



families commission
kōmihana ā **whānau**

THE ROLE OF WHĀNAU IN THE LIVES OF MĀORI WITH PHYSICAL DISABILITIES

ADELAIDE COLLINS AND HUHANA HICKEY
MĀORI DEVELOPMENT RESEARCH CENTRE

The Families Commission was established under the Families Commission Act 2003 and commenced operations on 1 July 2004. Under the Crown Entities Act 2004, the Commission is designated as an autonomous Crown entity.

A key role of the Families Commission is to promote research on issues that will give the Commission and the public a better understanding of family life. The Blue Skies Fund provides funding for dynamic new work that examines contemporary and emerging family issues. The fund is intended for new research, emergent ideas and 'ideas papers' which have the potential to lead to new research.

For more information on the Blue Skies Fund, visit the Families Commission website www.nzfamilies.org.nz

Blue Skies research reports, which result from studies funded under the Families Commission's Blue Skies Fund, are produced by independent researchers. The content of the reports and the opinions expressed by the author/s should not be assumed to reflect the views, opinions or policies of the Families Commission.

This report is copyright to the Families Commission. The copyright-protected material may be reproduced free of charge for non-commercial personal use without requiring specific permission. This is subject to the material being reproduced and attributed accurately and not being used in a misleading context. Requests and enquiries concerning the reproduction of information for any purpose other than personal use requires the permission of the Families Commission.

The Commission can be contacted at:
Public Trust Building
Level 5, 117-125 Lambton Quay
PO Box 2839
Wellington

Telephone: 04 917 7040
Email: enquiries@nzfamilies.org.nz
www.nzfamilies.org.nz

➤ Giving New Zealand families a voice *Te reo o te whānau*

ISBN 0-478 29269 4



THE ROLE OF WHĀNAU IN THE LIVES OF MĀORI WITH PHYSICAL DISABILITIES

**ADELAIDE COLLINS AND HUHANA HICKEY
MĀORI DEVELOPMENT RESEARCH CENTRE**

ACKNOWLEDGEMENTS

We wish to express our appreciation and thanks to Danica Waiti and Thomas Haapu from Amorangi ki Mua Ltd for their assistance with the interviews, and John Paenga for his research assistance.

We would also like to thank the whānau who gave their time and knowledge to help us to understand everyday living for Māori with disabilities and the role that their whānau played in their lives.
Thank you for your participation.

Finally, we are grateful to the Families Commission for their financial and professional support for this research.
Ka nui te mihi ki a koutou katoa.

CONTENTS

1.0	PURPOSE OF THE RESEARCH	4
2.0	METHODOLOGY	5
2.1	LITERATURE REVIEW	5
2.2	INTERVIEW PROCESS	5
2.3	DATA ANALYSIS	6
2.4	ETHICS PROCESS	6
3.0	HE ORANGA WHĀNAU/WHĀNAU WELLBEING	7
3.1	THE WHĀNAU CONCEPT	7
3.2	THE ROLE OF WHĀNAU	7
3.3	EVERYDAY LIVING FOR WHĀNAU MEMBERS WITH DISABILITIES	8
3.4	MODELS OF DISABILITY	9
3.5	MODELS OF MĀORI HEALTH AND WELLBEING	10
3.6	MODELS OF DIVERSE MĀORI REALITIES	11
3.7	TATAU TATAU MODEL OF WHĀNAU WELLBEING	11
4.0	ABOUT THE PEOPLE INTERVIEWED	13
4.1	SUMMARY DEMOGRAPHIC PROFILE	14
4.2	COMMON LIFESTYLES	14
5.0	PERSONAL WELLBEING AND THE WHĀNAU	15
5.1	WHANAUNGATANGA/FAMILY RELATIONS	15
5.2	MANA/AUTHORITY	17
5.3	TE ORANGA/COMMUNITY INVOLVEMENT	18
5.4	HINENGARO/COMMUNICATION	20
5.5	TAHA TINANA/PHYSICAL WELLBEING	21
5.6	DISCUSSION	23
6.0	ELEMENTS OF WHĀNAU WELLBEING	26
6.1	MANAAKITANGA/CARING	26
6.2	TATAU TATAU/SHARING	26
6.3	WAIRUATANGA/SPIRITUALITY	27
6.4	MANA TIAKI/GUARDIANSHIP ROLES	29
6.5	NGĀ TAONGA TUKU IHO/INHERITED RESOURCES	30
6.6	DISCUSSION	31
7.0	THE ROLE OF WHĀNAU IN THE LIVES OF MĀORI WITH PHYSICAL DISABILITIES	32
7.1	DIVERSE REALITIES	32
7.2	EVERYDAY LIVING AND THE ROLE OF WHĀNAU	33
7.3	WHĀNAU WELLBEING AND IDENTITY	33
7.4	FURTHER RESEARCH	33
	REFERENCES	34
	APPENDIX 1: MODELS OF WELLBEING	36
	APPENDIX 2: TATAU TATAU FRAMEWORK	37

1.0 PURPOSE OF THE RESEARCH

This research sought to discover the capabilities of whānau to adapt to their circumstances and maintain their wellbeing when one or more of its members lived with a disability. The whānau has traditionally been seen as the primary social and economic unit for Māori. However, recent research has concluded that the whānau is the secondary unit for Māori with disabilities, with the household being the primary 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 Māori 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 whānau we prefer to view the household as a significant unit within and in interaction with the broader whānau and community context rather than a replacement of it (Nikora, Karapu, Hickey and Te Awekotuku 2004:65).

Their conclusion that the whānau is second to the household is a significant departure from commonly held beliefs and one that we wished to explore further as it could be a key factor that distinguishes Māori with disabilities within Māori society. Of particular interest were the factors that determined the household as the primary unit and the contribution that whānau made in this context. As indicated in the above quote, positioning the household over the whānau could also be viewed as including the household as a significant unit within the whānau.

The objectives of this research were to identify:

- > whether the whānau is the primary or secondary social and economic unit in the lives of Māori with disabilities
- > the part that whānau play in the lives of Māori with disabilities
- > the factors that help and hinder the wellbeing of whānau when a member has a disability.

Kaupapa Māori principles underpinned the research, which comprised a review of literature, development of a model on whānau wellbeing, and in-depth interviews with whānau in the Gisborne/East Coast and Waikato regions.

2.0 METHODOLOGY

A literature review of models of wellbeing for Māori and in-depth, semi-structured interviews with nine informants were the methods used since this project was primarily exploratory in nature and was investigating an under-researched subject. The processes used are described in more detail in this section along with the Kaupapa Māori principles employed for the interviews and the ethical standards to which we adhered.

2.1 LITERATURE REVIEW

The search for literature of whānau and their role within the lives of Māori with disabilities was performed through the collation of books, research publications and government resources. An internet search was also conducted. Since there has been little research undertaken about Māori with physical, sensory or age-related disabilities and even less that investigated the role whānau played in the lives of Māori with disabilities, this research project reached into relatively unknown territory. There was extensive literature on Māori models of wellbeing and some recent research on whānau from which we developed a model of whānau wellbeing when one or more members lived with a physical disability.

2.1.1 Trialing the whānau wellbeing model

Issues and questions were developed around 10 Māori concepts of wellbeing that constituted the components of the whānau wellbeing model used for this project. The model was then trialed with a whānau and adjusted based on feedback from the trial whānau. The main change was the incorporation of mauri ora (inner strength, life force) and waiora (impact of the external environment on wellbeing) into wairuatanga (spirituality) because the trial whānau recognised and spoke most about the spiritual elements inherent in mauri ora and waiora. Questions relating to mana (authority) were altered to better reflect a predisposition to not claim mana for oneself but to allow others, such as whānau members, to make such claims.

2.2 INTERVIEW PROCESS

2.2.1 Selection criteria

The criteria we used to select participants were that they have a physical, sensory or age-related disability and were Māori. In-depth interviews were held with 13 Māori with long-term health conditions or impairments, either by themselves or with members of their whānau. Of the 13 interviews, nine were selected for inclusion in this project. We used our networks in the community to select and recruit whānau from each of the Waikato and Gisborne/East Coast regions. Due to the different needs and challenges that whānau face when disability occurs at different life stages, one whānau from each region was chosen because they were parents of a child with a physical or sensory disability and we spoke to the whānau while the child was present. Two people with disabilities who belonged to the same whānau were interviewed together.

2.2.2 Use of existing relationships

The researchers approached people they knew who fitted the selection criteria to ask them to take part in the project and seven whānau were recruited in this way. An intermediary recruited two whānau participants on behalf of the research team. The intermediary had a pre-existing relationship with the informants and was paired with an interviewer from the research team for interviews.

2.2.3 Interviewing

All of the participants were approached before the interviews took place and were given an information leaflet about the project as well as a brochure about the Māori Development Research Centre (MDRC)'s current work on disability issues for Māori. The lead investigators carried out the interviews for all but one of the whānau and a company affiliated to MDRC's network of members conducted the remaining interview. An assistant or intermediary was present at five of the interviews. Most of the interviews were conducted face-to-face at participants' homes or another place of their choice. Three whānau preferred telephone interviews and these were carried out by one of the lead investigators with an assistant sitting with the whānau. Interviews took between 30 minutes to an hour using a schedule of questions, but additional time was spent before the interview to get acquainted with one another and after the interview to have a meal together. The interviews were recorded and a member of the

interviewing team completed summaries of the conversations during the interview. A small koha was given to the whānau once interviews were finished in appreciation of their participation and to defray any costs they may have incurred in participating.

2.2.4 Kaupapa Māori principles

The interviewers adhered to the following Kaupapa Māori principles to ensure respect for participants:

- > Whanaungatanga (acknowledging the value of existing relationships between participants and other people; approaching participants through the existing relationships that they had; introducing interviewers to participants before the interviews were held).
- > Whakapapa (acknowledging the culture, places, and hapū/iwi to which participants belonged; explaining interviewers' whakapapa to participants and making whakapapa connections).
- > Whakamana (respect for the participants' decisions and opinions).
- > Tikanga (respect for cultural customs).
- > Kawa (respect for cultural practices in participants' homes).
- > Mihimihi (acknowledgement of each other's whakapapa and the possibility of whānau connections).
- > Koha (acknowledgement of the informants' sharing of knowledge by offering a gift in return and by providing feedback on the project).
- > Whakaiti (researchers' humble approach to the possibility that participants may lack confidence in the value of their views and opinions).
- > Tuakana/teina (acknowledgement of participants as the knowledge-holders and researchers as the knowledge-seekers).
- > Whakatau (respect for the need to 'settle-in' with each other before launching into the interviews).

The recordings were transcribed and the interview summaries were destroyed as each transcript was completed. Whānau were asked if they wanted a copy of the recording and transcript and these were sent to those whānau who requested them. Four requested a copy of the recording and seven requested a copy of the transcript. Whānau were given the option of withdrawing all or part of the information they had provided or changing the transcript but none of them did so. All of the whānau interviewed requested a copy of this report.

2.2.5 Informed consent

At the start of the interviews, the interviewers discussed the information leaflet with the whānau and asked if there were any questions, but there were none. Whānau were then asked if they still wanted to participate, whether they agreed to the interview being recorded, and whether they understood that they could withdraw at any time or that they could withdraw all or part of the information they provided. They all agreed. They were also asked for permission to use their information in future MDRC research projects related to disability issues for Māori and were told that they would be contacted should this occur. Eight of the nine whānau agreed to this as well.

2.3 DATA ANALYSIS

The transcripts were analysed using NVivo qualitative research software. Information pertaining to the research objectives was extrapolated from the two dimensions of the whānau wellbeing model: personal wellbeing and the role that whānau played; and the factors that helped or hindered whānau wellbeing.

2.4 ETHICS PROCESS

The Families Commission Ethics Committee reviewed and approved the research process before the research proceeded. Pseudonyms have been used in this report instead of informants' real names to protect their identities. A script was used to obtain consent from participants during the recorded interview. Access to the informants was restricted to the interviewing teams and access to information about all of the interviews was limited to the principal researcher. The informants' geographical locations are identified generally using large regions that have high Māori populations. The research data are stored safely and securely with access restricted to the principal researcher. Every attempt has been made to maintain the confidentiality of informants and the data and whilst we are confident that they cannot be identified, we cannot absolutely guarantee it.

