi appropriate activities can bring relief to whanau carers and their whanau. These activities are various and might include tangi, line dancing, concerts, hosting visiting groups, fundraising socials, working bees, wananga, and the like. Being out amongst other people increases a sense of belonging to a community and broader network of people and resources that can be drawn upon for support.

Sharing care with other whanau and friends allows time out for whanau carers. Key informants also acknowledge that it was often difficult to find the ‘right’ people to share care with. Sometimes, the person with the disability did not want any other person to provide care, and sometimes the whanau carer didn’t feel that anyone else could do the ‘job’ that they did. Formal respite care agencies were often not considered as an option for these same reasons.

Related to sharing care, is the internal whanau perceptions of who is responsible for providing whanau care. Often the carer was defined by roles and positions occupied within a whanau. For example, key informants felt that the roles of parent, spouse, grand parent, first born, last born, whangai, and the like, were all roles that could be argued by others as having more responsibility for providing care, than others. The question of who

provides care and support depends on willingness, circumstances and resources available to a whanau at anyone point in time.

Practical support from formal agencies and their workers was acknowledged as being a 'big help', if one qualified for such support. Indeed, one key informant considered a formal agency worker to be more like a 'family friend' rather than an employee. Where different types of support was available from varying organisations, key informants commented that there was often no sense of unity or coordination amongst providers.

Being a whanau carer or providing whanau care requires willingness, organisation, adaptability. Common to circumstances, fortunes, whanau, and disabilities is change. Skilled whanau carers were seen as those who were able to marshal the resources available to them to respond in practical and effective ways to change.

Lacking practical support results in not achieving tasks that could be achieved more efficiently with support. Key informants noted the frustration, wasted time, arguments, and stress that can result from inadequate support. Often carers spent time away from their own whanau, children and partners to afford care to a whanau member. Sometimes, the whanau member with a disability had to move to the home of their whanau carer. Irrespective of location, caring for a whanau member with a disability often meant a refocussing of energy and attention away from other whanau members.

The need for communication

Whanau carers need to be good communicators. Whanau carers need to sustain a variety of relationships with: the whanau member with a disability; other whanau members; the broader network of relatives; GP's, specialists, nurses and other medical staff; agency workers; day care staff; school staff; assessors; the public; and WINZ.

Often whanau carers occupy an unenviable position of determining the activities that a disabled whanau member can or cannot participate in. This may also include mediating

access by whanau and friends to a disabled whanau member. For the wellbeing of the disabled whanau member and themselves, they often have to say 'no'. Communicating a negative response is an art, particularly if offence is to be avoided. But this is not always possible. Occupying such a position can result in the whanau carer becoming the object of derision from both the disabled whanau member, and others. Being the 'meat in the sandwich' is not a pleasant position to occupy and key informants report both verbal and physical attacks on carers for their efforts.

Key informants perceived whanau carers to be more comfortable with conversations about disability, and about their disabled whanau member than those who had not had the same experience. Indeed, whanau carers were seen to benefit from talking about their roles, experiences, challenges and successes with others. But others often did not want to hear or know and key informants report feeling as if they were talking into a void. Conversely, many report only ever having conversations about caring for their whanau member and nothing else. It is as if the person with the disability had consumed the carer's social existence.

Key informants also reflected on carers being invisible and having their voice denied, particularly during consultations with medical professionals. The carer is constructed as a 'support person' or 'friend' and not recognised as an important contributor of information and to the health and wellbeing of the disabled whanau member.

When they are recognised, whanau carers sometimes fill the role of 'translator'. This may involve interpretation of Maori to English (and vice-versa), between technical and lay terms, and between abilities. This latter action involves consideration of capacity, particularly when capacity is assumed to be there, but in real terms, is not (eg., hearing, sight, comprehension). In some cases, non-verbal communication is more important than other forms of communication.

Lastly, communication is important for advocating on behalf of the disabled whanau member. Key informants report that whanau carers often ‘develop a mouth’ and become quite ‘pushy’, mostly as a result of negative past experiences.

The need for hauora

Being a whanau carer does not necessarily mean that the carer is in good health or that they will continue to be. Providing care on a daily basis, being the first point of contact for crises, performing as a doctor – albeit unqualified, recognising when a whanau member is in difficulty, coping with set backs, encouraging compliance with medical advice and directions, dealing with medical staff and agencies – these are all stressful events.

Caring is hard work and a stressful activity, particularly when the person with a disability is a loved one, and more so when their condition is ongoing or degenerative. In failing to attend to healthy lifestyle practices like good eating, sleeping and exercise routines, carer’s risk becoming physically and mentally ill themselves. With this latter point in mind, key informants reflected on how easy it is for carers to sometimes move towards thoughts of assisting their loved ones to die and the methods to do so. Thoughts of this nature bring home the vital need to construct a holistic approach to providing care and support for whanau carers and those that they care for.

The need for services

When whanau carers and their disabled whanau members need services they should not have to navigate additional hurdles to access those services. Key informants were critical of mainstream and support services. They reported a desperate need for Maori appropriate service providers who were responsive to the needs of whanau. With regard mainstream organisations, they commented on the lack of Maori staff to engage with. In addition, whanau carers sometimes felt as if they were being made to feel guilty for asking for assistance. And when they failed to obtain assistance whanau carers often felt as if it was their own fault and that they were inadequate. Racism, a sense of

powerlessness, a lack of control, starting on the back foot, a lack of visibility are how key informants characterised interactions with providers.

The need for finances

Having a disabled whanau member who requires care and support is an expensive circumstance. Key informants reflected on the financial losses that whanau carers endure. In some instances, whanau carers give up work to facilitate care, or put aside work and education opportunities. This sometimes results in financial stress and a constant juggling of priorities. If the carer has been out of the workforce for some time, getting back into the workforce is often difficult.

Where a whanau member with a disability does not qualify for a Community Services card and has substantial savings, getting that person to commit funds for medical and personal care is often a sensitive matter. If the whanau carer pressures too much for the spending of funds, they can come under scrutiny, if not attack, from other whanau members.

Although respite care is available to whanau carers by no means does this adequately meet the 'time out' needs or equate to the financial and personal contribution often made by whanau carers.

Lastly, the eroding of life time savings on medical and personal care expenses for one spouse often causes stress for both spouses.

The need for visibility

The issue of visibility and acknowledgement for the role that whanau carers play presented itself in much of what the key informants said. Added to their feelings related to role invisibility, were feelings of being discrimination against because of their role and because they were Maori. The following quotes speak for themselves.

- *Talked to as if the person with a disability is not there*
- *Dismissed of my role as carer once child reached 16 - not being acknowledged as his carer anymore*
- *Dismissiveness – feeling of NO value, not important*
- *You feel that the personal skills that you have learnt while caring for that person aren't easily transferable into a money paying job*
- *Isolation*
- *Disrespected*
- *People “look away” or look “sympathetic” or look “horrificed”*
- *Not believed! Heard! Dumped on!*
- *Loss of social life*
- *Discarded*

With these comments in mind, the issue of invisibility has a lot to do with the need to be respected and valued for the significant role that whanau carers play.

The need for social and emotional support

Key informants reflected on becoming and being a whanau carer. Such a role invariably means that priorities, resources, networks, activities and the like reconfigure to establish new or maximise existing support that can be bought to bear on the task of caring.

