

# Māori and Informal Caregiving

A Background Paper

Prepared for

The National Health Committee

by

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## EXECUTIVE SUMMARY

This paper seeks to provide insight into Māori informal caregiving by drawing upon relevant literature. Where available, comparisons have been made between Māori and non-Māori in order to explore any existing similarities or differences. Two parameters have been used to help distinguish between informal caregiving and naturally occurring phenomena in whānau and households: firstly, the recipient of care has a disability or chronic illness and secondly, the caregiving activities relate in some way to meeting the support needs associated with the disability or chronic condition. Responses from carers and care recipients have been used to make the distinctions. The paper focuses most on caregiving for Māori with disabilities because information on caregiving and Māori with chronic illnesses was limited.

Māori with disabilities have a strong preference for informal over formal support systems. Māori informal carers and care recipients suggested two approaches to understanding their situation and circumstances. One was to contextualise them within the social contexts through which they moved, from household to whānau, hapu, iwi and beyond. The other was to centre the person with a disability and encompass the people surrounding them, from those closest to them to those that helped generally. Both carers and care recipients agreed that the whānau was at the heart of informal caregiving relationships - thus Māori informal carers were often whānau carers. Whānau carers could be kin, as in whakapapa whānau, or people with a family-like commitment to a common interest, as in kaupapa whānau.

### **Informal caregiving roles**

Whānau carers played an integral role in care recipients' lives. They provided the necessary support that enabled care recipients to maintain their personal dignity and independence, live safely within their own homes, and participate fully in society.

### **Resources for whānau caregiving**

Whānau may have been resourcing caregiving as a collective. They were caregiving with limited material resources but a wealth of people resources and goodwill. Considering the proportion that was caregiving, their material resources were likely to be under severe pressure. Resources outside the whānau tended to be supplementary to those within the whānau.

### **The impact of caregiving on whānau**

A small amount of information existed on the impact of caregiving on carers, care recipients and whānau and was drawn from two key studies about carers and a third about kaumātua. Positive impacts for care recipients were associated with enhanced capabilities at home and in the wider community. Caregiving had a positive impact on carers' personal development and was perceived as strengthening whānau cohesiveness.

Negative impacts revolved around the strain placed on carers as well as whānau relationships and resources. Health impacts were difficult to determine because carers were not specifically aware of their own health, concentrating instead on the health of their care recipients. Mental health issues were the most frequently acknowledged potential impact because carers recognised that the stress of the work must inevitably affect their health in some way.

### **Support for whānau caregiving**

Whānau carers wanted to be able to obtain information so that they could access services and prepare for crises. A related issue was their need to develop advocacy skills especially with regard to obtaining entitlements and formal support as well as strategies for coping with the stress of the work and maintaining good health. Training programmes served as an effective means for skill development. Financial assistance was needed for caregiving generally and for transport in particular. Carers felt that the continued development of Māori service providers and easier access to Māori institutions would support them in their work.

## PURPOSE OF THIS PAPER

The objectives of this paper were to:

- a. provide a description of Māori informal caregiving and the participants in caregiving relationships, highlighting both commonality and diversity
- b. discuss whānau and the implied differences between Māori and non-Māori informal caregiving
- c. identify the impacts of informal caregiving on the lives, health and wellbeing of Māori informal caregivers
- d. provide an insight into the impact of caregiving for Māori and women
- e. identify barriers experienced by Māori informal caregivers to providing care
- f. identify the conditions necessary for caregivers to give best care to care recipients and any potential measures to remedy or mitigate negative health impacts, health inequality and unmet need.

# 1 APPROACH TAKEN

A key question in establishing the parameters of this paper was determining activities that qualified as informal caregiving. Two parameters were applied: one was that the recipient of caregiving was living with a disability or chronic illness, and the other was that the caregiving activities related in some way to meeting the support needs associated with the disability or chronic condition.

This paper focuses more on caregiving for Māori with disabilities because information on caregiving and Māori with chronic illnesses was limited.

## 1.1 Conceptual framework

Māori health models now inform health policies and the practices of many Māori health service providers.

The most notable in terms of this paper is Te Whare Tapa Whā (the four cornerstones of the house) comprising four components which, when applied to the whānau policy context, are:

- *te taha hinengaro*, which refers to the mental wellbeing of the whānau as well as each individual within it
- *te taha tinana*, which refers to the physical aspects of health as well as the physical symptoms of ill health
- *te taha wairua*, which is the spiritual health of whānau, and includes the practice of tikanga Māori in general
- *te taha whānau*, which refers to the whānau environment in which individuals live. It includes the cohesiveness of the whānau unit, the health of the environment created within the whānau (for example, whether it is safe and supportive), and the relationship of the whānau to its community.

Māori health models have not been designed to focus on sub-groups within Māori society (such as Māori with disabilities). However, it is relatively easy to fit whānau informal caregiving into the model. In addition, two health models that have congruence with whānau informal caregiving have been built more recently.

Collins and Hickey built on Māori health models to develop their model Tatau Tatau (Collective Sharing) specifically for Māori with disabilities and their whānau. Tatau Tatau was drawn from three areas: Māori health and wellbeing; whānau wellbeing; and a model for information gathering from people with disabilities. The model gauges the role of whānau in everyday life as well as aids and hindrances to whānau wellbeing.

Nikora and colleagues (2004: 65) developed a model of service provision to Māori with disabilities that contextualised the individual within a larger set of inter-related social contexts such as the household,

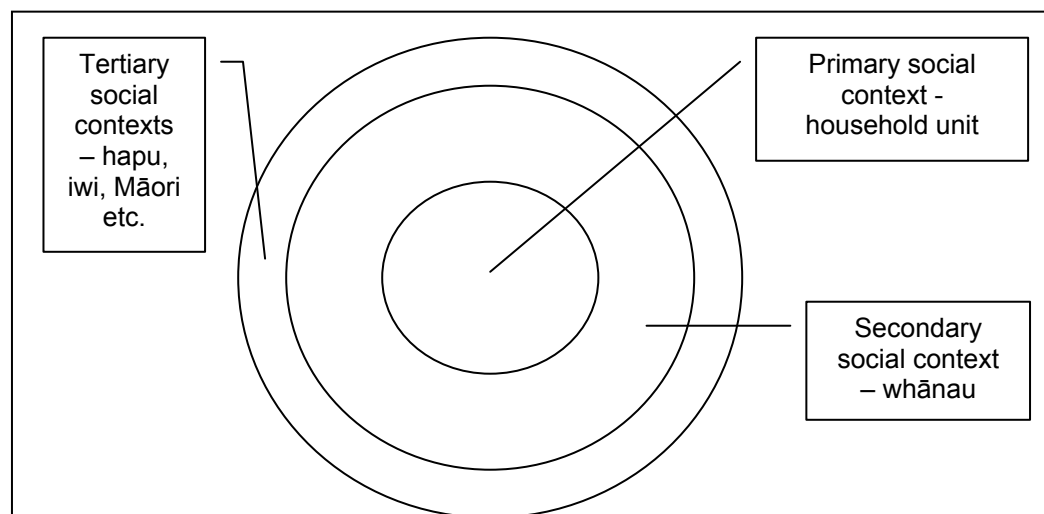
community and social environments. Within this analysis, the household is regarded as the primary context for Māori with disabilities.

### 1.1.1 Approaches to understanding Māori with disabilities and their whānau

Māori caregivers and recipients of informal caregiving suggested two approaches for improving the wellbeing of Māori with disabilities or chronic illness (Nikora et al. 2004; Collins and Hickey 2006). Both approaches involve consideration of the care recipient in their wider social context; but one could be considered an 'outsider' perspective and the other, a personal or 'insider' perspective.

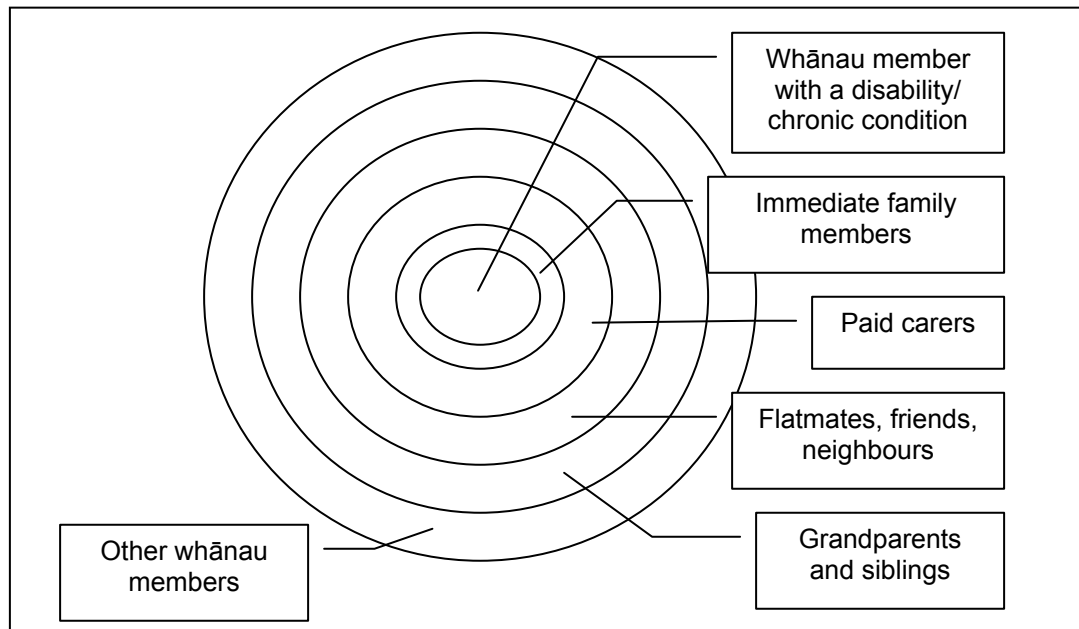
The outsider approach takes into account the social contexts that a person with a disability or chronic illness is likely to move through (Figure 1). Mapping can assist with identifying likely caregivers or other support systems and needs from within each context. The primary context is of most importance to those with health conditions requiring support, as it is the area from which personal, private support is drawn. Secondary or intermediary social contexts monitor the primary zone and can provide sources of finance and less intimate support. Tertiary zones are avenues of support for the primary and secondary zones (Nikora et al. 2004). A key feature of this perspective is that the household is the primary social context and the whānau is the secondary social context for Māori with disabilities (Nikora et al. 2004).