3.0 HE ORANGA WHĀNAU/WHĀNAU WELLBEING

The literature was sparse in relation to the whānau of Māori with disabilities so it was difficult to draw an analytic framework. While concepts of Māori health in general were well constructed, there was little in the way of literature around whānau and Māori with disabilities. The literature around children with disabilities and their whānau was largely in the context of special educational needs. The results of the literature review have been divided into four parts:

- > The whānau concept
- > The role of the whānau
- > Everyday living for whānau members with disabilities
- > Models of disability, health and wellbeing.

3.1 THE WHĀNAU CONCEPT

The whānau is widely recognised as the basic social structure within Māori society (Ministry of Social Development 2004) and has also been referred to as the social institution for change (Te Puni Kōkiri 2004). Whānau has been used to denote a core group of individuals, predominantly comprising three or more generations of a family, and who are intimately intertwined with the wider groupings of hapū, iwi and waka. The functions of individuals are determined within each whānau with the overall objective being that of reproduction, communal undertakings and socialisation (Metge 1995; Moeke-Pickering 1996).

The traditional whānau has been changing since Māori began to move from their rural homes into urban areas in the 1960s. Whānau ties to the extended family, hapū and iwi became less accessible due to distance, and without the type of support and close community spirit that existed in their rural environments, Māori began to create their own whānau structures. Whilst contemporary Māori often understand and use the concept in terms of whakapapa links, the term has been expanded to refer to any of the following groups:

- > a set of siblings and/or descendents of a relatively recent ancestor, which may or may not include spouses and whangai
- > the descendents of a relatively recent ancestor who interact on an ongoing basis
- > descent groups derived from hapū and/or iwi
- > a group of unrelated individuals who interact on an ongoing basis, and
- > a group of individuals gathered for the purpose of a specific kaupapa (Metge 1999).

Durie stated that, "...whānau is a word which has undergone change in parallel to the changes in Māori society, it lends itself to a variety of interpretations ... whānau refers to groups of people, brought together for a specific purpose. Generally the members of a whānau are Māori, though not always, and generally their association together is mutually beneficial" (Durie 2003:13). Distinctions have been made between three types of whānau: whakapapa, kaupapa and statistical whānau (Te Puni Kōkiri 2003). Whakapapa whānau refers to families with shared ancestry and a common line of descent. Kaupapa whānau is used to describe groups with members who may not be related and may not be Māori, but are bound together by a common interest or cause in relation to te ao Māori (the Māori world). Statistical whānau refers to a tendency for many publications to use whānau, household and family interchangeably (Cunningham, Stevenson and Tassell 2005). This has meant that Māori with disabilities have been able to incorporate a contemporary concept into their lives and have availed themselves of the redefined whānau concept because it better reflects their reality. For Māori with disabilities, the redefinition of the concept allows them to embrace their nuclear family, extended family, household, carers (both formal and informal) and support workers as whānau.

3.2 THE ROLE OF WHĀNAU

The role of whānau for Māori with disabilities is not widely identified in the literature and no distinctions have been made from the role of whānau for Māori who do not have a disability. Various authors (Cunningham et al 2005; Durie 1994; Metge 1995, 1999; Moeke-Pickering 1996; Palmer 2004) have assigned the following roles to whānau, although this is by no means an exhaustive list:

- > maintain and improve the wellbeing of their members
- > nurture and protect children
- > provide care to people who need it
- > provide material and emotional support
- > pass on culture, knowledge, values, attitudes, property rights and obligations from one generation to the next
- > mutual obligations to share with each other
- > provide access to the wider Māori community and New Zealand society
- > manage and develop whānau resources
- > reinforce and strengthen group identity.

The whānau concept carries an interdependent component in that each person supports others and secures their positioning within the whānau (Munford and Sanders 1999:19). According to Metge:

There is the duty to care for each other, expressed in the words ahu (tend, foster), atawhai (show kindness to, foster), awhi (embrace, foster, cherish), manaaki (show respect or kindness to), taurima (treat with care, tend) and whangai (feed, nourish, bring up). All these words imply meeting not only the physical needs of others but also their need to be nurtured mentally and spiritually... This duty of care for each other includes the responsibility laid upon older generations to teach the young right ways and to hand on knowledge that belongs to and will benefit the whānau as a whole (Metge 1995:98).

Whānau members are able to access a variety of skills and expertise from within their own whānau and can opt to gather support from one or more of their members as needed. They each have an equal share in the benefits, obligations and duties to care for one another. These whānau roles are consistent with those identified by writers (Durie 1994, 1995; Hohepa 1978; Rangihau 1977; Ritchie 1992; Walker 1989) who have commented on support provided to Māori. This has relevance for Māori with disabilities in that they are assumed to have a role within the whānau as integral members of that whānau.

3.3 EVERYDAY LIVING FOR WHĀNAU MEMBERS WITH DISABILITIES

Māori with disabilities want to be able to take for granted the same things that people without disabilities take for granted, such as being able to get around, to be heard, or to work. Their ability to have these things, however, is severely limited by the lack of understanding within Māori society of the barriers that exist to bring Māori with disabilities into inclusion in their community (Nikora et al 2004). The New Zealand Disability Strategy (Ministry of Health 2001) identified the gaps within the social strata for people with disabilities and Objective 11 outlined the vision for Māori with disabilities and their whānau. This strategy was implemented to address the attitudes of those without disabilities and the socialisation needs of people with disabilities. The Work in Progress report for 2004-05 states that Māori with disabilities have:

The highest age-standardised rates of impairment. Compared with non-Māori they tend to have more severe impairments at younger ages. Māori are also more than twice as likely to report an unmet need for transport costs. Half of all disabled Māori had a total annual income of \$15,000 or less. Over a third had no educational qualification considerably higher than their non-Māori counterparts (Office for Disability Issues 2005:81).

The report stated that nearly a quarter of disabled Māori living in households reported an unmet need for some type of health service (compared with 14 percent of non-Māori). Having an unmet need was particularly high for younger Māori (15-24 years), where the rate was almost double that of their non-Māori counterparts. Fifteen percent of disabled Māori had an unmet need for special equipment compared with 11 percent of disabled non-Māori (Office for Disability Issues 2005). Such a situation is likely to have profound effects on the whānau, a key source that Māori with disabilities are likely to access by way of informal care and support in order to try to satisfy an otherwise unmet need.

3.4 MODELS OF DISABILITY

Seven models of disability have been identified that prescribe to one of two philosophies: disabled people are either dependent on society or consumers in society (Nikora et al 2004; Rialland nd). The former leads to perceptions of disabled people as a non-contributing burden on society while the latter leads to perceptions of disabled people as participants in society. The seven models are:

The medical model – disability results from a person's physical or mental illness. Disability is a problem that lies within the individual.

The expert/professional model – professionals are the authorities who use the medical model to identify the disability and their expertise to 'fix' it.

The tragedy/charity model – disabled people are victims of tragic circumstances who deserve the pity of others and need care and charity to survive.

The social/minority group model – a person is disabled by social, environmental and attitudinal barriers that prevent him or her from participating in society. Society fails to adjust to meet the needs and aspirations of a disabled minority.

The social adapted model – a combination of the medical and social models, this model holds that while impairment is significant, social and environmental factors are far more problematic.

The customer/empowering model – the opposite of the expert model, this model holds that professionals are service providers to the disabled client and his or her family. The client decides on the services they need and selects the service providers.

The religious model – disability is a punishment inflicted on an individual or family by an external force. The disability may be a prelude to spiritual reward or retribution for misdemeanours by ancestors, kin or the afflicted person in a previous incarnation.

Whilst the seven models of disability lend insight into changing attitudes toward people with disabilities generally, none of the models adequately reflect the existing, albeit limited, knowledge about Māori perspectives and experiences of disabilities. Nikora et al (2004:9) suggested that aspects of the religious model and adapted social model came closest to reflecting existing Māori perspectives about disability. Despite this, the seven models of disability were considered to lack an appreciation of the influence of culture and its impact on people with disabilities. For example, government-funded Māori service providers make a correlation between disability and health to access funding while simultaneously attempting to broaden the terms of reference by using holistic wellbeing models that incorporate social, cultural, environmental and economic considerations (for example Durie 1994, 1999a; Palmer 2004; Pere 1991). This indicates that Māori providers view disability as a societal condition beyond health. A research study conducted in the 1990s found that Māori made a correlation between disability and oppression rather than health (Kingi and Bray 2000). The *Hoe Nuku Roa* longitudinal study of Māori households and identity indicates that kaumātua measure good health by the capacity to participate in the community rather than by illness (Durie 1999b). Kaumātua were, and continue to be, a valued group in Māori society and yet they are susceptible to the illnesses and impairments that constitute age-related disabilities. This suggests that, contrary to non-Māori disability discourses, Māori with disabilities continue to be valued and make a significant contribution to Māori society (Durie 1999b). Several personalities in Māori mythology had physical disabilities in conjunction with profound status.¹ The implication is that disability enhanced rather than diminished a person's status in Māori society. However, culture, in terms of both intra-cultural and cross-cultural interactions, poses its own barrier for disabled peoples' citizenship in society (Nikora et al 2004:15). A lack of research and knowledge about Māori perceptions of disability prevent further analysis into the relevance to Māori of the seven disability models.

A methodological model that the National Health Committee developed in consultation with the New Zealand disability sector has potential usefulness for Māori because it avoids the contentions that surround terminology and health/disability concepts to concentrate on everyday living for people with impairments and long-term ongoing health conditions. The information-gathering model that the National Health Committee used in research on adults with intellectual disabilities values a generic,

1 The legends of Maui feature several gods and goddesses with disabilities.

holistic approach to health and wellbeing that considers the social, cultural, economic and environmental factors in a disabled person's life (National Advisory Committee on Health and Disability 2003). Components of the model include culture, communicating, moving around, accommodation, looking after oneself, income, relationships, paid and unpaid work, learning, participating in the community, and having fun. This model fit snugly within existing Māori health and wellbeing models.

3.5 MODELS OF MĀORI HEALTH AND WELLBEING

Models of wellbeing specifically for Māori with disabilities have not been developed to date. Instead, Māori health models tend to be used to help shape particular settings. *Te Whare Tapa Wha* (the four-sided house) and *Te Wheke* (the octopus) were developed in the 1980s and are the two seminal models of Māori health and wellbeing for individuals and their whānau. The components of *Te Whare Tapa Wha* focused most on the individual and included te taha tinana (physical health), te taha hinengaro (thoughts and feelings), te taha wairua (spiritual side) and te taha whānau (family) (Durie 1994). *Te Wheke* focused on the family and had the same four components as *Te Whare Tapa Wha* but broadened te taha whānau to whanaungatanga (extended family relationships) and added:

Mana ake, the uniqueness of the individual and each family and the positive identity based on those unique qualities; mauri, the life-sustaining principle resident in people and objects, including language; ha a koro ma a Kui ma, literally the breath of life that comes from forebears and an acknowledgment that good health is closely linked to a positive awareness of ancestors and their role in shaping the family; whatumanawa, the open and healthy expression of emotion, necessary for healthy human development; and waiora, total well-being for the individual and the family, represented in the model by the eyes of the octopus (Durie 1994:75).