Initially, when first handed the role of whanau carer, often in the instant of a

diagnosis, friends, whanau, spouses, and the like express sympathy. During the initial crisis period they are supportive, understanding and try to help. Some whanau where a

What cannot be emphasised enough is the depth of stress and emotional turmoil experienced by whanau carers yet largely unacknowledged by others.

member requires a large amount of care and supervision, often arrange shifts between whanau members with people taking time off work, or foregoing other activities. When the long-term nature of circumstances come to be known, key informants report that things often change. Relationships can become strained, abusive or end. Friends, spouses and whanau may “fade away” to their own ‘ordinary’ lives. Those left to fill the role of carer often lose control over their social lives and are often perceived as “boring” or self-obsessed with their own circumstances. Sometimes they might become isolated, feel used and develop a sense of their own lives being suspended. And sometimes they experience a sense of grief, loss and helplessness in witnessing and living through a whanau member transitioning to a position of less function than that held earlier.

Whanau carers are sometimes seen as a magnet for the emotional outpourings of others – ‘a shoulder to cry on’, ‘someone to yell at’, ‘offload on’ and sometimes ‘blame’. They are seen as the ‘strong ones’ for the disabled whanau member, and for others. Others are often shocked when the carer becomes ‘short’ or agitated or an emotional ‘cripple’ – something they’re not supposed to do. Indeed, from our discussion with key informants, depression and emotional turmoil seems to be just part of the job. And some carers develop a ‘reputation’ or are stereotyped for being ‘pushy’, ‘aggressive’, ‘emotive’ and the like.

While key informants discussed the positive aspects of others providing support and time out (as presented below), they noted the guilt and shame that could sometimes arise from turning their attention away from the person they are providing care to. Carers may feel they are abdicating their responsibilities in order to take time out and that they were being judged by their whanau and community for leaving their whanau member in the care of some other. Indeed, the idea that the carer has a responsibility to ameliorate some *hara* (wrong) committed by the disabled whanau member or more broadly the whanau, is an interesting one and stems from the notion that sickness and disability are caused by metaphysical entities that need to be appeased (Marsden, 1975).

While family members and friends were seen as a great source of constructive criticism, support and encouragement, they could also be the source of the most painful, spiteful and soul destroying feedback and behaviour. Key informants noted that while siblings of carers could become suspicious, undermining and unnecessarily critical of the care they provided, and children could become demanding and seek their attention in negative ways, the demands made of them by partners were possibly the most disruptive. Key informants recognised that while many carers have supportive and loving partners who more often than not are just as actively engaged in the care role, some carers have partners who respond otherwise. They may present the ultimatum of “its your family or me”, withhold access to transport and mobility, set restrictive conditions like a time to be home or allow only a limited visiting period. They may also wilfully undermine what the carer is doing, by contacting other family members to complain about neglect or abuse, or by intentionally teasing the afflicted person.

Key informants also noted the frustration, overwhelming grief and “deep pain from watching person with a disability hurt and struggle and wishing I could help”. When this experience is joined with inadequate, inappropriate, inefficient or insensitive treatment by service providers like WINZ, ACC and health providers, it is not surprising that a sense of resentment towards these services results.

Key informants recognised that whanau carers may send out contradictory messages to others. They sometimes express “anger when other whanau members encourage a behaviour that [they] know will affect their [the person with a disability’s] health” with others not understanding where such a reaction came from. They themselves experience “pain – watching someone [they] love mutate and change and [they] can do nothing”. They may “become so emotionally involved with the person that [they] can experience jealousy when a new person attracts attention away from [them]”. Carers may experience a “great sense of embarrassment and shame when trying to access support” and may be perceived to be “emotionally detached” or “tuned out”.

Yet caring for a disabled whanau member is not all ‘doom and depression’. Key informants noted that affording care can also be a rewarding and meaningful experience. For some, it can create a feeling of purpose in life, a feeling of being needed. It encourages personal growth and maturity – carers, young and old, “grow up real fast” although there may be a persistent sense of “self-doubt”. The journey with person with a disability can result in “learning a lot and growing spiritually”.

Who cares for the carer?

Key informants reflected on their experiences of making new friends and alliances – with other carers, with people with disabilities, with providers and home care staff, and with new whanau members. They also discussed how their social lives change. Whereas, sports, nightclubs, movies, fishing, going to the bush, seeing friends may have occupied social time, carers found that they spent more time at home, or engaged in activities with provider agencies like Stroke Club, Heart Club, or in social activities that their disabled whanau member could also participate in. They themselves as carers, also changed. They became more sensitive and selective of others. They recognised when they were tired, stress, frustrated and worn down, and learned how to seek and ask for support. They learned how to take themselves out of being socially isolated and learned again how to be sociable. They learned to take time out, or to simply do something different. In short, they learned skills that would help them to take care of themselves.

They also learned how to share care. Key informants told us that if you’re lucky enough, new friends and alliances become absolutely invaluable. They, particularly partners provide support, time out, and distraction. They “hear the alarm bells” – the signs of stress and distress. They provide understanding, sympathy, a listening ear, transport, and some simply provide unconditional love and ‘help you laugh at your troubles and put things in perspective’.

Summary

The key informants brought invaluable knowledge and experience to light on the topic of discussion, that is, the nature and scope of whanau care, and the challenges that whanau carers meet. While willing to share their experiences with us as researchers, they were aware that the issues they were highlighting varied according to the age, gender, competencies, and circumstances of carers, and those cared for. For example, living a life as young child or rangatahi caring for a parent or grandparent versus an adult in their fifties caring for a child, spouse or elderly parent are quite different circumstances. They recognised that carers and whanau will respond and cope differently depending on how a disability manifests and is understood within a whanau. Added to this are issues related to socioeconomic status, rurality, type of disability and the availability of information and support.

While key informants felt that many whanau and whanau carers were coping admirably, the question of who is responsible when whanau and carers are not coping or when a whanau member with a disability is being abused or uncared for, remained a difficult one to answer. Key informants did have opinions about this. They generally felt the most favoured outcome occurred when caring for a whanau member with a disability in their own home, whanau or community context (eg., hapu, iwi, town, rural community) where support was afforded and whanau and community networks preserved.

Chapter Five: Developing a Model of Service Provision to Maori

Disabled Maori live in a series of nested contexts that act to define their existence, disability, worldview and quality of life. In using the term ‘nested’ we are referring to the individual existing within a larger set of inter-related and living social ecologies, for example, their households, communities, and social environments. Providing effective DSS’s to a person with a disability will vary according to their personal characteristics, their disability type and identity, and their primary social context. For example, age, sex, sexuality, cultural orientation, type and experience of disability all influence the behaviours and attitudes towards seeking and receiving help on the part of the individual with a disability. So too, will those people who live with the person with a disability. These factors form the basis of our rationale for choosing the ‘household’ as the primary nested context of interest, with family or whanau situated both within the household and in an intermediary context.

The household unit

The household tends to be the social and economic unit that, in the first instance, must respond to the disability and find a configuration that optimises the potential of all household members. The different understandings, assertions and manifestations of being Maori will cut across the household unit and will be influenced by the nature of the disability that the household lives with, and the presence of other cultural orientations within the household. While some will view this positioning of the household as being over and above that of whanau we prefer to view the household as a significant unit within and in interaction with the broader whanau and community context rather than a replacement of it.

