

How Should we Care for the Carers, Now and into the Future?

Manaaki tangata



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Now and into the Future?

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‘Informal caring is the mainstay of our long-term care systems, yet there appears to be a contradiction between the value we place on our carers and what we provide to assist them, both in material and psychological support.’

(From D Jorgensen, M Parsons and S Jacobs. 2009. *The Experiences of Informal Caregivers in New Zealand: Caring is like a jigsaw puzzle with no picture and pieces missing* (unpublished), p 37)

Photos on cover:

The Gordon Family

Annette and Jason

Losé and Tita

Angela and Mum Iris

Photos by Terry Winn www.terrywinn.co.nz

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Message from the Chair

Providing informal care is part of the day-to-day lives of many New Zealand families and households. About 420,000 people provide care for people experiencing ill health or disability in New Zealand. Around one in five disabled adults receive help only from informal carers, and 14 percent of all disabled children in households have high support needs, where care may need to be provided 24 hours a day.

The demand for informal caring will increase as population ageing, medical advances and improved life expectancy mean that many more people in New Zealand are likely to experience illness or impairment. Informal carers are already essential to the sustainability of the health and disability system because they care for people with a range of needs that may otherwise require support from publicly funded services.

The expectations of people needing care and their families have changed over recent decades. The way care is provided to those who are frail, or have a long-term condition, mental health condition or disability, has also changed. During the 1960s and 1970s older people tended to enter rest homes while still relatively independent to prepare themselves for age-related life changes. Policy has now shifted towards ageing in place and enabling older people to be supported in their own homes.

In the past many disabled people were hidden away in family homes, or were placed in institutions to meet their 'special needs' and to remove the 'burden of care' from their families. In 1985 the Government adopted a policy of community living for people in long-stay institutional care. It was expected that people would receive services to help them become more independent and engage with their communities and society.

In 2003 the NHC's report *To Have an Ordinary Life* identified many of the barriers that impede people with intellectual disabilities from participating in their communities on their own terms. Although people had moved into community-based facilities, the delivery of disability supports largely maintained institutionalised approaches that required people to 'fit in' to services. Many disabled people are highly dependent on family support. Disabled people expect to have ordinary lives like their non-disabled peers. Family members also want ordinary lives, meaning there needs to be a re-examination of how much unpaid care families can provide.

In writing this report the NHC has found it difficult to focus on the needs of informal carers without addressing the current structure of supports and services for people requiring care. The NHC is concerned that families providing care still have to fit within a menu of services that struggle to respond to their unique needs in a flexible way. This seems to be particularly so for carers of people with high and complex needs. Services should enable the person receiving care and their family to fully participate in their communities.

The NHC believes that the funding arrangements for disability, mental health, long-term conditions and aged care supports under Vote Health need to be reviewed, because the current arrangements are not meeting the needs of many carers or the people they care for. Such a review needs to address how funding silos might be broken down so that supports and services are simpler to access, seamless and equitable. The recent establishment of the National Health Board and consideration of devolving centrally funded disability support services provide an ideal opportunity for this review to occur.

The NHC also believes it is essential that there be adequate planning to address the projected increased need for care supports and services in New Zealand. This planning process needs to include ongoing engagement with informal carers. If this planning does not occur, it is likely carers and their families will be placed under increased pressure to provide care that is too demanding, putting their health and wellbeing at risk.

I would like to thank everyone who participated in the research that informed this project. Your willingness to share your stories provided the NHC with valuable insights into the ongoing commitment you as informal carers have to the people you care about. Thank you also to all of the NHC secretariat for their contribution to this report.

I hope this report stimulates ongoing discussion and thinking to inform the development of new models of care, to ensure informal carers are well supported to continue in their important role.



Pauline Barnett
Interim NHC Chair



*Salote Halaumotu (pictured in bed). Born Kolovai, Tongatapu, 5 July 1916. Died Auckland, 19 August 2009, aged 93 years.
Loved and fondly remembered by her family.*

Executive Summary

This report makes recommendations for how to better support and provide services for informal carers. The NHC believes that the health and wellbeing of informal carers should be protected. Informal carers need to be well supported in their role so that they can provide care in a sustainable and positive way.

New Zealand's health and disability system is facing several pressures, including an ageing population and the increasing prevalence of long-term conditions. These trends are likely to significantly increase the demand for family and friends to provide care. Therefore, informal carers are becoming integral to the sustainability of the health and disability system, because they care for people with a variety of needs who may otherwise require support from publicly funded services.

The NHC has defined an 'informal carer' as someone who cares for 'a friend, family member or neighbour who because of sickness, frailty or disability, can't manage everyday living without help or support'.¹ This role mostly goes unrecognised and unpaid because it is generally embedded in everyday family relationships.

The role of informal carer is carried out by people of all ages, ethnicities, socioeconomic circumstances and family structures. Similarly, people of all ages and many stages of illness or impairment require care. Every caring situation is unique and requires a flexible, personalised response. The caring relationship is intrinsically reciprocal.

Meeting the needs of informal carers is directly connected to the way services are provided for the person they care for. Carers consider their needs can be met and prioritised only when the needs of the person they care for are also being met. There is a complex interface between informal care and the formal services that supplement it. Carers have diverse views about how formal services should be configured to supplement the care they provide.

Many carers say that the system of supports and services available to them is complex and fragmented, which makes the system difficult to navigate, particularly where multiple agencies are involved in a person's care. Services are often viewed as lacking understanding, care and compassion, and as being inflexible and reactive. Carers feel there is a lack of quality choices in the services they need, particularly for respite care.

The influence of culture on the way carers access services is not always sufficiently recognised or understood. Ongoing engagement with community leaders, health and disability providers and service users is needed, to inform policy makers about the needs of Māori carers and carers from other ethnic groups living in New Zealand.

Health professionals are gatekeepers to the health and disability system. They need to be equipped to address the requirements of the person being cared for and their family holistically, considering their combined needs. The formal paid care and support workforce is undervalued, lacks training and experiences high turnover. This directly affects the quality of services provided to informal carers.

Long-term planning is required to address the increasing need for informal care and care supports and services. Planning must be underpinned by comprehensive and up-to-date information.

Recommendations

The National Health Committee recommends that the Minister of Health direct the Ministry of Health to:

reduce fragmentation in the care system by:

1. reviewing the structure of funding streams that provide supports and services to informal carers and the people they provide care for, with a view to improving equity and consistency in service provision ²
2. establishing a role in the Ministry of Health to lead health policy related to informal carers and coordinate relationships with government agencies and non-governmental organisations
3. re-focusing Needs Assessment Service Coordination (NASC) on the needs of the person being cared for and their informal carer(s), rather than solely according to the diagnosis of the person being cared for, which could be achieved by:
 - 3.1. having a greater focus on achieving positive outcomes for families
 - 3.2. strengthening the navigation and coordination functions of NASC agencies to improve continuity of services
 - 3.3. developing needs assessment as an accredited role that can be carried out within different health and community settings (eg, within a primary health care team, in a hospital ward or on a marae)
4. improving the way primary health care supports carers and their families through strengthening the pathways between primary health care and secondary and tertiary care, NASC agencies, health and social service providers, and non-governmental organisations.

achieve national consistency and local flexibility of services by:

5. working with District Health Boards (DHBs) to continue developing service specifications and contracts across funding streams, which should:
 - 5.1. improve national consistency in the services available for informal carers and require that an acceptable level of respite care is available in every locality
 - 5.2. give service providers more flexibility to tailor services to an individual's or family's needs (eg, through increased use of discretionary funds)
 - 5.3. provide incentives to deliver quality services that focus on outcomes, and improving carers' health and wellbeing
6. developing a programme of regular evaluation of services for informal carers separate from the evaluation and monitoring of individual service providers
7. widening the eligibility for individualised funding and developing multiple options for the level of management of the funding by the individual or their family

8. actively supporting the development of:
 - 8.1. new models of community-based care for people with high support needs to ensure there is an acceptable level of service available in every locality
 - 8.2. culturally appropriate models of community-based and long-term respite care

raise awareness by:

9. working with Māori and Pacific communities, and people from a non-English-speaking background, to increase self-identification among informal carers, empower people in their role as informal carer, and promote the supports and services available to informal carers
10. working with the Ministry of Social Development and the Department of Labour to use government workplaces as models for flexible working arrangements and portals for information about informal caring

improve workforce capability by:

11. using the role of informal carers as a case study when training health professionals in patient-centred, holistic models of care
12. working with service providers, DHBs and training agencies to prioritise training and the development of recruitment and retention strategies for the formal care and support workforce

prepare for the future by:

13. undertaking long-term planning and modelling to determine the cost, volume and optimal mix of supports and services that both informal carers and people requiring care may need in the future, taking into account the flow-on effect for the provision of other health and disability services
14. investigating the variety of supports and services that should be publicly funded in New Zealand for informal carers and the people they care for
15. working with the Ministry of Social Development to develop a demographic profile of informal carers to inform future planning, taking into consideration the ageing population, the rural–urban drift, changing family structures and increasing ethnic diversity
16. proposing to Statistics New Zealand that a section in the Census of Population and Dwellings be developed to collect information about the prevalence and nature of informal caring
17. developing a unit of the New Zealand Health Survey to collect information about informal carers' health status, within the next five years.

About this Report

The NHC first highlighted the needs of informal carers in its 1998 report *How Should We Care for the Carers?* The NHC is concerned that the needs raised in that report, now a decade old, are essentially the same issues facing informal carers today.³

The NHC began to revisit issues for informal carers in 2006 because research revealing the significant responsibilities of carers and their families had moved into the policy spotlight, and debate was increasing about whether the costs of supporting carers should be met primarily publicly or privately.⁴

Background information

Five reports in particular have contributed to this report:

- *Informal Caregivers Literature Review: A report prepared for the National Health Committee*
- *Māori and Informal Caregiving: A background paper prepared for the National Health Committee*
- *Qualitative Study of Elderly Pacific Informal Caregivers of a Young Person with an Illness or Disability (published July 2009)*
- *The Interface between Informal Caring and Formal Services in New Zealand*
- *Care Ethics for Informal Carers.*

The NHC encourages readers to review these five reports because the thoughts of carers articulated throughout this report are primarily sourced from them. These documents are available on the NHC's website (<http://www.nhc.health.govt.nz>). Each of these reports is summarised in Appendix 1.

The NHC also gathered information from a wider range of academic sources and government reports, meetings with stakeholders and relevant government agencies, by attending relevant conferences, and by meeting with carers themselves.

Terms used in this report

The term 'informal carer' is used interchangeably with 'carer' in this report. Where the word 'carer' is used, this includes situations where there are multiple carers.

The phrase 'supports and services' refers to the services listed in Table 1 (page 14), unless otherwise specified.

Where the term 'family' is used, it is intended to include whānau, aiga and concepts of the primary family unit within all cultures.

Terms in **bold** in sections 1–3 are defined in the glossary (Appendix 2).

Structure of this report

This report is divided into three sections, followed by two appendices and a list of endnotes. The three sections discuss:

- the value of informal carers
- the current system of supports and services for carers (including recommendations 1–12)
- planning for the future (including recommendations 13–17).



José and Tita

1 The Value of Informal Carers

Section 1 discusses the:

- diverse range of caring situations
- emotional and physical impact of caring
- factors contributing to New Zealand's increasing reliance on informal care – population ageing, the increasing prevalence of long-term conditions, and changing family structures
- costs of informal caring and of care and support services.

The demand for informal caring is predicted to increase in New Zealand. Informal carers are becoming integral to the sustainability of the health and disability system because they care for people with a variety of needs who might otherwise need support from publicly funded services.