Nga Pou Mana (the pillars of empowerment) outlined four socio-economic prerequisites to wellbeing for Māori as a people – whanaungatanga (family), taonga tuku iho (cultural heritage), te ao turoa (the physical presence) and turangawaewae (an indisputable land base) (Durie 1994). A fourth model developed in the 1980s was the *Gallery of Life*, a similar model to the others but distinctive because it introduced biculturalism as a component of Māori wellbeing (Palmer 2004). Other models have a specific focus: *Te Pae Mahutonga* (the Southern Cross constellation of stars) is a model of goals toward Māori health promotion. The four stars of the Southern Cross represent mauri ora (access to te ao Māori), waiora (environmental protection), toiora (healthy lifestyles) and te oranga (participation in society) (Durie 1999a). The two pointers of the Southern Cross represent two pre-requisites for Māori health promotion: ngā manukura (leadership) and te mana whakahaere (autonomy). *Homai Te Waiora Ki Ahau* is an assessment tool to measure a person's level of waiora, which is defined as psychological wellbeing (Palmer 2004). This tool is based on common components from the first four models mentioned above. The *Hoe Nuku Roa* study of Māori households uses "a relational framework of four interacting axes – paihere tangata (human relationships), te ao Māori (Māori cultural identity), ngā āhuatanga noho-a-tangata (socio-economic circumstances), ngā whakanekeneketanga (change over time)" (Durie 1999b:104). A second dimension of the framework is the set of indicators to describe the four axes in terms of choice, access, participation, information, knowledge and aspirations. *Whānau Whakapiripiri* (Cohesive Families) is an analytic framework that focuses on the particular features of whanaungatanga – a common component in all other models – and looks at how it operates in relation to the whānau. The framework is based on six principles that underpin the whanaungatanga process:

- > tatau tatau – collective responsibility
- > mana tiaki – guardianship
- > manaakitanga – caring
- > whakamana – enablement
- > whakatakoto tūtoro – planning, and
- > whai wahitanga – participation (Cunningham et al 2005:57).

The remainder of the *Whānau Whakapiripiri* framework comprises functions, indicators and educational implications. Some of the models concentrated on components of health or wellbeing for an individual. Such models showed a clear correlation between a component of the model and an individual's everyday life. Other models had broader scope and were more focused on whānau, hapū, iwi or Māori groupings. However, as the scope broadened, the components of these models became

less directly relevant to the everyday lives of individual members within the group. Common to all Māori models was the belief that an individual was a member of a larger group and that this perspective was critical for personal wellbeing, so *taha whānau* or *whanaungatanga* was present in all models.

The *whānau* concept is often used as a metaphor to develop models for a range of situations and circumstances involving some form of relationship management. For example, Smith (1995) believed the *whānau* concept could be used as a model for effective intervention into educational and cultural crises, a model that *kura kaupapa* (Māori language immersion schools) adopted. Bishop (1996) used the concept to describe *kaupapa whānau* as families of interest and he also prescribed *whakawhanaungatanga* (relationship building) as an effective research method. Moeke-Pickering (1996) described the use of the *whānau* concept as a management framework for organising and managing relationships. Durie (2005) used the concept to develop a model for early intervention into serious conduct disorders.

3.6 MODELS OF DIVERSE MĀORI REALITIES

One model of diversity for Māori was that developed by Durie in the 1990s (Durie 1995). Three broad groupings of Māori were identified: those linked with conservative Māori networks; those integrated into mainstream society and who have limited association with Māori society; and those with no association with Māori society. Cunningham et al (2005) expanded on this model to develop the *New Māori Diversity Framework*. The framework called Durie's three groupings the Conservative Māori, Integrated Māori and Isolated Māori, and added a fourth group, the Pluralistic Māori, who were able to move with ease between the mainstream and Māori worlds. While these models use the realities of Māori identity as their basis, the notion of diversity within Māori society rather than across cultures has expanded the possibilities for thinking about Māori ontology.

3.7 TATAU TATAU MODEL OF WHĀNAU WELLBEING

The existing Māori models and frameworks show that a model of *whānau* wellbeing when one or more of its members has a disability must take into account the diverse realities for Māori. Borrell (2005:34) argued that Māori models run the risk of making invisible those Māori who do not possess the traits evident in the models. Some Māori are therefore at risk of being doubly marginalised. Although she was referring to *rangatahi* (young people), her argument is equally relevant to Māori with disabilities. Nikora et al (2004) reiterate this point and warn that the experiences of disabled Māori could become invisible under the umbrella of Māori experience generally. The depth of oppressive influences experienced by Māori with disabilities as well as the corresponding pressure on their *whānau* could therefore be overlooked.

A model of *whānau* wellbeing must also take into account an holistic approach to wellbeing that allows for the consideration of broad social, economic, cultural, ecological and health influences on a *whānau* and its members. A fundamental principle for such a model is that of linking an individual's identity to his or her *whānau* rather than to illness, a medical condition or impairment. In other words, an individual will identify as Māori and, within that identity, may also opt to identify as disabled. There are few groups of this kind but *Ngāti Kapo*, the National Māori Blind Association, and *Te Hunga Haua Awhina Roopu*, the Disabled Māori Support Group, are examples. Nikora et al (2004:17) discuss the close connection between support services and identities of disability and how Māori are choosing not to identify as disabled, thereby giving up any possibility of accessing support services. The implication for *whānau* is that they are likely to be called on as the primary support for their kin who have needs related to disability.

The model of *whānau* wellbeing developed for this study is called *Tatau Tatau* (Collective Sharing) and attempts to accommodate the diversity of Māori, *whānau* and people with disabilities. In the absence of existing evidence to guide the development of appropriate components for a *whānau* wellbeing model when members have a disability, we have incorporated the common components of existing models in a manner similar to the *Homai te waiora ki ahau* model. The models were drawn from three areas: Māori health and wellbeing; *whānau* wellbeing; and a model for information gathering from people with disabilities. The *Tatau Tatau* framework encompasses the common components from all of the other health and wellbeing models. The framework is used to investigate the role of *whānau* in the everyday

lives of Māori with disabilities and the factors that help or hinder whānau wellbeing. Appendix 1 presents components of the *Tatau Tatau* framework alongside the models from which those components were drawn. *Tatau Tatau* has two dimensions: the first dimension focuses on the person with a disability and his or her relationship with the whānau; the second looks at the whānau as a unit and how it maintains its wellbeing. Each dimension has a range of components, issues and questions that may be put to people with disabilities and their whānau. The components and related issues within the first dimension are:

Whanaungatanga – the type of relationship that Māori with disabilities have with their whānau.

Mana – the mana of Māori with disabilities within their household and whānau.

Te oranga – the opportunities and barriers for Māori with disabilities to participate in society and whether the main support they draw on is their household or their whānau.

Hinengaro – the ability of Māori with disabilities to effectively communicate their thoughts and feelings.

Taha tinana – the support mechanisms that Māori with disabilities use to look after themselves, their household and their whānau.

This dimension places the individual at the centre looking outward toward the whānau and beyond. The second dimension places the whānau at the centre and the components within this dimension are:

Manaakitanga – whether caring for others is important in everyday life.

Tatau tatau – whether sharing responsibility for each other is important in everyday life.

Wairuatanga – whether spirituality is important for whānau wellbeing, including whether their Māoritanga is a source of strength for them.

Mana tiaki – whether members of the whānau have a guardianship role and its importance to whānau wellbeing.

Nga taonga tuku iho – whether having/not having inherited resources impacts on whānau wellbeing.

Appendix 2 outlines the *Tatau Tatau* framework by dimension, component and issue and includes a range of indicative questions. This framework was used as the interview schedule when talking to informants.

Whilst the literature on whānau as a concept, a structure and as a model for wellbeing is strong, there is little to indicate the issues for Māori with disabilities and their role within the whānau. Everyday living for Māori with disabilities and the part that whānau play in their lives is not well researched and therefore this review is correspondingly limited in scope. There is a clear need for further work in the area of whānau who have members with disabilities and the dynamics of those relationships.

4.0 ABOUT THE PEOPLE INTERVIEWED

Nine of the people interviewed have been included in this project. They reflect the diverse arrangements of whānau, households, age groups, location (from rural to urban) and social circumstances. However, there were some distinct commonalities and they have been discussed later in this section.

Hera

Hera comes from Ngāti Hine and Ngāti Kahungunu. She is in her 50s and has age-related disabilities. She lives in a multi-generational family household in the Waikato region. There are four generations in her whānau and she has a very good relationship with them: “No complaints there.” She is an avid churchgoer, supports her marae as much as she can although it is in another part of the country, and takes part in arts and crafts classes.

Hone

Hone is in his 40s, single and has a physical disability. He comes from a three-generational whānau from Te Taitokerau iwi and enjoys a good, supportive relationship with them. His disability has forced a career change so he is studying full-time and keeps fit cycling everywhere. He lives in a flat with others in the Waikato. His marae is in another part of the country but he helps when he can and contributes financially. Hone was interviewed with his sister.

Koro

Koro is over 60 and has age-related disabilities. He lives in the Waikato with his wife and children. He belongs to a two-generation whānau from the Waikato, Ngāti Tuwharetoa and Ngāti Raukawa iwi, although his wife’s whānau is larger. He enjoys a good relationship with his wife’s whānau but his relationship with his own whānau (other than his immediate family) is not close. He was once deeply involved in voluntary work with young people and some of them continue to visit him.

Kuini

Kuini is in her 60s and has age-related disabilities. She was interviewed with one of her daughters, who is in her 40s and has multiple disabilities. Kuini lives alone in her own home in the Gisborne/East Coast region but her daughter and many of her stepfamily live nearby. Kuini’s daughter also lives alone. Kuini is from the Waikato iwi and has a five-generation whānau when you include her stepfamily. She describes her relationship with her whānau as “fair”. She is enjoying the Māori language classes she attends each week. Kuini’s daughter is also from the Gisborne iwi and volunteers for a local community organisation.

Mark

Mark is unable to speak but can communicate in other ways, especially with his family. He was present while his mother was interviewed. Mark is from a three-generation whānau from the East Coast iwi. His mother describes their relationship with their whānau as very close. Mark lives with his parents and siblings in their own home in the Waikato. He goes to primary school and is a keen sportsman.

Molly

Molly is in her 50s and has a physical disability. She comes from a four-generation whānau from the Manawatu iwi. She lives in her own home in the Gisborne/East Coast region with two of her sons and a grandson. She believes that she has a very good relationship with most of her whānau. Molly works most of the time but spends her free time relaxing with friends.

Nati

Nati is in his 50s and has a physical disability. He comes from a four-generation whānau from the East Coast and Waikato iwi. He lives in a rental home in the Gisborne/East Coast region with one of his daughters. He describes his relationship with his whānau as excellent, “couldn’t be better”. Nati works for half of the week and has iwi community work to do in the weekends.

Riria

Riria started school not long ago and has a physical disability. Her mother, grandmother and great-grandmother were at the interview while she played with her brothers and sisters. Riria is from a four-generation whānau from the Gisborne/East Coast and Urewera iwi. She lives with her parents and siblings in the Gisborne/East Coast region in a farmhouse provided for them by her father’s employer. Riria loves swimming and visiting her grandmother in town.

Wi

Wi is in his 20s and has a physical disability. He was interviewed with his wife. Wi comes from a three-generation whānau from the Hawke's Bay iwi. He and his wife live in a rental home with a boarder in the Waikato region. He is a full-time tertiary student and enjoys playing racket sports.

4.1 SUMMARY DEMOGRAPHIC PROFILE

Age

Both children are under 10 years old and their parents are aged in their 20s. One other person is in the 20-29 age group, one is in the 40-49 age group, three are in the 50-59 age group, and two are over 60 years old.

Gender

Five are male and four are female.

Disability type

Five have physical disabilities and four have age-related disabilities.

Household composition

Four are single: one of them lives alone; one is flatting with others; one lives in a multi-generational family household; and one lives with one or more of their children. Two live with their partners, and three are in a household with their partner/parents and children/siblings.

Whānau composition

Eight come from whānau of three or more generations and the ninth person is a member of a two-generation whānau.

Location

Five live in the Waikato region and four live in the Gisborne/East Coast region. Six of them live outside of their iwi districts. Of the three who live within their iwi districts, two live in the Gisborne/East Coast region and the other lives in the Waikato.

4.2 COMMON LIFESTYLES

There are several striking commonalities amongst the people interviewed. One of the most striking commonalities is that almost all of them continue to live with members of their immediate family well into adulthood. Another commonality is that most live away from their iwi and whānau. Despite this, they attempt to maintain links by visiting, maintaining contact and keeping themselves informed of events happening in the hapū and iwi. They are all involved in some way with their community, the most common activities being sports, study and voluntary work. Most of the adults are unemployed or retired and only one is in full-time employment.