The function that first confronts the household is that of meeting their primary needs for shelter, food, and good health. Beyond this is the need to satisfy our basic human need for meaningful social identities and roles. Having a sense of purpose, meaning and

agency in life is essential to good physical and psychological health and can only be achieved within the context of positive social relationships. If a household is characterised by such relationships then it is more likely to thrive, rather than being one of resentment, dysfunction and depression.

For DSS's it is important to understand the nature of the household unit. For example, a low income household may view any additional financial or support benefits as a contribution to the whole household, rather than to the disabled individual alone. Providing care and support to the whanau member with a disability may cause someone else in the household to quit the paid workforce, in order to ensure a better quality of life for the disabled person, further reducing income into the household. A household marked by a religious view of disability as a 'sin', or as a consequence of some 'offence' may also be confined to a position of endurance and shame, choosing not to seek or be receptive to education or support services. A household marked by dysfunction may not be a safe or supportive environment for any household member except the most dominant. Indeed, in such households disabled whanau members are at risk of abuse, being deceived and taken advantage of.

Disability can be a highly charged and emotive experience that challenges the resources of a household unit. Some households will settle into a pattern that serves the totality of the household. Others will reconfigure temporarily or permanently with some members shifting out of the household while new members shift in. And other households will demand more of those in the intermediary zone, binding them to the household unit with significant roles.

Disability is a time conditioned reality and may be felt more or less intensively at different stages in the lifespan requiring different types of support and care. Examples include reaching school age, becoming sexually active, or when a child legally becomes an adult, or when they require surgery or specialist or crisis intervention. Sometimes disabilities improve with time, and others deteriorate. Disability is not a static condition, and neither are households. Members pass on, or choose to live in other households.

Children may come and go, and so too may grandchildren. The same is true of siblings, parents or grandparents. And partners may well change, not only for the person with a disability, but those of other household members.

Those formal agencies concerned with DSS delivery, including Kaupapa Maori agencies, need to view the Maori person with a disability, not just as Maori, or disabled. They are social beings situated within a dynamic household context. Those assessing need, and delivering services, must understand the natural rhythms of a disability, the household, and the fact that household configurations, however simple or complex, will influence the outlook of not only the disabled person, but of those close to them.

Figure 1. The Household with a Disability

Personal Characteristics	Disability Type	Primary Social Context
Age	Physical	Primary carers
Sex	Sensory	Whanau carers
Socio-economic status	Psychiatric	Intimate companions
Maori ID	Intellectual	Dependents
Disabled ID	Age related	Elders
Onset of disability	Identity Type	Siblings
Sexuality	Maori identity and cultural orientation	Relatives
Education	Disability identity & cultural orientation	Adult children
Maori identity and cultural orientation	Religion/Spirituality	
Disability identity & cultural orientation	Socio-economic status	Media (TV, Radio, Print)

Intermediary and Secondary Contexts

While a household may be described as a physical address that is useful for delivering mail and meals to, household configurations shift and change reflecting the need for people to seek satisfaction beyond the household unit. During the day or even at night,

the role of care and support may shift to different members of a household, or to those in the intermediary social context. Or the disabled whanau member themselves may do the shifting to some other care location, for example, a day care facility, school, marae, workplace or some social support group. While various possibilities exist, the least beneficial is one of social isolation and exclusion.

The intermediary and secondary social contexts perform a vital role, not just in providing formal or informal care and support to a whanau member with a disability, but also in monitoring and supporting the 'health' of the household unit. These broader social contexts can be sources of finance, care, respite, information and education, purposeful social interaction, companionship and advocacy. Formal DSS agencies are also situated in the secondary social context. While they may deliver services to the household unit (meals, personal grooming, transport, home based therapy) most require the disabled person and carers to move outside of their household unit to access services. For example, while some GP's will do home visits, the majority won't. While 'blood takers' will visit the bed-ridden, it is a rare event for them to make house calls. While speech therapists could deliver their services within the household context, travel to households is not considered a productive use of their professional time.

Formal DSS's who provide a needed service outside of the household unit require the disabled person and their carers to negotiate a maze of hurdles in the first instance related to the 'looseness' or 'density' of the secondary context. Dense environments are those where crises services and DSS's are readily available and within a short distance from where the household unit is situated. There is usually a diversity of resources, services and expertise available either publicly or privately. There is a choice of services. Dense environments are usually major urban centres that are more time and output conscious particularly if their service is under demand, or commercially run. In contrast, loose environments are marked by the need to travel to access services. Often this involves the expense of interim accommodation. In loose environments, the available services tend to be less diverse, less specialised and may lack the range of necessary resources to respond effectively to crises events. However, service providers may be known to the household,

and may well be 'connected', due to their being embedded within the local community. For households, this may be favourable, affording more direct access to local providers. For the provider, it may increase the risk of blurred boundaries.

When accessing DSS's in either loose or dense environments, disabled people and their carers need to negotiate readiness, appointments, the availability of carers and whanau if required, waiting times and lists, language and communication barriers, transport, care for others in the household, distance, in some cases accommodation, safety, and reception by the provider. Just getting to a service may well be a struggle for a household that is often ignored or inadequately acknowledged by service providers. To expect household or whanau participation without support is often unrealistic.

Once a DSS has been accessed, those delivering services need to be more than culturally competent or sensitive, or embedded in a Kaupapa Maori context. They also need to be aware of how other philosophical approaches to health care impact the household unit, person with a disability and carers. It is an extremely disheartening experience to arrive at a DSS for an expected appointment, only to be told that an 'error' had been made. The cost of that 'error' can be very expensive financially and emotionally. Given the fragmented nature of DSS's, the likelihood of 'errors' occurring is unavoidably high. Services need to adequately and efficiently address the real needs of the whanau member and carer without expending or placing undue stress on the household unit.

Institutional and Legal Facilitators

Entitlement to services are often defined legally and institutionally and on the basis of need. While the individual with a disability, their carers, or a health professional may ask for an assessment, causing an assessment to be completed still remains a challenge. One major barrier to assessment completion is the failure of DSS's, like hospitals, GP's and health centres, to make the appropriate referrals or to inform whanau and their carers of

their entitlements. While assessments may be completed, their completion does not necessarily guarantee that needs are met.

Assessments establish a level of entitlement to financial benefits and care services like home and personal care, and respite for carers. While benefits are available, they are not universal – entitlement is configured on the basis of financial stress rather than need. If a person with a disability, their parent (if a child) or spouse is assessed as having the means, then it is assumed they can afford to purchase the needed services.

Figure 2: The Nested Household with a Disability

Intermediary Social Context	Secondary Context Social and Functional		Institutional/Legal Facilitators
Close relatives Close friends Primary carers Whanau carers	Friends and companions	GP's	WINZ
	Relatives	Therapists	Hospitals
	Recreational circles	Bloods	PHO's
	Education	Counsellors	Education
	Peers	Equipment	Local Government
	Marae/Hapu	Educators	Assessors
	Work	Rehab	Courts
		Health Centres	IRD
	Community/Network Type	N4Profit Agencies	
	Dense	4Profit Agencies	
	Loose		

Assessments are based on the medical model of health with need determined by what the individual is incapable of doing, rather than what they are capable of. Much is assumed of the support and care available within the household unit. While 28 days respite care might be allowed for, it is usually nowhere near a reflection of actual care and energy provided by informal carers. For example, supervision of a disabled whanau member, who is considered a safety risk, in their own household is not compensated within the benefit structure.

