Informal Caregivers Literature Review

A report prepared for the National Health Committee

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Contents

Executive summary

This literature review was undertaken at the request of the National Health Committee as part of a project investigating the significance and impacts of informal caregiving on the lives of caregivers. The project extended previous NHC work that had resulted in the publication of “How Should We Care for the Carers?” in 1998.

For the purposes of the project, informal caregiving was defined by the NHC as:

> *…caring for a friend, family member or neighbour who because of sickness, frailty or disability, can’t mange everyday living without help or support…[it] is not usually based on any formal agreement or services specifications. Informal caregiving is characterised by relationships and social expectations*. (NHC 1998)

The nature and extent of informal caregiving

Caregiving is routine and ongoing. It arises out of a relationship with the recipient in response to the need for support which is greater than normally expected due to impairment in functioning. Because lower levels of caregiving merge into normal relationship reciprocity, and because it is outside any formal agreements, it is relatively invisible.

Prevalence surveys in Australia, the UK and Canada have estimated that about one household in twenty has a primary caregiver, that is, a caregiver who feels responsible for the person cared for. Although both men and women are involved in caregiving, women predominate in both the numbers involved and the nature of their contribution. Resident caregiving commonly involves a heavier caregiving commitment than those caregivers who live separately from the recipient of care.

Our knowledge of the prevalence of informal caregiving in New Zealand is limited. Census data suggests that residential care was given by 5.4 per cent of the population and extra-residential care was given by 5.9 per cent, with the more women involved than men. These figures are not directly comparable with overseas studies because they do not distinguish between temporary and ongoing incapacity.

Informal caregivers assist with the tasks that recipients are unable to do for themselves. These may involve undertaking personal care household, financial and administrative tasks, providing assistance with mobility, along with emotional support and companionship. Caregiving may also include some nursing. The caregiver role varies with the age and nature of the impairment of the recipient, but is likely to involve the caregivers taking responsibility to ensure the well-being of that person. This often includes ongoing monitoring, liaising with formal care systems, and attending to any shortfall not provided by paid health care workers.

The policy context

Caregiving arises in the context of relationships within families and whānau. These relationships have multi-directional patterns of exchange that interweave informal caregiving. Informal caregiving is intrinsically bound to notions of family and is subject to the demographic changes that affect families. Caregiving in part arises out of societal expectations of family and the obligations of family members to one another.

Informal caregiving as an issue has moved into the policy spotlight over the last three decades in response to research revealing that informal caregiving can place a heavy burden on those involved, feminist concern that this burden falls disproportionately on women, and debate over whether the care of those with long term disability should be primarily a public cost or a private one.

Research by demographers has indicated that there remain strong reciprocity patterns in New Zealand families which are based on choice rather than prescription. While family cultural patterns help ensure caregiving occurs, there are increased pressures on caregivers, particularly women, who combine traditional family obligations with paid work. The pool of people available to provide care is declining because of smaller families, more family break-down, more blended families making family management more complex, and more women participating in the workforce. At the same time, the need for care is increasing due to the ageing population and the importance now placed on enabling those with disabilities to participate fully in community life.

Some writers have urged policy makers to address the predicted shortfall in caregivers, starting with a recognition of their contribution. To value fully the contributions of caregivers requires an analysis of the costs and benefits to the caregiver, the recipient, and to society. Some approaches have been developed to do this but all have some weaknesses. A recent Australian evaluation used an opportunity costs method (work foregone) and the proxy goods method (hours spent at the wage rate of a paid caregiver) which could be used as a model if the data on prevalence was available.

Media interest in informal caregiving often focuses on human interest stories lobbying for a particular cause. Issues of concern in the formal caregiving arena also come to media attention. Many of the issues raised in the media parallel those discussed in this report. They include definitions/boundaries between caregiver and recipient, relationship factors, impacts of caregiving, pathways into caregiving, the interface between informal and formal caregiving, and things that help or hinder informal caregivers.

The policy regime in New Zealand and other countries

There are a number of laws and policies in New Zealand relevant to caregivers of people with health and disability support needs. However, convergence between the common interests of people requiring support and their caregivers results in a focus on the care recipient rather than the caregiver. New Zealand's benefits and allowances reflect this by being provided generally for a specific purpose, rather than for caregiving as a role or entitlement.

The political context for the development of a separate caregiving policy has been driven both by the emergence of informal caregiving as a community issue and by the New Zealand Carers Alliance, which acts as an umbrella organisation for NGOs representing and advocating for caregivers. In April 2007, the New Zealand Government endorsed the development of a national caregivers strategy. The Ministry of Social Development, Carers New Zealand and the New Zealand Carers Alliance, will work together with other government agencies to build the strategy. The strategy is expected to be launched in 2008 and be supported by a five-year action plan.

Although New Zealand does not have a single caregiver policy, the following strategies specifically mention caregivers: The *New Zealand Disability Strategy*, the *Māori Health*

Strategy – He Korowai Oranga, the *Health of Older People Strategy*, *Te Tahuhu – Improving Mental Health 2005-2015*, the *New Zealand Cancer Control Strategy Action Plan* and the *New Zealand Health Strategy*.

The Family Proceedings Act 1980 imposes a duty on spouses to provide care for each other if their earning capacity is impaired due to physical or mental disability. This is consistent with the Social Security Act 1964 which is also based on the belief that partners will care for each other. Other laws relevant to caregivers include: The Human Rights Act 1993, law related to privacy and information, the Protection of Personal and Property Rights Act 1988 and the Injury Prevention, Rehabilitation and Compensation Act 2001.

A review of the policy regimes in the UK, Australia, Canada, Germany, Japan, and USA shows varied support of caregivers recognised by specific policy and/or payments.

Informal caregiving and Māori

Māori caregivers experience many of the same issues as other caregivers, including the need for information and financial support. Consideration of the needs of Māori for support requires an understanding of whānau relationships.

The needs of Māori caregivers have to be considered within the context of whānau wellbeing. This may include expectations (both by family members and by professionals) that whānau members will be available to care. Social and economic pressures may prevent whānau from being able to help as much as they might want to.

Services for both recipients and caregivers need to be culturally safe and readily accessible. The reviewed literature suggests Māori are not receiving all the services they need when the services offered are not culturally appropriate. One response to this is resourcing more ‘by Māori for Māori’ services. However, as Māori caregivers also experience many of the same issues as other carers, fundamental institutional and criteria-based barriers also need to be addressed.

Impacts of caregiving

Caregiving almost always impacts on the life of the caregiver. Those heavily involved in caregiving, experience profound and wide-ranging changes to their lives.

In studies that compare caregivers with others, caregivers often report poorer physical health and higher use of medication than others. In many studies caregiving is associated with increased rates of depression and anxiety, less life satisfaction and a feeling of being burdened. There is some evidence to suggest cognitive impairment and mental illness in the recipient are more burdensome for caregivers than physical problems. In general, impacts on a caregiver’s mental health become greater as the time spent on caregiving increases. Being a co-residential caregiver are both factors associated with increased mental health impacts.

Caregiving is associated with financial impacts including direct costs, the financial consequences of decisions around caregiving, and the constraints on choices arising from the financial status. There are often significant and multiple costs arising from caregiving. Depending on the nature of the recipient’s disabilities, there may be increased heating, medical costs, transport costs and house modifications. Caregivers may choose to reduce hours or withdraw from paid employment to manage caregiving responsibilities. Those supported by income maintenance find it insufficient. Low income reduces the options for support with the caregiving burden.

Caregiving most commonly occurs in the wider context of the family/whānau. The effect on the family/whānau depends on the age of the recipient and the relationship of recipient to the rest of the family/whānau. However, all caregiving affects the allocation of time and attention among family members, for example by reducing time for family social activities. Parental caregivers of children with disabilities juggle the needs of other siblings with those of the child needing care. The recipient of care may also have behavioural problems which directly impact on other children. Strain between parents is reported to be common. Caregivers of older people sometimes come into conflict with other family members if they express disappointment with their caregiving contribution

Caregivers commonly experience a loss of social contact with others, which is concerning given that social support has been identified as protective against the strains of the caregiving role.

Caregivers have lower participation rates in the workforce compared to non-caregivers of the equivalent age range. Women are more likely to reduce hours of paid employment compared with men. Co-residential caregivers are more likely to reduce paid employment than those not living with the recipient. Caregivers used various strategies to try to fit employment with caregiving, including changing to a less demanding job, moving closer to work, and using lunchtimes, holiday leave and sick leave for caregiving purposes. Employers can create caregiver-friendly work-places by:

- providing access to a private telephone
- offering flexible hours and opportunities to work at home
- providing career breaks
- promoting supportive work relationships.

The responsibility of caregiving raises issues for the caregiver around planning for their recipient's future. Parents of children with high and complex needs may experience difficulties in planning for their child's future, especially when prognosis is uncertain. Grandparents who are caregivers may worry about living long enough to support their grandchild through to adulthood. Caregivers of adults with disabilities and of older people may also worry about what would happen if they were no longer be able to care for the recipient.

Despite the demands of caregiving, reviewed literature show that most caregivers provide care gladly and feel positively about the role. However, those who have heavier caregiving commitments are more likely to feel negatively. The quality of the prior relationship between caregiver and recipient influences how positively caregivers perceive their role. Caregivers of those with physical health problems are more positive than caregivers of people with cognitive issues, but caregiver satisfaction is otherwise unrelated to characteristics of the recipient. All caregivers are more positive when they have help from others.

Convergence and divergence

Caregivers from ethnic minority groups

Being from an ethnic minority accentuates the impacts of being a caregiver. Contributors include cultural unfamiliarity, language barriers, and isolation from family and community support networks. Cultural interpretations of disability may add further barriers.

Research with Pacific people in New Zealand found significant language and information barriers to accessing health and support systems. Culturally-based attitudes may make it difficult to acknowledge the need for help or to accept a support worker into the home. Financial pressures are common. Some Pacific people attach shame to the presence of disability within a family which can make it more difficult to ask for help. Traditionally, the support of a person with a disability is the responsibility of the extended Pacific family and community, but in New Zealand, Pacific people are often isolated from that wider support network.

A meta-analysis from the USA found that overall, caregivers from ethnic minorities had better psychological outcomes but poorer physical health than other caregivers. UK studies found language barriers and differing attitudes to the nature of relationship with support workers were both significant barriers to accessing support outside the family. Caregivers from ethnic minority groups may also be uncertain about their rights and entitlements.

Caregivers who are poor

There are few studies exploring the impact of poverty on caregiving, although income is sometimes included as a potential confounding factor. Available research suggests:

- poverty reduces the capacity of caregivers to cope with the impacts of caregiving
- having more income increases the choices open to caregivers
- poverty may distort choices about residential care if costs are involved
- poverty may increase social isolation
- those who are poor may have the most difficulty accessing services.

Women caregivers

There is strong evidence that women are more involved in caregiving than men. This includes the proportion of women involved in caregiving, the greater likelihood that women will be primary caregivers, and the hours women spend on their caregiving tasks. Women also bear greater financial costs of caregiving as it often further interrupts their working life and reduces their opportunity to save for retirement which in many cases is longer than that of men. Anecdotal research in New Zealand research is consistent with the view that women disproportionately carry the personal and financial costs of caregiving.

There is some evidence to suggest that women react to caregiving with a greater tendency to become depressed, distressed and to feel burdened by caregiving. This has been attributed to women experiencing more caregiving stressors, such as higher social expectations and lower social support for women than men. Gender differences in caregiving may be slightly decreasing. New evidence shows that both men and women are experiencing similar experiences of caregiving tasks.

Young caregivers

There is growing awareness of the need for a range of supports for young caregivers in New Zealand. Young caregivers may be offering substantial care as the sole caregiver, or lesser levels in a supportive role to the primary caregiver. The potential short and longer-term impacts on the lives of these young people are of concern.

Caregivers for people with a mental illness

Caregivers for people with a mental illness experience distinct issues which often put extra pressure on the relationship between the caregiver and formal care services that may be supporting the recipient. Relationships between the caregiver and recipient may require continuous adaptation due to fluctuations in the psychological state of the recipient.

The relationship between caregiver and recipient

Caregiving is strongly grounded in the relationship between caregiver and recipient. This relationship is dynamic and evolving. The relationship commitment means it is unthinkable for many would-be caregivers to do other than care for their family member regardless of the personal cost involved. For caregivers of the elderly, caregiving commonly arises out of:

- desire to continue the relationship
- choices for the recipient's wellbeing
- sense of duty
- cultural/ community/ family expectations which the caregiver has internalised.