5.0 PERSONAL WELLBEING AND THE WHĀNAU

The first dimension of the *Tatau Tatau* framework used during interviews enquired into the role that the informants' whānau played in their everyday lives. There were five elements in this dimension: whanaungatanga (family relations); mana (authority); te oranga (community involvement); hinengaro (communication); and taha tinana (physical wellbeing). The framework was prescriptive and constrained informants to such a point that any impact their impairments may have had on their lifestyles was not directly questioned. Such an approach allows for future comparative analyses to the answers that may be given by Māori who do not have disabilities and discourages preconceived notions of the effect of disabilities on people's lives, particularly notions of dependency and frailty. Any distinctive lifestyle features related to living with disabilities were revealed when informants volunteered such information only.

5.1 WHANAUNGATANGA/FAMILY RELATIONS

Most of the questions asked in this segment were about the informants' whānau size, location and the nature of their relationship. The responses helped to build the profiles of informants as recorded in the previous section of this report. There was a range of responses to the question: "How would you describe your relationship with your whānau?" most of which were positive and some that showed an affectionate exasperation with whānau. A few revealed that their relationship with their whānau was weak:

Mark's mother: Very close. We have family meetings every Sunday with the ones that are up here. Anything that gets discussed gets relayed back to the family if necessary in the East Coast and that's the parents and if they feel that the others need to know they let them know and that's pretty much how we do things.

Nati: Good, excellent, couldn't be better ... we have a huge whānau who care and look after each other and ... we get together about once every five years or so.

Hone: I think we're very supportive of one another and we're all good.

Hera: Good, very good. No complaints there.

Riria's mother: Good.

Molly: With my eldest not too good, with my other two very good.

Wi: On a need-to-see basis; we just want to get away and do things ourselves.

Kuini: Well, it ain't good so yeah, I'd say fair.

Interviewer: But is it bad?

Kuini: Oh no, not bad I'd say it's so-so eh, which is fair.

Interviewer: Ok, why do you say that?

Kuini: Well, we don't see eye-to-eye for a kick-off. We've all got different ideas eh, we haven't got the same opinions about anything.

Interviewer: And that gets in the way does it?

Kuini: Yeah, when you put it like that, geez you know, makes you think eh. Which is true, we've all got our own opinions and you can't shift them.

Interviewer: Are they close?

Koro: No. My wife's side it's good.

Whilst the majority of the informants were unequivocal in their positive response to a query about whether the whānau was important for their personal wellbeing, some revealed that they had mixed feelings:

Interviewer: Is having whānau around you important for personal wellbeing?

Hone: I think so.

Koro: Yeah, I suppose so.
Interviewer: Just don't think about it a lot?
Koro: Nah.

Wi: At times, depends, because there were some major issues with whānau so we decided to move away from home. But we're definitely there for support, if things get bad then we will help out but we just like our space.

Kuini: Sometimes yeah, but sometimes no eh... I don't think so, not for me anyway. I find it's too trying where I find I'd rather be left alone because I know what I can and what I can't do. With whānau around you've got one telling you, you can, you've got another one telling you, you can't, so you get to the stage where you think, well you can't do it anyway. But if you're left alone, you probably can ... whānau is good to have around when you're really, really sick, you know like when I was in hospital? It was good having [the whanaunga] then but as I got better, well it was a bit trying because everyone's trying to help you and you, you know, it was sort of, in other words a bit of a nuisance. Yeah, but when you're really sick, yeah, whānau is important. I don't really like them around because I find I do things to please them rather than myself.

Kuini's daughter: I tend to disagree with Mum. Mum's got her opinion but I lived in [the Hawke's Bay] for five years without family, without friends, without nobody and I found it quite trying without that. I got quite lonely, no visitors, no friends, it was quite trying.

Interviewer: Ok. So for you it really was important?

Kuini's daughter: For me it was, to have family around. It was the reason I came back to Gisborne.

The last question in this segment was: "Which do you consider has the biggest role to play in your everyday life, your whānau or your household?" The response from informants who were living with whānau members was predictably that both were equally important. However, most tended to refocus their definition of whānau to mean their immediate nuclear family more than the wider extended family definition of whānau:

Riria's mother: Both.

Hera: Both – your household running smoothly, your whānau will be running smoothly also. If you're happy in your household you'll be happy with the whānau too.

Hone: Both, there's no difference as far as I'm concerned, even though parts of my whānau are here and parts are not here, all play an important role.

Mark's mother: My whānau. They both have a role together, they are both important. I can't have a happy immediate family just by themselves because we do things as a collective. They both have an equal standing.

Nati: Both.

Interviewer: Are they the same thing for you?

Nati: Yeah, but my immediate whānau is [my daughter] and she's a great help with me and my disability although she's at an age where I don't want that to be put on top of her because she's still got her own thing to do and her own growing to do. Like she might have to go shopping by herself because I can't stand for long but when it comes to the bigger issues we just need to go to my sister's to have tea or to catch up with her kids because we miss each other terribly and she's only 10 minutes away. That closeness has always been there in the whānau.

The others chose between the whānau and the household:

Wi: Our household at this stage.

Kuini's daughter: The household.

Kuini: Well, because I haven't got whānau here [living with me], I've only got household.

Kuini's daughter: That's the same with me, my household.

Molly: Whānau.

5.2 MANA/AUTHORITY

Mana can be divided into two main types: the first type is spiritual in nature and refers to the free will and willpower that a person is born with and that is most commonly called mana atua, the self-empowerment that comes from the gods. The second type is usually called mana tangata and refers to the influence that other people give you over their lives (Edwards, McManus and McCreanor 2005). All of the informants were decision makers in their households, either as sole decision maker or as part of the collective decision making that members of the household shared. All of the women said that they were the decision makers but the married men attributed household decision making to their partners:

Interviewer: Who is the decision maker in your household?

Wi's wife: I am.

Wi: I like the fact that she is.

Koro: Yeah, the wife.

One informant said that her mother was the decision maker for her household even though they each lived in their own homes, indicating that the whānau had a major influence over her household.

Interviewer: Who is the decision maker in your household?

Kuini: Oh yeah, being only me here, well naturally it's me, eh.

Interviewer: What about you [Kuini's Daughter]? Same with you?

Kuini's daughter: Mum's the main person in my household. She comes over there, rings up, rings up – 'I'm coming over'.

Interviewer: That's interesting. So you're saying that your Mum's the decision maker in your household?

Kuini's daughter: Yeah.

Interviewer: What do you reckon Kuini?

Kuini: Yeah, I'd say so. She might say A and I'll say B and B it is.

Some of the informants felt that the whānau had a strong influence in their households:

Interviewer: Who is the decision maker in your household?

Hera: It all depends on what it is; if it's tikanga Māori I am but if there's other decisions to make we make it as a whānau.

Hone: All of us, it's collective it has to be just for the everyday running of the flat.

Mark's mother: We have the last decision as parents but we take into consideration what they [the children] say. Life is a lot easier when they're all informed.

Most of the informants were diplomatic and preferred to talk about mana in terms of mana atua. Those who referred to mana tangata preferred to say that they did not have any mana when specifically asked or mentioned whānau members other than themselves:

Interviewer: Who has mana in your whānau?

Koro: Both of us, like my mana comes from above.

Wi: We both do, we have mana of our own.

Hone: One's own self-respect on that; everyone has their own mana but if things need to be decided on concerning the household, we'd have to go back to the person that the whare is under.

Mark's mother: Because there's different types of mana, I made it a point that each whānau member knows they have a certain amount of mana for a certain reason. That's for Mark as well, he's no less a person just because he has a certain impairment. I think that's why we have an easier life with him.

Riria's grandmother: It better be me!

Riria's mother: Mother because she's had to bring us up on her own and she's done a massive job.

Two mentioned position within the whānau as a qualifying factor for mana tangata:

Interviewer: Who has mana in your whānau?

Hera: The eldest of each generation and I'm the eldest of this generation.

Nati: I think my sisters have, especially this one over here. The eldest one, well with descending into Alzheimer's, although we still call her the matriarch of our whānau because she's the oldest and she deserves it because she's earned it. As for mana, she has that mana regardless of whether she's aware of it or not. We ensure that we as a whānau look after her in ways like being with her, her being with us, joking with her, it's just that Ngāti Porou humour thing. She's 80, I mean she's fabulous. The one here is a fighter. She turned 70 at Christmas. As for me, I suppose I have that mana too because I'm young and the only boy and there's expectations of me to perform in the whānau. Before I never used to whaikōrero without the Ok of my sister so where mana is concerned, tikanga especially, with Ngāti Porou that tuakana-taina sequence has always been effective in our family. It's a safety thing, it's not only because I'm the only boy and I should be up there. The Ok has to come from my sisters because they have the role and the mana to whakapapa and also through the whānau.

Some appeared to believe that being the decision maker in the household did not necessarily mean that they had mana:

Interviewer: Who is the decision maker in your household?

Molly: Me.

Interviewer: Who has mana in your whānau?

Molly: Nobody.

Interviewer: How much mana do you think you have in your whānau?

Kuini: Stuff all!

Kuini's daughter: I'd say nil too for me.

5.3 TE ORANGA/COMMUNITY INVOLVEMENT

Several prompts were directed at informants for this segment to clarify our questioning, although informants could answer as they wished. The specific indicators we chose were: paid work; unpaid work; church; study; fun; recreation and sport; and marae/hapū/iwi activities.

Paid work: Molly and Riria's father worked full-time and Nati worked part-time.

Unpaid work: Four of the informants were involved in unpaid voluntary work including youth work, community crutchings and fundraising, and as an iwi radio supporter. Kuini's daughter was also involved in unpaid work for a community organisation.

Church: Hera was the only churchgoer, although Koro mentioned his Christian beliefs.

Study: The two children were attending mainstream primary schools and five informants said that they were studying. Wi and Hone were full-time students at tertiary institutions while Molly and Kuini took te reo classes part-time at tertiary institutions. Hera was attending part-time adult education classes in arts and crafts.

Fun, recreation and sport: There was a slight overlap with other indicators for this prompt because for some, their unpaid work and studies were recreational activities. Nevertheless, both of the children and Hone and Wi were involved in sports.

Marae/hapū/iwi activities: None were directly involved in these activities but some of them attempted to maintain links:

Hera: Very strong in the marae and hapū but I can't go back for much hapū things but anything to do with marae I'm right in there.

Hone: Distance, financial support.

Nati: I was heavy into kapa haka, Hikurangi choir and also Te Hokowhitu Atua but as I got older...

Riria's mother: Yeah, when there's tangis on or family reunions and that and whānau things.

Wi: Only when we go home, funerals and that's about the only time.

Interviewer: The marae is accessible?

Wi: If you've got shock absorbers and all-terrain wheels!

Interviewer: Would that have an impact do you think?

Wi: For me, yes.

Wi's wife: He needs strong men to push him around.

Informants were also asked about their mode of transport for getting around in the community, to which seven replied that they had motor vehicles. Of these, two were modified vehicles with wheelchair hoists. The mode of transport for two of the informants was bicycling or walking. Kuini's daughter was the only one to mention that she used public transport. Molly walked everywhere but said that she called on friends whenever she needed transport.

When asked who helped them most to take part in the community, four referred to whānau members, three said that they did not need help, and the others referred to health professionals and support services:

Hera: Whānau.

Hone: My sister.

Riria's mother: Me, the kids and [husband].

Wi: My dear wife.

Koro: No, I'm very independent ... I'm a pretty mobile fella eh.

Kuini: No, nothing.

Nati: As with my own job I do it all.

Kuini's daughter: My nurse helps me get involved with the people. She believes that if I get out more often, it's less time thinking of myself. Yeah.

Mark's mother: Various services and supports. Whatever he needs we have people to contact and through the school they let you know what's going on and what's out there.

Questions about any barriers they had encountered to participating in society received a range of responses, from no barriers to attitudes that caused barriers, to ignoring or breaking through any barriers encountered:

Kuini: Well, actually for me there isn't any really.

Molly: Actually I haven't encountered any.

Hera: There's no such thing as barriers. There's always some way of getting around those barriers. You yourself got the barriers but I can't see barriers – if you yourself can't do it then somebody else will do it.

Hone's sister: Not having the knowledge and information is a big barrier with ACC, being informed of what's available, what he's entitled to.

Hone: Whatever system they have in place to help me recover.