There has been a shift in government policy towards community living for younger people, ageing in place for older people and an increasing emphasis on self-care and care in the home. These policies also contribute to the increasing number of family and friends required to provide care in our communities.

The diverse range of caring situations

The National Advisory Committee on Health and Disability (National Health Committee – NHC) defines 'informal carer' as someone who cares for 'a friend, family member or neighbour who because of sickness, frailty or disability, can't manage everyday living without help or support'.⁵ The relationship between an informal carer and the person they care for is most often based on 'love, kinship or friendship, and usually exists before the need for care'.⁶

The role of informal carer is carried out by people of all ages, ethnicities, socioeconomic circumstances and family structures and is different for every person. This role is most often carried out within families, where there may be a primary carer or shared responsibility. Families have different norms, expectations, support networks and cultural beliefs, all of which influence the way care is provided.

Informal caring differs from the usual tasks and responsibilities that form part of a relationship between, for example, partners in older age or a child and parent, because it requires a commitment beyond usual levels of reciprocity. The role is different from formal care supports and services because it is unpaid and is not based on any formal agreement or **service specifications**, although it can be the carer's main occupation. Carers may have given up full-time paid work to provide care, or they may be juggling caring with employment and other family commitments.⁷

The support that carers provide ranges from emotional, spiritual and social support to physical, household and administrative support (eg, dressing, bathing and toileting; undertaking practical tasks such as cooking, cleaning and shopping; providing companionship; and supervising the person being cared for).⁸ People of all ages and many stages of illness or impairment require care, and the needs of such people often change over time. Carers also bring different levels of understanding and experience to their role.

The needs of an informal carer and the person they care for are intrinsically linked, which means in practice that ‘the needs of the carer can only truly be met or prioritised when they are certain that the person they support is being cared for’.⁹ In the words of one carer:

we are still having trouble convincing people ... that carers’ paramount reason for being is to care about their person – that is their top priority when it comes to what’s needed. You have to get past that before carers will give themselves the opportunity to look at things for themselves and identify what they need.¹⁰

To adequately identify and address carers’ needs it is essential to recognise that every situation is unique and requires a flexible, personalised response.

Informal caring within whānau

The Government has a responsibility to address Māori health and disability needs as part of honouring the partnership between iwi and the Crown under te Tiriti o Waitangi (the Treaty of Waitangi). **Whānau ora** and *He Korowai Oranga: Māori Health Strategy*¹¹ guide the development of health policy for Māori.

Whānau Ora involves facilitating positive and adaptive relationships within whānau (extended family) and recognises the interconnectedness between health and other contributors to whānau wellbeing, such as education, housing and employment. The NHC considers that any work undertaken as a result of the recommendations in this report should be informed by the whānau ora approach, particularly where it has an impact on Māori carers.

The NHC commissioned a literature review to develop a description of informal caring from te ao Māori (a Māori world view) to understand the impact of the caring role for Māori and identify any barriers to Māori providing care.

The literature review found that resources outside the whānau are considered supplementary to care provided within the whānau. For example, respite care arrangements were not seen as a clear choice or substitute to whānau-provided care.¹²

The roles and responsibilities associated with informal caregiving are similar to those practised as whanaungatanga [kinship] for Māori and are underpinned by notions of aroha [love] and tiaki [caring for, looking after]. Caregiving is not reserved specifically for those with impairments or health conditions.¹³

Caring within whānau involves the additional responsibilities of maintaining community links, providing spiritual guidance, and acting as an interpreter and advocate:

A close link with whānau, hapū, iwi and the marae is important to the cultural identity and holistic wellbeing of whānau. Whānau caregivers take responsibility for maintaining these links for themselves and their care recipients.¹⁴

Pacific carers

Pacific people in New Zealand:

occupy different social locations and encompass a range of backgrounds and experiences, depending on whether they are Pacific Island born, New Zealand born, multi ethnic, disabled, [or] religious.¹⁵

‘Cultural views, language and history significantly influence the way in which Pacific people perceive, access and continue to use health [and disability] services in New Zealand’.¹⁶ For example, Pacific people have a higher rate of usage of emergency departments and hospitals in New Zealand (similar to the pattern shown in Pacific Island countries). Pacific people also tend to delay treatment until their health concern has become severe or they have many issues to be dealt with. Unfamiliarity, discomfort and Pacific people’s perceptions of social or cultural isolation have also been identified as barriers to their accessing services.¹⁷

The NHC commissioned research into the experiences of elderly Pacific carers in order to provide some understanding of this vulnerable group. The research highlighted that elderly Pacific carers demonstrate high levels of resilience in the face of many challenges. Many participants were engaged in the caring role out of economic necessity. Poverty, poor housing and a lack of knowledge of care supports and services added significantly to the challenges they faced in the caring role.

The 2006 survey of disability and informal care in New Zealand found that disabled Pacific adults are much more likely to get help from informal carers than are disabled adults from other ethnic groups.¹⁸

Carers from a non-English-speaking background

Carers from a non-English-speaking background may also find it difficult to access care supports and services in New Zealand. This difficulty may be due to:

- language barriers and the need for translation and interpretation services
- a cultural background where there is stigma about a certain illness or disability
- lack of social support, possibly because of a lack of family in New Zealand
- a distrust of authorities or government services before arriving in New Zealand.¹⁹

The New Zealand literature says little about the needs of carers from a non-English-speaking background.

However, an Australian inquiry into services for carers found that cultural background and having English as a second language were important factors influencing people’s access to information.²⁰ A submission from the Centre for Cultural Research at the University of Western Sydney noted:

the capacity of carers to find information, make contact and negotiate services was influenced by what we describe as ‘cultural competence’ . . . This encapsulates knowledge of how the system of community and social care works, including the culture of service delivery, language of care provision, and the power structures within and across both government and non-government organisations.²¹

New Zealanders from a non-English-speaking background are a population the NHC considers that the Government, Carers New Zealand and the Carers Alliance could extend their focus to in the future.

Emotional and physical impact of informal caring

The commitment and responsibility required of informal carers can be intensive. Care may need to be provided 24 hours a day, seven days a week, particularly for primary or sole carers. The carer may find some kinds of care to be embarrassing, difficult, stressful, expensive, boring or exhausting to provide. On the other hand, the provision of care can be very rewarding for the carer because of the emotional bond that develops between the carer and the person being cared for.²²

Few carers make the deliberate choice to take on the caring role; most often they do so because they love the person they care for or feel a sense of family duty to care for them. Because most carers would not consider anyone else suitable to carry out their role, families (or whoever is providing care) generally look for formal services to supplement what they can provide themselves.

Several international studies have found that carers have poorer self-reported health than the general population. The Carer Health Effects Study conducted in the United States in 1999 analysed mortality risks after four years of caring. The study found that ‘carers who were providing care and experiencing caregiving strain’ were 63 percent more likely to die than non-carers in the comparison group, and those who had directly taken up a significant caregiving role had poorer self-reported health and health behaviours (such as missing doctor’s appointments and not exercising). The literature on primary carers’ physical health suggests that, as well as having poorer self-reported health, carers are more likely to have a major health problem, use medication and experience physical pain than non-carers.²³

Australian research identified that when an informal carer is unrecognised and unsupported, they are likely to have ‘significantly worse mental health and vitality and higher rates of depression than the general population’.²⁴

A significant proportion of carers have reported suffering physical and psychological effects as a consequence of providing care. This was due to the relentless physical and emotional intensity of the caring role, exacerbated by financial hardship, a lack of respite and other supports, and the social isolation that they experience.²⁵

The potentially high emotional and physical toll of providing informal care goes beyond that individual’s life. It also affects their family and support networks and, ultimately, has a broader impact on communities and New Zealand society.

Ethical questions in caring

The role of informal carer needs to be viewed within the context of the particular relationship (eg, whether the carer is a spouse, parent or child). The fact that informal caring is most often carried out within a family means the role can generate ethical questions and challenges. Some examples of complex situations carers may have to resolve are as follows.

- *Managing the tension between providing care and support, and enabling and empowering the person receiving care:* in any caring relationship there may be a power imbalance and a risk that the person receiving care feels they cannot contribute equally to the relationship.
- *Dealing with feelings of loss, social isolation and loneliness:* a person may be required to take on a caring role at any point in their lives, sometimes suddenly as the result of a traumatic change to an existing relationship. It can be difficult to communicate feelings associated with this transition.²⁶
- *Dealing with family and societal expectations to undertake a caring role:* many carers can feel duty-bound to care because of family obligations. Traditionally, women have felt a sense of obligation to take on the caring role.²⁷
- *Resolving difficulties with coping:* when to access formal services can be difficult to determine if a carer becomes overwhelmed by their role, particularly if a carer perceives the options available to them to be low quality.

New Zealand's increasing reliance on informal care

Many factors influence the future demand and supply of informal care in New Zealand. The NHC has chosen three factors it considers particularly important to highlight: the ageing population, the increasing prevalence of long-term conditions and changing family structures.

Ageing of the population

Statistics New Zealand projects that the number of people aged 65 and over will reach 1.33 million in 2051 and the number aged 85 and over will increase to 320,000.²⁸ As a result, many people providing care to someone over the age of 85 will themselves be aged 65 or over, and families may find they are providing care to both older and younger family members.²⁹

Statistics New Zealand also predicts that between 2001 and 2021 the number of older people living alone will increase. Generally, people living alone receive less informal care individually because they do not have immediate access to partners and family. This trend may add to the demand for family and friends to care, or for formal care services in the coming decades.³⁰

The number of people aged 65 and over who will remain in the labour force is projected to increase threefold between 2001 and 2026.³¹ As a result, many more New Zealanders may be carrying out a caring role as well as being in paid employment in older age.

Increasing prevalence of long-term conditions

The increasing prevalence of **long-term conditions**³² such as diabetes, asthma and cancer is another major challenge for the New Zealand health and disability system. An increase in the number of people with long-term conditions will result in an increasing number of people requiring some informal care in their lifetime.

The NHC's 2007 report *Meeting the Needs of People with Chronic Conditions: Hapai te whānau mo ake ake tonu* concluded that because people with long-term conditions are high service users throughout their lives, they need proactive support (with an emphasis on the role of primary care) and a redesign of the health system to deliver a continuum of care across hospitals and community-based services.³³

The report also concluded that the involvement of family in the assessment, care planning and management of a person with a long-term condition can improve the person's health outcomes, increase access to care, and reduce health inequalities. Much of what was learnt from this report can be applied to the challenge of supporting informal carers as the health and disability system faces similar policy questions in responding to their needs.

Changing family structures

New Zealand is experiencing a shift away from traditional nuclear family structures. This has a direct impact on the ability of families to provide care. Living situations are changing: the numbers of couples with children who are in several age groups, one-parent families and people living alone are predicted to increase.³⁴ Families may be spread across different cities and countries. Whether the need for informal care can be met is also influenced by increasing rates of relationship breakdown, the estrangement of parents from adult children, reduced family formation among young adults, and a change in the role of women in the home and workplace.³⁵

The Māori population is also diverse, with no one definition of 'whānau'. However, with whānau membership come roles and responsibilities that include looking after the whānau aged and disabled members.³⁶ How whānau define themselves influences the way caring is undertaken. For example, some whānau are heavily involved in hapū and iwi activities, meaning that responsibilities may shift between whānau members to accommodate caring.³⁷

The 2006 New Zealand Disability Survey found that disabled adults overwhelmingly lived with family (only 20 percent lived by themselves) and disabled people with high needs were unlikely to live on their own (only nine percent lived by themselves).³⁸ These statistics suggest that for a significant number of disabled people family are their primary source of support. Therefore disabled adults are a population that could become more vulnerable to not having their care needs met in older age.