Caregivers' motivations within, and responses to, caregiving have been found to contain a dynamic fluctuation between commitment, dissociation, obligation and repudiation. Caregiver satisfaction is closely aligned to dimensions of relationship. A positive previous relationship between the caregiver and recipient may reduce some of the strains of caregiving.

The caregiving relationship evolves in response to the health and wellbeing of the recipient. Changes in the relationship may mean caregivers have to adopt new roles. And loss of previous familiar roles can cause feelings of grief and loss for the caregiver.

Caregivers who care for more than one person in the family develop relationships based on exchange and transactions. These dynamics can cause complications in the larger family context. Other relationship issues for caregivers include:

- internalised societal attitudes to disability acting as a barrier to the recipient of care participating equally in the relationship
- power imbalances created by caregiving
- caregiver abuse and neglect arising out of caregiver stress, social isolation and (sometimes) psychopathology of the caregiver
- financial issues
- increased risk of distress and depression for caregivers of spouses

Styles of response to issues vary, which has implications for interventions considered.

Pathways into caregiving

There is little New Zealand research exploring the reasons why caregivers take up the role. Reasons may vary according to nationality or ethnicity.

Research suggests caregiving arises out of the existing family and community milieu with the primary caregiver status usually reflecting a long-standing emotional commitment. Primary caregivers are commonly helped by others, but spouse or partner caregivers are less likely to receive help than others. Caregiving most commonly stops when the recipient no longer needs the input, due to death, improvement in health, or moving into residential care. Caregivers rarely choose to give up.

Parental caregivers of adult recipients with a disability are committed to caregiving as part of an ongoing relationship and often persist despite the difficult behaviours of the recipient and high costs associated with caregiving for them. However, parental caregivers may decide to relinquish the care of a child with high needs due to the child’s increasing age and needs, a decrease in their own capacity due to ageing or ill health, the needs of others in the family, and/or the lack of respite care. Decisions to seek permanent residential placement are made over a long time and with great difficulty.

Grandparents caregiving for kin often take on the role due to the breakdown of the parental relationship, for reasons which include abuse of children, neglect, substance abuse in the parents, and abandonment. For Maori, being a grandparental caregiver can be a traditional cultural practice.

Caregivers are sometimes pressured into the role because they are perceived by others in the family as being available or having more time. Daughters more commonly feel responsible for elder care than sons. When an elderly recipient needs to move into residential care, the transition is often difficult for the caregiver and the caregiving role typically changes, rather than stops, at this point.

The interface with formal services

Informal caregivers have not received focussed attention by service providers in New Zealand. Despite increased risk of health problems, it is not clear that caregivers use primary care services more than non-caregivers. Possible systemic barriers limiting caregivers' access to services may include health professionals failing to recognise caregivers as patients in their own right, services not keeping a record of caregivers, services not fitting around caregiving demands, or language, culture, and information barriers.

Parental caregivers of children with intellectual disability are particularly sensitive to the attitudes of the professional caregivers. Poor service co-ordination and responsiveness as well as lack of clarity about who is the main case worker can make services seem impenetrable.

New Zealand research suggests cultural attitudes can be a barrier to receiving information and support. This includes lack of cultural sensitivity in developing relationships with the whanau and lack of information about appropriate methods of care. At an organisational level, lack of awareness of the needs of the caregiver may mean health professionals do not ensure appointments fit with the caregiver’s time commitments.

Part of the caregiver's role is to advocate for their recipient and to monitor the adequacy of the formal care delivered. The role of the informal caregiver fills any shortfall left by the formal caregivers. Health professionals may view the caregiver as an informant, as a proxy for the patient, as a patient themselves, or as co-therapist who requires education and training.

Supporting informal caregivers

Research with caregivers shows that actions they find supportive of them in their caregiving role include:

- good quality respite care
- respectful relationships and good communication with formal services
- good quality and readily available information
- practical assistance and emotional support from extended family and the community
- caregiver support groups.

Caregiver coping strategies include:

- being assertive in asking for informal support
- religious or spiritual beliefs
- adjusting work arrangements to fit more easily with caregiving
- involving other family members in caregiving
- investigating formal support options
- active coping and reframing strategies
- continuing paid work
- looking after their own health.

Caregivers state that they are hindered in their caregiving role by:

- lack of knowledge of services
- lack of information about the care recipient eg prognosis
- lack of support from extended family and from formal services
- high turnover of formal support workers
- being viewed as part of the pathology of the recipient by mental health or health professionals
- power imbalances between themselves and health professionals.
- poorly resourced and hard to access mental health or health services
- stigma and discrimination towards the recipients
- lack of coordination between agencies and provider organisations.

Other ways to support informal caregiving

Advocates of informal caregivers seek to have informal caregiving raised as a public health issue, and caregivers recognised as a productive part of the health system. A scan of other policy regimes suggests negative impacts of caregiving can be mitigated by routine assessment of caregivers' needs, provision of caregiver support services, compensation for caregivers who take time off work, superannuation credits, access to information about other options, and reimbursement for costs incurred through caregiving. It also assists caregivers when health professionals are educated to be aware of caregivers and their issues.

To a great extent, the needs of the recipient define the type of service or assistance sought by the caregiver.

- Caregivers of children with high and complex needs value a holistic assessment of the whole family, well coordinated services, flexible support packages, a reliable supply of competent and well-trained respite care workers, a planned approach to the transition of the young person into adulthood and quality out-of-home options.
- Caregivers of people with a mental illness seek early intervention, respite care, and involvement in treatment programmes, such as stress reduction.
- Caregivers of adults with a disability find it beneficial to receive assistance with strategies for managing the disability, as well as being provided with information and social support.
- Caregivers of elderly people seek services that are flexible and well co-ordinated. They value services that maintain the dignity of the recipient and uphold their role as the recipient makes the transition to residential care.
- Grandparental caregivers require adequate income support and recognition of their role when accessing services.

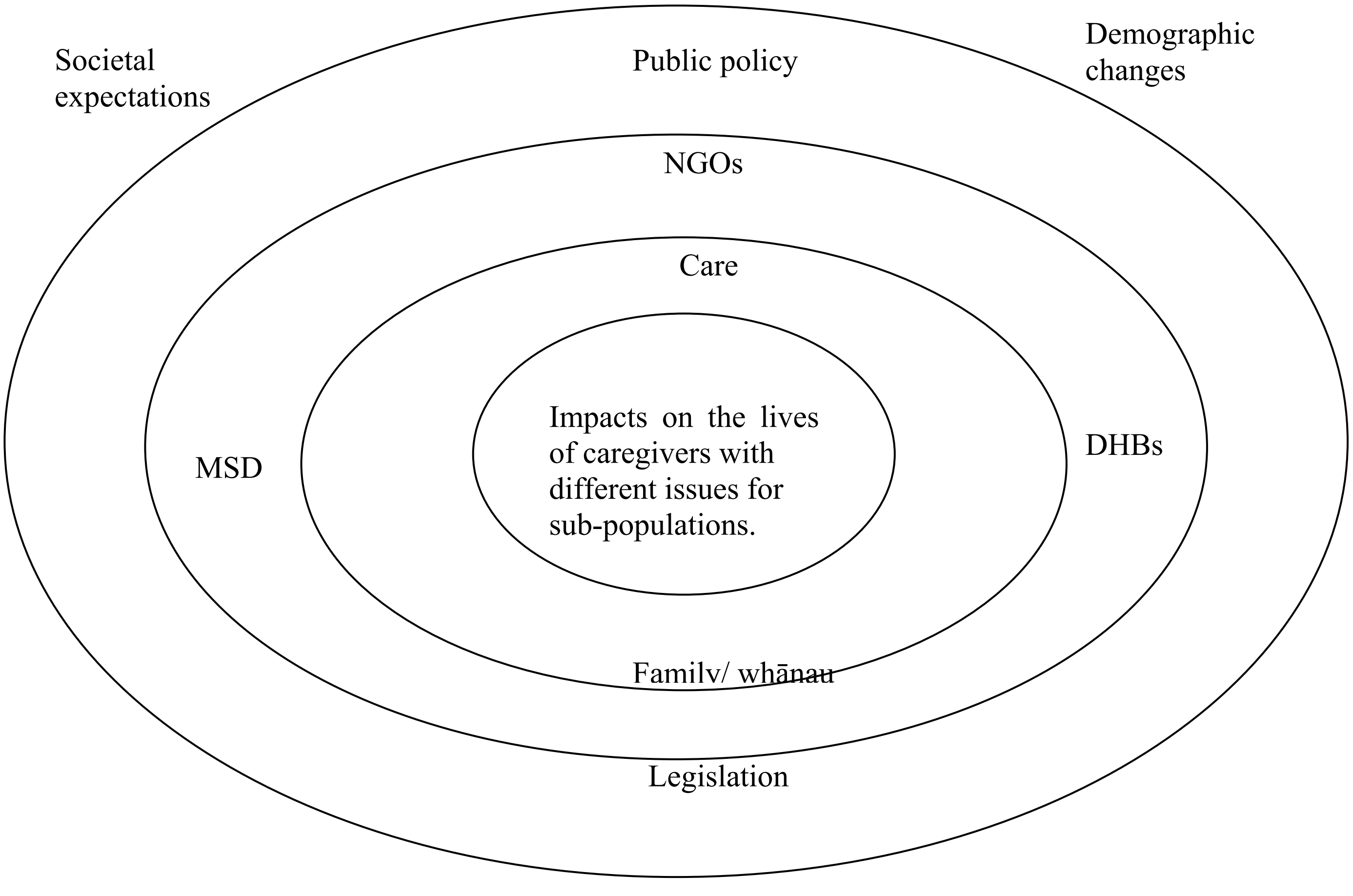
1 Introduction

In this report the term caregiver refers to informal caregiving unless otherwise specified. Informal caregivers are those:

> *…caring for a friend, family member or neighbour who because of sickness, frailty or disability can't manage everyday living without help or support ... [it] is not usually based on any formal agreement or services specifications. Informal caregiving is characterised by relationships and social expectations. (NHC 1998)*

Informal caregiving is an integral part of a caregiver's life, yet generates a number of relationships with those outside the caregiver's immediate circle. The caregiver-care recipient dyad is a dynamic entity; each dyad has its own history, unique features and path forward, reflecting the individual circumstances of the participants. Each also needs to be considered in the context of the larger family/whānau and community of which they are a part. Each is supported by, and interfaces with, a range of health and other services shaped by public policies. The policy environment reflects a wider societal context of attitudes, community expectations and demographic changes. In turn, the caregivers and recipients, and those who advocate on their behalf, influence the policy makers (see Figure 1).

Figure 1: Conceptual model of informal caregiving



1.1 The literature

This report aims to comprehensively cover New Zealand work on informal caregiving and include a sample of the published work from other countries - particularly those with cultures and policy regimes similar to our own. Research has been favoured over policy papers, commentary or advocacy, but not to their exclusion.

Although the New Zealand research and literature is relatively scant and very patchy in its coverage, where there is New Zealand material it is reported fully. To address some of the gaps, the New Zealand material is set within the context of international literature which can be extrapolated to fill in the gaps.

When informal caregiving was first researched in the late 1970s, the initial focus was on the hidden costs of caregiving to those providing the care, fanned by a strong feminist concern that women caregivers should not be unwittingly trapped into the role by societal expectations. This early research focused on the impact of caregiving on the caregiver and often dwelt more on the costs and other burdensome aspects.

As knowledge has grown, a more rounded view of the impacts of caregiving, including the positive aspects, has developed. In turn, the awareness of the personal costs and benefits to the caregiver has led to an interest in the benefits and costs to society as a whole. Commentators have drawn attention to the hidden contribution caregivers make to society by enabling the recipients of their care to be maintained in the community. Advocates for caregivers argue that if society wants to keep the costs of residential care to a minimum then more should be done to support caregivers and to mitigate the strains and reduce their stress.

Increasingly, there has been a focus on the policy implications of caregiving, the interface with formal caregiving services and how informal caregivers can best be supported.

1.2 Approach

The process started with a systematic search of catalogues and databases available through the Victoria University library, the Wellington Medical School and the Ministry of Health Library. Details of databases searched and search terms used can be found in Appendix A.

The time frame for the search was primarily the last five years, but significant earlier work is included. The New Zealand literature has been incorporated more fully given that there is not a large volume of it.

A range of government and non-government organisations were approached to check for additional published and unpublished material held or locatable. Details are in Appendix A.

The review also includes some recent press articles on informal caregiving as a way of canvassing how the issues are framed in the media and what public concerns are reflected.

References were recorded in an Endnote library database, and keyword notes recorded against each reference. This system enabled the authors to search for sub-sets of the literature relevant to different sections when integrating the material and writing-up the report.