Mark's mother: A lot of it's just the fact that people are not used to being around people who have got special impairments ... I wouldn't know how to do it [overcome the barriers]. I suppose letting people know that people with impairments are just like everybody else, they're not aliens from Mars or anything, and this is something I have encountered and they don't look they actually stare, and then you get the odd comments of people chucking off, throwing quite rude remarks, and then you get people who pity your child as if to say he's some kind of animal sitting in a wheelchair.

Nati: I try not to make any barriers; the only barrier is my car breaking down. Anything else I just go and do it.

Riria's grandmother: Don't let that worry us, we just take her out like normal; doesn't bother [Riria].

Wi: You've got the obvious ones – the ability to get there, the attitudes/judgement of people.

Wi's wife: The stigma, especially when he's playing tennis.

Wi: 'Someone give him a hand' assumptions. We just get on with living, we just get over it and do it.

5.4 HINENGARO/COMMUNICATION

Hinengaro is a concept relating to a person's thoughts, feelings and communication. When asked whom they shared their thoughts and feelings with, six of the informants mentioned whānau members in their household. Others mentioned friends and health professionals. All of them believed their views were taken into account:

Interviewer: Who do you share your thoughts and feelings with most often?

Hera: My family or the church and share with my tupuna at the urupa and it all depends what my feelings are.

Hone: That'd be my wife. We keep an open mind with each other and just talk.

Mark's mother: His sister, myself and dad. We do sign language as well, which makes it much easier for him so he won't be so frustrated if he wants to get out information.

Nati: With my baby, my daughter.

Riria's mother: [husband].

Wi: My dear [wife] most times.

Koro: I don't share with too many people because I don't trust.

Kuini: Oh with me, yeah, my nurse.

Kuini's daughter: My nurse is the same with me, does the same for me.

Interviewer: What about whānau or friends?

Kuini: Not inner feelings you know, not personal, with me not personal, I'd rather talk to the nurse.

Molly: Only my closest mates.

When asked whom they needed help to communicate with most of the informants said that they did not need such help. Others invariably referred to government agencies:

Kuini: That's my one, the bloody case manager [at Work and Income]... In the end I got embarrassed eh, it was like begging for it eh, so I gave up.

Hone's sister: I get back to ACC again if my brother's not informed of what he's entitled to and what he can access, it's like saying – well, what questions do you ask?

Informants were asked upon whom would they call should they need help communicating with others. Few of them sought external help to communicate with government agencies, preferring to advocate for themselves or rely on whānau members to advocate for them:

Interviewer: Who do you get help from when you need it?

Hera: If it's medical help I go outside but if you're talking social welfare I take my daughter with me.

Molly: That's my mates.

Nati: My baby, my sister.

Riria's mother: Mum and dad, whānau.

Wi: It'd be [his wife].

Hone's sister: Friends, relatives, whānau.

Hone: Government departments, I don't know much about them, never really dealt with them before, just don't come across them really.

Interviewer: Having whānau with you, does it help?

Hone: Yup.

Kuini: No. If I need something I do it myself.

Interviewer: Or miss out?

Kuini: Yeah, or miss out.

Mark's mother: CCS are very helpful and his local school keep you informed of what's going on.

5.5 TAHA TINANA/PHYSICAL WELLBEING

This concept relates to physical and material matters. The questions revolved around the household, convenience and comfort within the home, paying for things and assistance. Hone, Koro, Nati and Wi lived in rental accommodation. Nati rented out his rural home and had moved into a rental home in town. Kuini, Molly and Mark's whānau lived in their own homes. Hera lived in a home owned by the whānau. Riria's whānau lived in free accommodation provided at her father's place of work.

Seven of the informants lived with members of their immediate family and one of them also had a boarder. The other two informants lived alone. Nati and Riria's whānau had recently moved into their accommodation whereas Hone, Koro and Wi had lived in their rented homes for about two years. Hera had lived in her whānau home for about four years and Mark's whānau had lived in their home for seven years. Molly and Kuini had owned their own homes for 25 years and about 40 years respectively.

When asked if they could move around their homes comfortably, most admitted to some degree of discomfort:

Hera: No I don't, just take your time, you get around.

Hone: Between certain hours, yes.

Nati: No, not really, the hospital has got a waiting list for modifications; things take a long time to get done. It's a joke but that's the mentality here, we're off the beaten track. So I said this is the 21st century, wake up. I'm going to see them tomorrow and tell them if you're not going to put a ramp in here I'm going to get a builder and send you the bill. I need it, winter is coming and I need a ramp and assistance to get up on these things.

Interviewer: What do you need to make it better?

Nati: Inside, just rails it's helpful, no lights out there when I get home at night so I have to go slowly and feel my way up and in here. It just refines your thinking when you have a disability, makes you think.

Riria's mother: Riria can get around, besides the steps.

Wi: Most places is Ok, it's getting in the hallway, that could be a little bit bigger. It's not modified.

Koro: Yeah.

Kuini: Yeah I'm fine.

Molly: Yes, I can.

Mark's mother: Definitely. All got the facilities for Mark. So life could be a lot easier for him and if it's easier for him it's easier for us. Goes hand-in-hand.

Daily household tasks such as cooking, cleaning and lawnmowing were another area in which a degree of discomfort was experienced. Some left these tasks to others in the household, some were able to contribute and some tasks were allocated to others in the household either because of gender roles or household routines:

Interviewer: How do daily household tasks get done, eg cooking, cleaning, lawnmowing?

Riria's grandmother: Very slowly!

Riria's mother: I do it.

Hera: All the whānau does that and on my good days I get stuck in but sometimes when I lack strength and oxygen I lay off. Well, they're all here, the whānau is here.

Nati: I get up and do it, anything that's low is a hindrance.

Interviewer: Lawnmowing?

Nati: If I have to but it's hard. I'd love to but have trouble getting down low.

Kuini: Well, I do that myself because I'm still capable of doing all that.

Interviewer: You still do your mowing?

Kuini: Oh, I got a man come in to do that. If I had a mower I reckon I could do it myself. That's how fit I feel now.

Interviewer: How about you [Kuini's daughter]?

Kuini's daughter: Ah yeah, I manage to get around, I manage quite nicely to clean my house and stuff before mum turns up.

Molly: I do the cooking, cleaning; my son does the lawnmowing.

Wi's wife: I usually do that, oh we share.

Wi: I do the dishes.

Interviewer: So what you can't do she does so there's a bit of sharing?

Wi: Sometimes it's a little quicker if she does it.

Hone: Everyone just pitches in, usually we have a system who does the tea and dishes.

Koro: Yeah, I do the mahi [work].

Mark's mother: I do that but Mark has his chores like all the other children.

A question about the proportion of income that informants paid in rent or mortgages was the most personal of all of the questions for three of the informants and they chose not to answer. Of those who did respond, the proportion was between a quarter and a third of their income. Two of the informants did not pay rent or mortgages because their accommodation was either free or freehold. When asked who paid for things in their households, the informants who lived alone paid for things themselves and the other informants shared with others in their households.

When asked whom they would turn to should they need someone to help take care of them, their whānau or their household, some said that they did not need help but most of them referred to others in their household or wider whānau:

Interviewer: Do you need any help to take care of yourself, your whānau and your household? Who do you ask?

Hone: No.

Molly: No, I don't need any help.

Hera: I do need doctor's things for myself for my whānau, no.

Nati: Not yet.

Interviewer: If you do, who would help?

Nati: Probably my oldest daughter.

Koro: Yeah, like sometimes my back and my neck plays up and my leg gets tired and I get one of the cousins to give me that thing [mirimiri/massage].

Kuini: No, not really no ... well, when I was like that no one, I just tried myself or went without, and so I actually didn't know who to ask. I mean there's nothing out there that tells you, well not that I know of ... oh yeah, I'd ask my daughter alright, yeah.

Interviewer: So if you needed to ask someone who would you call on?

Kuini's daughter: Mum.

Riria's mother: Mum and dad.

Mark's mother: When the children were younger we did but now they're older they've taken responsibility. We've made a point of it because Mark's a part of the family but we've taught our children that whānau comes first.

Wi: A little but mostly [Wi's wife]... I've had some awkward moments sometimes but it's pretty Ok, she knows the things that I need help with and that I can manage... probably give a shout out to the boarder but that rarely happens; he's busy.

Wi's wife: It's hard, we try and work in together.

Wi: Yeah, we don't usually get into situations, we try and avert them.

At the conclusion of this dimension of the *Tatau Tatau* framework on personal wellbeing and the role that whānau played, the interviews turned to the second dimension on informants' views of the importance of several Māori concepts for whānau wellbeing and these are discussed in the next section of this report.

5.6 DISCUSSION

Use of the *Tatau Tatau* framework revealed the ubiquitous role of whānau in daily life for Māori with physical disabilities, irrespective of domicile. The relationship is so intertwined that to ignore the relationship is, in effect, to decontextualise and therefore alienate Māori with disabilities. This has significant implications for social policy development, especially in relation to disability support. Other research studies have already signalled the key importance of whānau for Māori children with disabilities (Mirin-Veitch, Bray and Watson 1997) and this research found the same for Māori adults. This study confirmed previous research findings that exposed the depth of unmet need with which Māori with disabilities live and their propensity for not accessing disability support services (Ashwell, Ridwell and Thompson 2004; Nikora et al 2004; Rua et al 1998). Instead, Māori with disabilities rely on their whānau and circumvent more formal support services available. Further inquiry would be needed to verify the possibility that this may be a result of the support services forcing individuals to choose between their whānau and the service. Even amongst this small sample of informants the household arrangements were diverse, from living alone to living in a multi-generational whānau household.

Most of the informants had strong relationships with their whānau; only a few had weak relationships and none were estranged from their whānau. Whilst they all believed their whānau were important for their personal wellbeing, especially in terms of their relationships with their nuclear families, one was candid about her exasperation with the over-zealous care and attention that her whānau showed her. A

desire to be seen as independent and self-sufficient was also expressed by other informants. All of the women said that they were the decision makers in their households whereas the married men deferred to their partners. The others referred to collective decision making to which they made an equal contribution.

The nature of the relationship between the informants and members of their whānau who lived with or near them was indubitably interdependent and the informants acknowledged it as such. However, the interdependence was seen as an effect of whanaungatanga (family relations) rather than as a consequence of living with a disability. At times, the informants refocused their definition of whānau to mean their nuclear family only and this gave rise to some ambiguous responses when asked whether the household or whānau played the biggest role in their everyday lives. For them, the whānau members living in the household played a significant role and could not be separated from either the wider whānau or the household. Therefore, informants responded that both the household and the whānau had equally important roles. The others gave an unequivocal response in favour of the household.

The questions about mana (authority) were difficult to ask and answer for most part because of the cultural importance of humility. Informants were able to answer that they had mana atua (willpower) because everyone has this type of mana. They were less forthcoming about mana tangata (status), preferring to attribute such to others than to themselves, although this may also have been a consequence of how the question was put. Evidence that the informants had mana tangata appeared as a secondary consideration when they answered other questions. For instance, when directly asked who had mana in the whānau, Koro referred to mana atua. However, in later questions he disclosed that his whānau called on him for important events and young people continued to visit him long after he had worked with them. Molly believed that no-one had mana in her whānau yet she was the decision maker in her household in which two other generations of her whānau lived. Kuini believed she did not have mana in her whānau yet she also acknowledged that she was the decision maker for her daughter's household. This was the case for most of the informants and could be attributed to humility on their part as well as to the possibility that they did not recognise such activities as that which sprang from mana tangata.

Unpaid work, study and sport were the most common community activities amongst informants. People in the older age groups in particular were involved with some type of unpaid work whereas young people were involved in sport. Studying cut across all age groups and encompassed community education as well as formal education. For many, these activities were also their fun and recreation. Only one was involved with the church and none were directly involved in marae, hapū and iwi activities. There is widespread anecdotal evidence that Māori with disabilities are unable to participate in marae, hapū and iwi activities for a variety of reasons including attitudinal, transport and accessibility problems. This research confirmed that Māori with disabilities were not participating despite their willingness. The primary reason was that of distance since almost all of them lived away from their iwi territories. Nevertheless, even those who lived within their iwi territories were not involved. The marae was considered to be a problematic environment for Māori with disabilities and this appears to have been an exceedingly difficult barrier to bridge that would allow them to be involved with their marae, hapū and iwi in any way other than from a distance.