While being declined a benefit can confuse and demoralize, gaining new help and assistance can be invigorating and enabling provided that assistance is delivered in a way that complements other informal and formal support activities. Often times, formal services fail to meet this need as they struggle to juggle staff needs as well as those of other consumers.

DSS are often funded to deliver specific services with purchasing agencies (eg., DHB's) ultimately defining the terms of the contract. Rarely do consumers come in contact with purchasing agencies, but their presence is felt through statements by DSS staff like 'we're not funded to provide that', or 'you need to go to ...'. At this point, advocacy becomes important, but this role is rarely contracted.

Perhaps the greatest mitigator of confusion and frustration is information that is up-to-date and provided in a timely and accessible fashion. Having information can solve many problems before stressful states result. It can mean the difference between having a safe and enabled household, versus suffering fatal negative events or unnecessary circumstances, or having a family member resign from work, or suffering exclusion and isolation.

How information is presented also makes a difference. In the last two years there has been an explosion of web based information resources, yet these remain largely inaccessible to Maori who have the lowest rates of home internet connections. Pamphlets and information provided by DSS remain the primary source of information for Maori.

Philosophical Determinants of Health, Attitudes and Support

Understanding the philosophical determinants of attitude and support provides a framework for analysing the factors which influence the funding and delivery of DSS.

If an agency is premised on the medical model of health, then the service and all other staff are more likely to be organised around the schedules, priorities and dominant views of medical experts. The extent to which other worldviews are allowed to enter into the activities of the service will depend on the beliefs and attitudes of medical experts. Some may view alternative treatments and therapists (eg., massage, reiki, herbal remedies, acupuncture, working with Tohunga) as complementary to their work, while others purposefully seek to discredit and exclude.

Figure 3: Philosophical Determinants of Attitude and Support			
Public Health	Primary Health	Medical Health	Maori Concepts of Health
Social model of Disability	Religious Model of Disability	Medical model of Disability	Able bodied vs Disabled
Community Development	Maori development	Maori advancement	Pakeha vs Maori

If a service subscribes to the primary health model, then the role and influence of medical staff may be balanced with input from health nurses, health promoters, and community developers. While the current approach to meeting the health needs of New Zealanders has been shifted to rest on the primary health model, tensions with subscribers to other models still remain.

While Maori with a disability and their carers may express a desire for more Maori health services, or mainstream services that have more Maori staff and are more receptive to Maori, many of the barriers that are encountered are more likely to be related to philosophical tensions about service delivery. For example, if a service is premised on a Maori model of health care, then one might expect priority to be given to Maori workforce development and Maori advancement activities.

The Living Nature of Disabilities

Disabling conditions are intimately linked to the lifespan. The older one becomes, the more likely a disabling condition will manifest. Those who have met the challenge of a disability early in life will encounter different challenges as the body matures and undergoes physiological changes due to the aging process. These challenges can be mitigated with assistance from medical professionals, health and education workers, advocates, whanau, friends and the broader community provided their intervention is accessible, timely, informed and enabling.

A Service Delivery Model

A model for the delivery of services to Maori must recognise...

1. how households configure, live and respond to a disability and whanau member with a disability
2. the nested, social and dynamic nature of households
3. the interaction of the household with intermediary and secondary environments
4. environmental, attitudinal and institutional barriers and facilitators
5. the underlying philosophical determinants of health, attitudes, support and service delivery
6. the living nature of disabilities

Irrespective of whether they are kaupapa Maori driven, or mainstream, DSS must resolve the underlying organisational and professional tensions between a variety of philosophical approaches to health and determinants of attitudes, support and service delivery. While cultural competence and workforce considerations are important and do contribute to better access for Maori to services, the problems that disabled Maori and their whanau experience are probably more related to institutional and criteria based

barriers, rather than those considerations based primarily on culture. These fundamental issues also need to be addressed.

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Appendix 1 Panui

Panui

“A study of needs and models of disability support services for Maori”

Kia ora, koutou. We are a research group from the Maori and Psychology Research Unit (MPRU) within the Department of Psychology at the University of Waikato. We have been contracted by the Ministry of Health to undertake research into the needs of Maori living with disabilities and models of disability support services available to them. The main aims of the project are to:

1. Identify and document the needs of disabled Maori living in the Midland area, and
2. Design a model of disability support provision matched to the needs and preferences of disabled Maori.

We are inviting you and/or a designated carer of your choice to be part of a study involving interviews with Maori people living with a disability. The objective of these interviews is to gather information on the range of needs experienced by Maori living with a disability in the Midland region.

Interviews

Participation will involve face-to-face interviews, approximately 45-60 minutes long. Participants can choose to have either a group or individual interview. We will be asking you questions on the types of needs you experience as a person who lives with a disability.

In order to ensure as wide a range of disabilities as possible is included, we have organised for interviews to be conducted using a variety of media. If you would prefer to take part in some way other than a face-to-face interview, please let the researcher know or you can contact the research coordinators, Rolinda or Huhana at the Maori & Psychology Research Unit, 07 856 2889, extension 8025.

We will be asking you for your consent to audiotape the interview. The tapes will be destroyed after the research has finished.

By taking part in this interview you can be assured that:

- Your anonymity will be protected
- You may refuse to answer any question(s),
- You can withdraw at any time,
- You will not be identified in any way in the final report.

Should you need further information, please contact the research coordinators below.

Rolinda Karapu (*Ngati Awa, Tuhoe*)
07-838 4466 ext 8025
rc3@waikato.ac.nz

Huhana Hickey (*Ngati Whakaue, Ngati Tahinga*)
huhanna@hotmail.com

Appendix 2 Information Sheet

Information Sheet for Participants and their carers/whanau

Project title: *“A study of needs and models of disability support services for Maori”*

Project Supervisors:

- Dr Mike Hills, Psychology Department, Waikato University, 07-838 4466 ext 8296, mhills@waikato.ac.nz
- Linda Waimarie Nikora, Psychology Department, Waikato University, 07-838 4466 ext 8200, psyc2046@waikato.ac.nz

Project Co-ordinators:

- Rolinda (Poli) Karapu (Extn 6563, mobile: 021146 8453) rc3@waikato.ac.nz
- Huhana Hickey (extn 6563, mobile 021 113 9150) sjh8@waikato.ac.nz

Tena koutou katoa

This is an invitation to you to participate in a research project about Maori living with a disability. We are particularly interested in what **needs** Maori and/or their carer support/whanau members experience while living with a disability. We wish to interview Maori with disabilities and/or their carer support who do not access health/disability support services. We are also interested in hearing from carers/whanau members who support Maori with disabilities.

Information gained from interviewing whanau member/s and support persons will form a key part of this study. It is expected that the information obtained from the interviews will help identify key areas of support needed for the effective delivery of Support Services for Maori and their whanau. If you do choose to participate, we will ask you to think about someone who has provided support to you (eg. Support worker, whanau member, friend) who we might further approach to be interviewed.

We want to meet participants from two regions: Waikato and the Bay of Plenty. If you reside in any of these regions we would appreciate your willingness to participate in the research project. There will be a total of 100 interviews (equally distributed across the two areas) for this part of the study. Interviews will be conducted by Maori interviewers (where preferred, competent in te reo Maori) who will be recruited and trained by the MPRU in collaboration with the researchers. If you agree to participate, a researcher will arrange with you a suitable time and place. The interview will ask about your living situation and the types of support available to you and your whanau.