1.3 Report outline

This report is structured as follows:

Chapter 2: *The nature and extent of informal caregiving*: What is meant by informal caregiving? How many caregivers are there, and what do they do?

Chapter 3: *The policy context*: Informal caregivers have historically been 'invisible' but demographic and social changes have brought them into the spotlight and led to their contribution being more valued. How the media describes informal caregiving gives an insight into social attitudes within which policy is framed.

Chapter 4: *The policy regime in New Zealand and other countries*: The policy regime for informal care in New Zealand is compared with that of the United Kingdom (UK), Australia, Canada, Germany, Japan and the United States of America (USA).

Chapter 5: *Informal caregiving and Māori*: Māori concepts of disability and whānau need careful consideration.

Chapter 6: *Impacts on caregiving:* Informal caregiving has a range of impacts on caregivers including on health, finances, social connectedness and employment. Lost opportunities, concerns for the future, and positive impacts are also part of informal caregivers' lives.

Chapter 7: *Convergence and divergence*: Informal caregivers are not a homogenous group and there are sub-populations of informal caregivers – caregivers from ethnic minorities, caregivers who are poor, young caregivers, women caregivers, and caregivers of people with a mental illness – who have particular issues.

Chapter 8: *The relationship between caregiver and recipient:* This dynamic and evolving relationship is central to understanding informal caregiving.

Chapter 9: *Pathways into caregiving:* How do caregivers become caregivers and how do they understand their choices? There are a range of pathways for sub-sets of the population of caregivers.

Chapter 10: *The interface with formal support services:* Informal caregivers have an increased risk of health problems yet this is not reflected in their use of health and other services. Possible barriers to access are explored.

Chapter 11: *Supporting informal caregivers:* Respite care, responsive health service, access to good information, and the support of extended family, groups and community all help informal caregivers with their task. Caregivers also develop their own coping strategies.

Chapter 12: *Other ways to support caregivers:* These include making informal caregiving a public health issue and offering support tailored to the needs of particular groups of caregivers.

2 The nature and extent of informal caregiving

2.1 What is meant by informal caregiving

In the late 1970s the Social Development Council (SDC) in New Zealand undertook an early review on families with special caregiving responsibilities. The SDC defines families with special caregiving responsibilities as:

> *. . . those whose households include people requiring more than usual assistance and attention from others. They include families caregiving for the aged; the physically disabled; the chronically ill; the intellectually handicapped; the mentally ill; and the emotionally disturbed. (Social Development Council 1979 p1)*

The SDC report authors observe these families are often overlooked by a society which makes the assumption the family can cope with the demands caregiving brings. However, this assumption does not recognise most families in these circumstances are motivated by warmth and concern, rather than by rational analysis of the wider costs. Furthermore, they may feel they have little choice. The authors conclude the responsibility of caregiving for dependants has profound implications and a lot more needs to be known about such families.

More recently, Winder and Bray (NZ) defined an informal caregiver as:

> *A person who performs tasks for another person that the recipient is unable to perform independently and should typically be able to perform given their age and developmental stage. (Winder and Bray 2005 pg 2)*

The informal caregiver is not required to care through an employment agreement or other official arrangement but instead acts out of choice.

Charlton (NZ) refers to the opportunity costs that caregiving often entails, describing an informal caregiver as:

> *Someone, usually but by no means always, a relative whose life is restricted by the need to take responsibility for the care of another person. (Charlton 1992)*

Gould (USA) offers a more encompassing definition which is based on the notion of assuming responsibility for the recipient. An informal caregiver is defined as:

> *Anybody who provides unpaid or arranges for paid or unpaid help to a relative or friend because they have an illness or disability that leaves them unable to so some things for themselves or because they are getting older. This kind of help could be with household chores or finances or with personal or medical needs. The person who needs help may live with you in your home, in their own home or in another place such as a nursing home. (Gould 2004 pg 18)*

Savage and Bailey (Australia) convey the ongoing, long-term nature of caregiving, which deals with every-day realities in this definition:

> *A relative, friend or neighbour who provides practical, day-to-day unpaid support for a person unable to complete all of the tasks of daily living. The person who receives care is the care recipient, defined as a person who lives with some form of chronic condition that causes difficulties in completing the tasks of daily living. (Savage and Bailey 2004 pg 111)*

Collings (2006) (NZ) summarises the differences between formal and informal caregiving in this way.

INFORMAL CARE	FORMAL CARE
Occurs in relationship context shaped by affective bonds	Professional relationship shaped by code of conduct
Tasks and responsibilities greater than normal reciprocal adult relationship, for undefined rewards	Reciprocated by monetary reward
Tasks include emotional support, direct service provision, liaison with formal services, and financial assistance. These adapt to the needs of the recipient and may evolve.	Tasks of a more specialised, restricted range of caregiving activities
Usually only one person cared for	May have caregiving duties towards a number of recipients
Usually unplanned and unspecified	Planned and regulated
Economically invisible	Economically visible
May be effectively on-call constantly	Defined hours
Commonly no respite care even when caregiver ill or in need of a holiday.	Can take respite leave and sick leave

2.2 The distinctions between caregiver and recipient

The roles of caregiver and recipient are not always clear cut. Some older caregivers may prefer to see themselves as primarily a spouse, partner or parent, rather than caregiver. Furthermore, it is not always possible to clearly differentiate caregiver and recipient, as in some households the roles are blurred with both members of the pair giving and receiving care. (Argyle 2001)

When survey respondents in an Australian survey were asked to self-identify as caregivers, fewer did so than when asked about whether or not they completed the tasks associated with the provision of care. Those who self-identified as caregivers were more likely to feel responsible for another person as well as have additional tasks to do. (Howe et al.1997)

Not only do people not always identify as caregivers, but those receiving care do not always have health issues or disabilities. A 1997 New Zealand telephone survey examined care and support exchanges between family members. Less than half of those with health problems reported receiving care and nearly one-third of those without health problems reported receiving care. Among those receiving care, about 20 per cent received care from their spouse alone, another 20 per cent received care from two caregivers, and a similar portion from three caregivers. Higher numbers of those with health problems received help from multiple sources. (Mitchell and Hendy 2000)

The population of caregivers is not static. Hirst found that each year about three out of 10 co-resident caregivers began caregiving and about the same number stopped. About four out of 10 extra-resident caregivers had started caregiving in the previous year and a similar proportion stopped in the following year. Among substantial caregivers (20 hours or more per week) the turnover rate was also about four out of 10. (Hirst 2005)

The prevalence of informal caregiving

Australia, United Kingdom and Canada

Despite some differences in methodology, sample surveys in Australia, the UK and Canada all found that at least one in 20 households are involved in caregiving.

Two Australian surveys, the Victorian Caregivers Project (VCP) conducted in 1993 and 1994, and the Australian Bureau of Statistics (ABS) 1993 Household Survey, found that approximately two-thirds of primary caregivers were co-residents. In the VCP survey 84 per cent of caregivers acknowledged other or secondary caregivers, indicative of the family and community context that surrounds the caregiver-recipient relationship. The ABS survey found almost half of principal caregivers reported receiving help from secondary caregivers. Spouse or partner caregivers were only half as likely to receive help from others.

Results from the UK General Household Survey (1985 and 1990) were very similar, with 21 per cent of UK households indicating they had a caregiver and 15 per cent a primary caregiver. A Canadian survey found 53 households out of 1000 (approximately one in 20) included a primary caregiver, with 87 per cent reporting receiving help from at least one other person. (Howe 1997)

More information about the prevalence of caregiving in other countries can be found in Appendix B.

New Zealand

There is little information about the prevalence or extent of caregiving in New Zealand. The two available sources are 2001 and 2004 census data and the 1998-99 Time Use Survey.

In both the 2001 and 2004 Census, respondents were asked to indicate how many of these activities they had done without pay in the preceding four weeks:

- household work, cooking, repairs, gardening, etc, for my own household
- looking after a child who is a member of my household
- looking after a member of my household who is ill or has a disability
- looking after a child (who does NOT live in my household)
- helping someone who is ill or has a disability (who does NOT live in my household)
- other helping or voluntary work for or through any organisation, group or marae
- attending or studying for 20 hours or more per week at school or any other place
- attending or studying for less than 20 hours per week at school or any other place
- none of these. (Statistics New Zealand 2001)

In the 2001 Census, 200,616 people reported they had looked after a member of their own household who was ill or had a disability. As the total population on census night was

3,737,277, this means 5.4 per cent (about one in 20) of the population reported looking after a member of their own household who was ill or had a disability. About 60 per cent of caregivers were female. In almost every age group other than those over 80 more females than males reported caregiving. In the over 80 age brackets, males slightly outnumbered females. For Māori, 37,464 people reported they had looked after a member of their own household who was ill or had a disability. Women again outnumbered men at every age except over 85. In total, 222,288 people (5.9 per cent of the census night population) said they had helped someone who was ill or had a disability and did not live in their own household (144,420 females and 77,868 men).

Unfortunately, these figures do not give a good indication of the prevalence of informal caregiving in New Zealand, as they only reflect the care given in the four weeks prior to census night, without indicating whether it is ongoing or temporary. They also seem low compared with the reported prevalence from international studies. They do suggest a gender imbalance, with more women than men caregiving at almost every age.

The first New Zealand Time Use Survey was conducted in 1998 and 1999, with a sample of about 8,500 people aged 12 and over. Respondents were asked to keep a diary recording their activities over a 48-hour period in five minute blocks. The data collected provides information on how much time people spent on different activities including unpaid work comprising four components: household work, caregiving for household members, purchasing goods and services for own household, and unpaid work outside of the home. For the purposes of this literature review, the focus is on caregiving for household members and unpaid work outside the home.

The following findings were obtained from the Time Use Survey.

- Primary caregivers in the 25-44 age groups spent more hours per day caregiving than those in other age groups. This is consistent with 95 per cent of caregiving time being for pre-school children.
- Female primary caregivers averaged about seven hours of care a week, with Māori spending slightly more time than non-Māori. Male primary caregivers averaged just over two hours a week.
- Women spend a higher proportion of their caregiving time on physical care tasks than do men, with Māori spending more time than non-Māori. Care given by men is much more equally distributed between physical care, play and travel.
- Less caregiving is done by those employed full-time compared with those working part-time or not in the paid workforce. Once again, women contribute more time to this activity than do men.
- Women spend more time on informal unpaid work (eg helping friends and neighbours) outside the home up to the age of 65, with a distinct peak in the 55-64 year age bracket. After retirement age, men overtake women in time spent on this activity.
- Māori females spend the longest time caregiving for members outside their household, while Māori males spent the greatest amount of time helping people in other households. (Statistics New Zealand/Ministry of Women's Affairs 2001)

The report concludes:

> *Women do more unpaid work than men at almost all ages and whatever their employment status. Their participation tends to peak at the ages when they are most likely to be raising children, whereas men's participation peaks in the retirement age group. Parents, particularly mothers, spend more time on unpaid work than non-parents, while full-time*

workers spend less time on this activity than others. (Statistics New Zealand 2001 page 51)

Graphs from the Time Use survey can be found in Appendix C.

2.4 The work of informal caregivers

A comprehensive account of the tasks that make up caregiving was provided by Arksey and colleagues who undertook qualitative research with 80 caregivers in the UK. In general, co-resident caregiving is more intensive and includes tasks such as toileting, washing and help with physical mobility. Non-resident caregivers tended to keep company, take a care recipient to social events, provide transport, help with paperwork and some other practical tasks (Arksey et al 2005).

Generic tasks of care-giving included:

- help with personal cares, including dressing, bathing, toileting
- help with mobility, such as walking and getting in or out of bed
- undertaking nursing tasks, including administering medication or changing dressings
- escorting the recipient to appointments
- supervising and monitoring the recipient
- providing emotional support
- being a companion
- undertaking practical household tasks, including cooking, shopping, housework, and
- help with financial matters and paper work.

In addition, parental caregivers were also likely to:

- manage behaviour
- provide social stimulation
- choose clothing appropriate for the day
- ensure personal hygiene
- provide constant supervision
- arrange entertainment and daily timetables
- supervise homework, and
- handle money for the child.

Many of these tasks are common to all parenting, but caregiving for a child with disability may demand more of this parental input.

In addition, spousal caregivers are also likely to:

- make decisions on behalf of their spouse
- run the household.

In addition to the general caregiving tasks, caregivers of older people are likely to also to take charge of:

- undertaking personal hygiene
- ordering and supervising medication
- ensuring proper diet
- arranging, not just escorting the recipient to appointments, and
- dealing with finances, paperwork, pensions, correspondence and phone calls.