The household, and especially whānau members within the household, provided the support that informants used to help them to participate in the community. However, many said that they did not need help because they could do it themselves. For others, support services and health professionals were called upon whenever necessary. All but two of them owned motor vehicles for moving about the community and the other two either walked or used a bicycle. Kuini's daughter was the only one to mention that she used public transport. The informants with visible disabilities appeared to have encountered barriers to participating whereas those with age-related but invisible disabilities were the ones most likely to say that they had not encountered barriers. The most common barrier was the attitudes of others and the most common response to overcoming them was to ignore them. However, there can be no doubt that the attitudes of others have at one time or another offended the informants.

Almost all of the informants shared their thoughts and feelings with whānau members in their households, especially their spouses. One lived alone and preferred to talk to her nurse, and another who lived with her children preferred to talk to her friends. All of them felt that their views were respected. None of them felt they had difficulties communicating their views and even Mark, who is unable to speak, could communicate his views in a manner in which his family could understand.

However, some had experienced difficulty in communicating with government agencies that had a significant impact on their lives, such as Work and Income and the Accident Compensation Corporation. Their response was to “arm” themselves with knowledge and information in order to “fight” with the relevant agency or to give up and lose access to resources. Although communication was not a problem area for the informants, whānau members within the household were the first ones called upon for support if any of the informants had difficulty dealing with government agencies.

Three of the five informants in the 50-plus age groups owned their own homes and a fourth lived in a home owned by her whānau. Conversely, only one whānau in the younger age groups owned their own home. The proportion of income spent on rent or mortgages was within the range of a quarter to one-third. All but two of the informants lived in households with other whānau members, usually their nuclear family. Most of them were forced to accommodate an unmet need that prevented them from moving around their homes easily and many also had some aspect of daily household living that was difficult for them to do by themselves. Whānau members within the household dealt with household tasks that the informants could not do and this does not appear to have been an issue since every person contributed to the household in some way. For example, paying for things was a shared responsibility within households. The most common feature of their responses was their capability for living independently and handling most situations within their households.

6.0 ELEMENTS OF WHĀNAU WELLBEING

Whānau wellbeing was the second dimension of the *Tatau Tatau* framework used during interviews. Informants were asked for their views on five elements of wellbeing that were common amongst Māori health and wellbeing models as factors that might help or hinder whānau wellbeing. These elements were manaakitanga (caring for others), tatau tatau (sharing), wairuatanga (spirituality), mana tiaki (guardianship responsibilities) and ngā taonga tuku iho (customary and inherited resources).

6.1 MANAAKITANGA/CARING

Manaakitanga was described to informants as caring for other people and they were asked whether this was important to them and their whānau. Most believed it was important but a couple gave cautious responses:

Koro: Yeah, it is to me; it might not be to others.

Molly: Yes, it is.

Riria's mother: Yes.

Nati: Yes, disability or not. We always have people calling in here; kapa haka whānau, school whānau, our own whānau, not only them coming to us but us going to them.

Wi: I think it's important to know how they are, just making sure they're Ok.

Mark's mother: Oh yes, definitely. My husband and I believe that if you're gonna look after anyone you've gotta look after yourself first. Once you've got yourself sorted out you can help other people.

Hera: Yes, all depends but gotta be careful with others. There are institutions they can go to and I can put them on the right track.

Hone: In a way yeah, to a certain point.

Kuini: Ah well, if I'm not feeling too good I just get my daughter over and vice versa. We look after one another.

6.2 TATAU TATAU/SHARING

This concept has broad connotations from a belief that personal property and ownership does not exist to sharing everything with others. The concept was described to informants as sharing responsibility for each other and they were asked whether they, and their whānau, were responsible for each other. However, the informants were already familiar with the concept and their responses reflect their understanding of it. All of them believed that being responsible for one another was important:

Hera: Yes.

Hone: Yes, it's just a natural thing.

Hone's sister: That's how our parents did it.

Hone: It's how we were brought up.

Koro: Yeah, I'm very protective of my kids.

Mark's mother: Definitely.

Molly: I do.

Nati: Yes, communicating with each other and how we're all getting on, keep in touch not only with my own immediate whānau but with the wider whānau.

Riria's mother: Yes.

Wi: Yes.

Kuini: Well yeah, her [daughter] and I do that. If she hasn't got, well I give, if I've got it I give it to her.

Kuini's daughter: And if I've got it I give it to her.

Kuini: Yeah, I mean we look after one another, so it's you know, it's just like if we're sick, if one's down the other one will go over, if I'm not feeling too good she comes over and the same as tatau tatau really eh, there's tatau tatau there too you know, if she's short on something well I'll get it if I got it. I give and vice versa. There's only tatau tatau between the two of us, no tatau tatau out, ah you know, outside of that.

6.3 WAIRUATANGA/SPIRITUALITY

After the interview schedule was trialed, this concept was changed from the broad notion of spirituality to incorporate the two previously separate elements of waiora, a concept that links wellbeing to the external/natural world, and mauri ora, a concept relating to one's life essence, inner strength and vitality. Informants were first asked how important spirituality was to them and their whānau. Their interpretation of spirituality included Christianity and religious beliefs as well as Māori spirituality. Hera was the only churchgoer but most of them acknowledged its importance in their lives if not in their everyday living:

Hera: Very important, it goes hand-in-hand with our household and that.

Hone: It's within me and all the ones I stay with have it as well.

Koro: It is to me because we've always had the wairua, without the wairua and without the Lord there's nothing to guide me.

Mark's mother: A hundred percent; all goes hand-in-hand.

Nati: To us it's always been a part of our existence, our wairua. Psychologists would say you're nuts but wairuatanga has always been a part of being Māori and Pākehās have a problem understanding it. It's not a problem with us, we always remember those who through them made us exist today and we wouldn't have these genes, these qualities we have today.

Wi: It keeps me happy.

Wi's wife: It's very important, he knows what sort of background I come from so we try to keep fishing about to really learn our tikanga Māori side, our wairua, so it's starting to become really important as we learn.

Kuini: I wouldn't say it's important you know, but I wouldn't ignore it but I wouldn't call it a ... not for everyday living I suppose, that's one way of putting it. I mean it's there sort of, but I wouldn't make it a priority.

Molly: Even though I have nothing to do with it I do believe it is important.

Riria's mother: Could improve.

Informants were then asked whether their Māoritanga was a source of strength for them and their whānau. This was the key question drawn from the concept of mauri ora and was intended as an enquiry about whether who they are and where they came from was a source of inner strength for them. All of them said that it was:

Hera: Yes, very much so, it identifies who I am and what I am. The things we do. My whānau isn't just myself, my children and grandchildren, it's extended whānau and it's all wellbeing.

Hone: Yup, but I'm still learning it.

Hone's sister: He might be still learning it but he lives it every day.

Koro: My own whānau are pretty Pākehā-fied ... I'm a bit different from the rest of the family and they tried to change me. They want me to transform to them, to their ways but my ways are not their ways...

Interviewer: Do you think your way and your consistency, like staying with being Māori and wairua Māori – like you look at it now at age 60 and you look at their lives, do you think you have a stronger wellbeing, a stronger sense of who you are?

Koro: Yeah, one of my brothers now, he's the tuakana of our family because the other one died. They've never really asked me to do anything. When we had my mother's unveiling my brother asked me to take the karakia, to take the service.

Interviewer: And that would've meant a lot?

Koro: Yeah, to me it was about honour and I did a korero on one of the Ten Commandments about honouring your parents and the land of the living. Even though they're dead you go and have a karakia with them.

Kuini: Yeah, I think it is in some way like ... when I was crook there I sent the kids up to the farm to get that dirt. Yeah, well that helped me a lot because I believed in it...

Mark's mother: Oh yes, very much, because it's all part of identity and you need to know where you're from to feel comfortable and know your place in the world, especially with a child with an impairment like Mark, he feels wanted and part of because he knows he's from the same lineage.

Molly: I really haven't been involved that much in Māoritanga but now the interest is there now ... I believe that it is important for your whānau.

Nati: My Ngāti Poroutanga is, my Māoritanga comes second. It's our history who and what we are, our reo.

Riria's mother: Tikanga yup, try and teach my kids.

Wi: Yes.

Interviewer: How is it a source of strength?

Wi: It touches on what I am instead of who I am.

The last question in this segment was "Do you think your relationship with the land, sea and other environments affects your wellbeing and that of your whānau?" This question was developed from the concept of waiora referring to land, water and the physical world and its influence on one's wellbeing. All but one believed that the natural world affected their wellbeing. Two mentioned its effect on their physical wellbeing but the others spoke of its effect on their spiritual and psychological wellbeing, that is, their connection to the world and their peace of mind:

Hera: Yes, because that's who we are, we're kaitiaki [caretakers] of our land, sea and natural resources. On top of that we are descendants from the gods, we have our whakapapa coming from the gods down and they're a part of us.

Hone's sister: It does, our turangawaewae, home is home, one day we're going to be buried there, we'll go back to where our parents are buried.

Hone: To me around here, not really, but if I was back home in my own turangawaewae, well, it's different again because home is home, our history is there and when it comes to things like the sea you go and collect kaimoana off the place and feed the family.

Hone's sister: See, we whakapapa [connect genealogically] to the place, take that away and who are we?

Kuini: Yeah, I suppose it does, yeah the weather does, yeah, well I know with me, mine is I can't stand the winter, oh never could eh, because I can't stand the cold.

Kuini's daughter: And she likes her plants around her.

Kuini: Yeah, well, I like living things around me you know, like plants and that, that's all I can say about that one, yeah, and I think that's with everybody though, how they react.

Mark's mother: Oh yes, totally, what has been handed down from ancestors, it's a respect thing. If you respect things you will be treated with respect. That helps you with the general things in life. It's part of nature, you look after things, it is part of the basic things in life.

Koro: No, because Papatūānuku [earth mother] is kua mate [dead] to me. I see the rising of the Lord that's alive. All things that pass away become anew. It's not a big thing for me. See with me I hop onto the paepae, I stand there in the name of Jesus and nobody else because the wairua is still alive in Jesus' spirit. My maunga [mountain] is Calgary even though I have a maunga in Taumarunui which is Tongariro.

Molly: Yes, I do, because I believe that if the land and sea and everything else is free of contamination it will be well for me, my family and everybody, but if it's polluted then it's not good for our wellbeing.

Nati: Sort of. The land will always be there like our whānau house, it's taking care of itself.

Riria's mother: Yes, like the sea, freedom, peaceful, relaxing, tranquility.

Wi: It affects our ideas, thoughts and actions. Gives me a sense of who I am and where I came from, it's good to be free, especially when I relax on the beach, just getting in touch, it's very busy here in the city.

6.4 MANA TIAKI/GUARDIANSHIP ROLES

Mana tiaki refers to the guardianship of one's cultural heritage such as turangawaewae (indisputable land base), tikanga (custom), whakapapa (genealogy) and so on. Informants were asked whether they held any cultural knowledge that they passed on to the rest of the whānau. All but one felt they were already passing on knowledge or would in the future:

Hera: Yes, and what my parents and grandparents have taught me but it's only some people of the whānau that will grasp it. I can't say this is meant for you or you but you know how some are meant to have that knowledge and some of your whānau is not meant to have that knowledge. It will stick with them.

Hone: Yeah, I suppose I do, it's there inside.

Hone's sister: It's sharing, we go to wananga together; there'd be about 20 of us in the same whānau at the wananga, sharing together.

Interviewer: You talked before about your brother ... have they given you the role of cultural knowledge and guardianship of that?

Koro: Yeah, to me it is because they're not really Māori; their thoughts are not.

Interviewer: Do you think they're losing it in the whānau?

Koro: They've never really had it. They've only just woken up since the old lady passed away.

Interviewer: What about cultural knowledge, have you personally got any that you pass on to the whānau?

Koro: My kids, they know. I've got three boys that speak the reo.

Kuini: Well, I have to [her granddaughter].

Kuini's daughter: Yeah, [Kuini's passed on] history about the family where we come from, she's always talking about her grandmother.