Costs of informal caring and of care and support services

During the 2009 Budget the Minister of Finance announced that New Zealand was in the midst of 'the deepest, most synchronised, recession since the 1930s'.³⁹ In 2009/10 Vote Health received an increase of \$899 million (a 7.4 percent increase from the previous year) and DHBs a \$2.1 billion increase in funding to provide services to local communities.⁴⁰ However, maintaining an increase of \$750 million in *new* spending for the health and disability sector in future budgets is unlikely.⁴¹

Importance of planning for effective service provision

The current economic situation has highlighted the importance of planning for the provision of care supports and services to ensure the right mix of services is provided in the future. The interface between the provision of informal care and formal services is complex. Australian modelling indicates that it is not clear whether informal care and formal care act as substitutes or are complementary. Research does indicate that informal care supplemented by community-based care can generally be provided at lower cost than residential care.

A joint review by DHBs, providers of **aged residential care** and the Ministry of Health is under way to determine the drivers of demand for aged residential care.⁴² Such planning should be extended to other areas of service provision that will play a significant role in supplementing informal care (such as various forms of respite care) in the future. Planners need to understand demographic changes, the health status of target populations and consumer preferences to deliver services efficiently and avoid budget pressures.

Economic value of informal carers

Informal care is generally provided without payment. However, it is not provided for ‘free’ in a broader economic sense because time spent caring could be directed at other activities, such as paid employment. Research from Australia puts the opportunity cost of income forgone as a result of unpaid informal caring at AUS\$4.9 billion – equivalent to 9.9 percent of the total value of formal health care in Australia.⁴³ Equivalent New Zealand figures are not available, but the unpaid contribution of informal carers to our economy is likely be significant, in a similar manner to unpaid child care and domestic work.

There is a direct cost saving to government in recognising the unpaid contribution of carers to the economy and investing early in protecting carers’ health and wellbeing. If informal carers are not provided with adequate services to support them to carry out their role in a sustainable way, they are likely to become more reliant on the health and disability system in the future than if the right supports were provided in the first place.



The Gordon Family

2 The Current System of Supports and Services for Carers

Section 2 discusses how supports and services are provided for informal carers across the health and disability system. The discussion addresses four issues and provides recommendations for each:

- reducing fragmentation in the care system
- achieving national consistency and local flexibility of services
- raising awareness
- improving workforce capability.

Reducing fragmentation in the care system

The NHC has identified that:

- informal carers experience barriers to accessing supports and services
- the care system is fragmented and lacks coordination.

Many carers say that the system of supports and services available to them is complex, fragmented and therefore difficult to navigate. This is particularly the case where multiple agencies are involved in a person's care.⁴⁴ The NHC first addressed the debate about coordination and continuity of services in 1998 in *How Should We Care for the Carers?* The NHC is concerned that over a decade later the Government has made insufficient progress to address this situation.

The NHC's recommendations

The National Health Committee recommends that the Minister of Health direct the Ministry of Health to reduce fragmentation in the care system by:

1. reviewing the structure of funding streams that provide supports and services to informal carers and the people they provide care for, with a view to improving equity and consistency in service provision⁴
2. establishing a role in the Ministry of Health to lead health policy related to informal carers and coordinate relationships with government agencies and non-governmental organisations

3. re-focusing Needs Assessment and Coordination (NASC) on the needs of the person being cared for and their informal carer(s), rather than solely according to the diagnosis of the person being cared for, which could be achieved by:
 - 3.1 having a greater focus on achieving positive outcomes for families
 - 3.2 strengthening the navigation and coordination functions of NASC agencies to improve continuity of services
 - 3.3 developing needs assessment as an accredited role that can be carried out within different health and community settings (eg, within a primary health care team, in a hospital ward or on a marae)
4. improving the way primary health care supports carers and their families through strengthening the pathways between primary health care and secondary and tertiary care, NASC agencies, health and social service providers, and non-governmental organisations.

Barriers to accessing supports and services

In the NHC's research for this report it found that most carers consider it difficult to access information about services, such as who they should contact and where they should go. Carers considered the interaction of health and disability services and social services complex, unclear and hidden.

It's like being in a merry go round that you can't get off . . . The information wasn't there, there was nowhere that I could go to find out things, and that was the biggest hiccup . . . I found out by accident how things work, or where I could access things.⁴⁶

Informal carers typically access services and have their needs identified through multiple points in the health and disability system. Factors influencing how carers access the system include:

- the carer's supporting role, which is often not the primary focus of treatment and services, so the carer may not seek support for themselves initially
- points of access to services being determined by the age and diagnosis of the person being cared for (eg, whether the person being cared for is a child eligible for special education support; the carer is identified through a social agency such as Child, Youth and Family; or the carer attends a medical specialist appointment as a result of a family member having a stroke)
- the carer's geographic location (eg, whether they are in a rural or an urban setting) and the services the local DHB funds
- the carer's existing knowledge and use of the health and disability system (eg, whether they have visited a doctor in the past 12 months or know about Needs Assessment Service Coordination – NASC).

Barriers for Māori and Pacific carers

The influence of culture on the way carers access services is not always sufficiently recognised or understood. Facilitating access to information and services is particularly critical for Māori

carers. Research from the Ministry of Health has identified that barriers to accessing health services for Māori fall into the following four categories:

- organisational (eg, distance to travel and availability of an appointment)
- cost (direct and indirect) and perceived value for money
- the practice of health providers (eg, perceptions of negative or racist attitudes and the feeling of being talked down to)
- cultural fit (eg, services' misunderstandings of cultural behaviours such as **manuhiri** and **noho whakaiti**, and people having a 'wait and see' attitude to accessing services).⁴⁷

Research with older Pacific carers (commissioned for this report) found that language is a major barrier to this group obtaining information. Participants did not generally use the internet and were hesitant about attending workshops or public forums to gain information.⁴⁸

Fragmented and un-coordinated services

Carers continue to be concerned at the fragmentation and lack of coordination of services available to them and the people they provide care for. Carers' experiences included:

- inequity between services across funding streams
- a lack of long-term planning and holistic case management for care
- limited communication between disjointed services
- inconsistency in the NASC process.

One carer commented:

Not only did I have to get him up in the morning, washed, changed, fed, dressed, take him to wherever, I could do all that, but then I found myself juggling appointments with 17 different agencies, receptionists and assessors, and advocates and counsellors, therapists, and you name it, and it was all put onto me, so there was no clear way through.⁴⁹

Participants in research with older Pacific carers found that:

Although many services were available, no one provider had oversight of their health needs and there was no coordination of the various health and support agencies. This led to their feeling isolated and marginalised by the health [and disability] system.⁵⁰

An informal carer's access to services is ultimately linked to the diagnosis of the person they provide care for and is addressed within the corresponding funding stream. Four examples follow.

- **Disability support services** are funded through 11 government votes, with 11 ministries each responsible for a different client group or type of disability support. Most people receive support from several agencies, often through contracted organisations.⁵¹ For people with disabilities, stand-alone NASC agencies provide needs assessments.
- **Mental health services** are provided through a mix of community, outpatient and inpatient settings and vary depending on the severity of illness. A person's needs are assessed so that a treatment programme can be developed. There is one stand-alone NASC agency for mental health in New Zealand.

- **Long-term conditions** are primarily diagnosed and treated through Primary Health Organisations (PHOs) and referred to medical specialists.
- **Older people's** health needs are primarily diagnosed and treated through a PHO. General practitioners (GPs) are the primary source of referrals for needs assessment. A stand-alone NASC agency provides needs assessment for older people.

Carers' experiences show there is limited coordination among primary health care, secondary and tertiary care, the social services sector, non-governmental organisations and service providers. This lack of coordination creates a complex system for the person being cared for and their family to navigate – particularly if responsibility for the overall management of treatment or care is not clear.⁵² Separate NASC agencies for disability support services and older people's health add to the fragmentation.

Table 1 demonstrates how services for informal carers are linked to the diagnosis of the person requiring care rather than to the carer's need, and the difference in services provided through the various funding streams.



Annette and Jason

Table 1: Summary of policy areas and funding available for informal carer

Policy area	Funding source	Description of services
Older people's health	District Health Boards (DHBs)	<p>Older people's health covers:</p> <ul style="list-style-type: none"> • people aged 65 and over • people aged 50–64 who have been clinically assessed as having health and support needs because of long-term conditions more commonly experienced by older people. <p>Services are accessed through a Needs Assessment and Service Coordination (NASC) agency.</p> <p>Indirect support for carers <i>Home and community support</i> (eg, household assistance and personal care) is primarily provided for the person requiring care, but can also be provided to help the informal carer. Access to home help is income tested.</p> <p>Direct support for carers The <i>Carer support subsidy</i> (CSS) is allocated to the person needing care as a number of days per year, based on need. The person or their full-time carer is responsible for arranging respite or relief care in their own home (informal) or a residential care setting (formal). The daily payment rate for formal carer support is higher than the daily rate for informal carer support.</p> <p>DHB CSS rates are the same in the older people's health and mental health areas. Rates vary between DHBs.^a</p> <p><i>Contracted respite care</i> is generally provided in a residential care setting through bulk contracts between a DHB and providers. Unlike the CSS, no direct payment is made to the client. Respite care may be scheduled in advance by a NASC agency or provided on an emergency basis.</p> <p><i>Other support services</i> such as night care, day care (mostly dementia-specific care) support groups, and information and advice services are funded by some DHBs.</p>
Mental health	DHBs	<p>For most people, access to mental health services will be by way of a referral from a GP. Access to mental health and addiction services is determined on the basis of highest level of need identified by a health professional or addiction worker who is a member of a recognised professional body.</p> <p>Direct support for carers CCS is funded under disability supports where the disability code 'psychiatric' is used in the assessment.</p> <p>The range of respite care / carer relief options provided by DHBs for carers of children and young people is limited. Crisis respite care, night care and day care are provided by a few DHBs.</p> <p>Provision of the various forms of respite care for adults is variable among DHBs.</p>

Policy area	Funding source	Description of services
Disability support services	Ministry of Health	<p>Funding for people with a disability generally covers people under the age of 65 who have a long-term physical, intellectual and/or sensory impairment that requires ongoing support.</p> <p>Indirect support for carers <i>Home and community support</i> (eg, household assistance and personal care, rehabilitation, environmental supports and home modification) is primarily provided for the person requiring care, but can also be provided to help the informal carer. Aspects of this support are means tested (eg, home modifications over \$7,900 including GST).</p> <p>Direct support for carers CSS: Ministry of Health rates are typically higher than those paid by DHBs.^b</p> <p>The daily payment rate for formal carer support is higher than the daily rate for informal carer support.</p> <p><i>Contracted respite care</i> is available for the carer of a person with a disability in a variety of settings. Respite care is also available to people with various degrees of deteriorating conditions (eg, multiple sclerosis) or conditions with particular needs (eg, stroke).</p> <p>Respite care may include night care for children or adults with disabilities.</p> <p>Day care is available for working-age adults.</p>
Long-term conditions	DHBs (with most funding for conditions such as diabetes managed through separate funding streams)	<p>Indirect support for carers Care Plus provides additional funding to primary health organisations (PHOs) to provide coordinated care for people who need to visit the doctor more frequently than is usual. People eligible for Care Plus include people with two or more long-term conditions (such as diabetes or heart disease) people who are terminally ill, and people who are on ‘active review’ for elective services.</p>
	Ministry of Health	<p>The Ministry of Health administers an Interim Funding Pool, which funds long-term support services for people with chronic health conditions and people who do not meet eligibility criteria for Ministry-funded long-term support services. The Government’s intention is to transfer this responsibility to DHBs in 2010.</p> <p>Interim Funding Pool packages are based on an assessment of individual support needs and take account of informal carer needs and preferences. They may include respite care and carer support.</p> <p>All packages must be signed off by the Interim Funding Pool Board.</p>

Policy area	Funding source	Description of services
Autism spectrum disorder (ASD)	Ministry of Health and DHBs	<p>If a person with ASD is severely affected by a co-occurring mental illness, they are likely to be eligible for specialist mental health services. If a person with ASD has a co-occurring intellectual, physical or sensory disability they are likely to be eligible for Ministry of Health-funded disability support services.</p> <p>If a person has ASD but no other condition or illness, they may not be eligible for funding, which means their carer may also receive no assistance.</p> <p>The Ministry of Health is completing work to clarify future responsibilities for the funding of services for people with ASD.</p>
Personal health	DHBs	<p>Personal health funding covers people assessed as having ongoing needs and who are aged:</p> <ul style="list-style-type: none"> • 0–15 years (child) • 16–64 years of age (young people and adults). <p>Access to services for carers is typically at the discretion of GPs.</p> <p>Support for carers is highly variable across DHBs for children, young people and adults with short-term conditions but includes:</p> <ul style="list-style-type: none"> • CSS • contracted respite care • night care.