*Figure 1: Outsider contexts for Māori with disabilities*



The second, insider perspective involves centring the care recipient and mapping the layers of support that he/she might use, from frequently-used support to intermittent support (Collins and Hickey 2006). This approach more directly captures the support that surrounds a person, starting from those with whom they have close relationships (usually people with whom they live) and spreading outward (Figure 1). A key feature of this approach is that support from health professionals and other formal types of support are further removed from the care recipient and there are several layers of informal support in between.

*Figure 1: Insider contexts for Māori with disabilities*



Both approaches assume an holistic position viewing the care recipient as one of several dealing with the disability. From either perspective, treatment regimens could include using these contexts as part of the treatment, accessing these contexts in order to provide support for the care recipient or monitoring the health of the agents in the support system with the aim of early intervention should signs of ill health appear. Both approaches have been used as analytic tools to inform this paper.

## 1.2 Literature review

A systematic review of the literature was undertaken to locate relevant information on Māori informal caregiving using the parameters noted above. The review formed the body of work on which this paper was based. The literature search was limited to work published between 1995 and 2006 in seven subject areas: Māori caregiving and carers, Māori concepts and models, Māori health, Māori and disability, Māori education, whānau (including welfare), and Māori women. The selection criteria for sources was based on their relevance to disability or chronic conditions, caregiving and carers, and Māori perspectives of informal caregiving.

The same sets of keywords were applied to each subject search other than the Māori concepts and models search. The keywords were a combination of the words Māori and: homecare workers, carers, caregiving, care giving, caregivers, disability, disabilities, support, informal care, helping, healthcare, special needs, and training. The keywords used for the Māori concepts and models search were: Māori concepts, awhi, manaaki, tiaki, tuakana teina, aroha, tautoko, tatau tatau, and whanaungatanga.

The databases searched included all of the New Zealand university library catalogues, INNZ, the National Library and Google Scholar, which includes subscription-based online journals. Sources that appeared to be relevant were entered into the Endnote bibliographic database software.

Two assessment tools were used to rate the relevance and report quality of each source. The quality of the subject matter was not assessed. Those rated as having medium to high relevance to Māori caregiving and moderate to strong report quality were selected for review. The sources rated with low relevance to Māori caregiving but moderate to strong report quality scores were used as supporting sources if they had high relevance to a specific sub-topic such as Māori concepts. Of an initial selection of 89 sources, ten were reviewed fully and 37 were used as supporting publications. The remainder were deemed to be too low in relevance for the purposes of the paper.

### **1.3 Outline of the paper**

The next chapter attempts to provide a comprehensive definition of whānau. This will present a number of working definitions of whānau that are often held in tension. This will assist non-Māori to have a clearer understanding of whānau such that any policy and discussion is relevant.

Chapter three of this paper describes some Māori perspectives of informal caregiving; chapter four outlines some of the roles that carers assume and explains some of the impacts of caregiving on carers and their whānau (including barriers they experience); and chapter five discusses some of the support available for whānau caregiving. Chapter six is a summary of the literature review. The final chapter draws some conclusions and highlights some themes that emerged, as well as the gaps in knowledge.

## 2 DEFINING WHĀNAU

### 2.1 Introduction

It is important to provide a context for informal caregiving amongst Māori. Informal caregiving is undertaken by whānau, however defined. Therein lies the crux of the problem in terms of understanding. Māori definitions of what constitutes whānau may differ significantly from mainstream definitions. The next section, therefore, provides a discussion of whānau to help broaden understanding of Māori concepts of whānau.

#### 2.1.1 Difficulties defining whānau

New Zealanders recognise that the word family has a range of meanings and use them in appropriate contexts. Attempts at creating an absolute definition for the term “family” are burdened with problems. The influence of continuing social change and the general flexibility of the family structure make an acknowledged global meaning for family a difficult if not impossible task (Cunningham, Stevenson, Tassell, 2005: 13). Asked what whānau means, most non-Māori define it as ‘extended family’. This is only one of many Māori meanings. Non-Māori may invest that phrase **with the meaning it has in their own lives**<sup>1</sup>. The attributed meaning may be significantly different from the meaning it has for Māori. Non-Māori stop searching for understanding once they believe they know what “whānau” means and then become hopelessly confused by Māori discourse on the subject (Metge, 1995: 308).

Any attempt at creating an overall definition for whānau is fraught. There is no one meaning. According to Metge (1995: 308), in less than a decade the term whānau has moved from being unknown to most non-Māori to being familiar such that it no longer requires translation. Two questions can be asked here:

1. Are Māori more culturally integrated now?
2. Does the majority population have a working understanding of Māori culture?

To begin to understand the magnitude of whānau in relation to informal caregiving it is essential to consider what is intended when the term is used in this paper. The mainstream translations of the term whānau are according to Metge “far from satisfactory” (1995: 64). Indeed in social policy, family and whānau are synonymous, even though “family” is generally defined in a nuclear sense ie, two parents and two children. According to Hana Tukukino (1985: 69) to Māori the whānau is the greatest asset as well as considered to be the central foundation of the collective life of Māori (Ministry of Health, 1997: 20). As with other Māori terms, whānau is determined by its context. This part of the paper deals with providing a definition of whānau, both from a “traditional” base as well as a contemporary perspective.

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<sup>1</sup> Emphasis added.

## 2.2 Traditional perceptions of whānau

Pre-contact eighteenth century whānau was described as a family and domestic unit comprising three generations including in-married spouses and whāngai (Boast, Erueti et al, 1999: 38-39). Whānau were also described as a segment of the descent group without noting the structural and functional differences between the two (Boast, Erueti et al, 1999: 39). This view about whānau was reinforced by various anthropological writers.<sup>2</sup> There was agreement that whānau was the smallest social unit. It was not thought to be the true family but the family group. There was also agreement that whānau extended to three or four generations (Best, 1952: 97; Te Rangi Hiroa, 1949: 333; Firth, 1959: 111) either living together or in close proximity to each other. Metge, in a number of her publications (1967, 1995), also describes whānau in a similar way.

So, prior to colonisation, Māori society was organised around whānau, hapū and iwi kinship groups, which identified with a common ancestor (Te Rangi Hiroa, 1949). Whakapapa identified the relationships between the whānau, hapū and iwi structures.

The whānau to Māori people is beyond the definition of 'nuclear' and 'extended family'. Hana Tukukino's description of the Māori concept of whānau can be represented as three components that are inter-related that provide balance, identity and cohesiveness to the working whole. These components are:

- tipuna
- whanui
- whānau te rito.

One component is related to **tipuna** and whānau members who have passed on. This provides spiritual and emotional wellbeing to the family. It is from ancestors that Māori whānau develop their identity. Whakapapa, family histories and stories of tipuna and loved ones are important – they provide a cohesive power for all those people who can trace their whakapapa back to certain tipuna.

The next component represents whanui or tribal families. Most Māori recognise the tribal names of those with whom they have links or ties. The fact that the actual connection may not be known is immaterial – the more important issue is to know whether the connection is made on the individual's mother's side or father's side. The whanui component is a way of developing and having a more personal relationship with a wider group of people. Again the strength of the whanui links are maintained by whakapapa, family histories, waiata, haka and hui opportunities.

The third component is the **whānau te rito** – the closer family, which generally refers to an individual's family of orientation such as great grandparents, parents, aunts, uncles, brothers and sisters, nieces and nephews and cousins. This part of the whānau provides the immediate nurturance and the physical and

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<sup>2</sup> Such as Best, Te Rangihiroa (Peter Buck), Firth, van Meijil and Webster.

emotional support. Members of the whānau te rito on both the mother's side and father's side are usually known to all individuals.<sup>3</sup>

## 2.3 Modern views of whānau

Durie makes it clear that te ao Māori is neither static nor a pristine memorial to the past. He goes further by noting that while some of the features of te ao Māori have survived the threats of time, their significance and their relationship to whānau has been shaped by modern understandings and experience of environment. Similarly although a 'corpus of basic convictions about reality and life' has remained relatively constant, the manifestations of culture are subject to flux, so that change becomes the norm (Durie, 2005: 3). It is clear such statements must also apply to attempting to define whānau.

Present-day Māori live in several realities. Māori are significantly disadvantaged on most socioeconomic indicators. Tribal organisation has thrived since 1984, as well as a range of cultural activities that have assisted to enhance a Māori identity. Notwithstanding these improvements, not all Māori have shared in those developments. As a result assumptions cannot be made about Māori aspirations or preferences. In short, there is no single Māori identity; the Māori population is as diverse as any other (Durie, 1993: 9). It therefore follows that although Māori will have similar meanings for the term whānau there is still no one definition that fits properly, nor should there be.

Commentators<sup>4</sup> have written at length about the changes through which whānau have gone. Changes have come about as a result of the normal dynamism of life and living that allows one to see other more effective ways of doing things. However, it seems apparent that although the former may be true there are also negative connotations to these changes, which may have been brought about due to circumstances beyond Māori control. Perhaps one of the most telling of the situations beyond Māori control is urbanisation.