Non-resident caregivers commonly:

- make regular checks by telephone
- do laundry, cleaning, gardening, shopping, and small repairs, and
- regularly stay overnight. (Arksey et al. 2005)

Caregivers of people with mental health problems may also need to:

- keep the recipient safe
- deal with socially unacceptable or aggressive behaviour
- prompt the recipient to undertake personal hygiene
- ensure medication is taken on time
- administer or provide finances
- ensure the environment is appropriate
- liaise with health and other professionals
- educate family and friends
- provide companionship and care, accommodation and advocacy, and
- be flexible about the level of care provided with no advance notice of change. (Arksey et al. 2005; Collings and Seminuik 1998)

There are no equivalent New Zealand studies. In the mid 1990s, Abbott and Koopman-Boyden interviewed 165 informal caregivers of older people recruited through a nation-wide telephone survey of 3000 New Zealanders. On average, the resident caregivers supplied 40 hours a week of caregiving. In this survey, men and women were equally likely to provide care but tended to do slightly different tasks. Men were more engaged in household upkeep, cooking, chores, shopping and visits, whereas women were more involved with providing personal cares such as bathing and washing, and were also more likely to provide companionship and support. On average, the caregivers in this study had provided care for nearly six years, and almost half of them were the sole care provider. The non-resident caregivers gave an average of five hours care a week. Most non-resident caregivers provided companionship and support, help with shopping and visits, household upkeep and bodily needs. (Abbott and Koopman-Boyden 1994)

Caregiving can also involve advocating for the recipient. In New Zealand, Ballard commented on the need for parents of intellectually disabled children to organise and train other adults in their life in order to ensure an ordinary life. At times they needed to be lobbyists for their child. Tucker also highlighted the advocacy role for parents of children with high support needs. In his small study, mothers of disabled children said they needed to be assertive and vigilant on behalf of their child. All mothers kept track of medical reviews, initiating them if necessary, and kept up to date with technologies and support available for their child. (Ballard 1994; Tucker 2004)

Further research could be undertaken to explore the degree to which access to services is dependent on parental advocates being educated and knowledgeable about the health system.

Milligan drew attention to the fact that caregiving of elderly recipients did not stop with the transition into residential care. The caregiving contribution remained substantial, and tasks fell in four main categories:

- *physical care*: feeding, changing clothes, cutting nails, personalising room and purchasing treats

- *social care:* visiting and entertainment, taking for drives, acting as conduit to the social world outside residential care
- *emotional care*: showing care, love and affection to recipient in ways not always explicitly spelled out by respondents but demonstrated through other tasks
- *quality care:* monitoring level of care, standard of treatment, and indicators of health, as well as dealing with any problems that arise.

Visiting caregivers also tended to befriend and monitor some of the other residents who received few visitors. (Milligan 2004)

Caregivers of people with Parkinson's Disease often have a pivotal role in ensuring the recipient undertakes treatment and rehabilitation sessions, including providing transport to the clinic, direct involvement in sessions, and supervising techniques and exercises. In a study by Chesson and colleagues, almost all of the 41 caregivers were involved in care management through contact with a wide range of health professionals. About half of the caregivers administered medications and provided follow-up to therapists in both hospital and home settings. Caregivers increased skills by being instructed by a therapist or observing them. Caregivers described their role as encouraging and facilitating the recipient's interactions and tasks, as well as monitoring and providing feedback to the therapists. (Chesson et al. 2000)

Mezey defined family caregiving skills as the ability to engage effectively and smoothly in nine core caregiving processes of:

- monitoring – keeping an overall vigilance over the care
- interpreting – making sense of what is observed
- making decisions – choosing a course of action as necessary
- taking action – carrying out care giving instructions
- providing hands-on care – medical and nursing procedures which address both safety and comfort aspects
- making adjustments – finding the right strategy as the situation requires
- accessing resources – ensuring the care recipient has their needs met
- working with the care recipient - showing sensitivity and respect
- negotiating the health system. (Mezey 2004)

2.5 In summary

Caregiving is routine and ongoing. It generally arises out of a relationship with the recipient in response to the need for support which is greater than normally expected due to impairment in functioning. Because lower levels of caregiving merge into normal relationship reciprocity, and because it is outside any formal agreements, it is relatively invisible.

Prevalence surveys in Australia, the UK and Canada have estimated that about one household in twenty has a primary caregiver, that is, a caregiver who feels responsible for the person cared for. Although both men and women are involved in caregiving, more women provide care, and women provide more personal care and social support. Resident caregiving commonly involves a heavier caregiving commitment than those caregivers who live separately from the recipient of care.

Our knowledge of the prevalence of informal caregiving in New Zealand is limited. Census data suggests that care provided by a resident caregiver is given by 5.4 per cent of the population and by a non-resident caregiver is given by 5.9 per cent, with more women providing care than men. These figures are not directly comparable with overseas studies because they do not distinguish between temporary and ongoing incapacity.

Informal caregivers assist with the tasks that recipients are unable to do for themselves. These may involve personal care, help with mobility, household support, financial and administrative tasks, emotional support and companionship. Caregiving may also include some nursing. The caregiver role varies with the age and nature of the impairment of the recipient, but is likely to involve the caregivers taking responsibility to ensure the well-being of that person. This often includes ongoing monitoring, liaising with formal care systems, and attending to any shortfall not provided by paid health care workers.

3 The policy context

3.1 Making the invisible visible

Expectations of caregiving within whānau and family are intrinsic to community perceptions of the role of informal caregivers, particularly in relation to those members who require additional assistance through illness, disability, or age-related decline.

Within 'normal' family reciprocity, caregivers absorb the additional demands arising from the impaired functioning of loved ones. Interdependence between family members leads to a reciprocity of physical and emotional labour exchanges. Based on this, Georgeson argues that constructs of disability can be challenged. For example, constructs that put forward a one-way relationship from caregiver to recipient, perpetuate social oppression. Being reliant on others for the provision of some aspects of care does not negate other contributions made by the person with disabilities. Under this view, informal caregiving merges seamlessly into family caregiving and sharing. (Georgeson 1994)

In practice, however, informal caregivers have become increasingly visible and are now on policy agendas. In New Zealand and comparable countries internationally, this has been the result of commentators pushing informal caregiving into the spotlight through a complex mix of demographic changes, shifts in policy climate, and changes in societal attitudes.

Britain

In Britain, informal care emerged with a policy identity when caregivers became the target of social policies in the late 1980s. Gilbert and Powell outline three successive government approaches to informal care in Britain. In the 1980s, they note a neo-liberal approach towards the family led to relying upon the family as a source of care and support for elderly disabled people to free up state resources. Where families failed to deliver care they were seen as neglectful or abusive. This was followed by social democratic policies in the 1990s that attempted to address the social damage of these policies. Finally, there has been a move to achieve a balance, with policy seeking to promote community participation and family values of mutual respect, autonomy, decision-making though communication and freedom from violence. (Gilbert and Powell 2005)

From these changes, a new partnership between caregivers and the state emerged, one which took into account the quality of life of caregivers and their right to remain in work if they choose to. Government narrative promoted both the civic good of informal care but also the civic responsibility to support caregivers. Gilbert and Powell note the inherent contradictions and tensions of this:

> *Government, while acknowledging the potential financial costs of caregiving should the willingness or ability of people to engage in informal caregiving decline, is nonetheless concerned not to provide levels of compensation, in particular financial compensation, which might undermine the moral commitment felt by caregivers. (Gilbert and Powell 2005, pg 56).*

In terms of economics, when the economy slowed, some policy makers to look to family caregivers to ease the pressure on the state to provide care. However, when the economy improved, more women entered the workforce and were less available for caregiving. (Gilbert and Powell 2005)

New Zealand and Australia

In New Zealand, views of where the responsibility rests for those needing care have turned full circle from societal expectations that family should be totally responsible for the care of dependent members, through a period of state support with the provision of institutional care, back to an expectation that the family will take increasing responsibility for dependent family members. The reasons behind these changes are complex, and involve changing family structures, evolving gender roles, increased economic expectations, and the challenges of an ageing population. (Mitchell and Hendy 2000)

Feminist concerns in the United States and in New Zealand focused on the obligations of caregiving and the disproportionate burden of care that fell on women. (Hooman 1990; Beigel and Blum 1990; Munford 1989, 1990, 1991, 1992) Opie has expressed concern about the potential negative impacts on women from policy emphasising community care. Assumptions by the state that women are available to provide unpaid care may diminish the ability of women to participate equally in the workforce and wider society. Opie perceived a trend towards the privatisation of care, formal social services being increasingly reserved for those at the margins, and an overall abdication of collective social responsibility towards vulnerable dependants. (Opie 1990)

A number of authors have raised concerns about cost-shifting from the public sphere to the private one of families. They argue when the contributions of caregivers are not recognised, caregivers are not seen as a productive part of the health system, and become socially, financially and legally marginalised. (Collings and Seminuik, 1998; Schofield 1999; Milligan, 2004) Schofield also suggests that long-term care of people with chronic disability or illness in Australia has increasingly focussed on as social, rather than as medical responses and this creates the potential for funding responsibility to become a personal rather than public responsibility (Schofield 1999).

3.2 The impact of demographic changes

Commentators have questioned the ability of families to deliver and sustain informal caregiving, primarily due to demographic changes in New Zealand society which challenge assumptions about the availability of the unpaid workforce of caregivers. (Abbott and Koopman-Boyden 1994; Collings and Seminuik 1998; McPherson 2000)

Some of the changes to impact upon the availability of caregivers are:

- increased number of women entering paid employment reducing the number of potential caregivers (McPherson 2000; Phillips and Bernard 1995; Evandrou 1995; Etner 1995; Biggs 1997)
- reduction of family sizes reducing the number of potential caregivers
- geographical mobility of family members making it harder to support relatives on a day-to-day basis
- later childbearing trends leading to a simultaneous requirement to provide caregiving for children and for parents
- increased rates of divorce, marital separation and reconstituted families leading to broken or complicated networks of care and responsibility for older people (McPherson 2000; Marks 1995; Lye et al. 1995)
- increased actual number of elderly people in proportion to potential younger caregivers

There is now an increasing population of key providers of informal care who are contributing more than they receive. This population are providing care for their parents and grandchildren, as well as continuing to provide material and emotional support for their own children who are now young adults. (McPherson 2000)

Research conducted by McPherson found those who support their grandchildren are also more likely to support their parents. The report concludes New Zealanders' sense of family obligation is based on choice and willingness rather than prescription or social expectation. This is contrary to views that point to trends undermining intergenerational social contracts, since it argues reciprocity and mutal interdependence are valued over concepts of family members competing to be care for. (McPherson 2000)

3.3 Valuing the contributions of caregivers

As early as 1978, the Social Development Council (SDC) highlighted that the responsibilities of caregiving for dependants has profound implications for family life.

> *If our society wants, where possible, to keep dependants out of institutions, it must attempt to ensure that families who assume their care are not penalised. Any belief that dependants are better off at home, must be accompanied by concrete and positive action to support the families taking on responsibility for them. (Social Development Council 1978 pg 29)*

New Zealand researchers have urged policy makers to value the contributions of informal caregivers. They fear the demographic changes, the lack of support for informal caregivers and an undervaluing of unpaid caregiving may cause a decline in the supply of caregivers at the time when demand is sharply rising through the ageing population. (See, for example Abbott and Koopman-Boyden1994; Mitchell and Hendy 2000).

While policy makers have been more concerned about the financial cost-benefit analysis to the community, particularly with regard to the delayed or avoided cost of institutional care, it has been argued that any valuation of caregiving must be grounded in the social realities of the individuals affected by such policies, with full costing of the impact on the families.

New Zealand research has pointed out that the groups most likely to provide care are also the groups of people often regard as unproductive to the economy – retired people, the unemployed and home-makers. Placing a higher value on their caregiving challenges conventional thinking and instead recognises the substantial contribution of caregivers to the welfare of older people, to society as a whole, and as producers of health and social services (Abbott and Koopman-Boyden 1994; Milligan 2004).

There are health economist methods to place a value on informal caregiving. Van den Berg and colleagues explored the relative merits and weaknesses of some approaches to valuing the costs and benefits to the individual caregiver. The main methods are described below.

- *The contingent valuation method*: Value is determined by establishing caregivers' and patients' willingness to pay for a marginal increase and willingness to accept a marginal reduction in care.
- *The conjoint measurement method*: Value is determined by asking respondent caregivers to rate four different hypothetical caregiving situations which vary on dimensions of time, tasks and monetary compensation. This way it is possible to

ascertain an individual's trade-off between opportunity costs, and the utility and disutility of providing additional informal care.