In the case of interviewing carer/whanau support, our aim is to ensure that **all** participants are guaranteed anonymity and confidentiality. As a result, unless stated otherwise, interviews with the participant and carer/whanau support will be done separately and kept confidential. This is to ensure that either party can speak freely and openly without fear of the other finding out. In most cases we imagine this will

not make a difference and both will freely tell the other afterwards what was said, but in case there are some issues that the participant would rather the support/carer did not know or vice versa, we would like to keep this confidential, even if you choose not to afterwards. If this concerns you then feel free to not participate at all. We would rather not interview you than cause dissention and distress in your family.

Your participation in the study is entirely voluntary and the information you provide will remain confidential. During the research process you will be completely free to withdraw at any time, for whatever reason. If you agree to participate in this project, we will ensure that Disability Support Service providers your region are available if you require support.

Finally, we would like to thank you for considering our research and for taking part if you choose to do so. We hope finding out the few small pieces of knowledge from this project can work towards better provision of support health/disability services for Maori.

Appendix 3: Consent Form

PARTICIPANT CONSENT FORM

“A study of needs and models of disability support services for Maori”

- I have read the information sheet for this study and have had the details of the interview explained to me. I have had a chance to ask any questions that I may have had. My questions have been answered to my satisfaction and I understand that I may ask more questions at any time.
- I understand that I am free to withdraw from this interview at any time, or not to answer any particular questions in the interview. I agree to provide information to the researchers on the understanding that my anonymity will be protected.
- I give consent for the interview to be audio taped with the understanding that no full transcripts of the interviews will be made, and that these tapes are solely for the purpose of data collection and will be deleted.

Name: _____

Email: _____ Phone: _____

Signed: _____ Date: _____

Should you need further information, please contact either Rolinda or Huhana at the Maori & Psychology Research Unit.

Project Coordinators:

Rolinda Karapu
07-838 4466 ext 8025
rc3@waikato.ac.nz

Huhana Hickey
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Participant Demographic Information

1. Gender:

Male ____ Female ____

2. Age: _____

3. Employment Status

- ___ Unemployed
- ___ Part time employment
- ___ Full employment
- ___ Unpaid employment/Voluntary

4. What town/city do you currently live in? _____

5. Do you live in a rural or urban area? _____

6. Do you live alone or with other people? (If with other people please state)

7. What disabilities/illnesses do you (the person you care for) identify as living with?

Appendix 4: Interview Schedule

Participant Demographic Information

1) Gender: Male ____ Female ____

2) Age: _____

3) Employment Status

- ___ Unemployed
- ___ Part time employment
- ___ Full employment
- ___ Unpaid employment/Voluntary

4) What town/city do you currently live in? _____

5) Do you live in a rural or urban area? _____

CARER INTERVIEW SCHEDULE

I'm going to ask you some background and then your opinion about the care and support available, and finally what you see as your needs.

1) What is the disabilities/illnesses of the person you provide support or care for?

a) What is your opinion on their diagnosis?

Agree

Disagree - - - - What do you think is the matter?

2) How long have they had this problem?

up to 2 yrs

2-10 yrs

over 10 years

3) How long have you provided support or care for them?

up to 2 yrs

2-10 yrs

over 10 years

4) How often do you see this person/people?

Daily
mth

2-3 times a week

2/4 times a

Monthly - 6 weekly
(specify)

Several times per year

Other

5) Do you live with the person you provide support for?

YES

NO

Health Service Providers

6) Are there other people or health workers who also provide support or care for them?

- NO - - - - Why is this?
- YES - - - - Who are they?

7) Do you have contact with these others?

- NO - - - - Why is this? (**Prompt:** Carer has not initiated contact, Services have not initiated contact, other explain)
- YES - - - - What is the nature of this contact?

8) How do you feel about your contact (or lack of contact) with these people?

Prompts:

- Happy with contact
- Happy with lack of contact
- Unhappy with (specify) -
- Other (give detail) -

9) Are there any improvements you would suggest?

- NO - - - - Why?
- YES - - - - What are they?

Prompts:

- More contact with networks for client
- More discussion with networks for carer
- More culturally sensitive staff & health services
- More Maori healing/craft activities for client
- More social outings for client
- Staff more available/accessable
- Other (specify) -

10) Who do you contact in a crisis?

- Hospital
- Doctor
- Nurse
- Whanau
- Other (specify) -

Now I will ask about your needs and suggestions

11)What are the important things that would help you in your role as a support person? (Is there any help or support you need but are not getting, whether or not you think anyone could provide it?)

(Prompt for more information around salient issues)

- Day programme for client near my home
- Independent living for client near my home
- Maori health/social worker or support/liaison person for carers to talk to
- More knowledge of medication and side effects
- More money
- More time for myself during day/to be able to work
- Rehabilitation situation for client between being in hospital & being at home
- Other (specify) -

We are also interested in some particular areas. As I go through them please think about whether you need any extra help or resources in that area.

12)Do you need any **more understanding or emotional support?** e.g. other people in the same role to talk to, understanding from health workers, etc

- NO - - - - Why?
- YES - - - - What kind?

Prompts:

- Family to understand carer's role
- More contact with Maori health worker/support/liaison worker
- Staff need to be sensitive to Maori needs
- Support when we are really stressed
- Other (specify) –

13)Do you need anymore information e.g. About illness, about how to get help, how to cope with/manage the disability?

- NO - - - - Why?
- YES - - - - What about?

Prompts:

- Community need to know more
- Clients illness and what I should/shouldn't let them do
- Medication
- Support services
- Other (specify) -

14) Do you need any financial assistance e.g. with travel and toll bills?

- NO
- YES - - - - In what way?

- Money for travel/holiday for myself
- More finance put into Maori health & rehabilitation services
- More knowledge of what is available financially
- Other (specify) –

15) Do you need any practical assistance e.g. home support?

- NO - - - - Why?
- YES - - - - What kind?

Prompts:

- Home help
- Help for client doing household tasks
- Other (specify) –

16) Do you need any extra time out or holidays for you or the person you support?

- NO - - - - Why?
- YES - - - - What are your concerns?

- Client becomes upset when time away for carer mentioned
- Nowhere for client to go while carer away
- Worried that client will be unable to manage while away
- Other (specify) -

17) Do you need any extra support for yourself?

- NO - - - - Why?
- YES - - - - What kind of support?

18) Is there anything else that would be helpful?

- NO
- YES - - - - What would help?

19) Looking at the most important issues mentioned, is there anything, which stops you from satisfying your needs?

- NO - - - - Why?
- YES - - - - What stops you?

Prompts:

- Client's benefit/finances not enough
- Client not occupied during day
- Facilities not available
- Lack of knowledge about who to contact
- Lack of Maori health workers
- Other (specify) -

20) What would make a positive difference to your situation?

Prompts:

- Client having more time occupied, e.g. job, programme
- Client getting a home/place to live
- Client being taught independent living skills e.g. cleanliness, budgeting housekeeping
- Knowing where to go for information
- More Maori health workers
- Other (specify) -

21) If and when you need support or guidance or a listening ear, who provides it?

- Close friends
- Family
- Day programme staff
- Residential programme staff
- Other (specify) -

22) Has anyone ever asked your opinion on the management or care of your client's problem?

- NO - - - - What are your feelings around this?
- YES - - - - (specify)

23) Has anyone ever asked how you were coping?