### 2.3.1 Urbanisation

The role of urbanisation in the more modern definition of whānau is more than it would first appear. Our first thoughts are positive, "moving to the city", "better access to the trappings of society"<sup>5</sup>. However, if we carefully consider the implications of urbanisation on Māori society in the twentieth century we will recognise some negative effects as well. Durie claimed that as a result of urbanisation tribal control became effectively absent; that the population was heterogeneous (including other ethnicities); that an individual gains property rights by living in a place rather than because he/she belongs to a particular

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<sup>3</sup> "Māori Families: The Support System". Child Abuse Treatment and Prevention Mental Health Foundation of New Zealand, 1985 M Abbott (ed) at pages 69 and 70.

<sup>4</sup> Such as Metge, Durie etc.

<sup>5</sup> Such as education, employment, better housing etc.

place; that claims to land are based on ownership, which excludes those who do not purchase or rent (Kawharu (ed), 1989: 289).

Urbanisation has had some positive effects but generally disadvantaged Māori. The culture, language and customs in cities were Pākehā dominated. A traditional whānau structure had very little, if any, support. Tangaere (1989: 19) claims Māori were forced to change their lifestyles from the collective support of the whānau to the more 'nuclear' family. Families were smaller. Grandparents and extended whānau support were also absent. Māori society became destabilised to such an extent that progress led to Māori alienating themselves from their own whānau structures, values and culture.

Consequently, despite some positive effects of urbanisation, it was generally detrimental to the whānau structure.

### **2.3.2 Many meanings**

According to Metge (1990: 68),

“The time has come for us to recognise that, in the real world... Māori people use the word whānau with an array of references, that its use varies according to context, and that its meaning in particular situations must never be taken for granted.”

Metge ascribes eight different meanings for whānau, the most important of which are:

- [Māori] people related through a recent ancestor, traced through both male and female lines of descent
- a group of [Māori] people related through a recent ancestor, traced through both male and female lines of descent who participate in ongoing but occasional activities
- an extended family group (Walker, 2006: 12).

Defining whānau membership more closely raises a problem. This is due to the many definitions that whānau themselves will use. Some limit whānau membership solely to descendants of the tipuna, which excludes most spouses. Others include those spouses and whāngai who are not descendants but actively participate in whānau activities. This is known as the extended family. To have a better understanding of the whānau as it functions in Māori social life it is necessary to hold these two views in tension, recognising that they assume primacy for different purposes (Durie-Hall and Metge, 1992: 60). Whānau are not exclusive groups.

### **2.3.3 Kaupapa-based whānau**

Metge developed the theory of whakapapa-based whānau based on descent. She went further by recognising that kaupapa-based whānau refers to people who come together for a common purpose. Metge noted that:

“Lacking descent to serve as a unifying principle, kaupapa-based whānau place particular stress on the other characteristic feature of the whakapapa-based whānau, that is, whānau values and the ways of working derived from them (Metge, 1995: 305).”

The non-traditional whānau differ from the traditional view of whānau in important ways. The main reason for establishing these whānau is **not** whakapapa but commitment to one or more common kaupapa. By choosing to describe themselves as whānau, members of these non-traditional whānau signal that they look to the whānau of primary reference as model and reference group. Lacking descent to bind them together, they lay particular emphasis on adherence to whānau values (Metge, 1995: 292).

“There is an inextricable relationship between the social, cultural and economic emancipation of Māori on the one hand, and the revitalisation and maintenance of whānau structures on the other.... The whānau provides a culturally appropriate and nurturing context for Māori language, knowledge and culture.... the future of Māori is very much the future of the whānau and vice versa.” (Graham Hingangaroa Smith).

Māori have always responded to issues on a collective and usually whānau-centred basis. Such collective bases outside the traditional view of whānau have included churches that grew out of the nineteenth century prophets, such as Ringatū and Ratana. Their strength lay in a support base that was iwi, hapū and whānau. Political and social organisations like Kotahitanga, Māori congress and the Māori Women’s Welfare League also depended on a collective way of working.

Collectivity also includes modern social configurations like gangs, flatting, school and work-based whānau groups and many others. Even groups that are isolated from whānau seek to recreate whānau-like structures, often demanding the same commitment from all those involved as if they were whānau, and describing these organisations as whānau (Ministry of Health, 1997:37).

Māori recognise at least two distinct kinds of family, the nuclear family and the whānau (Durie-Hall and Metge, 1992: 60). This distinction would not have been possible without taking into account the diversity of current Māori thinking. This thinking recognises that whānau are not exclusive groups and there will be a lot of juggling of loyalties.

## **2.4 The role of whānau**

Whānau, like families, have roles that have come about as a result of many things. To have a better understanding of the perceived role of whānau it is essential to recognise the values that inform the inherent rights and obligations for them. Beliefs and values are a significant part of Māori cultural identity. These values help establish cultural integrity, and can be strong determinants for regulating, modifying or controlling behaviour (Durie, 1993: 10).

A modern Māori world view is derived from a mixture of action and association, traditional values and concepts, modern values, Mātauranga Māori, and western science (Harmsworth, 2005: 3-4).

### 2.4.1 Māori values

It is clear that Māori values form the basis for explaining the Māori worldview, and provide the concepts, principles and lore Māori use in everyday life to varying degrees, affecting their interaction with others, and governing responsibilities and the relationship with both the natural and spiritual environment.

Metge outlines in more depth some of these essential Māori values that assist to strengthen whānau, however defined.

- *Aroha* – love (in all its permutations), longing, closely associated with kinship ties and the caring acts expected to be performed towards kinsfolk, especially in times of sickness, need or other trouble (Metge, 1995: 81).
- *Whanaungatanga* – kinship in its widest sense. The value of whanaungatanga reinforces the commitment members of a whānau have to each other but also reminds them of their responsibilities to all their other relatives. This imperative of extending aroha to all whanaunga ensures that every whānau is embedded in a web of cross-cutting kinship ties (Metge, 1995: 82).
- *Taha wairua, taha tinana* – the spiritual and physical dimensions complete and enrich each other. What is valued most is the connection and appropriate balance between them (Metge, 1995: 84).
- *Tapu and noa* – Tapu often attracts public attention and respect but is closely associated with danger, anxiety and restrictions on freedom of action. Noa attracts little or no public respect and attention but allows relaxation and freedom of action, within the limits of tikanga (Metge, 1995: 85).
- *Ora* – is life of a special quality ie, energised life. It is life in all its fullness (Metge, 1995: 86).
- *Tika, tikanga, pono* – Tika refers to what is right. Tikanga refers to doing the right thing in a given situation. Pono relates to being true, genuine and loyal in relations with others. This latter quality is reserved for those in leadership positions within the whānau (Metge, 1995: 87).
- *Mana* – there are various meanings for mana. It is 'divine power made manifest in the world of human experience'. Individuals and groups have mana. This is a combination of mana acquired by inheritance from ancestors (mana tupuna), by direct contact with the supernatural (mana atua) and as a result of human achievement (mana tangata). The store of mana is not fixed but is ... affected by the holder's behaviour, by the actions of others and by the vicissitudes of life (Metge, 1995: 88).
- *Ahi-a-ngakau* – work done from the heart (Metge, 1995: 98).
  - There is the duty to support each other in good times and bad.

- There is the duty to care for each other; includes meeting the physical needs of others as well as the need to be nurtured mentally and spiritually.
  - There is the duty to protect each other against physical and spiritual attack.
  - There is the duty to work together for the common good.
  - There is the duty to value and cherish those of the most senior generation (Metge, 1995: 99).
  - There is the duty to value and cherish those of the youngest, the tamariki and mokopuna (Metge, 1995: 100).
- *Utu* – this is the principle that anything received should be requited with an appropriate return (Metge, 1995). It is essential to the management of internal relations. Recipients of affection, approval, support, care, protection and respect from other whānau members are under an obligation to reciprocate in kind and to do so generously, without counting the cost. The returns made are widely distributed to the givers' close kin and descendants, to those in need, and to whānau members as a group (Metge, 1995: 101).
  - *Kotahitanga* – oneness or unity that is achieved when whānau members invest time and energy in getting to know each other to work through differences. It also means accepting responsibility for each other's actions (Metge, 1995: 102).
  - *Relations with outsiders* – Whānau members recognise a collective responsibility to reciprocate the help received from other groups. They also recognise a collective responsibility to their own group to secure compensation for insult or injury by others (Metge, 1995: 102).

Metge makes it clear that whānau values both compete with and reinforce each other. She quotes Epa Huritau to stress this view.

“The Māori value system has the flexibility built into it to accommodate variation... ...If we know the principle, we can make adjustments.” (Metge, 1995: 105)

According to the value system underpinning the whānau (and noting that these will differ from whānau to whānau), whānau members have responsibilities to help each other in trouble, to protect the hurt and vulnerable among them (Metge, 1995: 258).

So far there have been a number of Māori 'values' identified that begin to illustrate why whānau may choose to take on the informal caring of a whānau member with a disability or a chronic disease. The identified values are: whakapapa links, aroha, loyalty, commitment, as well as an in-built support system.

#### **2.4.2 Whānau qualities**

Pere (1988: 23) outlines some of the qualities that she believes whānau display. These qualities include loyalty, obligation and commitment. Such an in-built support system worked towards making the whānau

a strong, stable unit within the hapū and consequently the iwi. These qualities traverse the range of whānau members. For instance the roles of kaumātua include the protection and nurturing of younger adults and children (Cunningham et al, 2005: 23).

When a whānau is fully functional its members are bound to each other by ties of aroha (loyalty as well as affection) and feel a commitment to provide financial and moral support to each other and group hospitality to guests (manaakitanga) (Durie-Hall and Metge, 1992: 61). As far as Māori are concerned, when there is trouble with Māori individuals or nuclear families, the whānau will be referred to as the first line of defence (Durie-Hall and Metge, 1992: 65).