Kuini: Well, my way of looking at it you see, I mean I talk to my daughter a lot about my parents, my grandparents and all that. I mean it'd be good for her, I think it's important, good to know, because when I die she's not going to know anything, eh. This way she's got a fair idea where her grandparents come from, her great-grandparents come from, who they were, yeah, I think it's important.

Kuini's daughter: Yeah, gives me a sense of belonging, identification, eh.

Molly: No, I got no guardianship of cultural knowledge, I got hardly any knowledge at all when it comes to Māori but I believe it's important when it comes to wellbeing. Now that I'm going to te ara reo I'm starting to learn things now that I've never been interested in and I do believe that this is something very important to all – that we should have some knowledge that we can pass on to our offspring.

Nati: Oh yes, to my son and granddaughter, it'll be given to them in book form and audio media, photos, korero [speech]. My grandchildren are the most delightful things in my life. It's the extended whānau too, who feed them, so it's the sharing of knowledge.

Riria's mother: I think it's important.

Wi: Cultural knowledge, general for our own and I'm still learning that sort of thing.

Wi's wife: 'Cos we're still young.

Interviewer: Do you envisage holding any cultural knowledge?

Wi: Yes.

6.5 NGĀ TAONGA TUKU IHO/INHERITED RESOURCES

This element referred to the same resources mentioned in the previous concept that derived from their cultural heritage and that the informants had inherited. They were asked whether having or not having inherited resources like land shares affected them and their whānau. All of the informants focused most on land shares and most of them had inherited shares. Most felt that having inherited resources was important, two were unconcerned at having them and one was unconcerned that she did not have them. Only one felt that having them hindered the wellbeing of her whānau:

Hera: That's my whānau's turangawaewae, that's their right. We're kaitiaki for the next generations and if they're ever in the wide world they got somewhere to come home to.

Hone: Probably not, I think we're pretty well alright, that's just me, having it.

Koro: That doesn't bother me because we're only kaitiaki.

Mark's mother: Oh definitely, because of ancient teachings and because of today. Like what dad's trying to do, keeping the hapū together, he has a lot of responsibilities that the average Joe Bloggs doesn't have and he gets pressured and stressed quite a bit and that's where us children try to make it a lot easier for him. And that's regarding our land, our rivers.

Molly: No, I don't think it does. From personal experience both my sons, he's my eldest and myself, have land shares from his father. But because of all the bitterness concerning the shares I haven't taken much time to have it passed over to him because what's the point when you just fight about. So no, I don't think having them is going to help me or my family, it's just going to make us bitter against others who have taken them off us.

Nati: It does, especially Māori. If you're landless you're nothing. So land is important but it's also identity, knowing who and what you are. First you are Ngāti Porou, second you are Māori.

Riria's mother: Doesn't bug me that I don't have them; I'm a girl and I've already been told that I'm out. Kids can get funding.

Wi: Yes, it depends who's got it. It's no biggie. We get a big cheque of \$50, yeah, thanks.

Interviewer: Having those resources, is it positive or negative?

Wi's sister: It's our identity.

Wi: A strength, if you have them.

Wi's sister: Our turangawaewae, a place to stand, stand our ground.

Interviewer: So there's something other than the monetary?

Wi: Yeah, it's more than the money, it's never bound up with money.

6.6 DISCUSSION

Whilst the questions for this dimension of the *Tatau Tatau* framework were esoteric in nature compared to the first dimension on personal wellbeing, the informants were easily able to make connections to their lives and beliefs. All five elements were considered to be important for whānau and personal wellbeing but few could explain them in terms of everyday living. Instead, most of the elements tended to underpin informants' everyday living and help shape their actions. This dimension relied to a large extent on the informants' understanding of Māori values and beliefs so their responses indicated whether they held such values or agreed with such beliefs. The overarching impression was that the informants had a strong sense of identity as well as a spirituality that influenced their everyday lives. This dimension showed that the concept of caring was intrinsic to whānau wellbeing whether it be caring for oneself, whānau, environment or whānau resources.

7.0 THE ROLE OF WHĀNAU IN THE LIVES OF MĀORI WITH PHYSICAL DISABILITIES

The *Tatau Tatau* framework was used to examine the wellbeing of whānau when one or more of its members live with a disability. Aside from the components for each dimension of personal and whānau wellbeing, there were other key considerations that the framework needed to allow for, including the diverse realities of Māori, whānau and people with disabilities, as well as an holistic view of whānau lifestyles. The main assumption for the framework was that of linking whānau wellbeing with cultural identity, an assumption inherited from the base Māori models from which the *Tatau Tatau* framework was drawn. These particular aspects of the framework are discussed in more detail below in relation to the findings of the research.

7.1 DIVERSE REALITIES

The diverse realities of people with disabilities were evident when this research was compared with that carried out by the National Advisory Committee on Health and Disability (2003) on people with intellectual disabilities. Elements of the NHC's information-gathering model concerning participating in the community, work, having fun, learning, moving around, relationships, communication, accommodation, and paying for things, were incorporated into the *Tatau Tatau* framework. For the most part, this research was at the opposite end of the scale to the NHC report in terms of responses. Whilst all groups were disadvantaged to some extent, people with intellectual disabilities were more severely disadvantaged compared to people with physical disabilities. The informants in this research led independent lives, had interdependent relationships, were articulate, were easily participating in the community and were confident in their ability to address any issues and barriers encountered. However, our research is indicative only due to the small sample of informants and the different methodology used. Further research would be required to gain a more comprehensive picture of diverse realities for people with disabilities.

The diverse realities of Māori also require further research. The *Tatau Tatau* framework was designed so that the responses of sub-groups within Māori society could be compared and this awaits future studies. As stated at the beginning of this report, the objectives for this research were to identify:

- > whether the whānau is the primary or secondary social and economic unit in the lives of Māori with disabilities
- > the part that whānau play in the lives of Māori with disabilities
- > the factors that help and hinder the wellbeing of whānau when a member has a disability.

A particular focus of this research was to confirm or disprove the hypothesis that the household was the primary unit in the lives of Māori with disabilities. This contrasted with common perceptions that the whānau was the primary unit (Benton 2002; Cunningham et al 2005) and was a possible factor that distinguished Māori with disabilities within Māori society. Our research confirmed the hypothesis but was qualified by the fact that the household usually comprised members of the whānau. Nikora et al (2004) referred to this subtle shift in perception as one that could be viewed either as the household being positioned as more important than whānau in the everyday lives of Māori with disabilities or that the household could be seen as a significant unit within the wider whānau. Responses from most of the informants indicated that they held the latter view. The clearest indication that the household was more significant than whānau became apparent when talking to those who did not live with whānau members.

Informants moved between notions of household, whānau and family in such a manner that the differences between the three were discernible. Although the differences were subtle, the household, whānau and family were not used interchangeably but to distinguish certain conditions. Family was used when referring to the immediate or nuclear family only. The household referred to those living in the same house, including whānau members. Whānau, on the other hand, could be described in broad strokes to incorporate family and household, relatives and non-relatives. Whānau could mean members of the same family living in the same household, living nearby or living in the whānau's tribal homeland, as well as members of the one household, whether or not they were related. Relatives from a common ancestor of at least three generations earlier were also described as whānau. These

distinctions lend further insight into the diverse usage of the whānau concept and raise the possibility that the statistical whānau type (that is, the tendency to use family, household and whānau interchangeably) is an inaccuracy. Despite the household being the more important unit in everyday living for people with disabilities, the whānau was an all-encompassing concept for the informants and therefore more important in life generally.

7.2 EVERYDAY LIVING AND THE ROLE OF WHĀNAU

Overall, whenever the informants needed help, most of them called upon the whānau members living within their household, then other whānau members. Other people they might call upon included non-whānau members in the household, friends, health professionals and support services. Most of these groups of supporters represented, in effect, informal carers for the person with a disability, although such was the nature of the relationships that few saw themselves as such. Instead, they viewed the relationship as mutual support, friendship or the normal duty of whānau to care for each other.

The role of whānau was not solely as helpers, supporters or advocates for Māori with disabilities. Whānau members were friends, companions, students and teachers, and had roles across a broad spectrum of relationship types. The significant factor for Māori with disabilities was that they looked first within their whānau for such relationships. Further research would be required to determine whether this is the case for Māori generally or is another factor that distinguishes Māori with disabilities.

7.3 WHĀNAU WELLBEING AND IDENTITY

The strength of the informants' identity and that of their whānau proved to be the underlying factor that ensured whānau wellbeing. Informants drew strength from their cultural heritage, peace of mind from Māori spirituality, a sense of connectedness from Māori customary resources, and a deep respect for people from the values they inherited from their whānau and tupuna (ancestors). A certain level of disruption in this strength of identity was evident amongst a small number of informants and caused a corresponding obstacle to the wellbeing of their whānau.

7.4 FURTHER RESEARCH

Our fervent hope is that this project is a precursor to more comprehensive research on the role of whānau in the lives of Māori with disabilities and not the sole contribution to that area of inquiry. We encountered large gaps in what is known about Māori with disabilities as well as in the role of whānau. Although the Ministries of Social Development, Education, Health and Māori Development (Te Puni Kōkiri) have undertaken some research on whānau development, much of this work is yet to find its way into the public domain. The following list indicates the areas in which we discovered a lack of research and serves as a list of suggestions for areas of further research:

- > the diverse realities of people with disabilities
- > the impact of culture on the lives of people with disabilities
- > the factors that distinguish Māori with disabilities within Māori society
- > the roles that whānau members have in the lives of Māori with disabilities
- > the roles that whānau members have in each other's lives generally
- > evidence that the elements in Māori wellbeing models are necessary prerequisites to personal and whānau wellbeing
- > models of whānau wellbeing that take into account the diverse realities of Māori.

REFERENCES

- Ashwell, A., Ridwell, S., & Thompson, K. (2004). *Evaluation of the whānau carers training programme delivered by Life Unlimited*. (Report): Māori & Psychology Research Unit, University of Waikato, Hamilton.
- Benton, R. (2002). *Wellbeing and disparity in Tamaki-Makaurau*. Te Puni Kōkiri, Wellington.
- Bishop, R. (1996). *Collaborative research stories: Whakawhānaungatanga*. Dunmore Press, Palmerston North.
- Borrell, B. (2005). *Living in the city ain't so bad: Cultural diversity of South Auckland rangatahi*. Unpublished MPhil Thesis, Massey University, Palmerston North.
- Cunningham, C., Stevenson, B., & Tassell, N. (2005, May). *Analysis of the characteristics of whānau in Aotearoa. A report prepared for the Ministry of Education*. Retrieved February 2006, from www.minedu.govt.nz/web/downloadable/dl10524_v1/characteristics-of-whānau-31-may-2005-final.pdf
- Durie, M. (1994). *Whaiora: Māori health development*. Oxford University Press, Auckland.
- Durie, M.H. (1995). *Ngā matatini Māori: Diverse Māori realities*. Te Pumanawa Hauora, Palmerston North.
- Durie, M. (1999a). 'Te pae mahutonga: A model for Māori health promotion'. [Electronic version]. *Health Promotion Forum of New Zealand Newsletter*, 49.
- Durie, M.H. (1999b). 'Kaumatautanga reciprocity: Māori elderly and whānau'. [Electronic version]. *New Zealand Journal of Psychology*, 28(2):102.
- Durie, M.H (2003) *Ngā Kahui Pou Launching Māori Futures*. Huia Publishing, Wellington.
- Durie, M. (2005, June). *Whānau as a model for early intervention in conduct disorder*. Paper presented at the Severe Conduct Disorder Conference, Wellington.
- Edwards, S., McManus, V., & McCreanor, T. (2005). 'Collaborative research with Māori on sensitive issues: The application of tikanga and kaupapa in research on Māori sudden infant death syndrome'. *Social Policy Journal*, 25:88-104.
- Hohepa, P. (1978), 'Māori and Pākehā: The One People Myth'. In M. King (Ed.), *Tihe Mauri Ora* (pp. 98-111). Hicks Smith, Wellington.
- Kingi, J., & Bray, A. (2000). *Māori concepts of disability*. Donald Beasley Institute, Dunedin.
- Metge, J (1995). *New growth from old: The whānau in the modern world*. Victoria University Press, Wellington, New Zealand
- Metge, J. (1999). 'Changing whānau structures and practices'. In Te Pumanawa Hauora (Ed.), *Proceedings of te hua o te whānau – whānau health and development conference*. Te Putahi-a-Toi School of Māori Studies, Massey University, Palmerston North.
- Ministry of Health. (2001). *The New Zealand disability strategy. Making a world of difference: Whakanui oranga*. Author, Wellington.
- Ministry of Social Development. (2004). *New Zealand families today. A briefing for the Families Commission*. Author, Wellington.
- Mirin-Veitch, B., Bray, A., & Watson, M. (1997). "'We're just that sort of family": intergenerational relationships in families including children with disabilities'. *Family Relations*, 46(3):305-311.
- Moeke-Pickering, T. (1996). *Māori identity within whānau: A review of literature*. Retrieved February 2006, from <http://wfass-trinity.fass.waikato.ac.nz/docushare/dsweb/Services/Document-1051>