Notes

- a In the Northern, Midlands and Central DHBs the CSS rate for informal care is \$64.50. Northern and Central DHBs also compensate 'non-family private carers' at \$75.56 per day. Southern DHBs compensate informal carers at \$75 per day. Northern and Midlands DHBs compensate formal care at \$75.56 per day. Central and Southern DHBs compensate formal care at \$85 per day. Only Southern DHB rates are comparable with Ministry of Health-funded rates (see note b). All figures are GST inclusive.
- b Ministry of Health-funded CSS rates are \$85.50 per day for formal care and \$76 per day for informal care. All figures are GST inclusive.

The role of Needs Assessment and Service Coordination (NASC) agencies

The role of NASC agencies is to:

- assess a person's care and support needs, including, where appropriate, those of their family and carer(s)
- tailor a package of support to meet those needs
- manage an annually allocated budget.⁵³

NASC agencies provide a direct service to carers by allocating services (eg, respite care) and indirectly support carers through services allocated to the person being cared for.

The relationship between NASC agencies and other parts of the health and disability system varies throughout New Zealand. For example, some NASC agencies sit within a DHB's provider arm, some provide an 'in-reach' service in hospitals, and some cater more widely than for people eligible for disability supports and people aged 65 and over. This variation has contributed to inconsistency in the quality and continuity of the services provided, and the parameters and focus of NASC agencies has become unclear to some informal carers.

A Social Services Committee inquiry into the provision of disability supports in New Zealand reported in 2008 that:

originally NASC services were to be 'one-stop-shops' where a disabled person's needs in various sectors (for example, health, education, welfare, or justice) could be determined . . . however, NASC systems have become confined to providing only those services and resources funded through Vote Health, although they do refer people to community-based services and other agencies that may be able to assist them.⁵⁴

Submitters to the inquiry also commented that NASC agencies did not always give people control and choice, and lacked flexible responses to meet people's needs. It was suggested that NASC agencies operated bureaucratically, fitting people's needs into service boxes rather than engaging with clients in a meaningful way.

The NHC has also identified what appears to be a significant operational issue: the difference between what the service specifications state a NASC agency should provide and what is provided in practice.⁵⁵ The NHC recognises that the ability of NASC agencies to operate in a way that is acceptable to their clients may be constrained by the level of funding they are allocated and the services available to meet people's needs.

Philosophy of needs assessment

Some carers are concerned about the needs assessment process.

We're sick and tired of being assessed and then finding out well what help was that? Our needs as carers weren't addressed, my daughter's needs weren't really addressed because you know they've got no money, they've got no funding or they don't understand what it's like living with it 24/7 so why bother – why put us through that?⁵⁶

It is clear that the quality of the needs assessment process relies on the approach and aptitude of management and staff, the philosophy of the NASC agency (eg, how closely it follows the service specifications and its use of discretionary funding) and its health and disability sector relationships.

The NHC's 1998 report *How Should We Care for the Carers?* listed a number of important considerations for needs assessment. The NHC has revisited this list to inform this report. Needs assessment ought to take into account the:

- nature of the carer's relationship with the person they care for
- carer's social contacts and the support they get from their family, friends and community
- carer's emotional, physical and mental health
- carer's willingness and ability to provide care, particularly if they are employed or have other family members to look after
- carer's understanding of the illness or impairment of the person they care for
- carer's strengths and natural ways of coping.

The Ministry of Health has been piloting the use of the InterRAI Minimum Data Set Home Care (MDS-HC) New Zealand assessment tool in NASC agencies for people aged 65 and over (currently in use in five DHBs). The InterRAI tool takes a medical approach to assessing health needs, although it includes questions about social needs. The tool enables clinicians to collect consistent data that is accessible to others electronically on a person's record. Data can be aggregated to assist regional planning for patient needs.⁵⁷

The NHC is concerned that the InterRAI tool will not be effective for assessing the full range of a person's domestic and community needs as well as those of their carer. Carers have stated that they want their needs assessed in a trusting environment, where the focus is not just a person's health needs, but also their abilities, aspirations and personal circumstances. For carers, needs assessments should be designed to capture the complexity of caring situations and do so in a holistic and respectful way.⁵⁸

Proposed solutions

The NHC considers that increasing access to a coordinated care system requires the Ministry of Health to take a stronger leadership role. The structural points at which carers' needs are identified and assessed need to be strengthened, and a coordinated pathway from diagnosis and medical treatment to needs assessment and service allocation provided. Collaborative working arrangements between primary health care, NASC agencies, secondary and tertiary levels of care, the social services sector and non-governmental organisations are integral to achieving this.

In making recommendations about carer supports and services, the NHC believes that the needs of the carer should be considered in conjunction with the needs of the person they care for. This approach recognises that the caring relationship is reciprocal and mitigates the risk that funding and service provision silos will develop.

Review the responsibility for policy, funding and service provision (recommendations 1 and 2)

Within Vote Health, funding for NASC and care supports and services is provided separately across (predominantly) the disability supports, older people's health and mental health policy areas. This has created inequity and inconsistency in the services available. The NHC considers that to achieve more consistent and equitable access to quality services, this funding structure, including the optimal degree of funding devolution, needs to be reviewed.

Devolved funding allows for a flexible and community-focused approach to the planning and funding of services.⁵⁹ Flexibility may sometimes be achieved at the expense of national consistency. However, given carers' desire that services meet their needs in a personalised (ie, tailored) way, local rather than national decision-making about service provision seems more appropriate.

Leadership from the Ministry of Health is essential to implement the improvements to the delivery of primary health care and NASC services recommended by the NHC. The Carers' Governance Group has been established to oversee implementation of the Carers' Strategy.⁶⁰ The NHC supports this group continuing in its role, but believes that to plan and provide for the future needs of informal carers a role should be established within the Ministry of Health to:

- lead health policy related to informal carers
- coordinate relationships with government agencies that are responsible for policy related to informal carers and maintain links with non-governmental organisations, particularly Carers New Zealand and the Carers Alliance.

Strengthening the role of primary health care (recommendation 4)

GPs are the first point of access to the health and disability system for most people and the pathway to most other publicly funded health services.⁶¹ Therefore, providing coordinated and holistic primary health care is a priority for effectively identifying an informal carer's health needs, ensuring their smooth path through the system and managing individual and family health and wellbeing long-term.⁶²

The NHC has five proposals to strengthen primary health care.

- When a person is first diagnosed and/or assessed as needing care supports and services, the full extent of their needs and options for both informal care and formal services is discussed in a comprehensive consultation.
- A health care team is assembled to provide appropriate medical treatment in accordance with the complexity of the person's needs and to identify, where appropriate, their carer's and family's needs.
- A long-term plan is developed for the person's ongoing health care. This plan is developed in conjunction with the relevant allied and specialist health professionals.
- A needs assessment is carried out. Depending on the extent to which the assessment covers health or domestic and community needs, it could be undertaken in a health or community setting (eg, in a primary health care team, on a marae or by referral to an NASC agency). This is a case-by-case decision that requires flexibility.
- A case coordinator is assigned to continue regular contact with the family. This person could sit within the primary health care team, the NASC agency, or a social service agency. Primary care maintains an active overview of the health needs of the individual and their carer(s).

The interface between a carer's health needs (assessed initially through primary health care) and their domestic and community needs (which currently may be assessed and coordinated through an NASC agency) is particularly important. Support and services provided to a carer through primary health care, NASC agencies and other social support agencies should be viewed as part of a full package of care. However, overall responsibility for a carer's health and wellbeing should be clearly assigned. The success of the relationships within this interface contributes directly to the effective identification and ongoing management of a carer's needs.

Learning from Māori models of service delivery

The Ministry of Health has supported the development of Māori providers through the Māori Provider Development Scheme since 1997.⁶³ A recent study by the Ministry profiled nine Māori health providers. The study gives some insight into the distinctive features contributing to Māori health providers' success. Tikanga Māori and Māori models of wellbeing underpin the providers and are applied in the development and delivery of services.⁶⁴ Five further distinctive features of Māori health providers are as follows.

- *Developing relationships and effective communication:* trusting relationships between the provider, the patient and their whānau have a positive impact on patient understanding, satisfaction and adherence to treatment.
- *Taking a holistic approach:* Māori health providers treat the whole person and often consider the wider whānau as part of the picture of an individual's health. Practitioners recognise they are dealing with the health status of their patients, but also respond to housing, income, employment and other contextual issues.
- *Using multidisciplinary teams:* many Māori health providers are committed to using multidisciplinary teams that involve both clinical and community expertise (especially in the treatment of chronic illness).
- *Being community oriented:* Māori health providers have a strong community base and strong alliances with other health and social service providers. Methods of service delivery are flexible (eg, on-site, on marae and mobile services).
- *Being nurse led:* 'Māori nurses are at the forefront of primary health care . . . proactive monitoring and follow up, and support of the patient was often the primary responsibility of these nurses.'⁶⁵

The NHC considers that the characteristics and practices of successful Māori providers are extremely valuable for adoption into primary health care to meet the needs of informal carers.

Re-focusing Needs Assessment Service Coordination agencies (recommendation 3)

NASC agencies are an ongoing point of contact with the health and disability system, particularly for people with disabilities and older people. NASC agencies can provide a connection between the health care, and social and domestic services that carers and the person being cared for receive. However, carers are not always clear about what to expect from an NASC service. Parameters for eligibility and prioritisation need to be clearly communicated to clients.⁶⁶

The NHC considers that in terms of the function of NASC agencies:

- NASC agencies should focus on the *needs* of informal carers and the person they care for, rather than solely the *diagnosis* of the person being cared for
- needs should be assessed holistically, with a greater focus on achieving positive outcomes for NASC clients and their families, rather than NASC agencies being guided by a prescribed list of services and their budget
- the navigation and coordination of services by NASC agencies could be strengthened and expanded to provide a comprehensive and ongoing service to clients in the way that **Intensive Service Coordination** does currently.

The NHC considers that in terms of the form of NASC agencies:

- the various NASC agencies (eg, for older people and people with disabilities) could be consolidated within localities to provide one channel of information, provide an ongoing point of contact for carers, and reduce duplication of NASC services, although NASC agencies should maintain specialist expertise appropriate to their client base
- needs assessment could be developed as an accredited role carried out in different health and community settings (eg, within a primary health care team, in a hospital or on a marae) to maintain continuity of care.