The collective basis of te ao Māori means that whānau as the smallest unit must work together on an occasional basis ie, when necessary to fulfill four main functions:

- caring and management of *turangawaewae* and *taonga*
- organising hui
- providing mutual support
- socialising children (Durie-Hall and Metge, 1992: 61).

Along with whānau membership comes a range of roles, obligations and responsibilities, and a number of functions. Durie identified five primary needs that are satisfied by the family and whānau. These are:

- *manaakitanga* – protection and nurturing
- *tohatohatia* – capacity of the whānau and the family to share resources
- *pupuri taonga* - role of guardianship in relation to family/whānau physical and human resources and knowledge
- *whakamana* – ability of the family/whānau to enable members
- *whakatakoto tikanga* – ability of whānau to plan for future necessities (Ministry of Health, 1998: 2-3).

Another role of the whānau is that “it looked after its own aged or disabled members”. (Walker, 2006: 11). The expectation whānau members have that they will be cared for is part of being whānau. Members of whānau are therefore entitled to expect the support of their whānau through life’s milestones – as well as through times of crisis. The aroha and support that whānau provide can be the critical element that ensures a safe transition through difficult times (Ministry of Health, 1997: 27).

Even where whānau are not fully functional it is a mistake to think that the ‘ideal’ whānau structure does not apply to the Māori nuclear family (Durie-Hall and Metge, 1992: 62). This assertion is evidenced by

the urban Māori rōpu (groups), which provide access to collective caring.<sup>6</sup> These ‘whānau’ although not necessarily linked to whakapapa are no less whānau as they provide those values identified earlier.

The majority of whānau members that [Tariana Turia] has encountered do not shy away from their responsibilities and reciprocal obligations towards each other. They are committed to creating relationships which are elevating and enhancing. Most whānau are trying to live in an environment where the care and welfare of one’s neighbour is still important. [Those whānau want to live in an environment] where they can care for themselves, care for each other, and care for the world (Turia, 2005).

## 2.5 Diverse Māori identities

A report to the National Advisory Committee on Core Health and Disability Support Services (1995: 35) (National Advisory Committee) makes it clear that Māori are a diverse group living in a wide range of cultural and socioeconomic realities. Durie reinforces this view:

“Māori live in diverse cultural worlds. There is no one reality nor is there any longer a single definition which will encompass the range of Māori lifestyles... A Māori identity, even when vigorously defended, cannot be presumed to mean a conventional Māori lifestyle. Nor should it be forgotten that for many Māori, cultural identity is a sophistication; it is more than enough simply to get through the day.” (Durie, 1998: 215)

Durie recognises that there are a number of factors that impinge on Māori and whānau. He notes that Māori individuals do not have a great deal of personal control over their social environments (Durie, 1998: 217). He suggests that the “traditional” basis for whānau no longer necessarily encompasses every Māori. Metge (1995: 291) reinforces this sentiment by noting the whānau survives changes in its environment and even transplantation to a new one by making appropriate adaptations. What this means is that whānau informal caregiving may differ from Māori to Māori and whānau to whānau.

The relevance of traditional Māori values and participation in a Māori cultural context varies between individuals, and does not necessarily dictate the extent to which a person may identify as Māori (National Health Committee, 1995: 35).

People belong to families, communities and a nation and are reflections of the values and policies therein. Whānau are not exclusive groups; Māori who belong to one whānau by descent traced through one parent can also belong to the other parent as well as to that of their spouses. Many Māori juggle loyalties and commitments to two or three whānau, sometimes favouring one; sometimes trying to keep a balance (Durie-Hall and Metge, 1992: 61).

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<sup>6</sup> Examples are The Waipareira Trust and Manukau Urban Māori Authority (MUMA).

## 2.6 Terminology

### 2.6.1 Whakapapa, kaupapa and statistical whānau

Distinctions have been made between the different types of whānau (Cunningham et al. 2005; Collins and Hickey 2006).

- Whakapapa whānau are described as families with shared ancestry and a common line of descent
- Kaupapa whānau are described as 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). The term kaupapa whānau may be used as a descriptor for the entire formal and informal support network that surrounds the person with a disability, including family members, whānau, friends, neighbours, companions, paid caregivers, health and medical professionals, counsellors, and advocates.
- Where the words families, households and whānau are used interchangeably, Cunningham suggests the term 'statistical whānau' may be appropriate (Cunningham 2005).

Nikora and colleagues report that informal whānau care is concerned with:

“...enhancing the wellbeing of the whole whānau and ensuring a person with a disability maintains a sense of purpose, independence, dignity, health and connectedness with whānau, hapu and community across the person’s lifespan.”  
(Nikora et al 2004:49)

Applying these definitions to the caregiver’s context, whakapapa whānau remain the primary caregiving context for Māori, while kaupapa whānau may be more significant to caregivers and disabled people living away from their whānau and hapu networks.

### 2.6.2 Whānau carer and informal caregiver

Literature about Māori and informal caregiving predominantly uses the term ‘whānau caregiver’ instead of ‘informal caregiver’ (Nikora et al. 2004; Ashwell et al. 2004). A whānau caregiver is defined as “a person linked to the person with a disability by whakapapa and who has inherited or assumed the role out of a sense of duty, obligation and love” (Nikora et al. 2004: 50). In addition the definition of whānau has been discussed in earlier sections. It is to be remembered that the term ‘whānau’ has numerous meanings and whānau caregivers may also have differing definitions from those depicted by Nikora.

## 2.7 The 'ideal whānau'

The concept of the 'ideal whānau' is a set of social assumptions and expectations that can have considerable influence on decision-making. Nikora and colleagues (2004) argued that living up to the standards set by the ideal whānau may be a source of stress and emotional turmoil for some caregivers. Their study found some whānau members were perceived as being obligated to undertake the role of caregiver. Obligations are created by either close relationship (for example, grandparent, parent, spouse, child) or the person's status in the whānau – as a tuakana, teina, maataamua, pōtiki, mokopuna, or whāngai. The obligations do not extend to aunts, uncles, cousins or siblings when the care recipient is an adult.

“There is a perception within whānau, particularly with respect to caregiving for the elderly, that the care role should fall to the eldest daughter or eldest mokopuna (usually female), or to the child that is gay, or the one who is unmarried or unpartnered and seemingly without obligations.” (Nikora et al. 2004: 55)

When a person is seen as having the capacity to take up caregiving, the researchers found this leads to considerable pressure being exerted on them to pick up the caregiving role. Whānau caregivers in the study had been seen by others as having free time, no obligations and sufficient energy (for example they were beneficiaries or students). Regardless of how a whānau member came to take up the role of caregiver, or what pressures had been brought to bear, caregivers still stated that they were caregivers “for love” (Nikora et al. 2004: 51).

## 2.8 Non-whānau caregivers

People from outside of the whānau who live near Māori with disabilities and provide caregiving can include flatmates, friends and neighbours. A small proportion of Māori adults with disabilities receive help from this group of people. Help may be provided for heavy household work, shopping, preparing meals or normal housework, but is unlikely to include personal care. Just as the reciprocity of familial love and expectation can blur the lines for spouses and family, so the reciprocity of friendship can blur the lines with flatmates, friends and neighbours.

## 2.9 Examples of diversity among caregiving whānau

To assist understanding of diversity among informal whānau caregivers examples are provided. Examples are found in some of the review documents. Cunningham (2005) offers four vignettes of fictional whānau to illustrate the diverse range of structures, household compositions and socio-economic circumstances. Each vignette is an example of the “New Māori” diversity framework.

Nikora et al. (2004) included in their report, case studies of the lived experiences of disability from the perspective of four Māori women, three of whom were caregivers. One case study describes the experiences of adult whāngai (adopted children) coping with their mother's behavioural changes as her

Alzheimer's disease progressed and the guilt when they admitted her into a nursing home. A second case study describes the experience of a beneficiary single parent with a deaf child and the poverty that continued once her child became an adult and moved into supported living arrangements. The third case study describes the whānau attempt to give care when their mother had a series of strokes. In this description, the father prefers to maintain his kaumātua duties, the mother becomes isolated, and the children search for an appropriate caregiving routine amongst them that can fit around their own immediate family routines.

Collins and Hickey (2006) described the social circumstances of their informants, all of whom were Māori, with physical, sensory, or age-related disabilities. Also included were references to the informants' caregivers. The following examples have been drawn from the report to illustrate the diversity amongst whānau living with disability.

Each of these examples provides a view of the relative importance of the whānau to each of the care recipients. It is clear that whānau has differing meanings and emphases.

Riria's parents rely on the wider whakapapa whānau so as to be able to be effective in matters relating to Riria.

### **Riria**

Riria's parents were teenagers when Riria was born. Riria has a physical disability as a result of an illness she contracted while only a few months old. She is the second child and has four brothers and sisters. Riria is from a four-generation whānau from the Gisborne, East Coast and Urewera tribes. Her grandmother, great-grandmother and most of her wider whānau live in Gisborne and the East Coast. Riria's mother describes whānau relationships as good. This is borne out by the close proximity of the whānau.

Riria lives with her parents and siblings in a rural area in the Gisborne region in a farmhouse provided for them by her father's employer.

Riria's parents recognise the importance of both the whānau and the household and would likely hold both definitions in tension. Riria's parents rely on the wider whānau to ensure they can advocate effectively on their daughter's behalf.

Despite the close proximity of Kuini's whānau and the interdependence with her daughter other caregiving activities are undertaken by the nurse.