- Munford, R., & Sanders, J. (1999). *Supporting families*. Dunmore Press, New Zealand.
- National Advisory Committee on Health and Disability. (2003). *To have an 'ordinary' life: Kia whai oranga 'noa'*. Retrieved February 2006, from www.nhc.govt.nz/publications/PDFs/NHCOrdinaryReport.pdf
- Nikora, L., Karapu, R., Hickey, H., & Te Awekotuku, N. (2004). *Disabled Māori and disability support options. A report prepared for the Ministry of Health*. Retrieved February 2006, from <http://wfass-trinity.fass.waikato.ac.nz/docushare/dsweb/Get/Document-1071/MāoriDisability.pdf>
- Office for Disability Issues. (2005). *Work in progress 2004-2005. Fifth annual report from the Minister for Disability Issues to the House of Representatives on implementing the New Zealand Disability Strategy* (Report). Author, Wellington.
- Palmer, S. (2004). 'Homai te waiora ki ahau: A tool for the measurement of wellbeing among Māori – the evidence of construct validity'. [Electronic version]. *New Zealand Journal of Psychology*, 33(2).
- Pere, R. (1991). *Te wheke: A celebration of infinite wisdom*. Ao Ako, Gisborne.
- Rangihau, J. (1977). 'Being Māori'. In M. King (Ed), *Te Ao Hurihuri: The world moves on: Aspects of Māoritanga*. Hicks Smith, Wellington.
- Rialland, A. (nd). *Models of disability: Keys to perspectives*. Retrieved February 2006, from http://akmhweb.org/ncarticles/models_of_disability.htm
- Ritchie, J. (1992). *Becoming bicultural*. Huia Publishers/Daphne Brasell Associates Press, Wellington.
- Rua, M., Faull, K., Parata, K., Haereroa, M., Ansley, C., & Wihongi, H. (1998). *Evaluation of Māori access to disability support services – Literature Review* (No. 2). Māori & Psychology Research Unit, University of Waikato, Hamilton.
- Smith, G. (1995). 'Whakaoho whānau ohanga: The economics of whānau as an innovative intervention into Māori cultural and educational crises'. *He Pukenga Korero: A Journal of Māori Studies*, 1(1):18-36.
- Te Puni Kōkiri. (2003). *Proceedings of whakapumau whānau: Whānau development national hui*. Author, Wellington.
- Te Puni Kōkiri. (2004). *New Zealand disability strategy implementation work plan 1 July 2003 – 30 June 2004* (Report). Author, Wellington.
- Walker, R. (1989). 'Māori Identity'. In Novitz, D. and Willmott, B. (Eds.), *Culture and Identity in New Zealand* (pp.35-52). Government Printer, Wellington.

APPENDIX 1

The *Tatau Tatau* Framework and Māori Models of Health, Wellbeing and Whānau

COMPONENTS	Whare Tapa Wha	Te Wheke	Ngā Pou Mana	Gallery of Life	Te Pae Mahutonga	Homai te Waiora ki Ahau	Whakapiripiri Whānau	NHC Information Gathering Model
Whanaungatanga	Taha whānau (family)	Whanaungatanga (extended family relationships)	Family	Whānau	Whanaungatanga	Whanaungatanga	Tatau Tatau (collective responsibility) Manaakitanga (caring)	Relationships
Tatau tatau						Toiora (healthy lifestyles)		
Manaakitanga								
Mana		Mana ake (individual uniqueness)			Mana whakahaere (autonomy)	Mana	Whakamana (enablement)	
Te Oranga				Taha tangata (social realm)	Te Oranga (participation in society)	Te ao hou (modern world) Ngā Manukura (leadership)	Whai whaitanga (participation)	Community participation
				Pakehātanga (non-Māori ways of life)		Tikanga Pākehā		Income Work Learning Fun
Hinengaro	Taha hinengaro (thoughts and feelings)	Hinengaro (communicating thoughts and feelings) Whatumanaawa (expressing emotion)		Hinengaro		Hinengaro		Communicating
Taha tinana	Taha tinana (physical side)	Taha tinana (physical health)		Tinana		Tinana		Looking after yourself Moving around Accommodation
Wairuatanga	Taha wairua (spiritual side)	Wairuatanga		Wairua		Wairuatanga		
		Mauri (life essence)			Mauri ora (access to te ao Māori)	Mauri		
		Waiora (total wellbeing)			Waiora (environmental protection)			
Ngā taonga tuku iho	Ha a koro ma a kui ma (breath of ancestors)	Te ao turoa (physical world)	Taonga tuku iho (cultural heritage)	Māoritanga (Māori way of life)		Te ao tawhito		Culture
Mana tiaki			Turangawaewae (indisputable land base)	Taha tikanga (cultural protocols)		Tikanga Māori	Mana tiaki (guardianship)	
				Taha whenua (land)		Whenua		

APPENDIX 2

Tatau Tatau Framework of Whānau Wellbeing

1.0 Personal wellbeing and the role that whānau play in the individual's everyday life

- 1.1 WHANAUNGATANGA (Family, Relationships)**
The type of relationship that key informants have with their whānau
- 1.1.1 Where are you and your whānau from?
 - 1.1.2 How many generations are in your whānau (1 /2 / 3 or more)?
 - 1.1.3 How many generations of your whānau live with you?
 - 1.1.4 How many of your whānau live near you (all, many, several, some, a few, none)?
 - 1.1.5 How would you describe your relationship with your whānau?
 - 1.1.6 Is having whānau around you important for personal wellbeing?
 - 1.1.7 Which do you consider has the biggest role to play in your everyday life, your whānau or your household?
- 1.2 MANA (Whakamana, Mana whakahaere, Enablement, Control)**
The mana of key informants within their household and whānau
- 1.2.1 Who is the decisionmaker in your household?
 - 1.2.2 Who has mana in the whānau and why?
- 1.3 TE ORANGA (Whai wahitanga, Participating in society, Being part of the community)**
The key informants' opportunities and barriers to participating in the community and the support they use, their household or whānau
- 1.3.1 What community activities are you involved in?
 - 1.3.1.1 · Paid work
 - 1.3.1.2 · Unpaid work
 - 1.3.1.3 · Studying
 - 1.3.1.4 · Fun, recreation and sport
 - 1.3.1.5 · Marae, hapū and iwi activities
 - 1.3.1.6 · Church
 - 1.3.2 What mode of transport do you use to get around?
 - 1.3.3 Who helps you most to take part in the community?
 - 1.3.4 What barriers have you encountered and how do you overcome them?
- 1.4 HINENGARO (Thoughts and feelings, Communication, Mentality)**
The key informants' ability to communicate their thoughts and feelings effectively; Are their views valued or disregarded and by whom
- 1.4.1 Who do you share your thoughts and feelings with most often?
 - 1.4.2 Do you feel that your views are listened to?
 - 1.4.3 Who do you need help to communicate with?
 - 1.4.4 Who do you get help from when you need it?
- 1.5 TAHA TINANA (Physical health, Looking after ourselves)**
The support mechanisms that key informants use to look after themselves, their household and their whānau
- 1.5.1 What type of housing do you live in eg rental, own home, with whānau?
 - 1.5.2 Who else lives there?
 - 1.5.3 Can you move around your home comfortably?
 - 1.5.4 How do daily household tasks get done eg cooking, cleaning, lawnmowing?
 - 1.5.5 Who pays for things in your household?
 - 1.5.6 Do you need any help to take care of yourself, your whānau and your household? Who do you ask?

2.0 The factors that help and hinder whānau wellbeing

- 2.1 MANAAKITANGA (Toiora, Caring for others, Protecting, Nurturing, Promoting wellbeing, Minimising risk-laden behaviour)**
Is caring for others seen as important for whānau wellbeing
2.1.1 Is caring for other people important to you and the whānau?
- 2.2 TATAU TATAU (Tohatohatia, Reciprocity, Sharing, Expectations, Obligations)**
Is sharing responsibility for each other seen as important for whānau wellbeing
2.2.1 Do you think you and your whānau are responsible for each other?
- 2.3 WAIRUATANGA (Spirituality, Mauri ora, Access to te ao Māori, Inner strength and vitality, Waiora, Relationship with the environment and external world, Psychological wellbeing)**
Is wairuatanga important for whānau wellbeing
2.3.1 How important is spirituality for you and your whānau?
2.3.2 Is your Māoritanga a source of strength for you and your whānau? How?
2.3.3 Do you think your relationship with the land, sea and other environments affects your wellbeing and that of your whānau? How?
- 2.4 MANA TIAKI (Pupuri taonga, Whakatakoto tikanga, Whakatakoto tutoro, Guardianship)**
Do the key informants have a role in guardianship of the cultural knowledge of their whānau and is this important for whānau wellbeing
2.4.1 Do you hold any cultural knowledge that you pass on to the rest of the whānau? Is it important for the whānau to do this?
- 2.5 NGA TAONGA TUKU IHO (Ha a koro ma kui ma, Te ao turoa, Turangawaewae, Cultural heritage, Ties with land, Inherited resources)**
Does the possession of customary resources impact on whānau wellbeing
2.5.1 Do you think that having / not having inherited resources like land shares affect you and your whānau? How?

Blue Skies Research

- 1/06 *Les Familles et Whānau sans Frontières: New Zealand and Transnational Family Obligation*, Neil Lunt with Mervyl McPherson and Julee Browning, March 2006.
- 2/06 *Two Parents, Two Households: New Zealand Data Collections, Language and Complex Parenting*, Paul Calister and Stuart Birks, March 2006.
- 3/06 *Grandfathers – Their Changing Family Roles and Contributions*, Dr Virginia Wilton and Dr Judith A. Davey, March 2006.
- 4/06 *Neighbourhood Environments that Support Families*, Dr Karen Witten, Liane Penney, Fuafiva Faalau and Victoria Jensen, May 2006.
- 5/06 *New Communication Technologies and Family Life*, Dr Ann Weatherall and Annabel Ramsay, May 2006.
- 6/06 *Families and Heavy Drinking: Impacts on Children's Wellbeing, Systematic Review*, Melissa Girling, John Huakau, Sally Casswell and Kim Conway, June 2005.
- 7/06 *Beyond Demography: History, Ritual and Families in the Twenty-first Century*, Jan Pryor, June 2005.
- 8/06 *Whānau is Whānau*, Tai Walker, Ngāti Porou, July 2006.
- 9/06 *Supervised Contact: The Views of Parents and Staff at Three Barnardos Contact Centres in the Southern Region of New Zealand*, Anita Gibbs and Margaret McKenzie, August 2006.
- 10/06 *New Zealanders' Satisfaction with Family Relationships and Parenting*, Jeremy Robertson, August 2006.
- 12/06 *The Role of Whānau in the Lives of Māori with Physical Disabilities*, Adelaide Collins and Huhana Hickey, September 2006.

These reports are available on the Commission's website www.nzfamilies.org.nz or contact the Commission to request copies.

Families Commission
PO Box 2839
Wellington
Telephone 04 917 7040
Email enquiries@nzfamilies.org.nz

Wellington office

Public Trust Building, Level 5
117-125 Lambton Quay
PO Box 2839, Wellington
Phone 04 917 7040
Fax 04 917 7059

Email

enquiries@nzfamilies.org.nz

Website

www.nzfamilies.org.nz

Auckland office

Level 5, AMI House
63 Albert Street, Auckland
Phone 09 970 1700