- *The opportunity costs method:* Value is determined by measuring the hours spent on caregiving and establishing the value of the foregone wages.
- *The proxy goods method:* Value is determined by valuing informal care hours at the wage rate of a formal caregiver. (van den Berg et al. 2005a, 2005b, 2005c, 2006).

Each method has its limitations. Measuring the hours spent caregiving is often problematic. For instance, unless a distinction can be made between normal housework undertaken to maintain the household and any extra input required because of the dependency of the recipient, the amount of time spent on caregiving can be over-estimated. A study comparing retrospective recording of time spent and diary keeping showed that retrospective recording results in an over-estimation of the time spent in providing care. (van den Berg and Spauwen)

Valuing the time spent caregiving in terms of foregone or equivalent wages is not always meaningful either. The caregiver may be a retired person for whom forgeone wages are not the issue, whereas foregone leisure time may be the cost. Alternatively the time provided in caregiving may not impact on paid employment. The assumption that informal care and the care provided by a formal caregiver are equivalent is not realistic. If caregiving is a positive experience for the caregiver the wage equivalent may be an under-estimation of the benefits.

The conjoint measurement method does address some of the shortcomings of other methods but it is challenging for participants and in a trial of the method, only 70 per cent were able to complete the task.

An Australian approach estimated the contribution of informal care to the economy as a whole, comparing an opportunity cost method with a replacement valuation method (the equivalent of van den Berg's proxy goods method). While the actual dollar value figures calculated are not relevant for our purposes, this study provides a model which may well be useful as a step towards making the contributions of caregivers more transparent. (Access Economics, 2005). More detail about Access Economics' approach to valuing informal caregiving in Australia can be found in Appendix D

Two USA studies attempted to separate out the costs of caregiving for elderly patients with dementia and depression over and above that incurred by co-existing health problems. In both studies using nationally-representative data, respondents (or their agents) were asked about home-based informal and formal care they received. The amount of caregiving was calculated by determining the time provided and then the cost generated by multiplying the time spent by the national average wage for a home support worker. Although the 2001 study did show the quantity of care increased with cognitive decline (confirming the hypothesis), and a dollar value was calculated, the study is seriously flawed by relying on those with dementia to estimate the care given. The presence of depression in the 2004 study was also found to increase the burden of care, and those with depression were more likely to have disabilities and other chronic medical conditions. (Langa et al. 2001; 2004)

The studies by Langa attempt to measure the objective burden of caregiving and do not adequately take in to account the subjective experience of the caregiver. In fact, in most instances, it is only the recipient who responded to the survey. The authors noted that in the dementia study, where proxies responded in place of the recipient, the estimates of caregiving hours were markedly higher. However it is not possible to separate out whether the person with dementia under-estimated caregiving hours, caregivers over-estimated caregiving hours, or whether recipients with dementia needed more caregiving input.

Valuing informal caregiving through undertaking cost-benefit analyses, is clearly challenging. In New Zealand, however, the first challenge remains the one of obtaining accurate data on the prevalence and scope and informal caregiving.

3.4 Media references to informal caregiving

For the purposes of this report, New Zealand media sources were searched to develop a picture of how informal caregivers and the issues they face are presented in the media.

Many of the articles about caregivers are ‘human interest' stories, often providing background for a particular cause or fund-raising initiative such as Alzheimer's Awareness week, Autism week, Schizophrenia week, and Stroke Awareness week. Some issues raised may be specific to a particular situation, but many raise general issues for caregivers. This section gives a small selection of the media references found. Further references can be found in Appendix D.

These quotes show that the media has picked up on the fine line between a normal reciprocal relationship and informal caregiving.

A woman caregiving for her husband who has Alzheimer's disease comments:

> *He tells me I’m not his caregiver, I’m his wife…And we’re happy together…we look after each other. (Illness robs couple of conversation, Taranaki Daily News 24/7/06 p2)*

Associate Minister for Health, Hon Jim Anderton, said:

> *In many cases it will be family members, who provide care, and often their care is a life-long commitment. Families of people with mental illness often become caregivers by default. They often give their support without payment and so it’s sometimes difficult to tell the difference between caregiving …and ordinary support for family and friends.'(Anderton launches Schizophrenia Awareness Week, Government Press Release 7/3/06)*

Changes in society may also mean family members are less available to care, with more women in the workforce and grandparents often not close by. A woman who cared for her elderly mother says:

> *I was still feeling incredibly guilty that I wasn’t doing enough for her. (''Course aims to help those caregiving for elderly relatives’, Stuff: The North Shore Times 18/5/06)*

Caregivers can also experience stress from their caregiving role and from lack of support:

- *The branch [of Autism New Zealand] is so concerned about the stresses facing families who can’t get the funding, the caregivers or the quality help they need. . . (Autism still hell for families, Manawatu Standard 23/9/06 p3)*
- *A study of family caregivers of people with schizophrenia showed they often suffer high levels of stress and anxiety. (Schizophrenia week acknowledges family assistance, Taranaki Daily News 8/3/06 p2)*
- *A woman whose daughter has autism reports having major surgery and being advised to have six weeks recovery time, including three weeks complete rest from the daily physical*

stress of caregiving for her autistic daughter but getting 12 days. 'Daily struggle with little help, Manawatu Standard 25/9/06 p1)

A commonly reported theme was the need for respite care, yet the difficulty in finding it.

- *People may have an allocation of respite care days, but be unable to find suitable caregivers. ('Good care needed', The Nelson Mail 25/5/06 p11)*
- *The low pay available for respite caregivers makes it difficult to attract and retain them. ('Hit hard by pneumococcal disease', The Dominion Post 7/8/06 p10)*
- *Over the years, there have been more than 100 [support caregivers]. Some of them have been great, she says, but others she wouldn't be confident 'leaving in charge of the dog.' ('Daily struggle with little help', Manawatu Standard 25/9/06 p1)*

The media also consistently report on the financial costs of caregiving:

- *She says a recent survey found most caregivers of those with chronic mental illness are women, and many give up paid jobs to look after a relative. ('Schizophrenia group says Rotorua attack shows families' view', Radio New Zealand newswire 29/3/06: 16:26)*
- *A study of family caregivers of people with schizophrenia showed more than half were forced to leave their usual employment. ('Schizophrenia week acknowledges family assistance', Taranaki Daily News 8/3/06 p2)*
- *In addition, caregivers spent on average $64.96 per week on medical and other expenses. ('Counting the costs of caring for sick', The Southland Times 10/3/06 p2)*

3.5 In summary

Informal caregiving is intrinsically bound to notions of family and is subject to the demographic changes that affect families. Caregiving in part arises out of societal expectations of family and the obligations of family members to one another. Caregiving arises in the context of relationships within families. The many levels of exchange can obscure the role and contribution of informal caregivers.

Informal caregiving as an issue has moved into the policy spotlight over the last three decades in response to research revealing informal caregiving can place a heavy burden on those involved, feminist concern that this burden falls disproportionately on women, and debate over whether the care of those with long term disability should be primarily a public cost or a private one.

Demographic research suggests strong reciprocity patterns in New Zealand families and some researchers argue these are based on choice, not social pressure. While family cultural patterns help ensure caregiving occurs, there are increased pressures on caregivers, particularly women, who combine traditional family obligations with paid work. The pool of people available to provide care is declining because of a reduction in size of families, increased numbers of divorced and blended families making family management more complex, and more women participating in the paid workforce. At the same time, the need for care is increasing due to the ageing population and the importance now placed on enabling those with disabilities to participate fully in community life.

Some writers have urged policy makers to begin addressing the predicted shortfall in caregivers by recognising their contribution. To value fully the contributions of caregivers requires an analysis of the costs and benefits to the caregiver, the recipient, and to society. Some approaches have been developed to do this but all have some weaknesses. A recent Australian evaluation used an opportunity costs method (work foregone) and the proxy goods method (hours spent at the wage rate of a paid caregiver) which could be used as a model if the data on prevalence was available.

Media interest in informal caregiving often focuses on human interest stories lobbying for a particular cause. Issues of concern in the formal caregiving arena also come to media attention. Many of the issues raised in the media parallel those discussed in this report. They include definitions/boundaries between caregiver and recipient, relationship factors, impacts of caregiving, pathways into caregiving, the interface between informal and formal caregiving, and factors that help or hinder informal caregivers.

4 The policy regime in New Zealand and other countries

This chapter is not intended to provide a full coverage of relevant policy and legislation in New Zealand, but an overview of areas that can be explored more fully. Relevant legislation has a complex history and policy relating to caregivers is subject to ongoing work by government policymakers.

Policy overviews for other countries have been compiled from information publicly available in 2006. Caution should be exercised in making superficial comparisons with other countries on the basis of having a caregiving policy. New Zealand's benefits and allowances are generally for a specific purpose eg respite care, rather than for caregiving as a role or entitlement. Comparison should involve analysis of each component embedded in relevant policies in New Zealand with provisions made by other countries with caregiving policies. Such an analysis is not the purpose of this review.

4.1 New Zealand

Government policy forms in response to community expectations, and policy in turn shapes broader societal attitudes. Informal caregiving has emerged as an issue worthy of policy attention. The following outlines one part of the context in which the endorsement of a Carers' Strategy took place.

Carers NZ, a national charitable trust established in the mid 1990s, provides information, advocacy and support to carers[1]. Carers NZ acts as a secretariat for the New Zealand Carers Alliance (the Alliance). The Alliance, which was formed in 2004, provides a forum for approximately 41 non-government organisations (NGOs) to advocate on behalf of their caregiver members.

The Alliance has made strong representation to the Minister for Disability Issues to develop a carers' strategy for New Zealand to provide government focus and direction on caregiver issues. To support this, the Alliance commissioned a review of legislation and related strategies[2] affecting caregivers in New Zealand. (Palairet Law 2006) The review includes relevant legislation in a number of areas. The authors suggest there is no discrete legislative recognition of caregivers because their interests are aligned with and submerged by the needs of the recipient of care.

> *The relative paucity of legislative rights or recognition of carers is consistent with a more general lack of recognition of carer issues. Partly this is because there is a convergence between the interests of people requiring support and their family carers or supporters. The interests of carers tend to be treated as being collateral to the interests of people with illnesses and/or disabilities, sometimes to the point that carers' interests can be submerged or invisible.* (Paliaret Law 2006)

The review noted that New Zealand tends to legislate to remedy a perceived problem, rather than creating legal rights or entitlements to individual consumers. (Palairet Law 2006)

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[1] Source: http://www.carers.co.nz/files/pdf/CNZ_brochure.pdf

[2] This review was funded initially by Carers NZ and later reimbursed by the Government. Carers NZ is currently undertaking an update of the review.

In April 2007, the New Zealand Government endorsed the development of a national carers' strategy. The Ministry of Social Development is working in partnership with the New Zealand Carers Alliance and other government agencies to develop this strategy. The Strategy is expected to be launched in 2008 and be supported by a five-year action plan.

Although there is not, as yet, a single carers strategy, New Zealand has a number of strategies that make reference to caregiving in relation to populations most likely to need caregiving, such as disabled people or people living with a long-term illness.

- The *New Zealand Disability Strategy* (2001) has, as one of 15 objectives, to *'value families, whānau and people providing ongoing support.*'
- The *Māori Health Strategy – He Korowai Oranga* (2002a) supports achieving whānau ora and encourages the involvement of whānau caregivers in decision-making.
- The *Health of Older People Strategy* (2002b) provides a framework for integrated service provision, identifying actions health agencies can undertake to involve caregivers in health care decision-making and to provide support services for caregivers.
- The second *New Zealand Mental Health and Addiction Plan – Te Tahuhu: Improving Mental Health 2005-2015* (2006) includes whānau and friends who care for those with mental illness as a key stakeholder group. There is specific reference to ensuring informal caregivers maintain their own wellbeing and participation in society.
- The *NZ Cancer Control Strategy Action Plan* aims to ensure access to appropriate resources for support and rehabilitation for people with cancer as well as their families and whānau.
- At a more general level, the *New Zealand Health Strategy* (2000) refers to supporting caregivers as part of the goal of achieving healthy communities.

Both the Ministry of Health (DSD) and DHBs use Needs Assessment and Service Coordination (NASC) to assess eligibility for disability support services. NASCs usually consider caregivers' needs as part of, not separately from, assessing the needs of the care recipient.

- Caregivers may be offered respite care (residential care facility) or carer support (in the care recipient's home). However, availability can be limited by high demands on providers where carer support is not available (for example in rural or isolated areas). In addition, some respite care providers limit provision to people with specific impairments. The Ministry of Health, who contract respite care providers, have funded increased respite care in Christchurch and Auckland.
- Care recipients may be offered home help and personal care, relieving caregivers of some part of these tasks. Increased funding has been allocated to home based support services (HBSS) in the past three years and a review of HBSS is likely to benefit families undertaking informal care.