### **Kuini**

Kuini is in her 60s, retired, widowed and has age-related physical disabilities. She is from the Waikato tribe and has a five-generation whānau when you include her stepfamily. She raised her eldest grandchild but now lives alone in her own home in Gisborne city. One of her daughters and many of her stepfamily live nearby. Kuini's daughter also lives alone, is in her 40s, is a beneficiary, and has multiple disabilities. Kuini and her daughter look after each other and have a very close relationship.

This mutual caring appears to be a feature for whānau.

As noted earlier the whānau live close by but far enough away so as not to crowd Kuini. This allows her to maintain her independence as well as know that if required whānau members are available for her.

Kuini feels more able to talk with the nurse. This is an example of non-immediate whānau, ie, the whānau members that people choose to be their caregivers.

Wi prefers to rely on his wife for support as his primary caregiver.

### **Wi**

Wi is a fulltime tertiary student in his 20s and has a physical disability. His primary carer is his wife.

Wi and his wife both recognise the importance of whānau. They are prepared to support other whānau members but still enjoy living away from them. They "just like their space." Wi tends to rely on his wife to advocate on his behalf.

### 3 WHĀNAU INFORMAL CAREGIVING ROLES

Two studies have found whānau caregivers undertook caregiving to enable their whānau member with a disability to continue to live safely in his/her own home. This suggested to the researchers that whānau caregivers are an integral part of care recipients' lives (Nikora et al 2004; Ashwell et al 2004).

The roles and responsibilities associated with informal caregiving are similar to those practiced as whanaungatanga for Māori and are underpinned by notions of aroha and tiaki. Caregiving is not reserved specifically for those with impairments or health conditions.

The authors developed a list of roles that whānau caregivers performed. A similar list was developed in a study of United Kingdom caregivers (Arksey et al. 2005 cited in Goodhead and McDonald 2006). Both lists are summarised below for comparison.

#### **Nikora et al. (2004)**

- Companionship
- Personal care/private affairs
- Home help (cooking, cleaning, housework)
- Nursing
- Community link
- Medical information provider/administrator
- Advocates and mediators
- Interpreters
- Counsellors
- Gatekeeper
- Spiritual guides

#### **Arksey et al. (2005)**

- Companionship/emotional support
- Personal care/private affairs
- Home help (cooking, cleaning, housework)
- Nursing/supervision
- Escorting to appointments
- Educate family and friends
- Advocates
- Parental caregiving
- Spousal guardianship
- Keep the recipient safe
- Provide financial subsidy
- Provide accommodation

While the two lists are similar, Nikora et al. (2004) emphasised the roles of spiritual guide, interpreter, advocate, and maintaining community links.

### 3.1 Spiritual guide

Many Māori take an holistic approach to health and disability that acknowledges the importance of caring for the mind, body and spirit, rather than solely the body (Collins and Hickey 2006; Ratima 1995).

According to Nikora and colleagues (2004), some whānau may view disability as a metaphysical consequence of a wrong the disabled person or their whānau has committed in the past. Caregiving is then seen as a whānau responsibility of atonement<sup>7</sup>.

### 3.2 Advocate

Advocacy was a role that whānau caregivers felt forced into if they wanted to improve the situation for their care recipients or themselves (Nikora et al. 2004). In the Arksey study, undertaken in the UK, advocacy was mentioned as a role for caregivers of people with mental health problems only. However Mezey (2004 cited in Goodhead and McDonald 2006) considered negotiation of the health system as a core caregiving process.

Ashwell and colleagues found that while caregivers could advocate for others, they appeared to be unsuccessful when advocating on their own behalf. Caregiver training programmes were recommended to guide caregivers through system processes (Ashwell et al. 2004).

### 3.3 Maintaining community links

A close link with whānau, hapu, iwi, and the marae is important to the cultural identity and holistic well-being of whānau (Durie et al. 1996; Cunningham et al. 2005). Whānau caregivers take responsibility for maintaining these links for themselves and their care recipients. However, maintaining links tends to involve out-of-town travel, making transportation costs a recurring problem for whānau caregivers (Nikora et al. 2004). In the Waikato region, caregivers reported problems in travelling from rural to urban areas within the district (Ashwell et al. 2004). In comparison, Arksey and colleagues (2005) mention transportation as a role for caregivers in relation to taking the care recipient to appointments only.

### 3.4 Shaping self-identity

Caregiving roles varied depending on the nature of the disability of the care recipient. The National Health Committee (2004) reported that, in the case of people with intellectual disabilities, not only did informal

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<sup>7</sup> Huakau and Bray (2000, cited in Goodhead and McDonald 2006) found a similar attitude among Pacific peoples: This included notions of disability being a punishment from God, reflecting some wrong-doing in the family, or resulting from a negative relationship with high-status people, such as chiefs or ministers. This means there is an element of shame for some, focused not on the disabled person but on how others may gossip or interpret events negatively (Goodhead & McDonald 2006, p. 56).

caregivers provide emotional as well as physical support; they played an important role in shaping self-identity:

“Parents or main caregivers play a pivotal role in the lives of offspring with an intellectual disability. As well as providing physical and emotional support, and assistance with co-ordinating services and activities, research indicates that they play a role in shaping the self identity of adults with an intellectual disability.”<sup>8</sup>

The way whānau carers help to shape the cultural identity of care recipients with high support needs is also discussed by Nikora and colleagues (2004).

In addition whānau, however defined, remind their members who they are, who they belong to and why they are important to the life of the whānau.

### **3.5 Preventing long-term disability**

Caregivers may also play a health prevention role within their whānau. McCreanor and colleagues (2004) studied the experiences of Māori parents who lost a child to Sudden Infant Death Syndrome (SIDS). They found that, following the death of the child, many parents developed self-destructive behaviours and/or became physically and mentally unwell (McCreanor et al. 2004). Although the parents were supported by paid counsellors, whānau members provided essential informal care, support, and healing, which both reduced the extent of self-destructive behaviour and prevented an escalation of mental illness in the parents.

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<sup>8</sup> *To Have an Ordinary Life*, National Health Committee, Wellington 2004, at page 119.

## 4 THE IMPACT OF CAREGIVING ON WHĀNAU

### 4.1 Negative impacts

#### 4.1.1 Strain on carers

Whānau caregivers find that accessing necessary entitlements for the person they care for can be stressful and time consuming. Whānau get frustrated when they know a service is available but can't access it easily because of barriers of distance, transport, timing or costs (National Health Committee 2007).

Some caregivers find that information on available supports or entitlements is difficult to obtain. Medical information is not necessarily available or is difficult to understand (Nikora et al. 2004; National Health Committee 2007).

There can be tensions for parental caregivers when their disabled children reach adulthood and they no longer have access to information on their child's condition (Nikora et al. 2004). According to the authors, the Privacy Act 1993 prevented parents from continuing to access information about their children once they became adults, thus inhibiting parents from ongoing caregiving. Carers felt frustrated in knowing what was available yet not being able to access it easily resulting in, for example, rural residents travelling to gain access to services. Carers in the study felt that they had to be determined and assertive to get necessary entitlements.

Many whānau caregivers believe it is unfair that a person's entitlements are determined on whether the person has a disability or a chronic condition rather than on need.

Some carers in the Nikora et al. (2004) study felt that their social world narrowed to relationships and activities associated with their care recipients' health and caregiving needs.

“Those left to fill the role of carer often lose control over their social lives and are often perceived as ‘boring’ or self-obsessed with their own circumstances. Sometimes they might become isolated, feel used and develop a sense of their own lives being suspended.” (Nikora et al. 2004: 61)

This appears to be the case for carers of people with high support needs. Goodhead and McDonald (2006) found the same was occurring for carers that provided palliative caregiving.

These examples illustrate the importance of whānau caregivers being involved in health decisions for their whānau member.

Caregivers are often unaware of the negative effects of caregiving, such as a build-up of stress or slide into depression, until they reach a level of serious concern (Durie et al. 1996; Nikora et al. 2004; Ashwell et al. 2004). The impact of feeling isolated, under-valued, aggressive, grief-stricken, or ashamed were emotions that carers were not always immediately aware of and had difficulty coping with once they became conscious of it (Nikora et al. 2004). Contributing experiences of isolation or being under-valued tend to be cumulative and emotions of grief and anger, frustration and shame can be difficult to articulate.

#### **4.1.2 Strain on whānau relationships**

The way that whānau define themselves will impact on whether whānau caregivers are able to fulfil other whānau duties adequately. For instance some whānau are heavily involved in hapū and iwi activities. Where this is the case, there may need to be a shifting of those responsibilities to other whānau members. This may significantly affect their relationship with their whānau, and as a consequence their self-esteem.

Despite this, the role of caregiving can become such a large part of a caregiver's life they lose a sense of purpose if they are no longer able to fulfil a caregiving role (Nikora et al. 2004; Ashwell et al. 2004).

Sometimes being a caregiver requires whānau members to spend less time with their immediate whānau members than they would like. Examples are where caregivers sometimes spend time away from their own immediate family in order to provide care for others, or the person receiving care moves in with the caregiver and her/his family. Meeting both the new caregiving needs and the existing needs of the caregiver's immediate family has the potential to cause tensions within the caregiver's household (Nikora et al 2004).

“The [whānau] may present the ultimatum of ‘it’s your family or me’, withhold access to transport and mobility, set restrictive conditions like a time to be home or allow only a limited visiting period. They may also wilfully undermine what the caregiver is doing by contacting other family members to complain about neglect or abuse or by intentionally teasing the afflicted person.” (Nikora et al. 2004: 62)

Relationships between whānau caregivers and members of their whānau or friends can become strained or come to an end. Initially, whānau and friends can be a source of substantial encouragement and support. However, once the long-term nature of caregiving is understood those supports lose momentum and dwindle. This can leave whānau caregivers feeling isolated and used. Caregivers may become the target of, or subject to, the frustration and aggression experienced by the wider whānau – especially when the caregiver assumes the role of gatekeeper or advocate (Nikora et al 2004).