Many issues regarding the functioning of NASC agencies are not new, and the Ministry of Health is making gradual adjustments to improve their operation. In the area of disability support services the Ministry of Health has recently developed qualifications in assessment, planning and coordination for NASC as part of the Workforce Action Plan to 2014. The Ministry is also working to improve the consistency and transparency of NASC services by developing a performance management framework; establishing a national reviewer role to assist NASC agencies in applying Ministry guidelines, processes and funding allocation and pricing tools; and improving the definitions used in the Support Allocation Tool. The NHC hopes that any improvements made to the functioning of NASC for people with disabilities can be shared across NASC agencies generally.

The NHC notes that the Ministerial Committee on Disability Issues recently agreed that the Ministry of Health should investigate the use of the **Local Area Coordination** model, in conjunction with other measures such as individualised funding and supported living arrangements, to improve the coordination of services for people with disabilities.

A positive example of what can be achieved with an innovative approach to service coordination is provided in Case Study 1.



Angela and Mum Iris

Case Study 1: Wairarapa District Health Board – Rethinking service coordination and delivery

New Clinical Services Action Plan

Wairarapa DHB is rethinking how it delivers services to its population. The DHB's new Clinical Services Action Plan recognises that:

- many of the DHB's services are provider- or diagnosis-focused rather than focused on meeting the needs of patients in a holistic way
- aspects of patient care are fragmented and poorly coordinated between services.

In response, the DHB has identified the need to work collaboratively both internally (eg, between primary and community health care services) and externally with its service providers. Collaborative working arrangements ensure a smooth and clear pathway for patients and comprehensive, tailored service allocation.

The success of a collaborative approach is evident in the incremental improvements that have occurred in the delivery of community-based services.

FOCUS: Needs Assessment and Service Coordination Agency

FOCUS is Wairarapa DHB's Needs Assessment Service Coordination agency. The agency has been redeveloped as a single point of entry for people requiring community and support services. Anyone, regardless of their health or disability diagnosis, duration of illness, or age, may contact or be referred to FOCUS.

Services that can be allocated through FOCUS include:

- disability support for people of any age
- community nursing
- a health recovery programme
- home and community support, and respite care
- support for people caring for others
- palliative care.

If a patient has a carer, the carer's needs are assessed at the same time as the patient's. The FOCUS support coordinator can help carers to find a service and provides information through newsletters and support meetings.

As a result of this change in approach, referral rates to FOCUS have increased greatly. The relationship between FOCUS and primary care clinicians has improved, and patients with complex needs have had access to a coordinated package of services. The DHB has achieved these results within its existing funding arrangements.

Source: Wairarapa District Health Board. 2009. *Clinical Services Action Plan* (unpublished); personal communication with Joanne Edwards, Wairarapa DHB, 21 October 2009.

Achieving national consistency and local flexibility of services

The NHC has identified that within service provision there is a need to improve:

- quality, compassion and flexibility
- choice, accessibility and national consistency.

There is a complex interface between informal care and the formal services that supplement it. Carers have diverse views about how formal services should be configured to supplement the care they provide.

The main service provided directly to support informal carers is respite care. For the purposes of this report, respite care includes in-home care, residential services, day care, overnight care and emergency care. The services referred to in this section include **home and community support services**, the **carer support subsidy** and contracted **respite care** (for more detail see the full funding and service breakdown in Table 1, page 14). This section encompasses services for the person being cared for because these services contribute to the needs of an informal carer being met.

Budget 2009/10 included *new* funding for services that have some impact on informal carers to the amount of:

- \$2.5 million in 2009/10 and \$5 million in out-years for targeted residential respite for older people
- \$60 million for hospice care over four years, including \$1.3 million to address difficulties in accessing palliative care services.

The NHC believes some tangible changes to the way supports and services for carers are planned, specified and contracted can be made within current funding arrangements. Questions about funding the provision of care supports and services long-term are discussed in section 3. Improvements can be made to the needs assessment process (within the existing guidelines) and more flexibility could be provided for carers and their families through the use of individualised funding packages.

The NHC's recommendations

The NHC recommends that the Minister of Health direct the Ministry of Health to achieve national consistency and local flexibility of services by:

5. working with DHBs to continue developing service specifications and contracts across funding streams, which should:
 - 5.1 improve national consistency in the services available for informal carers and require that an acceptable level of respite care is available in every locality
 - 5.2 give service providers more flexibility to tailor services to an individual's or family's needs (eg, through increased use of discretionary funds)
 - 5.3 provide incentives to deliver quality services that focus on outcomes, and improve carers' health and wellbeing

6. developing a programme of regular evaluation of services for informal carers separate from the evaluation and monitoring of individual service providers
7. widening the eligibility for individualised funding and developing multiple options for the level of management of the funding by the individual or their family
8. actively supporting the development of:
 - 8.1 new models of community-based care for people with high support needs to ensure there is an acceptable level of service available in every locality
 - 8.2 culturally appropriate models of community-based and long-term respite care.

Lack of quality, compassion and flexibility in service provision

A key finding of the NHC’s research that should underpin the Government’s approach to service provision is that:

the well-being of the care recipient was intrinsically linked to the informal carer’s own sense of well-being. Quality care for their loved one appeared fundamental, a prerequisite for their [the carer’s] decision to utilise any support services, such as respite care.⁶⁷

Quality care was described as care that provided a healing environment, meaningful activities for the person being supported, and a place where staff ‘really cared’ about those they look after. Carers expect that service providers will show respect and understanding in the way they and the person they care for are treated, and will walk alongside them in their role. Services that engaged the carer and respected their specialised knowledge were highly valued.⁶⁸

Many carers described services as being rigid and unable to meet their needs and circumstances. Some carers felt that services responded only when they were desperate:

It’s like you call up and say I really need help – they are not going to bother. What annoys me is that you have to break down and it’s only at that point when they bother doing something and that’s really upsetting.

It’s the night time carer that costs so much – they only pay for so many hours a day and then over and above that you can’t use two days subsidy together for one day.⁶⁹

Another experience related to the NHC was the inflexibility of home and community support. For example, the Individual Service Plan may provide 40 minutes for the formal care support worker to shower an individual. However, if a shower will take longer than this, some workers feel they cannot safely carry out the task.

The 2007 report *Whakanui Oranga: Lessons on culture and policy from the New Zealand Disability Strategy* found that Māori carers generally felt frustrated and disappointed with services. Māori carers cited a lack of awareness of their culture from providers as a reason for preferring whānau to provide the majority of care. They also perceived services to be fragmented and inflexible.⁷⁰

The Ministry of Health has developed the Whānau Ora tool to assist providers to place Māori ‘at the centre of programme planning, implementation and evaluation’.⁷¹ The tool provides questions to assist health care providers to develop effective health and disability services for Māori and to contribute to improving Māori health outcomes. The NHC supports the use of this tool to improve services for Māori carers.

Some carers acknowledged they have high expectations of services and that they will always prefer to provide care for their family member or friend (in a sustainable way).

Lack of choice, accessibility and national consistency in service provision

Many carers said limited service options were available to them and they felt forced to put up with services or staff they were unhappy with. When services were inadequate, this could create tension within the caring relationship because the person being cared for no longer wished to use the service and the carer did not get the breaks from caring they needed.⁷²

Many carers felt uncertain about what services would be available to them, particularly at short notice.

I've got three weeks coming up . . . my daughter is getting married in Australia. So I want to use that by Mum going into residential care for three weeks. She's happy with that and Dad is happy with that sort of thing, but sadly the residential care provider doesn't know if they can take her and I can't get in there until nearer the time.⁷³

Most carers were also uncertain about the future and how the needs of the person they care for would be met if they were no longer able to provide care. The course of an illness or disability and consequently what the caring role may entail in future are unknown for many carers. The level of some families' concern is reflected in this observation from the parents of an intellectually disabled adult:

If you were to ask us parents . . . when you die, would you like your dependent child to pass on with you rather than be a burden on your children and your grandchildren . . . I would say in my perfect scenario, I'll be driving in my car, and we'll be singing, to the woodlands and a log truck will come across and drop its load right on both of us and we'll both go together, that would be the perfect solution for us.⁷⁴

The NHC's research found that many services for carers were designed to be used intermittently or on a one-off basis, not reflecting the fact that many people undertake caring roles for several years.⁷⁵ People go through transitions in their life and a person's illness or impairment changes over time. As a result, the caring relationship evolves.

Choice and accessibility are largely determined by the services contracted by each DHB and the Ministry of Health, the diagnosis, and the age of the person requiring care. Respite care and carer-relief services for older people appear to be the most comprehensive, while there is a gap in services for children and young people.

Other service gaps of concern to the NHC relate to:

- forms of respite care that are culturally appropriate
- community-based care options for people requiring a high level of support (eg, where 24-hour care is necessary)
- services for people who fall between funding streams (eg, people with autism spectrum disorder) or with multiple conditions (eg, people with a mental health condition and physical disability).

The NHC is aware that the Ministry of Health is looking to address some of these gaps. In particular the Ministry is:

- undertaking a stock take of respite care and carer-relief options funded through Vote Health
- reviewing the service needs of people with autism spectrum disorder
- developing service specifications for mental health services aimed at family and whānau
- purchasing additional out-of-family respite services in the area of disability supports.

Proposed solutions

Informal carers want the allocation of funding and eligibility criteria for services to be more consistent. They want services that are of a high quality; are flexible, caring and respectful; and acknowledge the specialised knowledge carers have about how to provide care. Services should assist carers to empower the person being cared for to lead an independent and ordinary life and to achieve full participation in the community.

Planning for more effective service provision (recommendation 5)

A key concern for carers is the lack of consistency between the services provided across funding streams. Robust planning processes are central to achieving national consistency in service provision. The Ministry of Health's Statement of Intent 2009–2012 says that in response to inconsistent, short-term and isolated planning decisions it intends to better coordinate planning at the national, regional and DHB district levels.

The NHC hopes that more collaborative planning processes will result in a clearer translation of a national strategic direction to meeting local needs. Regional planning for the consolidation of some specialised and costly forms of respite care services may help to pool resources and enable a service to be more financially viable (eg, as occurs with specialised hospital services).

Planning that incorporates a degree of flexibility for DHBs to allocate funding on a needs basis (eg, funding for NASC agencies and community-based health services) could assist in the efficient use of that funding by reducing the need for duplicated infrastructure and services (eg, between needs assessment for older people and people with disabilities).

Transparent long-term planning should enable funders to provide more certainty for service providers. This is particularly important for specialised forms of respite care that often rely on flexible bulk funding to be financially viable over the long-term.

Effective service specifications and contracts (recommendations 5 and 6)

Service specifications and contracts are immediate levers through which the quality and range of services can be improved. How services are specified and contracted varies across the different funding streams that provide services for carers. The NHC is concerned that the way services are currently specified and contracts are structured remains broadly outputs focused. For example, contracts may specify the number of beds and staffing levels that a respite facility must provide, rather than focusing on the outcomes and quality of the service provided for the end user.⁷⁶

As a result, service providers can be constrained because they are not funded and monitored in a way that allows them to easily expand or adapt a service in response to changing needs. This can make it difficult for some specialised services to be provided in a financially sustainable manner.⁷⁷

Submitters to the 2008 inquiry into services for people with disabilities noted:

audit checks monitored compliance with systems and processes, and did not focus on the quality of life offered to the people with disabilities in the facilities . . . While contracts may also contain requirements that services observe principles such as ensuring people with disabilities enjoy a high quality of life, submitters told us that providers and staff tend to focus on ensuring paperwork is up-to-date and all standards for equipment and processes met.⁷⁸

The Ministry of Health has changed how it conducts contract-based audits of community-based residential services. The Ministry now uses **developmental evaluations** that give disabled people and their families a role in the monitoring process.⁷⁹ The NHC is encouraged by this change in focus and hopes that it is indicative of a broader change in approach to include services for mental health, disability, older peoples' health and long-term conditions.