The Social Security Act 1964, administered by the Ministry of Social Development, defines benefits and allowances available to support people in need. The financial support available to a carer is dependent on variable factors in the carers' circumstances. It is also based on the assumption that partners should care for each other. Some examples of benefits are outlined below.

- The Domestic Purposes Benefit – Care of Sick or Infirm (DPB:CSI) provides income support for people who are caring full-time at home for someone other than their partner who would have to receive hospital care, rest home care, residential disability care of the kind referred to in section 141 of the Children, Young Persons and Their Families Act 1989, or care of an equivalent kind if they were not being cared for at home. (The Act does not refer to children in a caregiving role.)

- The Child Disability Allowance is a non-taxable allowance that is available to the principal carer of a dependent child who has a serious disability
- The Social Security benefit system includes additional entitlements to those with disability, which may indirectly assist the caregiver.

The Family Proceedings Act 1980 imposes a duty of spouses to provide care for each other if their earning capacity is impaired due to physical or mental disability. This is consistent with the Social Security Act which also is also based on the belief that partners will care for each other.

The Injury Prevention, Rehabilitation and Compensation Act 2001 sets out the range of support that the Accident Compensation Corporation (ACC) can provide. Where a person is assessed as needing attendant care or other support for independence such as home help or child care, due to personal injury, the Act allows for this to be funded as an entitlement to the injured party.

The Human Rights Act 1993 protects caregivers from discrimination on the grounds of having caregiving responsibilities, for example in relation to employment, but these are defensive legal rights rather than the right to any positive consideration. Employment legislation does not contain any specific rights for caregivers.

The law related to privacy and information allows a representative of the care recipient (who may be a caregiver) to disclose or receive information about the care recipient when the recipient is not in a position to give consent or exercise their rights. A representative can receive information from a health agency on request unless the agency believes the request is against the wishes, or not in the interests of, the recipient.

The Protection of Personal and Property Rights Act 1988, although focussed on the disabled or older person’s situation, addresses the issue of caregivers being granted power of attorney.

4.2 The United Kingdom

The UK introduced a Caregivers Strategy in 1999, which builds on earlier policies allowing cash payments to caregivers. The 1999 Caregivers Strategy formally acknowledges the contributions made by the one in eight British people with a caregiving role, and introduces a number of legislative changes to support caregivers. Key aspects put forward in 1999 include:

- changes to pension policies to give caregivers increased social security benefits eg the Invalid Care Allowance for caregivers aged 16-65 who provide care for more than 35 hours a week to someone assessed as having a disability and a commitment to providing a second pension to informal caregivers
- local health authorities being required to inform caregivers of their entitlement to a needs assessment, which must take into account any work, study and leisure interests that the caregiver has
- improved respite care service programmes

- encouragement to employers to allow more flexible and family friendly employment conditions
- access to information on services available to caregivers and those they provide care to from housing, health and social services
- increased consultation and the planning and provision of community care services. (Montgomery and Feinberg 2003; Palairet Law 2006)

4.3 Australia

The Commonwealth of Australia Department of Human Services and Health developed the National Agenda for Caregivers in 1996. Caregivers are considered an integral part of the aged care system and have been recognised as clients in their own right since the establishment of the national Home and Community Care Program in 1984. This introduced a range of services to caregivers, including respite care options, general community support services, information and counselling, employment related benefits, and cash benefits. The National Respite for Caregivers Program includes care in hostels, day centres, and home respite for a specified number of days per year.

The Caregiver Allowance, intended to provide some compensation for the extra costs of co-residential caregiving for an adult or child with a disability or chronic condition, is set at the equivalent of 20 per cent of the single-rate retirement pension. The Caregivers Allowance is not means tested nor is it taxable. The Caregiver Payment, a benefit specifically for caregivers who are unable to work due to caregiving, is means tested and is equivalent to the retirement pension.

Although much employment law is state or territory dependent, under the federal Workplace Relations Act of 1996 employees can use up to 5 days of sick leave for family caregiving. (Montgomery and Feinberg 2003; Palairet Law 2006)

4.4 Canada

In the Canadian health and social service system, caregivers are eligible for support services and some limited respite but are not officially recognised as clients. Caregivers do not have a strong policy voice in the design of provincial community services. (Montgomery and Feinberg, 2003)

The Canadian Caregiver Coalition is the national body representing the interests of family caregivers. The Coalition appointed a Minister of State for Families and Caregivers and drafted a Working Paper for a Canadian Caregiving Strategy for which there is wide support. However, a change in government has resulted in the loss of the ministerial position and the future of the Working Paper is unclear. (Palairet Law 2006)

4.5 Germany

The Long Term Care Insurance (LTCI) is a mandatory social insurance scheme funded by employer and employee contributions to cover long term illness and disability. This scheme explicitly recognises and supports family caregivers, including provision for cash payments to reimburse family members who provide services to disabled relatives. Caregivers are also eligible for skills training, home visits, and up to four weeks respite care a year. Caregivers delivering family care earn credits towards a state pension in recognition of the impact of informal caregiving on employment. Employment law does not include family or medical leave for caregiving. (Montgomery and Feinberg 2003)

A recent survey of LTCI beneficiaries and caregivers elicited positive endorsement from approximately two-thirds of respondents who considered the policy regime encouraged responsible care for their relatives and gave adequate recognition to family caregivers. (Montgomery and Feinberg 2003)

4.6 Japan

Japan has comprehensive Long-term Care Insurance covering all disabled elderly people. This is financed by general revenues, mandatory payroll contributions for people aged 40-64 and public pension deductions for individuals aged 65 and older. This funds formal care but not family caregivers. However family caregivers are eligible for respite care. In 2000, the LCTI scheme removed eligibility criteria reflecting the expectation that women would undertake the caregiving and assume the responsibility for aging parents. The change was driven by an increase in older people requiring care and a decreased capacity to provide informal caregiving resulting from an increase in women joining the workforce.

4.7 The USA

Support for caregivers is highly variable between states. The National Family Caregiver Support Programme established in 2000, is the first federal law to acknowledge the needs of the family members who provide support to older persons. This program grants funding to states for the provision of a limited range of support services, including respite care. Medicaid does not have flexibility to provide assistance directly to caregivers.

The Family and Medical Leave Act 1993 authorised unpaid leave of up to 12 weeks for the birth or adoption of child or to be family caregiver. However it is restricted to larger firms and people with an established work record. (Montgomery and Feinberg 2003)

4.8 In summary

There are a number of laws and policies in New Zealand relevant to caregivers. However, convergence between the common interests of people requiring support and their caregivers results in a focus on the care recipient rather than the caregiver. New Zealand's benefits and allowances reflect this by being provided generally for a specific purpose, rather than for caregiving as a role or entitlement.

The political context for the development of a separate caregiving policy has been driven both by the emergence of informal caregiving as a community issue and by the New Zealand Carers Alliance, which acts as an umbrella organisation for NGOs representing and advocating for caregivers. In April 2007, the New Zealand Government endorsed the development of a national caregivers strategy. The Ministry of Social Development, Carers New Zealand and the New Zealand Carers Alliance, will work together with other government agencies to build the strategy. The strategy is expected to be launched in 2008 and be supported by a five-year action plan.

Although New Zealand does not have a single caregiver policy, the following strategies specifically mention caregivers: The *New Zealand Disability Strategy*, the *Māori Health Strategy – He Korowai Oranga*, the *Health of Older People Strategy*, *Te Tahuhu –*

Improving Mental Health 2005-2015, the *New Zealand Cancer Control Strategy Action Plan* and the *New Zealand Health Strategy*.

The Family Proceedings Act 1980 imposes a duty on spouses to provide care for each other if their earning capacity is impaired due to physical or mental disability. This is consistent with the Social Security Act 1964 which is also based on the belief that partners will care for each other. Other laws relevant to caregivers include: The Human Rights Act 1993, law related to privacy and information, the Protection of Personal and Property Rights Act 1988 and the Injury Prevention, Rehabilitation and Compensation Act 2001.

A review of the policy regimes in the UK, Australia, Canada, Germany, Japan, and USA shows varied support of caregivers recognised by specific policy and/or payments.

5 Informal caregiving and Māori

Despite extensive searches, little literature was found that focused specifically on Māori and caregiving. This could indicate it has not been well researched or that it needs to be seen within the broader context of health and disability rather than as a separate component.

The Māori concept of health is holistic, with the well-being of an individual dependent not only on the absence of illness, but also on their historical, social, cultural, economic, political and environmental circumstances. This is reflected in several well-known models of Māori health, including Whare Tapa Whā, Te Wheke, Ngā Pou Mana and Te Pae Mahutonga. However these approaches are not congruent with approaches driving current mainstream health statistics, which focus more on ill-health. (Durie 1994)

5.1 Health and disability

Māori have the poorest health status of any population in New Zealand. Māori are also over-represented in disability statistics at 24,000 per 100,000 compared with 16,700 per 100,000 for non-Māori. (Ministry of Health website 2006; Durie 2001)

A 2001 survey of disability (prepared for the Ministry of Health/Intersectoral Advisory Group, 2004) found Māori with disabilities are much more likely than non-Māori to live in the most deprived areas of New Zealand and many also have a low income likely to restrict choice - at least of non-publicly provided services. An estimated 700 Māori with disability live in residential facilities such as rest homes and private hospitals. This represented only one per cent of all Māori with disabilities and contrasts with four per cent of non-Māori with disabilities in residential care. The survey also found that the proportion of Māori and non-Māori with disabilities receiving help with everyday activities was similar, but Māori adults reported higher unmet need for at least one type of help for everyday activities.

Since statistics show a greater number of Māori with disabilities and these Māori report a higher unmet need, this suggests further information needs to be obtained on both the availability and acceptability of services for disabled Māori.

5.2 Attitudes to and experience of caregiving

Māori cultural concepts are likely to influence understandings and expectations of caregiving.

When Bevan-Brown undertook research with Māori on their experience of knowing or caregiving for intellectually disabled people, she found their understandings of, and attitudes towards, intellectual disability differed from Pākehā. To begin with, there was no exact Māori word equivalent in meaning to ‘intellectual disability’ and a wide variety of attitudes were recorded (Bevan-Brown in Ballard 1994:207). Differing cultural concepts intertwined with other Māori beliefs and values such as *whanaungatanga* (kinship relationships), *aroha-ki-te-tāngata* (respect for people), *wairua* (spirituality), *āwhinatanga* (assistance), and *manaakitanga* (hospitality). (Bevan-Brown in Ballard 1994:211)

Timutimu-Thorpe interviewed parents and grandparents from four Māori families about their experiences of raising a child with an intellectual disability. She found the child-rearing was shared by the whānau, and in these cases, three generations were involved. A contributor to grandparental involvement may have been the young age of the parents. (Timutimu-Thorpe in Ballard 1994)

Research to inform the development of a model of disability support for Māori with disabilities was undertaken for the Ministry of Health. The research involved interviewing 49 Māori living with a disability, 18 whānau caregivers and seven key informants. The following are key findings.

- Almost 90 per cent had received or given support for more than two years, usually on a daily basis.
- Most caregivers were whānau members who lived in the same household - usually a spouse, child or parent. Fewer than one in five received support from agency care workers or friends.
- Two-thirds received support from sources other than their whānau - usually professionals or specialists and generally on an 'as needed' basis.
- Two-thirds accessed mainstream health and disability support services, one fifth used mainstream services with a Māori component, and only one in 20 used Māori-specific services. However over 80 per cent said they would use Māori health and disability support services if they were available
- Over two-thirds reported they were dissatisfied with the way the health system is currently configured. In particular, they sought an increased consumer responsiveness and removal of cultural barriers. (Nikora 2004)

5.3 Services

Services need to be readily available and accessible. Service issues are barriers for caregivers, not just those requiring care.