#### **4.1.3 Strain on whānau resources**

Nikora and colleagues (2004) found caregivers disadvantaged themselves by taking on some of the financial burden of caregiving and giving up work or education opportunities, which led to post-caregiving

problems of re-establishing work and education pathways. In addition, the amount of available respite care fell well short of what caregivers reported needing.

Caregivers manoeuvre around sensitive issues regarding the disabled person's inability to financially support informal caregiving. For example, one instance was reported of a caregiver financially supporting a disabled partner by using their life savings, which caused stress for both of them (Nikora et al 2004).

#### **4.1.4 Stress**

Caregiving is considered by a number of researchers to be difficult work:

“What cannot be emphasised enough is the depth of stress and emotional turmoil experienced by whānau caregivers yet [it is] largely unacknowledged by others.”  
(Nikora et al. 2004: 60)

Emotional stress, exhaustion, depression and loneliness are common among caregivers, increasing the risk of developing mental or physical illnesses. Stress arises from a number of sources. Some of those previously discussed include: socioeconomic disadvantage, organisational or systemic barriers, high level of care recipient need, tensions within the caregiving household, and difficulties in accessing or effectively using respite (Nikora et al. 2004; Ashwell et al. 2004).

For Māori, the expectations of whānau may either add to or alleviate the stress that arises as a result of caring for a whānau member. For example the whānau values such as aroha and manaakitanga suggest that the tensions of caring for a whānau member would be spread around the entire whānau. However, in those whānau where there are few members or the caregiving is not spread out amongst many members, the stress will have considerable impact on the entire whānau.

#### **4.1.5 Carers neglecting their health**

Nikora and colleagues found caregivers neglected their own health when caregiving (Nikora et al. 2004). This has long-term implications for caregiver health outcomes.

Out of all Māori caregiving age groups, Durie and colleagues (1996) considered caregiving may have greater negative impacts on kaumātua caregivers compared with other groups because of their age and likely health status. Since disability or illness is high amongst Māori of this age, reciprocal caregiving with this group can be particularly critical.

In general, Māori access mainstream primary health services less frequently compared to non-Māori, present to secondary health services acutely (with often advanced conditions), and have less access to life-saving tertiary interventions. This generalisation is likely to be equally true for whānau carers. The reality is that many Māori, as an ethnic group, experience some degree of compromised access, use, effectiveness, and quality of health services. Universal approaches to health care undertaken in the delivery of mainstream health services are not meeting their needs. This is evident from the continuing

'gaps' in health status, and the ongoing pleas by Māori and other ethnic groups for culturally appropriate and acceptable health services (Wilson [n.d.]).

## 4.2 Positive impacts

Care recipients have reported a number of tangible positive outcomes from informal caregiving. It helps improve or maintain their community participation and reduces the potential for social isolation. It also enhances their personal capabilities and supports job opportunities, education pursuits, voluntary work and Māori community involvement (Nikora et al. 2004; Ashwell et al. 2004; Collins and Hickey 2006).

The positive impact of caregiving on caregivers was less tangible and articulated as part of personal growth in life. For example, respondents reported:

- becoming sensitive to the needs of others
- benefiting from a raised awareness of disability
- developing a depth of knowledge about their care recipient's condition and a proficiency in dealing with it
- developing resourcefulness in getting what they and their care recipients needed
- becoming adaptable in coping with change
- experiencing a sense of purpose and satisfaction with the high value of caregiving for recipients and the whānau (Nikora et al. 2004).

Durie (1999) considered caregiving could be rewarding to Māori elders because it could 'offer a satisfying lifestyle in which older people are fully and productively involved within their communities, contributing at an influential level and sharing in the vicissitudes of their wider families, if not the tribe as a whole' (1999: 103).

For whānau, caregiving strengthened the whānau unit's cohesion and closeness. In particular, strong relationships were built between care recipients and their caregivers in both whakapapa and kaupapa whānau. Feedback from caregivers and care recipients revolved around them having meaningful roles within the whānau and participating fully in New Zealand society (Nikora et al. 2004).

## 5 SUPPORT FOR WHĀNAU CAREGIVING

### 5.1 Support for caregivers

Ratima and colleagues (1995) found improved information dissemination was viewed as the most significant factor in improving access to services, in particular information on service availability.

Ashwell and colleagues found training programmes were seen as an effective means of gaining necessary information about systems and procedures and developing caregivers' advocacy skills (Ashwell et al. 2004).

When carers were asked about any areas they would have liked covered in the training programme evaluated by Ashwell et al. (2004), their responses revolved most around information on specific disabilities, accessing other agencies and WINZ funding, developing communication skills, transition from school to work, and workshops on services in rural areas.

One of the many advantages of whānau caregiving is the ability to share care with other whānau and friends. Also, paid workers can help reduce stress and frustration in whānau carers and ultimately, negative health impacts.

According to the carers in the Ashwell (2004) study, respite care to relieve whānau carers temporarily, did not adequately meet their "time out" needs or equate to the financial and personal contributions often made by them.

Respite care arrangements are unlikely to provide the same contributions the main whānau carer provides, so is not seen as a clear choice or substitute for the caregiver's responsibility (Nikora et al. 2004).

"It was often difficult to find the 'right' people to share care with. Sometimes, the person with the disability did not want any other person to provide care, and sometimes the whānau carer didn't feel that anyone else could do the 'job' that they did. Formal respite care agencies were often not considered an option for these same reasons." (Nikora et al. 2004: 33)

One feature that distinguished informal carers from formal carers was that informal carers were not readily able to consider giving up their caregiving permanently, accept respite care, or even to be relieved temporarily. Not only do caregivers find it difficult to know when they need temporary 'time out', they do not always find it easy to share care on an ongoing basis.

Providing respite once a caregiver is seriously burdened by caregiving is ineffective in relieving the intensity of the pressure. It may also compound stress by making it necessary to raise emotions caregivers have not been able to face, or increase guilt over not being able to continue to cope, or just the strain of applying for and organising respite care.

## 5.2 Support from institutions

Ashwell and colleagues (2004) argue Māori providers of support services are crucial to improving Māori uptake of support services. At the hui arranged by the Disability Services Directorate, most Māori wanted a coordinated Māori needs assessment service. Priority issues for those at the hui included support for whānau caregivers and the need for more support options - especially in small towns where formal caregivers were not readily available. One recommendation was for a national network of Māori with disabilities and their whānau (Ministry of Health Disability Services Directorate 2006).

The iwi, hapū and marae play significant roles in Māori informal caregivers' lives and it can be argued that whānau identity and involvement is founded on, and perpetuated by, these three closely inter-related institutions. Strong relationships with these institutions can strengthen the whānau not just through reinforcing a caregiver's cultural identity, but also by increasing the type of experiences and networks they can have access to (Cunningham et al. 2005).

Durie noted 'good health depends on many factors but among indigenous peoples the world over, cultural identity is considered to be a critical prerequisite' (Durie 1999:2). Active marae participation is seen by some kaumātua as being significantly associated with higher levels of health and wellbeing (Durie et al 1996). However, for Māori with disabilities who can't access the marae environment, achieving involvement with the marae, hapu and iwi is problematic (Collins and Hickey 2006: 24). For their whānau caregivers, these barriers to access may lead to them also becoming distanced from the key institutions of identity and sacrificing their wellbeing. Raising awareness of the participation needs of Māori with disabilities is one response to this issue (Ministry of Health Disability Services Directorate 2006).

## 5.3 Resources outside the immediate whānau

### 5.3.1 Kaumātua housing

A number of researchers, government departments and private organisations continue to form responses to the anticipated needs of an ageing population. For example, the Health of Older People Strategy promotes older people accessing health care while being supported to stay in their community and be part of community and family networks, where previously the only option may have been to enter a rest home.

Urban Māori authorities, iwi with Treaty settlement resources and Māori community organisations concerned with kaumātua housing, have considered options for older Māori. The New Zealand Institute for Research on Ageing, Business and Economic Research (2004) considered transitioning through living situations with varying levels of dependence, such as:

- nursing care and serviced accommodation (dependent)
- complexes of whānau housing for all age groups surrounded by marae, hapu or community (interdependent)

- own home/flat near whānau, marae, hapu or community (independent).

A series of hui with Māori using disability support services supported the development of marae-based services where whānau and people with disabilities could live in clustered housing near a marae. Home-based services could also be delivered on a regular basis (Ministry of Health Disability Services Directorate 2006). This was particularly appealing to rural communities.

### **5.3.2 Carers' training programmes**

The whānau caregivers in the study by Ashwell and colleagues (2004) felt that caregiver training was empowering, useful and informative. In particular, their confidence in accessing formal support was greatly enhanced as the programme advised caregivers about the available support services, as well as showing them how to navigate barriers to accessing the services.

### **5.3.3 Subsidised transport**

Two thirds of Māori adults with disabilities (68 percent) had at least one household motor vehicle and more than half (59 percent) were drivers (Ministry of Health 2004). Just under a third (30 percent) used taxis and a similar rate (28 percent) used buses.

The Total Mobility Scheme helped to defray taxi costs for users and 20 percent of Māori with disabilities had heard of the scheme (Ministry of Health 2004).

Seventeen percent of Māori with disabilities reported an unmet need for financial assistance with transport costs compared to seven percent for non-Māori. Of those, children under 15 years old were the most affected and had the highest rates of unmet need: 29 percent for Māori and 24 percent for non-Māori (Ministry of Health 2004).