- NO - - - - What are your feelings around this?
- YES - - - - Who?
 - Family
 - Friends

- GP
- Programme staff
- Other (specify) -

24) Do you feel there are positive aspects to the role of support person/carer?

NO - - - - Why?

YES - - - - What are they?

- Better for client at home
- Has given me a greater understanding of health/disability problems
- Keeps client out of hospital
- Other (specify) -

25) If we had an ideal community, with ideal people in it (and money was no object) how would you suggest the needs of supporters/carers should be met?

- At times of crisis?
- When the person first comes out of hospital?
 - Better follow-up by hospitals
 - More rehab day programmes and care
 - More rehab/halfway accommodation
 - Other (specify) -
- Day to day living situations?
 - More acceptance from community
 - More carer respite
 - More day/rehab programmes
 - More jobs for clients
 - More supported accommodation
 - Other (specify) –

Appendix 5: List of Key Informants

Glenda Raumati

Hana Harawira

Linda Waimarie Nikora

Ngahuia Te Awekotuku

Huhana Hickey

Mohi Rua

Keri Thompson

Appendix 6: Tables and Data

Tables 1-6 have been reported and discussed in the main report and do not appear in this appendix.

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Table 7: Have key support person
(n=67)

53 (79%)	Yes
12 (18%)	No
2 (3%)	Did not respond

*This data set also includes the whanau carer group

Table 8: Length of Support
(n=53)

Up to 2 years	6 (11%)
2 – 10 years	22 (42%)
Over 10 years	25 (47%)

Table 9: Frequency of Support
(n=53)

	Whanau member	Whanau carer	Population
Daily	26	15	40 (75%)
2-3 times a wk	4	4	8 (15%)
2-4 times a mth	2	0	2 (4%)
Monthly-6 wkly	1	0	1 (2%)
Several times a yr	2	0	2(4%)
Total	35	18	53 (100%)

Table 10: Relationship to key support person
(n=53)

	Whanau member	Whanau carer	Population
Whanau	26	13	39 (74%)
Friend	0	2	2 (2%)
Health Worker	5	3	8 (15%)
Not Answered	4	0	4 (9%)
Total	35	18	100%

Table 11: Are there other people or health/disability workers who also provide support or care for you?

(n=67)

	Whanau member	Whanau carer	Total
Yes	27	16	43 (64%)
No	22	2	24 (36%)
	49	18	67(100%)

Table 12: Level of satisfaction with other Support Sources

(n=67)

Level of Contact	Number
Satisfied with contact	32 (48%)
Satisfied with lack of contact	10 (15%)
Unsure	2 (3%)
Dissatisfied with contact	9 (13%)
Dissatisfied with lack of contact	10 (15%)
Did not respond	6 (9%)
Total	67 (100%)

Table 13: Health and Disability Support Services accessed by Participants

(n=67)

Health and Disability Service Provider	Number
Mainstream	47 (70%)
Mainstream and Maori	15 (22%)
Maori	4 (6%)
Other	1 (2%)
Total	67 (100%)

Table 14: Suggestions for improvement to the delivery of health and disability support services

(n=53)

Prompts	Number
More contact with networks for whanau member/whanau carer	19
More discussion with networks for whanau member/whanau carer	19
More culturally sensitive staff & health/disability services	34
More Maori healing/activities for whanau member	32
More social outings for whanau member	16
Staff more available/accessible	23
Other	37

*Responses in this table do not calculate to 53 as most participants made multiple responses

Table 15: Who do you contact for advice about accessing health/disability care?
(n=67)

Prompts	Number
Whanau	26
Doctor	50
Nurse	6
Maori health/disability provider	17
Hospital	14
Other people who provide care to people with similar disabilities/illnesses	26
Other	3

Table 16: Who do you contact when there is a crisis?
(n=67)

Prompts	Number
Whanau	34
Doctor	46
Nurse	3
Maori health/disability provider	8
Hospital	26
Other people who provide care to people with similar disabilities/illnesses	18
Other	4

*Responses in this table do not calculate to 67 as participants chose more than one option

Table 17: As a user what are your general feelings about the way the health system is set-up?

(n=67)

Prompts	Number
Satisfied with the current set-up of the health system (what do you like about it?)	17 (25%)
Dissatisfied with the current set-up of the health system (what don't you like about it?)	41 (62%)
Other	4 (6%)
Did not answer	5 (7%)

Table 18: The important things that would help you get the right support for your needs?

(n=49)

Prompts	Number
Day/Marae programme for whanau member near my home	8
Independent living for whanau member near home	13
Maori health/disability/social worker or support/liaison person for whanau carers to talk to	25
More knowledge of medication and side effects	15
More money	25
More time for myself during day/ to be able to work	16
Rehabilitation situation for whanau member between being in hospital and being at home	8
Other (specify)	18
No Response	19

*Responses in this table do not calculate to 49 as most participants made multiple responses

Table 19: Need more understanding or emotional support?

(n=35)

Prompts:	Number
Family to understand	17
More contact with Maori health/disability support/liaison worker	21
Staff need to be sensitive to Maori needs	16
Support when really stressed	20
Other	13

*Responses in this table do not calculate to 35 as most participants chose more than one response

Table 20: Do you need any financial assistance?

(n=48)

Prompts	Number
Money for travel/holiday for myself	37
More finance put into Maori health/disability and rehabilitation	23
More knowledge of what is available financially	30
Other	20

*Responses in this table do not calculate to 48 as most participants chose more than one response

Table 21: Do you need practical assistance?

(n=24)

Prompts:	Number
Home help	17
Help for doing household tasks	15
Other	12

*Responses in this table do not calculate to 24 as most participants responded more than once

Table 22: Do you need extra time out or holidays for you or your whanau carer?
(n=29)

	Number
Yes	29
No	33
No Response	5

*Responses in this table do not calculate to 29 as most participants chose more than one response

Table 23: Do you need any extra support for yourself?
(n=67)

	Number
Yes	24
No	20
No Response	23

*Responses in this table do not calculate to 67 as most participants chose more than one response

Table 24: Looking at the most important issues mentioned is there anything which stops you from satisfying your needs?
(n=48)

Prompts	Number
Benefit/finances not enough	23
Facilities not available	23
Lack of knowledge about who to contact	23
Lack of Maori health/disability workers	26
Other	9

*Responses in this table do not calculate to 48 as most participants chose more than one response

Table 25: What would make a positive difference to your situation?
(n=57)

Prompts	Number
Having more time	18
Getting a home/place to live	6
Being taught independent living skills	8
Knowing where to go for information	25
More Maori health/disability workers	32
Other	20

*Responses in this table do not calculate to 57 as most participants chose more than one response

Table 26: If and when you need support or guidance or a listening ear, who provides it?

(n=67)

Prompts	Number
Whanau	52
Close friends	43
Day programme staff	7
Residential programme staff	3
Other	12

*Responses in this table do not calculate to 67 as most participants chose more than one response

Table 27: Do you feel there are positive aspects to the role of support person/whanau carer?

(n=58)

Prompts	Number
Better for whanau member at home	33
Keeps whanau member out of hospital	25
Has given me a greater understanding of health/disability problems	23
Other	36

*Responses in this table do not calculate to 58 as most participants chose more than one response

Table 28: When the person first comes out of hospital?