Despite a strong preference for family caregiving, all those involved in Bevan-Brown's research recognised the need for additional support - particularly as fewer Māori families now live in or around a marae with extended family support at hand. She found strong support for the need to integrate Māori language, concepts, belief, and values into care and support services. Consultation and involvement of whānau in partnerships with service providers was considered essential to overcome barriers to accessing services, such as feeling '*whakamā*' (embarrassed, ashamed) about asking for help. Timutimu-Thorpe found when community support services were not available, some children needed to be placed in residential care for a time. (in Ballard 1994)

Tihi and Gerzon put forward the benefits for Māori with disabilities of receiving care from Māori. They seek for Māori to be enabled to develop their own services and for the Treaty of Waitangi to be honoured as the basis for the whānau, *whenua* (land and one's connection to it) and *wairua* (spirituality) of all Māori - including those with disabilities - to remain strong or regain strength. However until appropriate Māori services are developed, they anticipate the need for *Tauiwi* (non-Māori, literally new people) support. Such support needs to be culturally safe in attitudes and practices. (in Ballard 1994)

A 1994 consultation by Ratima and colleagues for the Core Services Committee[3] included a consultation with 30 people with a range of disabilities as well as 13 caregivers and nine disability support service providers. Findings emphasised the importance of culturally-appropriate services, specifically identifying the need to recognise whānau participation. Culturally unsafe practices and general ignorance of Māori issues were cited as aspects of services which made them feel uncomfortable and delayed use of services until there was a health crisis. When the consultation explored what encouraged caregivers and those they care for to use services, the answers focused on services being culturally sensitive and meeting disability-related needs. Other barriers to accessing services included lack of knowledge about available services, transport difficulties, financial problems and a general lack of resources. These same barriers to access were found a decade later in a report by the National Health Committee on people with chronic conditions (NHC). (NHC 2007)

Suggestions for improvement of services within the 1995 report included

- an understanding and knowledge of *tikanga Māori* (Māori customs, traditions) and its application to health
- raising awareness among the Māori community of service availability
- an integrated approach to service delivery which increased opportunities for participation by providing links to Māori communities and services
- increasing the number of Māori staff and opportunities to develop abilities related to being Māori.

The authors conclude three cornerstones underpin a culturally appropriate approach: *te hā o te tangata* (respect for clients), *te herenga tangata* (a community focused approach), and *whakapakari Māori* (workforce profiles). (Ratima et al. 1995)

Research conducted by Nikora and colleagues to inform the development of disability support services for Māori recommended the following to improve services for caregivers:

- more culturally sensitive staff and providers
- increased access to Māori healing
- improved referral to support networks for both the person with a disability and whānau members who provide care for them
- more knowledge of what financial assistance is available to both the person with a disability and whānau members who provide care for them
- more home help to enable time-out from caregiving responsibilities
- information on disabilities written to assist caregivers
- practical support for caregivers (such as equipment, or training in safe lifting techniques)
- assistance with transportation. (Nikora et al. 2004)

While acknowledging the significance of culture on Māori, Nikora and colleagues conclude institutional and criteria-based barriers for all people with disabilities may have the bigger impact.

> *Irrespective of whether they are kaupapa Māori driven, or mainstream, disability support services must resolve the underlying organisational and professional tensions between a variety of philosophical approaches to health and determinants of attitudes, support and service delivery. While cultural competence and workforce considerations are important*

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[3] The National Health Committee, established as an independent statutory committee in 1992, was formerly known as the National Advisory Committee on Core Health Services.

> *and do contribute to better access for Māori to services, the problems that disabled Māori and their whānau experience are probably more related to institutional and criteria based barriers, rather than those considerations based primarily on culture. These fundamental issues also need to be addressed. (Nikora 2004 pg 73)*

As Māori caregivers experience many of the same issues as caregivers in the general population, fundamental institutional and criteria-based barriers need to be addressed in addition to culture or race-based barriers. The NHC recommendations for people with chronic conditions address both race-based barriers and ways in which the design and delivery of services do not assist caregivers and care recipients (NHC 2007).

5.4 Supporting whānau

When considering the needs of a person with a disability and the support that their whānau may offer, it is essential to consider the needs of the whole whānau.

> *Although the focus on the individual with a disability is an important perspective, so too is attention on the wellbeing of the whole whānau. Any definition of whānau care needs to be cognisant of both internal demands of other whānau members, as well as external demands upon the whole whānau (i.e. economic demands). A holistic approach is therefore critical to the outcomes for the individual. (Nikora 2004 pg 49)*

Corbett examined the experience of whānau caregiving for members who had been disabled by stroke. She found that cultural safety was poorly considered in the provision of care for Māori stroke patients. Health professionals did very little to integrate whānau into care programmes, despite expecting exercise and daily living programmes to be undertaken at home. There was a significant cost to Māori and their whānau when the stroke resulted in being unable to participate in Māori community life because of resulting loss of functioning. (Corbett 2003)

Collins and Hickey comprehensively explored the role of whānau in the lives of Māori with physical disabilities, encompassing the perspectives of both care recipients and caregivers. Most of the informants had a strong relationship with their whānau and all believed their whānau were important for their personal wellbeing. The research:

> *. . . revealed the ubiquitous role of whānau in daily life for Māori with physical disabilities, irrespective of domicile. The relationship is so intertwined that to ignore the relationship is, in effect, to decontextualise and therefore alienate Māori with disabilities. This has significant implications for social policy development, especially in relation to disability support [showing the key importance of whānau for Māori with disabilities]. (Collins and Hickey 2006:23)*

The researchers found that the relationship between participants and the members of their whānau who lived with or near them was one of interdependence, although importantly, the interdependence was an effect of *whanaungatanga* (kinship relationships) rather than a consequence of living with a disability.

Reliance on whānau, and circumventing of more formal support services available, increased the need for whānau wellbeing to be considered. Collins and Hickey found five elements common to Māori health and wellbeing models were important for whānau and personal wellbeing: *manaakitanga* (caregiving for others), *tatau tatau* (sharing), *wairuatanga* (spirituality), *mana tiaki* (guardianship responsibilities) and *ngā taonga tuku iho* (customary and inherited resources).

5.5 In summary

Māori caregivers experience many of the same issues as other caregivers, including the need for information and financial support. Consideration of the needs of Māori for support requires an understanding of whānau relationships.

The needs of Māori caregivers have to be considered within the context of whānau wellbeing. This may include expectations (both by family members and by professionals) that whānau members will be available to care. Social and economic pressures may prevent whānau from being able to help as much as they might want to.

Services for both recipients and caregivers need to be culturally safe and readily accessible. The reviewed literature suggests Māori are not receiving all the services they need when the services offered are not culturally appropriate. One response to this is resourcing more ‘by Māori for Māori’ services. However, as Māori caregivers also experience many of the same issues as other carers, fundamental institutional and criteria-based barriers also need to be addressed.

6 The impacts of informal caregiving

Substantial commitment to caregiving has a marked impact on the life of the caregiver. Early research on impacts focused on establishing the burden of caregiving. More recent investigations into the impact of caregiving on the caregiver recognises that caregiving can also include enriching and positive experiences.

This summary of research literature describes positive and negative impacts separately, although in most informal caregiving situations, these distinctions are artificial. In part this is because the caregiving commitment usually arises out of complex longstanding relationships based on familial love, kinship bonds or other positive ties. These ties are explored in later chapters of this report, and should be considered in conjunction with discussion in this chapter on costs to the caregiver.

6.1 General impacts

Impacts on caregivers in New Zealand

The impacts of informal caregiving in New Zealand were documented in a seminal report on *Families in Special Circumstances* undertaken by the Social Development Council. The report aimed to inform and stimulate discussion about ways to assist these families, and included sections on the circumstances, the prevalence, the decision paths, the community attitudes the problems that these families commonly face as well as possible interventions. This report suggests that at least some New Zealand researchers, health workers and policy makers, were aware of the impacts of informal caregiving decades ago.

In the early 1990's, Opie provided a poignant account of caring for elderly people with dementia in the Wellington region. The qualitative approach and sensitive analysis has been very influential in raising awareness in New Zealand of the negative impacts of caring on caregivers. She found all caregivers suffered from chronic exhaustion and most of the elderly caregivers had some physical illnesses. She drew attention to the profound and wide ranging impacts, which she summed up as dominated by isolation, absence and loss. The demands of caregiving caused caregivers to lose touch with normal social contact and leisure activities. Interactions with the outside world were reduced to the few people who entered their world - immediate family and staff of day care centres. Opie concluded caregivers are relatively invisible. She attributed this to ageism in society, and diminished opportunities for social contact both from caregivers' lack of time and energy to maintain previous interests or contacts and from friends tending to disappear. (Opie 1990; 1992)

Williams captured a New Zealand caregiver's experience as her elderly husband developed dementia. The wife did not want to trouble others and was too tired to socialise with them, so she became isolated. She struggled to cope with the difficult aspects of caregiving for her husband alone while also trying to shield her husband from his own distress about his loss of memory. Her sleep was disrupted because of her husband's nightly wandering. The wife tied string around her and her husband's wrist to alert her to him getting up out of bed to wander and estimated two hours sleep in a night was common. Not surprisingly she felt exhausted. Her many frustrations included the difficulties of toileting her husband. The relentlessness of every day wore her down and at times she felt hopeless and despairing. During the six years of providing constant care she grieved for her husband's changed character. At his death, her grieving process included a complex mix of loss for the person with whom she had shared happy times and desire to block out her recent memories of caregiving. (Williams 1991)

The impacts of caregiving are profound for caregivers whatever age group they provide care to. Carpinter and colleagues reported on discussions with 54 New Zealand parental caregivers of children with high care needs. These parents were exhausted from providing for children with high care needs and having to exercise extreme vigilance to ensure the safety and comfort of the child and others in the vicinity. They had to coordinate all aspects of their child's care and cope with additional health crises. These parents were often sleep deprived due to night-time caregiving tasks or the abnormal sleep habits of the child. As well as caregiving for the child, these parents juggled the demands of their other children, coped with the normal tasks of keeping the household financially and domestically afloat, and tried to maintain their own well-being. (Carpinter et al 2001)

A literature review by Horsburgh on palliative caregiving detailed the impacts of caregiving on informal caregivers. Subsequent research by Horsburgh and Trenholme on New Zealand parents providing palliative caregiving to a child with terminal illnesses found that despite the demands of informal caregiving, most families want to have a terminally ill child at home, and sick children usually also want to be at home in as normal a situation as possible. However, palliative caregiving has a number of negative effects on the caregiver and family including:

- increased marital stress
- experiences of being overwhelmed and in a state of crisis
- feelings of guilt, anger and devastation
- decreased family cohesion and functionality of relationships
- severely curtailed social time
- lack of rest and sleep
- financial burden. (Horsburgh 2002, Horsburgh and Trenhholme 2002)

Impact on caregivers in Australia

Aoun, examining the impacts of palliative caregiving in Australia, noted:

- income is often insufficient due to the costs incurred through caregiving
- health impacts on caregivers are common, yet caregivers often ignore or diminish the importance of maintaining their own health
- disruption to sleep leads to caregiver fatigue
- caregivers have reduced opportunities for social and physical activities and can become socially isolated
- palliative caregiving is emotionally demanding with caregivers reporting feelings such as guilt, anxiety, resentment, frustration, fear, anger, depression, loss of control, and a sense of inadequacy. (Aoun 2004)

6.2 Physical health impacts

Internationally, the most compelling evidence for health impacts on caregivers is provided by the meta-analysis of Vitaliano and his colleagues who conducted a review of studies looking at health impacts of caregiving on the caregivers of elderly people with dementia. This research used matched control studies to compare the health of caregivers of dementia patients to demographically similar non-caregivers. The review of 23 studies included around 1,500 caregivers and a similar number of non-caregivers. The median percentage of women in the studies was 65 per cent.