Nikora et al. (2004) found that the availability of free or subsidised transport to hospitals is sporadic, especially in rural areas. The majority of disabled Māori use their own vehicles and do not access public transport subsidies. There is no nationwide data on availability of transport enabling access to healthcare.

The cost of transport is a key issue for Māori with a disability or chronic conditions. These costs tend to be borne by whānau caregivers (Nikora et al 2004; National Health Committee 2007). While subsidies and grants are available to Māori with disabilities to buy vehicles, there is no support for ongoing transport costs for whānau using the vehicle for the benefit of a disabled whānau member.

### **5.3.4 Formal support**

Choices for Māori seeking care are based on understanding whānau as principal caregivers.

'One of the barriers within Māori health issues is the problem of employing whānau members as principal caregivers. The system believes that whānau support is expected to be provided without any cost. For paid care, the client is forced to look outside the whānau and may set up the possibility of care being

culturally unsafe. It is felt that this attitude towards whānau members actually reduces the whānau wellbeing and does nothing for a holistic approach to Māori wellness.' (Ministry of Health 1998: 14)

### ***Types of support used***

Whānau caregivers used formal support most often to access technical information and treatment related to their own or care recipients' medical conditions. General practitioners, nurses, specialist doctors, physiotherapists and other medical professionals were regular resources for Māori with disabilities (Nikora et al. 2004; Collins and Hickey 2006). The study found:

- 84 percent used a family doctor
- 33 percent used a nurse
- 68 percent used a pharmacist
- 37 percent used a dentist
- 35 percent used a medical specialist
- 23 percent used special equipment (Ministry of Health 2004).

Less often used resources were: residential facilities (1 percent), paid caregivers (5 percent) and private organisations for home help (6 percent).

### ***Barriers to accessing formal support***

Formal support has a place in relieving the strain on the more frequently used informal support systems. However, moving through formal support systems can be difficult for both care recipients and caregivers.

A number of researchers have drawn attention to communication difficulties. Ashwell and colleagues (2004) found misunderstanding and misinformation created problems for Māori accessing services and seeking funding or respite care entitlements. Nikora and colleagues (2004) agreed that medical language or language used to outline entitlements posed a barrier.

Whānau caregivers felt they were not recognised or acknowledged when talking with medical professionals (Nikora et al. 2004; Ashwell et al. 2004). They felt that they were regarded as 'friends' or 'support people' and not as important people who had a strong influence on the health of their care recipients. This is a systemic issue since similar findings are also reported by non-Māori informal caregivers (National Health Committee 2007).

Māori with chronic conditions report relationship problems resulting in mistrust of health professionals and an unwillingness to use the services (National Health Committee 2007). Poor communication between providers and caregivers may result in caregivers using services in times of urgent need only rather than at early stages (Ratima et al. 1995). The National Health Committee (2007) found Māori do not seek early health care for themselves or their whānau because of associated costs. This reflects earlier findings by

the Ministry of Health (1998) that caregivers may suffer loss of wages or jobs as a result of taking time to assist the care recipient to access these services.

Kingi and Bray (2000) argued most Māori were distrustful of and cynical about the health system and called for a more determined effort by the health system to support whānau carers. Māori in their study felt accessing services to support someone with a disability led to a waste of time and resources. Some caregivers felt that it was better to receive little or no support from medical professionals than be treated the way they were. Whānau carers admitted adopting a forceful approach when advocating on behalf of the person they were caregiving for (Nikora et al. 2004; Ashwell et al. 2004).

Whānau responsibility for caregiving for each other may be one reason that formal support services, especially formal, institutional care, has not been strongly utilised. Just one percent of the disabled Māori population were in residential facilities (Ministry of Health 2004). However, it is also possible that Māori use of residential care is limited by economic factors.

Over time the New Zealand Government has moved from expectations of family responsibility for people with disabilities through a period of institutionalisation and has now returned to understandings of family responsibility (Goodhead and McDonald 2006). Māori have continued to hold expectations of whānau and institutionalisation has been a rare occurrence. Whānau in general have not used institutions except as a measure of last resort, preferring instead to persevere with their caregiving responsibility. One reason for this may be informal support systems were well established and used amongst Māori and so remained a first choice for Māori. It is possible that Māori have stronger informal support systems than those available to non-Māori.

Recognition of informal support systems for Māori with disabilities and chronic conditions can significantly enhance provision of appropriate care. For example, involving whānau caregivers in care planning can ensure a person with a chronic illness eats appropriate food and is able to attend appointments (National Health Committee 2007).

## 6 SUMMARY OF THE LITERATURE

There were two key studies about Māori informal carers. However, additional relevant information is contained within literature about Māori and grief, whānau, kaumātua, and Māori with disabilities.

The literature revolves around four main topics: Māori perspectives of informal caregiving; the roles that carers assume; the largely negative impacts of caregiving on carers and their whānau; and the support available for caregivers.

Māori perspectives of informal caregiving centre on the whānau as the core unit from which caregiving is drawn. Whānau members within the same household as care recipients or nuclear family members are the most common carers by virtue of their close relationships. Other whānau members help out of a sense of obligation or because they contribute to ensuring the wellbeing of the whānau as a whole.

The roles that whānau carers assume are the same as those for non-Māori but some roles appear to be emphasised more. This may be due to the differing definitions of whānau and the attributed values and qualities.<sup>9</sup> The role of spiritual guide attended to the belief that some Māori held about disability being associated with metaphysical wrongdoing. The role of interpreter addressed language barriers between whānau members and service providers or government agencies, as well as making sense of the nature of the care recipient's disability. Carers found it difficult to advocate for care recipients mainly because their views were undervalued by health professionals, support service providers and government agencies.

Maintaining links with their whānau, hapu, iwi and wider community was seen by Māori carers and care recipients as important to their wellbeing. Some carers took on the role of helping to shape the cultural identity of care recipients with severe disability and high support needs. For whānau members helping those experiencing severe grief, caregiving also prevented the escalation or development of mental illness.

The impact of caregiving on carers was emotional and traumatic for many. On the one hand, helping a loved one was an opportunity for carers to express their affection, but carers suffered grief and isolation as the health condition of their care recipient worsened. Ongoing caregiving had repercussions for carers' relationships with their immediate family and wider whānau, which carers struggled to reconcile. While carers were willing to continue to give care, the experience was intense at times.

Increased information and knowledge was seen to help whānau carers to minimise some of the institutional barriers associated with caregiving. For example, a better understanding of their care recipient's condition allowed them to provide more effective nursing support and helped prepare whānau carers for dealing with crises and challenges. Monitoring carers' health alongside that of care recipients

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<sup>9</sup> For clarification see chapter 2.

could be adopted more readily if people with disabilities or chronic illness were considered within their whānau context. Problems with transport costs are a key ongoing issue for carers, one that they continued to subsidise.

Formal support has a place in relieving the strain on the more frequently used informal support systems but at this stage, care recipients and carers tend to move through the formal support systems with difficulty. Access to, and delivery of, some formal support services were contentious issues for Māori carers and care recipients alike. Formal support provided in culturally appropriate ways was encouraging for carers.

## 7 CONCLUSIONS

### 7.1 General observations

There is little information about Māori informal caregivers or informal caregiving from a Māori perspective and this paper has presented the main points from the available information. In the absence of relevant information, most authors rely on the trends and patterns occurring amongst the non-Māori population. However, the authors of this paper believe this serves to overshadow the trends within Māori circles and in particular, hide the extent of the information gaps.

Informal caregiving is of great importance to Māori. Caregiving roles are the same as those associated with maintaining whānau relationships and integrity. Caregiving is a common activity across all age groups and especially for women in the middle age range. Care recipients see caregiving and their carers as crucial to their wellbeing.

The idealised whānau is the benchmark for family relationships and members' obligations to each other. The more severe the disability or chronic illness, the more reliant a person is on these values functioning within their whānau. Possibilities for this occurring amongst whānau depend to a large extent on the strength of their identity.

Whakapapa whānau remains the primary arrangement for Māori. Kaupapa whānau may be more significant to caregivers and disabled people living away from their whānau and hapu networks. The term "kaupapa whānau" may be used as a descriptor for the entire formal and informal support network that surrounds the person with a disability, including family members, whānau, friends, neighbours, companions, paid carers, health and medical professionals, counsellors, advocates and so on.

Establishing kaupapa whānau of friends, neighbours, health workers, social workers, church, and community volunteers may become increasingly important to whānau carers living in urban areas. Differences were found between Māori informal caregiving relationships in rural and urban communities and in particular that "rural Māori communities tended to provide greater support to one another, whereas many Māori in urban settings reported feeling excluded and isolated from their Māori community" (Nikora et al. 2004: 15). Cunningham et al. (2005) had similar findings:

"Auckland had the lowest proportion of adults who were members of three or more generations whānau [sic] (59%), and the highest proportion of single generation whānau (10%), while the East Coast had the highest proportion of adults in three or more generations whānau (90%)." (p. 16)

Two inferences can be drawn from the Cunningham study: that Auckland whānau were more likely to be living in nuclear families than East Coast whānau, and that East Coast whānau had a higher likelihood of

whānau support networks. Therefore, while caregiving on the East Coast may have been well supported in terms of people available, caregivers in Auckland had greater access to material and formal support resources.

According to Ashwell et al. (2004), the roles and responsibilities associated with informal caregiving were similar to those practiced as whanaungatanga (family relations) for Māori. Therefore, caregiving was given to, and received by, any member of the whānau that needed or asked for it and was not reserved specifically for those with impairments or health conditions. This was perhaps the over-arching reason that caregiving responsibility was accepted amongst whānau. Whanaungatanga was underpinned by notions of aroha (love) and tiaki (care for, look after).