The NHC makes six suggestions regarding the funding, specification and contracting of services.

- DHBs should have the flexibility to merge funding streams for services, such as respite care, where a service could be more cost-effective if targeted at two or more populations or targeted on a needs basis.
- Where a highly intensive or specialised service is required, it should be funded with bulk, multi-year funding to make it more financially viable to provide.
- An acceptable level of services for each locality should be determined and reflected within service specifications.
- Contracts for services such as out-of-home respite care should have sufficient flexibility, such as the ability for terms to be renegotiated quickly, so that services can adapt to changing needs.
- Contracts should focus providers on ensuring consumers are satisfied with the outcome of the service for their quality of life, rather than just specifying the level of service to be provided (eg, the number of beds or staff).⁸⁰
- Feedback should be gathered from service users and staff during the auditing and monitoring process to ascertain whether a service is of an acceptable standard.

The NHC proposes that to reinforce what is learnt from the evaluation of individual service providers and ensure the need for care supports and services is being met, the Ministry of Health should develop a programme of regular evaluation of the range of services available to informal carers.

Widening the use of individualised funding (recommendation 7)

Individualised funding is money paid by the Ministry of Health directly to someone assessed by an NASC agency as needing disability supports or services to purchase the support they require.

The NHC is particularly concerned that families of people with very high and complex needs can be under extreme levels of stress because they are unable to access services that meet their needs. It can be very difficult for the family of a person who requires significant home modification and specialised equipment to access respite care outside of their own home.⁸¹ For the family of a person with mental illness, difficult or unsociable behaviours may make it difficult for that person to be cared for in shared respite services. Individualised funding appears to be the most appropriate option to meet such people's needs because it is a flexible method of tailoring supports and services to someone's unique circumstances.

Under Objective Two of the Ministry of Health's Statement of Intent 2009–2012 the Ministry states that it will be expanding the availability of individualised funding arrangements for people with disabilities. The NHC understands that this is occurring in two ways initially: by widening the eligibility criteria beyond people with high and very high needs, and by working towards having more than one provider through which the funding can be managed.⁸²

The NHC recommends that eligibility for individualised funding be further widened; for example, by exploring the application of individualised funding beyond disability support services to other groups requiring ongoing care services. The NHC also recommends there be a wider range of options for the level of management of individualised funding undertaken by the individual or their family.

Innovative models of care (recommendation 8)

Carers say that there is a limited range of quality service options available to them and the person they care for, particularly for respite care. The NHC considers that the Ministry of Health needs to respond to this situation by encouraging the development of a greater range of service options and promoting innovation in existing services. The NHC proposes that the Ministry particularly support the development of:

- new models of community-based care for people with high support needs, to ensure there is an acceptable level of service available in different localities
- culturally appropriate models of long-term and respite care.

Actively supporting the development of new models of care could be achieved by providing templates for health and safety policies and certification standards to potential service providers. Assistance to move through the accreditation process would be particularly valuable to smaller, community- and family-oriented services.

Case studies

Although carers have identified many issues with the provision of services, there are many cases of innovative, compassionate and person-centred services across the country. Case Studies 2 and 3 show that solutions can be found within the existing funding constraints and by looking outside existing models of care for answers.

Case Study 2: Waitemata District Health Board – Respite Service Coordination for older people

Respite Service Coordination is part of NASC at Waitemata DHB. The service packages bring together a variety of flexible and responsive services to support full-time carers of older people with high and complex health and disability support needs.

The service aims to provide for the needs of both the carer and the older person being cared for, and for all services to be coordinated through one point. This has required the DHB to work closely with the NASC agency, GPs and other specialist staff (eg, hospice and palliative care staff) to understand each other's functions.

Respite coordinators take a partnership approach with the carer, the family and the older person. The respite coordinator can become an ongoing key contact for the carer and family if this is needed (eg, to coordinate other specialist appointments for the older person).

An NASC assessor is positioned as an 'in-reach' person within the hospital to identify people who have been admitted and require a respite care package. The development of this role was in response to the high number of older people who were referred to the NASC agency through acute services.

How is support for the carer tailored?

Options for respite care include residential respite care, day care, and sleep-over or night care.

The DHB surveyed its respite care users to find out what services they needed. As a result of the survey the service was re-designed and a mixture of existing and new providers was contracted to provide a broader range of options to carers, including in-home respite care – identified by the majority surveyed as a popular option.

If carers become unwell, their package of support can be reconfigured (eg, by shifting approved support payments into the period during which the carer is unwell) to provide a higher level of care to the older person during that time.

Services available in addition to home and community support, and respite care include:

- linkages with volunteer and special interest groups
- the engagement of specialist services such as geriatricians, physiotherapists and social workers.

Source: Waitemata District Health Board. 2009. *Home and Older Adult Services*. URL: <http://www.waitematadhb.govt.nz/SecondaryHealthServices/HomeandOlderAdultsServices/tabid/92/language/en-NZ/Default.aspx> (accessed 14 December 2009); and personal communication with Kate Matthews, Waitemata DHB, 2 October 2009.

Case Study 3: Totara Trust, Horowhenua

Totara Trust, Horowhenua, is a charitable trust that was founded in January 2004 in response to the concerns of parents of adults with intellectual disability that no appropriate long-term care was available to their children as they grew older. The families were unable to find suitable long-term care, with the right home environment and philosophy, in Horowhenua–Manawatu. Even respite care became impossible to find. One parent explained:

Out of desperation we decided to do something for ourselves and so, after a very long and arduous journey, Totara Trust evolved . . . Totara House, a beautiful residential family home, surrounded by huge mature trees, including two giant Totara, was purchased in Levin in December 2003.

After a long period of establishing its case to provide a new facility with the Ministry of Health, Totara Trust was eventually granted full residential funding for six residents. The residents moved in from May 2004.

Subsequently, the trust has had many other parents of intellectually disabled young adults approach them looking for a long-term care solution for their children. In September 2007 the trust's board purchased a neighbouring property, and Karaka House was established. However, the trust has made a conscious decision to provide care for only 10 residents to 'maintain the intimacy and personal homely atmosphere that a smaller community engenders'.

Totara Trust is a family environment. This environment has been a key factor in the trust's success, along with the personal commitment of the parents of the disabled people living there. The trust highly values its staff and has been able to maintain a high level of continuity in its carers.

In addition to full-time residential care, Totara Trust provides a vocational programme (partly funded by the Ministry of Social Development). The programme encourages the residents to maximise their potential to live as young adults in the Horowhenua community. It offers weekly music therapy, reading and literacy classes, horse riding, massage and relaxation therapy, farm visits, aqua aerobics and swimming, and café and city excursions.

Raising awareness

The NHC has identified that there is a need to increase self-identification of informal carers and the level of community awareness about the role of informal carers.

The NHC's recommendations

The National Health Committee recommends that the Minister of Health direct the Ministry of Health to raise awareness by:

9. working with Māori and Pacific communities, and people from a non-English-speaking background, to increase self-identification among informal carers, empower people in their role as informal carer, and promote the supports and services available to informal carers
10. working with the Ministry of Social Development and the Department of Labour to use government workplaces as models for flexible working arrangements and portals for information about informal caring.

Increasing self-identification and community awareness

The role of an informal carer can remain invisible within communities precisely because it is embedded in everyday routine and is predominantly carried out by family members.⁸³ Someone may not recognise themselves as a carer because they consider their role to be a normal part of their contribution to family or community life.

If carers do not recognise their role, and families and communities are unaware of the services available to them, a carer's health and wellbeing could deteriorate before they access support. Evidence suggests that some carers reach crisis point before seeking help, potentially resulting in their needing a more acute and costly health intervention than if they had sought help earlier.⁸⁴

Views about the caring role can be strongly influenced by a person's culture. For example, within Pacific populations there tends to be a higher level of informal caring undertaken as part of everyday relationships within the aiga.⁸⁵ Young carers are another group less likely to self-identify as carers or to be identified through social services.⁸⁶

In the NHC's 1998 report *How Should We Care for the Carers?* carers identified that they needed more recognition at all levels of the health and disability system.⁸⁷ Recognition of informal carers' needs has improved in the decade since the 1998 report with the development of the Carers' Strategy and the partnership between Carers New Zealand, the Carers Alliance and the Government.

The Carers' Strategy outlines the Government's vision for carers in New Zealand.

It provides a framework of principles to guide policy development and the delivery of services [and identifies] what actions are needed to ensure carers are supported, valued and recognised for their important role in caring for other people in New Zealand society.⁸⁸

Although the principles underpinning the strategy and its overarching objectives are commendable, these have been translated into limited actions within discrete policy areas. The NHC strongly supports the continued implementation of the strategy, but considers that the Government needs to plan comprehensively for informal carers' needs on an ongoing basis (discussed further in section 3 of this report).

A *Guide for Carers* was developed in mid-2009 and widely disseminated by the Ministry of Social Development and Ministry of Health as part of the implementation of the Carers' Strategy. The NHC supports initiatives to disseminate information to carers and recommends that the Government work in tandem with communities most likely to face barriers to accessing support and services in doing so (eg, carers who are Māori, Pacific carers, and carers from a non-English-speaking background). If the Government expects families and communities to take on more responsibility for people requiring long-term care, it is vitally important that they are well prepared and informed, and understand the balance of responsibility between government and families.

Raising community awareness needs to be tackled more broadly through partnerships between the Government, employers and the non-governmental sector. Workplaces are one avenue through which information can be provided to carers and higher levels of awareness generated among the public about the increasing need for informal care. In its role as an employer the Government can also set an example of best practice.⁸⁹ The NHC proposes that the Ministry of Health work together with the Ministry of Social Development and Department of Labour to use government workplaces as models for flexible working arrangements and portals for information about the prevalence of informal caring.

Many carers who identify as being unemployed have said they would 'welcome the opportunity to combine care with paid employment or look forward to doing paid work when their circumstances allow'. A recent report led by the Department of Labour recognised that the Government can support workplaces to 'better meet the needs of parents and carers and better utilise their skills through providing information and support, and facilitating information sharing between workplaces on what works, especially smaller workplaces'.⁹⁰ The Employment Relations (Flexible Working Arrangements) Amendment Act 2007 is also a significant milestone in recognising the value of carers in the workplace and their needs.⁹¹

Case Study 4 demonstrates an innovative approach taken by British Telecom, which has adopted many of the strategies promoted by a non-governmental organisation in the United Kingdom called Employers for Carers.

Case Study 4: Employers for Carers and British Telecom

Employers for Carers

In the United Kingdom a non-governmental organisation called Employers for Carers has taken steps towards recognising that many informal carers want to remain in the workforce but need recognition that they are juggling paid work and caring responsibilities. The organisation's key purpose is to 'ensure that employers have the support to retain employees with caring responsibilities'.

Employers for Carers argues that by recognising the needs of carers in the workplace through strategies such as flexible working hours, businesses can retain experienced staff, reduce stress in the workplace, reduce the use of sick leave, reduce recruitment costs and increase productivity.

Employers for Carers advocate implementing within workplaces:

- flexible working practices such as flexi-time, home working, staggered hours and job sharing
- emergency leave for when leave is required at short notice because care arrangements break down or the person being cared for falls ill
- flexible leave arrangements such as compassionate leave, planned leave, and paid leave for emergency or planned caring
- workplace support such as in-house networking groups, employee assistance programmes and carer policies
- simple adjustments such as access to a private telephone or car parking close to the workplace to make access in and out of work quicker and easier.