(n=43)

Prompts	Number
Better follow-up by hospitals	23
More rehabilitation day programmes and care	23
More rehab/halfway accommodation	9
Other	24

*Responses in this table do not calculate to 43 as most participants chose more than one response

Table 29: Day to day living situation?

(n=54)

Prompts	Number
More acceptance from community	24
More whanau carer respite	24
More day/rehab programmes	25
More jobs for whanau member	23
More supported accommodation	17
Other	29

*Responses in this table do not calculate to 54 as most participants chose more than one response

Appendix 7: Key informant brainstorming session – What do whanau carers go through?

The following is a list of statements provided by key informants in response to the question: What do whanau carers go through? The exercise was designed to highlight both positive and negative experiences of being a whanau carer. Key informants were asked to take a broad approach to this exercise and to include a focus on the following:

In dealing with Maori things (whanau, marae, associations i.e. MWWL, taurahere, extended whanau, church i.e. Paimarire, Ringatu)

In dealing with non-Maori things (medical fraternities, institutions, GP's, social workers, assessment agencies, WINZ, banks, specialists etc)

In dealing with friends and associates of the carer (workmates, sportsmates, people they may/or use to hang out with) – what do they go through with them?

In dealing with spouses (loved ones)?

Carer themselves (that aren't easily shared, contemplated, negative or positive outcomes...the carers themselves)

The following list of responses have been organised by thematic area.

Practical Support:

- Partners provide awesome support
- You become friends with people that you know can help you
- Caregiver has to be physically strong to be able to lift the equipment and or the person (but often isn't strong enough)
- Growth and changing circumstances – adaptability
- Tuakana/teina hassles – who has right of control
- Lack of support
- No sense of unity amongst providers
- Gate keeping between providers so not allowing full picture of person with a disability
- Cathartic sessions
- Transportation issues - getting to services or arranging home visits
- Privacy Act – families getting information
- Cost of GP visits
- Missed appointments – long cues at medical specialist services
- Separation from children and partner

Knowledge Information

- determination to deal to system

- no connections with the person who has a disability so caregiver needs to ensure advice is relevant and takes into account other specialist information
- knowledge of (or lack) adequate services and benefits
- expert at everything
- knowledge
- terminology
- lack of information about the disability, paediatricians not wanting to diagnose a disability
- medical versus protocol wins
- inability to find a service or to find help
- wild goose chase – navigating the system
- dealing with the loose ends after verdicts are delivered
- what about EUTHANASIA? What happened o nehera?
- Expectations to be the best

Communication

- Saying “no” to whanau, friends and community and getting shit from disabled person
- Talk heaps about it
- Same stuff as what go thru with whanau but they control and use that to have power over us
- Have to deal with their attitudes and issues around disabilities
- Misunderstandings of what you do
- Loss of voice – being unheard
- Frustration at not finding specialists
- Assumed to be “thick!”
- Loss of power
- Non-Maori unable to read what is not said (cultural misinterpretation)
- Don’t talk about the disability at all
- Misunderstood
- Conversations that are always about caring
- Language barriers between Maori and non-Maori
- Verbal/physical attacks from whanau
- Developing a mouth (become pushy)
- Abuse

Hauora (Physical)

- Rural communities being forced to access urban services
- Thinking about assisting loved ones to die (euthanasia)
- Forget about the pills
- High levels of stress is maintained to be physically damaging e.g. high blood pressure
- Unqualified doctor
- Drastic ageing
- Perform
- Lack of support i.e. resources
- Get sick

- Often become disabled
- Develop health problems due to stress
- Hard work

Services Provision

- Culturally unimportant - loss of control over care
- Lack of Maori services
- Given priority status/access networks
- Very few Maori providers, Maori workers in mainstream services – Work and Income, medical, social education
- Act like its their money or equipment we are asking for
- Feeling as if it's your fault – you can't negotiate/comprehend their system (even if you have a PhD!!)
- Theft – protecting taonga – protecting rights
- Racism

Finances

- Financial loss
- Financial stress and juggling priorities
- Unqualified/unpaid nurse
- Financially broke (always)
- A caregiver who has spent 5 – 7 years with the disabled person drops out of the workforce – if the person dies the caregiver usually stays on the dole
- Personal financial cost
- No pay
- Walk a tight rope between institution and whanau member
- Travel

Invisibility

- Talked to as if the person with a disability is not there
- Dismissed of my role as carer once child reached 16. not being acknowledged as his carer anymore
- Dismissiveness – feeling of NO value, not important
- You feel that the personal skills that you have learnt while caring for that person aren't easily transferable into a money paying job
- Isolation
- RAGE (it's so unfair!)
- Disrespected
- Reserved (within themselves)
- Stereotyped – another Maori!
- Disempowered
- Poverty
- People “look away” or look “sympathetic” or look “horrified”
- Piss off you dumb Hori and don't waste my time and my Christmas break
- Not believed! Heard! Dumped on!
- Loss of social life
- Discarded

Social Support

- Make new friends and miss out on stuff e.g. movies, games etc
- More dependant on friends for support
- Sympathy (initially)
- Strain on relationships
- Scrutiny
- Separation
- Are a shoulder to cry on
- Offloading
- Friends help you laugh at your troubles and put things in perspective
- Are the greatest support
- Lack of access to private home and public venues
- Pressure to perform
- Isolated
- Their visits become infrequent – they disappear in time
- Withdrawn due to misunderstanding
- Excluded from expressing their wairua spiritual community
- Friends all disabled – most non-disabled friends have gone
- Caregiver loses control over the social life and will abdicate responsibility to have respite, often causing the whanau/community to judge them
- Associate might feel uncomfortable
- Conversations can become centred on “carer” issues boring
- Partner can walk away, can become abusive and controlling lack the understanding
- Lost opportunities e.g. marae, work, careers, education etc
- Timeout – doing something different
- They go thru the disability
- Become socially excluded
- Gay friends all disappeared
- Friends disappear
- What friends
- No longer associate
- Disappear
- Loneliness – being abandoned

Emotional Needs

- Relief and joy when help is found
- Na wait e he? Blaming – idea of paying for a hara!
- Frustration and inadequacy and isolation
- Frustration
- Shame
- Frustration also overwhelming grief and empathy for turoro
- Deep pain from watching person with disability hurt and struggle and wishing I could help
- Sense of frustration and resentment towards services WINZ, DSL, ACC etc
- People don't really want to know!
- Undervalued

- Unwillingness to visit you – abandoned
- Friends feel neglected
- Isolated from friends
- Exclusion socially
- Friends get you drunk, feed you and make sure you get back in one piece
- Judgemental comments
- Lack of intimacy
- Emotional and physical
- Painful reminders
- Continual self doubt
- Anger when other whanau members encourage a behaviour that you know will affect their (the person with a disability) health
- Self satisfied
- Sense of duty
- Sense of feeling needed – purpose in life
- Grow up real fast – emotionally, intellectually and maturity
- Expectations
- Used
- Deep depression
- Sense of loss
- Deprivation (personal)
- Stereotyped (difficult)
- Deep loneliness
- Unable to open up to partner
- Emotional support and material support
- Go thru the trauma with you
- Are traumatised with you!
- Spouses live through the disability and the care
- Why? Why us? Why her?
- Despair – will this ever end?
- Pain – watching someone you love mutate and change and you can do nothing
- Helplessness
- Constant guilt and feeling inadequate
- Tuned out
- Go into denial
- Stress
- A concern for loved ones future
- Also go through journey with person with a disability – I've learnt a lot and grown spiritually
- Great sense of embarrassment and shame when trying to access support, funding etc
- Emotionally detached
- Exhaustion
- Guilt being blamed
- Hurtful remarks
- Abuse

- Blame
- Sense of achievement
- Isolation, abused, exhaustion
- Isolation – unable to go out, mix with own age group
- Not getting it “living in la la land”
- Constantly drama and jealousy ‘cos spouse feels neglected’
- You become so emotionally involved with the person that you can experience jealousy when a new person attracts attention away from you
- You can become dependent on siblings for emotional support and companionship but they can also become your worst critics
- Depression and anxiety of being declined a service
- A caregiver copes with the influx of whanau in the beginning of a persons disability and the grief of that person when people stop coming around

Appendix 8 Disability Services Supplement Sept 2004

Service funding allocation details

This supplement provides detail of service funding that will be retained within the Disability Services Directorate (DSD) and funding that will be transferred to the District Health Boards (DHBs) on 1 October 2003.