A caregiving role not mentioned by other authors is parenting on behalf of a person with a disability or chronic illness. For example, if a single mother develops a disability that requires caregiving, she may seek the assistance of an adult in the whānau to help her and seek someone else to help care for her children. Alternatively, the care for the children may be undertaken by the eldest child, so that both the mother's caregiver and the eldest child take on caregiving roles.

The profiles on caregivers made a strong connection between informal caregiving and the household. Less than one percent (700) of Māori lived in residential facilities and the majority of the others lived in one-family households (Ministry of Health 2004).

An option for Māori with disabilities was to move closer to whānau members who could help them but this may have forced a choice between access to adequate hospital/medical treatment and access to informal caregivers. The choice they made may have negatively impacted on their health if choosing to move near whānau carers, or overall wellbeing if choosing to move near to a hospital. The possibility that people may have been sacrificing personal health to be closer to whānau help would require further investigation.

The socio-economic circumstances of the general Māori population highlighted the paradox that, while caregiving was high, resources were low. It was not inconceivable that whānau resources were under severe pressure. Also, the quality of care may have been compromised with consequences to the health of the care recipient, carer and whānau. Resources from outside of the whānau were limited or reserved for certain groups or difficult to obtain.

While it could be argued that amongst some carers the caregiving relationship was a source of significant stress, through, for example the high support needs of some recipients, it appeared that for most whānau carers, the main stressors came from external relationships through, for example, accessing health and support services.

Despite the potential relief that funding, equipment, home-based services and other services could provide, the value of formal support to carers was hard to determine. Carers' perceptions of formal support were marred by adversity and this had proven to be a primary disincentive for them in using formal support.

Further ongoing health sector support for Māori support services was seen as a key enabler for Māori. The benefits for carers ranged from support for their caregiving to support for the carers themselves. There was however, a need to evaluate the progress and outcomes of Māori services as much of the findings regarding this issue have become dated.

In general, the focus on persuading formal support services to become more accessible to whānau obscured whānau preference for informal support. Supporting the integrity of the whānau while offering non-threatening assistance appeared to be the biggest challenge for formal support services.

Also, a closer examination of the support for those suffering from severe grief may provide more information about whānau carers and how they attempt to prevent deterioration into long-term disability.

There were indications of a crisis for Māori women because they were heavily over-represented amongst both caregivers and care recipients. More Māori women were living with a disability than Māori men (57%). The rate of disability among non-Māori women was 51 percent. More Māori women were caregivers than men (63%). The proportion of non-Māori women who were informal carers was also 63 percent. Prevalence studies of informal caregivers conducted in Australia, New Zealand, Canada and the UK found that “women predominate in both the numbers involved and the nature of their contribution” (Goodhead and McDonald 2006: 4).

Cram and Smith (2003) emphasised the financial struggles faced by Māori women stating that poverty for many Māori women was “a day-to-day reality” and that “unless this broader, societal issue is addressed, a major barrier to Māori women accessing health and well-being for themselves and their whānau will remain” (p. 1).

## **7.2. Emergent themes**

### **7.2.1 Caregiving is an ingrained value in Māori culture**

Defining caregiving by that provided to people living with a disability or chronic illness raised two questions: how is caregiving different from the usual things that people and families do for each other and, how can you tell when a caregiving task is carried out because of a disability/chronic illness or because the person with the condition benefits as part of the household? This paper relied on the perspectives of, and information about, the caregiver and care recipient to make the distinctions.

### **7.2.2 Some were obligated into caregiving roles because of their position in the whānau**

This occurred across age groups such as for the first-born, adopted or eldest child in the whānau. These children may have been caregiving from a young age well into adulthood. It also occurred amongst kaumātua, who were caregiving most often for children without disabilities or chronic illnesses.

### **7.2.3 There were two types of caregivers providing direct and indirect care**

The direct carer carried out tasks that directly involved the care recipient such as nursing, companionship or transporting the recipient to appointments. The indirect carer took over the responsibilities that the recipient was no longer able to do for him/herself without help such as housework or parenting. Whereas adult carers were easily visible as direct carers, children (especially older siblings), members from the wider whānau and friends, flatmates and neighbours were visible as indirect carers. Both direct and indirect caregiving was associated with being close at hand so those who lived with or near the recipients were most likely to be carers.

### **7.2.4 There were two forms of caregiving support: personal and reciprocal support**

Personal support most often included everyday tasks around the home, intimate personal care, and assistance with private affairs such as legal or financial matters. Reciprocal support was not necessarily housebound nor intimate but offered general support on a regular or intermittent basis such as financial assistance, respite care, or transport. Although reciprocal support could also encompass personal caregiving, a key element was the perception of mutual and interdependent support for each other. Examples that have been mentioned in previous chapters are the reciprocity between kaumātua and their marae and hapu communities or the intermittent support that the wider whānau offered their members that were either caregivers or care recipients. It could be tackled by direct or indirect carers as well as whānau, marae, hapu and iwi communities.

## **7.3 Gaps in knowledge**

### **7.3.1 The extent of caregiving among Māori with chronic illnesses**

Further investigation into chronic illness amongst Māori and associated caregiving requires classification of individual illnesses as chronic illnesses, further distinctions between chronic illnesses that are/are not disabilities and inquiry into the extent of self-management compared to dependent management for each illness.

### **7.3.2 The extent of caregiving among children**

The prevalence, nature and impact that caregiving has on child carers.

### **7.3.3 The implications of caregiving as a long-term, unpaid occupation**

The ramifications if informal caregiving becomes a full-time unpaid occupation and how carers might finance their caregiving.

### **7.3.4 The future availability of informal caregiving from whānau**

Informal caregiving seemed vulnerable considering the number of Māori adults with disabilities who were living alone or who were unpartnered. Therefore, reliance on formal caregiving assistance could increase.

### **7.3.5 The socio-economic circumstances of carers**

In particular, the impact of carers' health or disability on their living standards as opposed to the impact of poor living standards on carers' health. Also, were people unemployed because they were carers or did they become carers because they were unemployed?

### **7.3.6 The nature of Māori informal support systems**

How Māori manage to resource their caregiving despite the poverty and disadvantages that they face.

### **7.3.7 The connection between informal caregiving and disability prevention**

A closer examination of the support for those suffering from severe grief may provide more information about whānau carers and how they attempt to prevent deterioration into long-term disability.

### **7.3.8 How carers were being supported by formal support services**

Whether government agencies, Needs Assessment Service Coordination (NASC's), District Health Boards (DHBs), and health and disability support services offer support to carers. If so, how could that support be improved?

### **7.3.9 The ramifications if informal caregiving amongst Māori declines**

The cost to the public of losing informal caregiving, supporting existing caregiving structures or replacing them.

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## GLOSSARY OF MĀORI TERMS

<i>Ahi-a-ngakau.</i>	Work done from the heart
<i>Aroha:</i>	Love, affection
<i>Hapū.</i>	Sub-tribe
<i>Hui.</i>	Community gathering
<i>Iwi.</i>	Tribe
<i>Kaumatua:</i>	Elder
<i>Kaumātua:</i>	Elders
<i>Kaupapa Whānau.</i>	A group of people bound together by family-like commitment to a common interest. Members of the whānau may not necessarily be related as kin
<i>Kotahitanga.</i>	Unity as well as accepting responsibility for each other's actions
<i>Mana:</i>	Power made manifest in the world of experience
<i>Manaakitanga:</i>	Caring
<i>Marae:</i>	Communal home of a whānau or hapu
<i>Maataamua:</i>	First-born child
<i>Mauri.</i>	Life-sustaining essence
<i>Mokopuna:</i>	Grandchild
<i>Ora.</i>	Energised life
<i>Pākehā:</i>	Caucasian New Zealanders
<i>Pono:</i>	True, being true

<i>Pōtiki.</i>	Youngest child
<i>Pupuri taonga.</i>	Role of guardianship
<i>Rangatahi.</i>	Young people
<i>Rōpu.</i>	Groups
<i>Tamariki.</i>	Children
<i>Tatau Tatau.</i>	Literally means collective sharing. This is a model of wellbeing for Māori with disabilities and their whānau
<i>Te ao Māori.</i>	Māori world
<i>Te Puni Kokiri.</i>	Ministry of Māori Development
<i>Te taha hinengaro.</i>	Thoughts and feelings
<i>Te taha tinana.</i>	Physical health
<i>Te taha wairua.</i>	Spiritual side
<i>Te taha whānau.</i>	Family health
<i>Te Whare Tapa Whā.</i>	Literally means the four-sided house. This is a model of Māori health
<i>Te Wheke.</i>	Literally means the octopus. This is a model of Māori wellbeing
<i>Teina.</i>	Younger sibling
<i>Tiaki.</i>	Caring for, looking after
<i>Tika.</i>	Right, correct
<i>Tikanga.</i>	Doing the right thing in a particular situation
<i>Tipuna.</i>	Ancestors and whānau members who have died
<i>Tohatohatia.</i>	Capacity for whānau to share resources

<i>Tuakana:</i>	Senior
<i>Utu:</i>	Principle that anything received should be repaid with an appropriate return
<i>Waiora:</i>	Total well-being for the individual and the family
<i>Wairua:</i>	Inner spirit
<i>Whakamana:</i>	Ability to empower whānau members
<i>Whakapapa:</i>	Genealogy
<i>Whakapapa Whānau:</i>	Family related to each other by genealogy
<i>Whakatakato tikanga:</i>	Whānau ability to plan for the future
<i>Whānau te Rito:</i>	Closer family
<i>Whanau<u>k</u><u>a</u><u>t</u><u>a</u><u>k</u><u>a</u>:</i>	Family relationship building in Kai Tahu dialect
<i>Whanaungatanga:</i>	Family relationship building
<i>Whāngai:</i>	Foster/adopted child
<i>Whanui:</i>	Wider tribal family