British Telecom

British Telecom (BT) is a large, international company in the United Kingdom that is leading the way in recognising carers' needs in the workplace. The company currently chairs Employers for Carers. BT have adopted a 'carers policy' that acknowledges the informal caring role, and have identified that the two things carers most value in the workplace are information and flexibility. BT supply a wealth of information to their employees about supports and services for carers through their internal web portal.

Sources: Employers for Carers. Business Case. URL: <http://www.employersforcarers.org/BusinessCase> (accessed 14 December 2009); and Caroline Waters. 2009. British Telecom's Journey. Carers' Conference, Auckland, 24 September 2009.

Improving workforce capability

The NHC has identified the need to:

- value the skills and knowledge of informal carers
- address the attitudes and practices of health professionals
- develop the formal care and support workforce.

This section refers to the *paid* workforce – health professionals (eg, doctors, nurses and allied health workers) and care and support workers (eg, home help and personal care workers).

The NHC's recommendations

The NHC recommends that the Minister of Health direct the Ministry of Health to improve workforce capability by:

11. using the role of informal carers as a case study when training health professionals in patient-centred, holistic models of care
12. working with service providers, DHBs and training agencies to prioritise training and the development of recruitment and retention strategies for the formal care and support workforce.

Valuing the skills and knowledge of informal carers

The NHC's 1998 report *How Should We Care for the Carers?* identified that carers want to be considered as *co-clients* who have their own needs, and *co-workers* who need to be consulted, listened to and supported. The NHC still supports this view and is concerned that insignificant attention has been given to this perspective since 1998.

Over time informal carers develop specialised knowledge about how to care for the person they support. Research for this report found that carers reported a better experience with formal services when staff valued their knowledge and skills regarding how to care. Carers want to feel engaged by formal services and feel they are not being judged by staff about their ability to provide care.

One participant in a mental health focus group commented that:

A lot of the serious incidents we read about come about in part because family weren't involved in the treatment assessment and the clinical teams weren't listening to what the family were saying.⁹²

Taking the time to value a carer's knowledge not only increases the level of satisfaction with the service for the carer, but can also be very important in making sure formal care is provided safely.

Addressing the attitudes and practices of health professionals (recommendation 11)

Practitioners at the forefront of New Zealand's health and disability system provide a critical service in diagnosing and treating people, but are also the 'face' of health care. Maintaining face-to-face relationships and effective communication skills is very important for sustaining a good relationship with patients and identifying individuals and families with more complex issues.⁹³

Informal carers want access to appropriate clinical expertise, but they also want health professionals to show understanding, respect and insight into the challenges and rewards associated with the caring role.

I've had a couple of examples of doctors saying you poor thing when I got upset with them, lost my rag. We feel sorry for you, it must be so hard, I said he's not the problem, you are. You don't listen, it's a rare disorder, I've been dealing with it for four years. I know what he needs.⁹⁴

In the NHC's 1998 report many carers stated that they did not get the support, recognition and information from health and disability sector professionals they needed. They also suggested that despite doctors being the gatekeepers to most health care pathways, doctors often did not know what services were available, or value a carer's input into planning and decision-making.

The NHC found that the relationship participants have with health providers matters greatly to people with long-term conditions. Participants in research conducted by the NHC in 2007 related stories of poor relationships with health professionals. Not being understood by health professionals – or not being able to understand them – caused participants distress and frustration.⁹⁵

It is well documented that trusting relationships are very important to Māori in their overall satisfaction with health services. Poor communication skills and a lack of understanding of and respect for Māori culture and values contribute to a Māori person's negative experiences. Research suggests that younger Māori feel more empowered than older generations to express dissatisfaction with the health care they receive and are more critical of the recognition of Māori culture within hospitals.⁹⁶

Research by the NHC into the experience of older Pacific carers found that Pacific people do not want to embarrass themselves when talking to authority figures (such as GPs) by showing ignorance, so were unlikely to be assertive, as they did not want to be seen as 'dumb'.⁹⁷

A GP is described as someone who:

delivers generalist medical care by purposefully engaging with patients as people over time, developing professional person/whānau relationships . . . this holistic approach places value on knowing the individual as a whole person and recognises the context of that individual within home, family and community.⁹⁸

A registered nurse is described as providing a:

comprehensive nursing assessment to develop, implement and evaluate an integrated plan of health care [as occurring] in a range of settings in partnership with individuals, families, whānau and communities.⁹⁹

Although these descriptions reflect the kind of approach advocated in this report, the prevailing view about the role of the GP and nurse may still be based on historical modes of service delivery.¹⁰⁰ The attitudes and practices of professionals within the health and disability system are equally as important in ensuring the system's successful functioning as the structures put in place to enable this.¹⁰¹

Carers are a very diverse group of people who rely on many different professionals within the health and disability system. To facilitate the kinds of relationships carers have said they want with health professionals, training should encourage practitioners to become aware of carers' needs and the supports and services available to them. The NHC recommends that training providers should include patient-centred, holistic models of care in their curricula, using the role of informal carers as a case study for how this approach is implemented.

Developing the formal care and support workforce (recommendation 12)

It is well recognised that issues with the recruitment, training and retention of formal care and support workers significantly affect the availability and quality of services.¹⁰² There is also growing recognition that society needs to place more value on the work of the formal care and support workforce. In mid-2009 Paul Mackay, the employment relations policy manager at Business New Zealand, commented:

We have to have a shift in the appreciation of the value of that work . . . How that is going to manifest itself is unsure, but it behoves all of us to start showing that connection between the work that is done and the value it creates.¹⁰³

The importance of training

There appear to be difficulties with both the nature of the training available to the care and support workforce and the ability of service providers to access and use training as a mechanism to retain quality staff.

A report by the Health Workforce Advisory Committee in 2006 noted that service providers recognised the importance of training to ensure safe and quality services. However, many faced difficulties providing that training due to funding constraints, high turnover, the diverse needs of clients and a lack of workforce readiness for training.¹⁰⁴ In 2008 the inquiry into services for people with disabilities reported that 'affordable foundation courses for disability support workers to teach them to respect and understand the needs of people with disabilities' were needed.¹⁰⁵

In response to such barriers, the Ministry of Health has developed a workforce action plan specific to disability support services to guide workforce planning and development until 2014. The plan's objectives include:

- establishing career pathways based on agreed competencies and qualifications
- ensuring the workforce highly values and actively supports disabled people, and their families, whānau, aiga and carers
- promoting disability support work as a desirable career choice.¹⁰⁶

The NHC supports this piece of work, but notes that it relates only to disability support workers and so does not cover the entire care and support workforce. The value of high-quality staff was clearly demonstrated at the NHC's visit to Totara Trust, Horowhenua (see Case Study 3). The retention of staff has been a key factor in the trust's success.

Ensuring the formal care and support workforce is equipped to provide services that families trust and are willing to use involves:

- listening to what carers and the people they care for want from a caring, compassionate and quality service – qualities such as care, respect and understanding, although they cannot be gained simply from training, should be imbued through steady, structured reinforcement within the workforce
- putting strategies in place to improve how the care and support workforce is valued socially and financially
- working with service providers, DHBs and training agencies to prioritise training across the care and support workforce and to develop recruitment and retention strategies for the formal care and support workforce.

Meeting workforce demand

Demand for formal care and support workers will require a significant increase in this workforce in the future.¹⁰⁷ It is likely that New Zealand will not have the required workforce to cope with the growing demand for formal care and support workers, particularly for the growing population aged over 65. Future and settled migrants could be a focus of recruitment for this workforce, as New Zealand already relies significantly on migrant care workers, particularly from the Pacific Islands and the Philippines. It is particularly important that this workforce is provided with the appropriate training so that they have the skills to carry out their profession in a competent and culturally appropriate way.¹⁰⁸

The NHC also considers that new migrants employed in the care and support workforce could provide a valuable role in acting as information brokers between the health and disability system and their own migrant communities. This would increase communities' understanding about the supports and services available in New Zealand and assist in the identification of informal carers.

3 Planning for the Future

The NHC has identified that:

- the care system faces a number of long-term considerations, including how to plan for and target care supports and services
- more information about informal carers is needed.

Long-term planning is required to determine how best to provide for the predicted increase in demand for informal care and formal services. If this planning does not occur, it is likely that future pressures on the health and disability system will in turn place carers and their families under increased pressure to provide care that is too demanding, putting their health and wellbeing at risk.

The NHC's recommendations

The NHC recommends that the Minister of Health direct the Ministry of Health to prepare for the future by:

13. undertaking long-term planning and modelling to determine the cost, volume and optimal mix of supports and services that both informal carers and people requiring care may need in the future, taking into account the flow-on effect for the provision of other health and disability services
14. investigating the variety of supports and services that should be publicly funded in New Zealand for informal carers and the people they care for
15. working with the Ministry of Social Development to develop a demographic profile of informal carers to inform future planning, taking into consideration the ageing population, the rural–urban drift, changing family structures and increasing ethnic diversity
16. proposing to Statistics New Zealand that a section in the Census of Population and Dwellings be developed to collect information about the prevalence and nature of informal caring
17. developing a unit of the New Zealand Health Survey to collect information about informal carers' health status, within the next five years.

Long-term considerations for the care system

Decisions about how services are provided for informal carers and the people they care for need to be considered as part of the Government's long-term planning for the provision of health, disability and social services in New Zealand. Issues arising for the care system include the:

- tension between providing services for informal carers and for the person being cared for
- need to develop clear, equitable and forward-looking policy regarding supports and services for informal carers
- likely need to prioritise care supports and services in the future.

Providing separate supports and services for informal carers?

Should the needs of informal carers be addressed separately or in conjunction with the needs of the person receiving care? The NHC believes that if a carer's needs and the needs of the person they care for become too distinct – and are addressed separately – the familiar silo approach to the provision of services may develop. Many carers have expressed the view that their needs are intrinsically linked with the needs of the person they care for. This is why the NHC advocates for a holistic, family-focused approach to service provision in this report, consistent with the Whānau Ora approach.

At the same time, the Government has a responsibility to recognise the role of informal carers, provide adequate supports and services for them and protect their health needs. The NHC has recommended (see recommendation 2) that a role be developed in the Ministry of Health that is responsible for policy relating to informal carers. The NHC sees this role as providing leadership from the Ministry on work already being undertaken by the Carers' Governance Group. Within the lifespan of the Carers' Strategy the role could be expanded further to include:

- developing the strategic direction for informal carer policy and maintaining inter-departmental relationships
- developing services for informal carers, and maintaining relationships with DHBs, PHOs and non-governmental organisations.

Carer-specific centres

What carers want first and foremost are improvements at a local level to facilitate their access to supports and services. The NHC believes that this is the immediate challenge for the health and disability system. Action One of the Carers' Strategy under the principle 'Provide Information' is to scope a national specialist carer centre to develop information products, such as a national respite locator and a generic carer information pack.

The NHC considers there are more cost-effective mechanisms for achieving national direction for carer policy, such as further developing the relationship between the Government and Carers New Zealand and the Carers Alliance. The function of a national carers' centre should be clear before it is pursued in such a constrained fiscal environment, although there may be value in developing a central point of representation for informal carers in the future.

Given the importance of recognising a carer's needs in conjunction with the needs of the person they care for, the NHC also considers that a regional network of carers' centres (or one-stop-shops, as exist in Australia)¹⁰⁹ is not the best use of any funding for carer initiatives currently.