In early July Government confirmed that the transfer of funding and services to DHBs for older people was to proceed according to previously agreed rules and exceptions.

General Rules

- Funding for people aged 65 and over receiving Disability Support Services will be devolved to DHBs.
- Funding for people under 65 receiving Disability Support Services will be retained by the DSD.

Exceptions

- People with long-term impairment who are receiving disability support services from the DSD at the time of the funding separation (even if they are over 65) will continue to be funded by the Directorate, unless they are assessed as requiring aged residential care, at which time the DHBs will take over funding responsibility.
- People between 50 and 65 who have been clinically assessed by a DHB and/or needs assessor as 'close in

interest' to persons aged 65 and over, and who require access to disability support services will be funded by DHBs.

To do this work DSD has categorised its services into three groupings:

- a) Services and contracts which are exclusively for younger or older people. In these cases, decisions are reasonably clear cut with funding for younger peoples' services to be retained by DSD and funding for older peoples' services to be devolved to DHBs.
- b) Services and contracts which cross age ranges and are able to be split according to Cabinet's general rules and exceptions. DSD is splitting funding and contracts for these services between DSD and DHBs in accordance with these criteria.
- c) Services and contracts which cannot be allocated according to Government's general rules and exceptions. These have been allocated on a case-by-case basis.

The following tables show where specific service funding will sit using the three categories above.

The total funding to be devolved is \$840 m (incl GST).

If you have any questions about this information please contact Kate Hirst at DSD, kate.hirst@moh.govt.nz

Summary of Service Allocations

Service	Decision
Services and contracts which are exclusively for younger or older people.	
i. Aged Residential Care (including psychogeriatric residential care)	Devolve to DHBs
ii. Residential Care for Younger People	Retain within DSD
iii. Specialist Support Services for People with Intellectual Disabilities	Retain within DSD
iv. Child Development	Retain within DSD
v. Kimberley and Braemar Deinstitutionalisation Projects	Retain within DSD
vi. ID high and complex	Retain within DSD
vii. Head Injury Rehabilitation	Retain within DSD
viii. Cochlear Implant Programme	Retain within DSD
Services and contracts which cross age ranges. Split according to original Government criteria.	
ix. Home-Based Support Services (personal care, home help)	Split; devolve older component, retain younger/lifelong disability component
x. Carer Support and Respite	Split; devolve older component, retain younger/lifelong disability component
Services and contracts which have been split on a case-by-case basis.	
xi. Needs Assessment and Service Co-ordination (NASC)	Split; devolve component for older people to DHBs, retain component for younger/lifelong disability clients with DSD. Administrative arrangements will vary across regions
xii. Assessment, Treatment and Rehabilitation (AT&R) including Psychogeriatric AT&R in Southern and Central regions	Generic AT&R services – split strictly on client age – under 65 / 65 and over and devolve services for clients 65 and over to DHBs Psychogeriatric AT&R services – devolve in total to DHBs
xiii. Environmental Support Services (Equipment Management Services – long-term equipment, housing modifications, vehicle modifications; specialist wheelchair, seating, assistive technology assessment)	Split; retain with DSD all except contracts for short term equipment which will be devolved to DHBs

Service	Decision
xiv. Day / Vocational Programmes and Day Care Services	Devolve day care services for older people and people with dementia to DHBs; retain with DSD day programmes for younger/lifelong disability clients including vocational programmes
xv. DHB Provided Community Services (Southern and Northern regions only)	Southern – devolve to DHBs, Northern - devolve contracts for personal health services (district nursing, ambulatory paediatrics, stomal services, continence services, podiatry, dietetics) to DHBs; split accredited equipment assessment between DHBs and DSD (DSD retaining a component of complex wheelchair and seating assessment); split specialist allied health therapy services between DSD and DHBs (DSD retaining therapy services for lifelong disability clients)
xvi. Orthotics	Devolve in total to DHBs
xvii. Prosthetics	Devolve this single national contract to a 'lead DHB'
xviii. Spinal Injury Services (Otago)	Retain with DSD
xix. Environmental Support Services Subsidies and Benefits (hearing aids, spectacles, wigs and hairpieces, breast prostheses, contact lenses, stump socks, artificial eyes and Salvation Army Salary).	Retain all with DSD pending determination of most appropriate long-term funder excluding contact lens benefit; work jointly with DHBFP to devolve contact lens benefit to DHBs
xx. Disability Information and Advisory Services (DIAS)	Devolve to DHBs contracts for which the client group is older people or people with dementia; transfer contracts for which the client group is predominantly people with chronic health conditions to DHBFP; retain with DSD contracts for which the client group is predominantly younger/lifelong disability clients
xxi. Pilot programmes	Devolve local pilot programmes for older people (eg, 'Ageing in Place' Initiatives) to DHBs; transfer national 'Ageing in Place' policy/evaluation contract to HOP Sector Policy; retain with DSD pilot projects for younger/lifelong disability clients
xxii. Expenses to Attend Treatment (ETAT)	Retain with DSD pending completion of service development work DHBFP is undertaking on the Travel and Accommodation Subsidy

Service	Decision
xxiii. Accredited Visitors Services (including national Age Concern contract)	Devolve all to DHBs excluding the national Age Concern contract which will be split (the national policy and training component to be transferred to HOP Sector Policy and the direct service delivery component to be devolved to a lead DHB)
xxiv. Carer Training	Devolve contracts exclusively for carers of older people and people with dementia; retain with DSD contracts exclusively or predominantly for carers of younger/lifelong disability clients and the national Carers NZ contract
xxv. DHB Equipment Contracts	Devolve to DHBs
xxvi. Carer Support for People with Personal Health Conditions in Northern and Southern regions	Devolve to DHBs
xxvii. Palliative Care Services (primarily carer support) for People in Midland and Northern regions	Devolve to DHBs
xxviii. Community Services – non-DHB provided	Devolve contracts with a personal health focus (eg, domiciliary nursing) and those for older people to DHBs; retain with DSD contracts for younger/lifelong disability clients
xxix. Home-Based Support (home help, personal care) and Carer Support for people under 65 with Mental Health conditions (Southern), and Carer Support for People with Mental Health Conditions in all regions but Central	Devolve to DHBs
xxx. NDOC Policy and Service Development Contracts	Split: retain with DSD contracts for younger/lifelong disability clients; transfer contracts related to older people/people with dementia to HOP Sector Policy NDOC