Targeting care in the future (recommendation 14)

Future financial sustainability is a significant issue facing the health and disability system in New Zealand. In response to the demographic and social changes the United Kingdom is going through, the Government there has embarked on a substantial review of the country's care and support system. Substantial reform is considered necessary to develop a system that is fair, simple and affordable for everyone. (In the United Kingdom the care and support system is separate from the national health system.)¹¹⁰

The NHC proposes that the Ministry of Health investigate the variety of support and services for informal carers and the people they care for that should be publicly funded in the future. Following are some of the questions that could be considered.

- How can we provide consistent, high-quality services for carers and people requiring care across New Zealand that are flexible enough to meet the needs of local communities?

In answering this question we need to consider the significant variation expected between communities. For example, Statistics New Zealand projects that Auckland will be the only region with a population with a median age under 40 in 2026.¹¹¹

- In light of future supply and demand pressures on Vote Health, how should we prioritise access to supports and services for people with different levels of need?

For example, are the needs of a young person with a disability a higher priority because they are likely to have limited resources to pay the costs of their care, compared with an older person who has had time to save for the potential cost of their future health care?

- What is the most efficient means of funding care supports and services that also meets public expectations of fairness and reliability? Consideration could be given to the relative costs and benefits of funding via taxation, private insurance and user pays.

Planning and modelling (recommendations 13 and 15)

Although an increase in demand for informal care in the future has been identified, the rate and scale of this increase are unclear. Long-term planning needs to take into account the effect of an increase in the number of people requiring care on the financial sustainability of the whole health and disability system. The projected decrease in the number of working-age people available to provide informal care and fund health services through taxation also warrants particular attention.

The NHC recommends that the Ministry of Health undertake long-term planning and modelling to determine the cost, volume and appropriate mix of care supports and services that will be required in the future. A demographic profile of informal carers should be developed to inform planning and modelling. To ensure interdepartmental input, this work could be overseen by the Carers' Governance Group.

Collecting information about informal carers

Comprehensive and up-to-date information is critical to inform planning for the provision of supports and services for informal carers. In researching this report the NHC has found that the information available in New Zealand about informal carers is sparse.

The NHC sees a significant need to better understand how Māori consider caring within whānau should be supplemented by formal services, and consider that Māori carers should be a strong focus within any future information gathering and planning. The NHC's research on elderly Pacific carers illustrates the unique challenges they face in accessing care supports and services, and the lack of research available to inform policy. Similarly, it appears that there is little information available about the needs of carers from a non-English-speaking background.

Information about the profile and prevalence of informal caring could be gathered through existing mechanisms, as discussed on the following page.

Census of Population and Dwellings (recommendation 16)

The Census of Population and Dwellings contains one question about the number of hours a person has spent in the preceding four weeks looking after or helping someone with an illness or disability, as part of an overall measure of unpaid labour.¹¹² The NHC considers that a unit of the Census should be developed to collect information about the prevalence and nature of informal caring provided in New Zealand as distinct from other forms of unpaid labour.

New Zealand Health Survey (recommendation 17)

The Ministry of Health undertakes the New Zealand Health Survey at regular intervals to monitor the health of the population and its use of health services. From 2011 the various survey topics will be integrated into a single survey, which will be in continuous operation. The survey will consist of a core questionnaire with changing thematic modules. Quantitative data about the health and wellbeing of informal carers in New Zealand is lacking. The NHC proposes that one of the changeable modules of this survey could be used to collect information about the health and wellbeing of carers.

New Zealand Disability Survey

Disability and Informal Care in New Zealand in 2006: Results from the New Zealand Disability Survey was released in September 2009. Statistics New Zealand is reviewing the content of this survey before its next release in 2011. This review will take into account the Carers' Strategy, as it is recognised that 'monitoring progress of implementation of the strategy and whether it is achieving its vision will require information on the families and carers of people with disabilities'.¹¹³

New Zealand Carers Research Coalition

Since its establishment, Carers New Zealand has played a key role in commissioning research about informal carers and has recently established a Carers Research Network.¹¹⁴ The NHC supports the development of collaborative research opportunities between the Government and Carers New Zealand because the organisation has significant networks from which to draw on the experiences of informal carers.

Appendix 1: Supporting Documents

The five documents summarised in this appendix can be accessed on the website of the National Health Committee (NHC): <http://www.nhc.health.govt.nz>

Informal Caregivers Literature Review: A report prepared for the National Health Committee¹¹⁵

This literature review was undertaken to investigate the significance and impacts of informal caring on the lives of caregivers. The review extended the work already undertaken by the NHC that resulted in the publication in 1998 of the report *How Should We Care for the Carers?*

Māori and Informal Caregiving: A background paper prepared for the National Health Committee¹¹⁶

Adelaide Collins and Greg Wilson's paper *Māori and Informal Caregiving* describes Māori informal caring practices, discusses the concept of whānau, identifies the impacts of informal caring on the health and wellbeing of Māori carers, identifies the barriers experienced by Māori carers and the conditions necessary to give the best care.

Qualitative Study of Elderly Pacific Informal Caregivers of a Young Person with an Illness or Disability¹¹⁷

This study was commissioned by the NHC to find out about elderly Pacific people's experiences of caring, and what they considered they needed to support their own health and wellbeing and to support them in their caring role. The NHC chose elderly, Pacific carers as a case study because of the significant complexity involved in understanding the health needs of Pacific elderly in New Zealand (due to the many nations, languages and cultures represented).

The Interface between Informal Caring and Formal Services in New Zealand¹¹⁸

The NHC commissioned a study into the interface between informal caring and formal services provided for carers in New Zealand. The study is divided into two parts:

- a review of the international literature, which highlights new and innovative ways of delivering formal support to informal carers and scans New Zealand literature for models of care and formal supports provided to informal carers
- interviews and focus groups with informal carers, carer advocates and formal care service providers.

Care Ethics for Informal Carers¹¹⁹

Mary Butler's essay provides a framework within which to discuss the ethical question, what is the 'right thing' for carers to do when caring for someone with a severe disability? The essay aims to look beyond the burdens faced by carers to what the best care might look like in practice. The paper suggests that the goal of care is to help the person being cared for to live

a life that is expressive of the human condition. That is, to provide care beyond ensuring mere survival and meeting the basic physical needs of the person being cared for. Discussions about the ethics of care must represent both the perspective of the carer and the person being cared for.

How Should We Care for the Carers? Better support for those who care for people with disabilities¹²⁰

The NHC developed *How Should We Care for the Carers?* in 1998 to seek feedback on strategies proposed to support carers. Feedback was sought from a variety of people affected by issues associated with the provision of informal care, including carers, health and disability organisations, and Needs and Assessment Service Coordination agencies.

The report comprehensively describes what carers do, the stresses carers may experience, and the types of support services available to minimise these stresses. The report recorded important statistics about the lives of people with disabilities in New Zealand.

Appendix 2: Glossary

Term	Definition
aged residential care	Residential care for older people, including rest-home care, dementia care, hospital care and specialised hospital (psycho-geriatric) care.
Care Plus	A primary health care initiative targeting people with high health need due to chronic conditions, acute medical or mental health needs, or terminal illness. Care Plus aims to improve chronic care management, reduce inequalities, improve primary health care teamwork, and reduce the cost of services for high-need primary health users. ¹²¹
carer support subsidy	A subsidy to assist unpaid, full-time carers to take a break from caring. The Ministry of Health funds the carer support subsidy for people with disabilities. DHBs fund the carer support subsidy for older people and people with mental health conditions. The subsidy is a direct payment to the care recipient or carer that reimburses some of the costs of home-based or residential care.
community residential support	Services that assist disabled people under the age of 65 to live in a supported community environment. Services provide 24-hour support at a level necessary for people to have a safe and satisfying home life. Support can be provided through a combination of services determined at the time of a needs assessment for each individual. ¹²²
developmental evaluations	Evaluations that consider whether a service allows people to achieve their goals, have input into their living arrangements, influence the choice of facility in which they reside, and have some say about with whom they will live, compared with evaluations that focus on systems and processes. ¹²³
disability support	Ministry of Health-funded services, including home-based services such as personal care and home help, residential services, support for carers in the home, respite services, supported independent living services, and environmental support services such as equipment, housing and vehicle modifications.
home and community support	Services designed to allow people with disabilities, people with mental health conditions and older people to keep living in the community. Services are categorised as household management (eg, cooking, cleaning and shopping) and personal care (eg, bathing, toileting and feeding). The Ministry of Health funds home and community support services for people with disabilities. DHBs fund home and community support for older people and people with mental health conditions.

Term	Definition
individualised funding	Money paid by the Ministry of Health directly to someone assessed by an NASC agency as needing disability supports or services to purchase the support they require. It is based on a philosophy of person-centred control, in which disabled people should be empowered and enabled to live ordinary lives and have control and choice over that life. To access individualised funding, a person must have support needs that are within the ‘high’ or ‘very high’ range of the Needs Assessment and Service Provision Guidelines. ¹²⁴
intensive service co-ordination	NASC agencies are responsible for providing intensive service coordination for people with high and complex needs, usually requiring the involvement of multiple providers and ongoing problem solving. The decision that intensive service coordination is needed will be made by the service coordinator following assessment. ¹²⁵
Local Area Coordination model	A model of service coordination for people with disabilities and their families based on principles of self-sufficiency, self-determination, and relationships with family, whānau, friends and the community. ¹²⁶ Local Area Coordination agencies were first developed in Western Australia in the late 1980s. In the last decade they have been adopted in Scotland and Northern Ireland. ¹²⁷
long-term conditions	Also known as chronic conditions, chronic diseases and chronic illnesses. Long-term conditions are any ongoing, long-term or recurring condition that can have a significant impact on a person’s life. Long-term conditions include cardiovascular disease, cancer, diabetes, respiratory disorders, arthritis, chronic pain, depression, Parkinson’s disease, epilepsy, Alzheimer’s disease, HIV/AIDS, bipolar disorder, and alcohol and other drug dependency. ¹²⁸
manuhiri	Guest or visitor. Also refers to appropriate behaviour when interacting with unknown people in a new environment. ¹²⁹
mental health services	For most people, access to mental health services will be by way of a referral from a GP. Access to mental health and addiction services is determined on the basis of highest level of need identified by a health professional or addiction worker who is a member of a recognised professional body. ¹³⁰
(noho) whakaiti	Belittle, condescend, indignity. Also refers to being appropriately quiet and watchful when in the presence of someone of higher status. ¹³¹

Term	Definition
older people	For the purpose of eligibility to government-funded aged care, an older person is someone aged 65 and over, or someone aged 50–64 who has been clinically assessed by a DHB and/or needs assessor as having health and support needs because of a long-term condition(s) more commonly experienced by older people. ¹³²
personal health	Personal health services are goods, services and facilities provided to an individual for the purpose of improving or protecting the health of that individual, and include goods, services and facilities provided for related or incidental purposes (see section 6 of the New Zealand Public Health and Disability Act 2000).
respite care	Short-term care for people with disabilities, older people and people with a mental health condition to provide informal carers with a break from providing care. Respite is provided in a variety of settings, including residential care, hospitals or in the home. The Ministry of Health funds respite care for people with disabilities. DHBs fund respite care for older people and people with mental health conditions.
service specification	A description of a service to be funded and delivered, in a measurable manner, which incorporates the relevant purchase units and reporting requirements. Nationwide service specifications are jointly agreed between the Ministry of Health and DHBs. ¹³³
Whānau Ora	Māori families supported to achieve their maximum health and wellbeing. Whānau, including kuia (older females), koroua (older males), pakeke (adults), rangatahi (young people) and tamariki (children), is recognised as the foundation of Māori society. As the principal source of strength, support, security and identity, whānau plays a central role in the wellbeing of Māori, individually and collectively. ¹³⁴

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