In aggregate, the caregivers reported poorer physical health and took more medications than non-caregivers. The study found a nine per cent greater risk of health problems in caregivers and a 23 per cent higher rate of stress hormones than for non-caregivers. Other results showed caregivers had poorer antibody production, a higher incidence of sleep problems, less adequate diets and more sedentary behaviour. The health impacts were greater for older caregivers. The authors suggested two possible explanations of their findings. Firstly, chronic stress and distress may lead to elevated stress hormones, primarily through the hypothalamic-pituitary and adrenal axis, causing repeated arousal and inefficient control of physiological responses. Secondly, distress may trigger risky health behaviours such as poor diet, sedentary behaviour and substance abuse. Individual differences and dispositions moderate the impacts of caregiving. (Vitaliano et al. 2003; 2004)

Doran et al reported on the 2001 UK Census which found that of 57.7 million people, 5.9 million provided informal care for another person. Of these, only 3.3 million (56 per cent) reported themselves in good health. However, this report did not provide health ratings of the non-caregiver population as a comparison. (Doran et al. 2003)

A 1999 Australian Caregivers Association Survey of 1449 caregivers found that almost 60 per cent reported adverse health impacts. Of the affected sub-sample, 55 per cent were tired and exhausted, 34 per cent complained of back, neck or shoulder problems, and 13 per cent complained of high blood pressure or heart problems. Sleep disturbance, stress and injuries incurred in the course of caregiving were also common reports. (Aoun 2004)

New York research by Janicki and colleagues on grandparents caregiving for grandchildren with developmental delay or disability suggested grandparental caregivers denied or minimised their own ill-health because of concern that they would be considered unfit to for caregiver duties. Although grandparents generally self-reported good health, these did not always tally with other observations, raising the possibility of under-reporting. Other researchers have suggested grandparents often overestimate positives to avoid children being taken into foster care. (Minkler and Roe 1993 in Janicki et al. 2000)

Research in the Netherlands used a postal survey of 153 caregivers of rheumatoid arthritis patients to examine objective and subjective burden, and health-related quality of life. On average, almost 90 per cent of caregivers were married to and co-residential with the recipient and caregivers had been looking after recipients for more than 11 years, for 27 hours a week or more. Three quarters of the sample were men, reflecting the higher incidence of rheumatoid arthritis in women. The study found the more time spent caregiving, the lower the quality of life, and the lower the probability of being in paid employment. Disrupted life schedules and health problems were most predictive of subjective burden scores. However, the quality of life of all caregivers was not significantly lower than the reference group. (Brouwer et al. 2004)

New Zealand research

A review by Perkins found caregiving is commonly associated both with stress and health impacts (Perkins 2006). Davey and Keeling found negative feelings were more likely when the caregiver did not have anybody to help them regularly or when caregiving conflicted with work and other activities. (Davey and Keeling 2004)

A small study by Campbell of four New Zealand rural women caring for their terminally ill partners found self-neglect became accentuated as the health of their partner deteriorated and increasing care was required. Within this small sample one woman did not take prescribed medication for blood pressure, and another ignored breast lumps which later resulted in a double mastectomy. (Campbell 2004)

When Nikora and associates (2004) held a hui with caregivers of disabled people to assess the services needed to better support whānau caregivers, they found physical and mental health risks of caregivers were increased by not undertaking healthy lifestyle practices, such as regular eating, sleeping and exercise regimes.

Research on New Zealand parental caregivers of children with high care needs found caregivers had general conditions of ill health precipitated by mental and physical exhaustion, persistent stress, worry and lack of sleep. In addition, these caregivers had a range of back or other injuries caused by the child's behaviour. Behavioural problems were sometimes extreme, yet were attributable to the disability or illness, rather than to poor management. (Carpinter et al. 2000)

Worrall reported on the results of 323 postal surveys from grandparent respondents linked to the Grandparents Raising Grandchildren Trust. Over half of the respondents stated their health had declined since taking on the caregiving role. A further third reported their health was unchanged and a small number reported their health had improved. These results show a greater impact on health than that found by the American studies cited above. This may be the result of greater trust in the group undertaking the research. It may also be due to the researchers not using a matched control group to rule out the changes in health associated with ageing. (Worrall 2005)

6.3 Mental health impacts and distress

Hirst (2005) provides the most convincing evidence of mental health issues arising directly from caregiving. Using British Household Panel Survey data from 1991-2000 Hirst tracked the paths of individuals as they entered and left caregiving, recording their distress levels at regular intervals. The study showed that those providing more intense care (20 hours or more per week) were at twice the risk of psychological distress as non-caregivers and this effect was greater on women. The risk of distress rose with increasing hours of caregiving per week.

This study provides some intriguing findings about transitions and pathway. Both men and women in the intense caregivers group had a higher prevalence of distress (31 per cent for caregivers compared to 22 per cent for non-caregivers) in the year prior to becoming a caregiver suggesting the move into caregiving may not be a discrete event[4]. A general pattern was for prevalence of distress to rise over the first year of caregiving, stablise for a

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[4] Hirst proposes a number of possibilities for higher than expected levels of distress from the outset including: ill health predisposing a person to leave paid work to care (Parker and Lawton 1994), the emotional commitment underlying increasing caregiving tasks and the stress of caregiving for someone with advancing impairment (Bowers 1987, Nolan et al 1996), sharing response to their spouse's health status as well as sharing life risks with spouse. (Hippisley-Cox, Coupland, Pringle, Crown and Hammersley 2002; Wilson 2002)

time and then rise again when caregiving continued for four or more years. Despite an apparent adjustment to the caregiving role, the study showed there was a substantial minority of caregivers who experienced chronic distress and that the risk increased with caregiving responsibility. The transition out of caregiving also was a time of increased distress, and recovery from distress could take up to five years from the time caregiving was discontinued. The more intense the caregiving, the more prolonged the recovery time taken.

This well-designed study provides very compelling evidence that caregiving is independently associated with psychological distress since the effect was shown to be additional to other known contributors to health inequalities (such as income and socioeconomic circumstances). (Hirst 2005)

Other literature reviews support Hirst's research finding of increased prevalence of distress.

- Savage and Bailey reviewed studies on the impact of caregiving on mental health, finding less life satisfaction, increased self-reporting of worry and depression, and increased levels of psychiatric morbidity among caregivers. (Savage and Bailey 2004)
- Cummins reviewed research on caregiving for a severely disabled family member at home, finding elevated stress associated with caregiving, after studies were controlled for potentially confounding factors such as age, sex, degree of social support, education level, income and race. (Cummins 2001)
- Horsburgh reviewed research on paediatric palliative care, finding parental caregivers experienced being overwhelmed and in a state of crisis, as well as having feelings of guilt, anger and devastation. (Horsburgh 1002)

In general other research is consistent with Hirst's finding that the impact of caregiving on mental health increases with time committed to caregiving. (Cochrane 1997; Nieboer et al. 1998; Cannuscio et al. 2004)

A group of studies found the effect on mental health of making the transition from caregiving was influenced by the reason the caregiving had ended. A study by Bond and colleagues of the spousal caregivers of those with dementia, found that following the institutionalisation of their partner, the caregiver's mental health gradually improved, but following widowhood, improvements in mental health were mixed with some deterioration in physical health. (Bond et al. 2003)

Vitaliano and colleagues undertook a meta-analysis of 23 studies of the impacts of providing care to dementia patients, comparing rates of depression in a general population of older people with those of caregivers. They found an 11 per cent prevalence rate for major and minor depression among non-caregivers compared with a 22 per cent rate among caregivers. (Vitaliano et al. 2003)

Other studies which lack a matched control group have survey results consistent with these findings.

- A survey of 164 grandparents in New York found 50 per cent had some level of clinical depression, contributed to by social isolation. (Janicki et al. 2000)
- MENCAP, a British organisation advocating for families caregiving for children and adults with severe or profound learning disabilities, found that eight out of 10 families had critical events during which their level of desperation was so high

> they were frightened about their ability to control their behaviour. They also reported an increased level of marital breakdowns due to one of parents being unable to cope with the caregiving role. (MENCAP 2003)

New Zealand research

The few New Zealand studies about the mental health of caregivers are mostly qualitative in nature. While these studies are richly informative about the experiences of the caregivers, they lack the rigour of more representative sampling and provide no relevant comparison groups.

Abbott and Koopman-Boyden used the General Health Questionnaire to interview 165 caregivers of older people identified by a telephone survey of 3000 people in December 1992. They found 30 per cent of caregivers living with care recipients were classified as suffering a psychological disorder compared to 19 per cent of caregivers not living with care recipients. There was a strong relationship between the presence of psychological disorder and overall caregiver task burden. Predictors included having major caregiving responsibility, caregiving for a person with high disability levels, caregiving for a spouse, caregiving for a male, and having considered terminating the caregiving role. Other predictors included being over 60 years of age and receiving low social support, The authors concluded informal caregiving is a high risk occupation from a mental health point of view. Despite the length of time involved, on average most caregivers did not find the tasks undertaken to be burdensome. However most tasks were burdensome to at least a minority of caregivers, and caregiving for an elderly person with dementia and troublesome behaviour was found to be the most burdensome across the sample. (Abbott and Koopman-Boyden 1994)

Caradoc-Davies and Dixon statistically analysed the relationship between stress for 64 caregivers of elderly patients and readmission of the care recipient to a rehabilitation unit. Patients re-admitted within six weeks of returning home had caregivers with significantly higher stress scores on initial admission. Stress levels in the caregiver one week after discharge were predictive of whether the patient would need re-admission. Stress was correlated to levels of social functioning. Caregivers who felt in control and who had good emotional support reported significantly less stress. (Caradoc-Davies and Dixon 1991)

Parental caregivers of 54 children with high and complex needs reported feeling run down through mental and physical exhaustion, persistent stress, worry and lack of sleep. Mental health suffered due to ongoing stress, lack of opportunity to relax, and exposure to aggression and violence. Many reported feeling suicidal on occasions. The lack of acknowledgement from health professionals was a further source of hurt and frustration. (Carpinter et al 2000).

In a study of over 100 caregivers of people with multiple sclerosis or traumatic head injury the amount of time spent caring and the difficulties in planning were perceived to be the most negative aspects of their situation, with women reporting feeling more burdened than men. The most significant predictors of a low sense of burden were caregivers' satisfaction with their ability to cope and their satisfaction with support received from social networks. The authors did not undertake a gender analysis of this information. (Devereux 1996)

Qualitative research with 37 New Zealand caregivers of people multiple sclerosis and schizophrenia found that taking on the caregiving role usually brought a huge change into the life of a caregiver with wide ranging impacts. Participants reported a deep sadness for the person with the disability and fear for the future of that person. Many had lost a sense of personal control and freedom, and experienced their lives as determined by the disability of the person cared for. Health impacts from ongoing caregiving for arose from both the physical work and the emotional stress. (Lungley et al. 1995)

A research hui with 18 whānau caregivers to discuss the needs of disabled Māori people revealed the depth of emotional turmoil and stress experienced by whānau caregivers yet largely unacknowledged or unseen by others. Caregiving was experienced as hard and stressful work, particularly if the recipient had a long-term or degenerative condition. Participants shared the overwhelming grief and frustration of watching the person with disability struggle and wishing they could help more. (Nikora et al. 2004)

Knight and colleagues undertook a survey of 742 women in midlife on issues related to women's health. They found 12 per cent of caregivers were depressed. The most significant factor was the role of social support. Women who were dissatisfied with their network of social contact were more likely to see caregiving negatively. It is not clear whether caregiving impedes the maintenance of social network or whether underlying personality factors are responsible for both the dissatisfaction and degree of burden felt. (Knight et al. 1998)

A thesis by Soutar documenting five mothers' experiences of caregiving for an adult child with schizophrenia found that the physical strains and emotional stress involved in caregiving caused one caregiver to develop a physical illness and another to develop depression. All caregivers found it highly stressful to have someone acting in an unusual, unpredictable or antisocial manner. (Soutare 1997)

Patterson's thesis records the experiences of eleven women caregivers of elderly dementia recipients. A dominant theme was distress about the loss of the person they knew and lack of communication. (Soutar 1997; Patterson 1997)

Kalliath and Kalliath, reporting on a case study of a New Zealand caregiver of a stroke victim, observed emotional burnout was associated with symptoms of exhaustion, depersonalisation and reduced personal accomplishment. (Kalliath and Kalliath 2000)

Knight and colleagues countered the trend of the majority by finding no difference between the mental health of caregivers and non-caregivers. They conducted a health survey of 742 New Zealand women aged 35 to 67. Of these 97 (12 per cent) were involved in caregiving and 90 completed a psychometric assessment and were asked to rate their overall health on a four-point scale. Participants were also assessed on a care burden scale, and a social support questionnaire. These researchers found the physical and psychological health of the caregivers was no different from that of 614 non-caregivers in the sample. In this study the most significant factor in predicting how burdened caregivers felt was the role of social support. Women who were dissatisfied with their network of social contact were more likely to see caregiving negatively. It was not clear whether caregiving impedes maintenance of social networks or whether underlying personality factors are responsible for both the dissatisfaction and the degree of burden felt. (Knight et al. 1998)

Tools for measuring caregiver burden

Many of the early studies attempted to measure the degree of burden experienced by the caregivers. For example, the Caregiver Burden Scale developed in 1985 by Zarit and colleagues in the USA, is designed to assess the strains of caregiving for a dependent parent. In this scale, five dimensions of emotional and behavioural strain together accounted for 61 per cent of the variance:

- *general burden:* caregivers' sense of control over their lives, their feelings of being burdened, the degree to which their social life suffered, competing responsibilities, insufficient time for themselves, feeling their health had suffered and that caregiving had affected their social relationships
- *guilt and uncertainty:* caregivers feel they should be doing more for their parent, that they could do a better job of caregiving, they feel uncertain what to do, and fear the future.
- *social embarrassment*: caregivers feel uncomfortable about having friends over, are embarrassed over recipient's behaviour, and become angry at recipient's behaviour.
- *the recipient's demands:* caregiovers feel they are expected to provide care, are asked for more than is needed, and care recipients are dependent upon them.
- *financial burden*: caregivers incur financial strains and losses. (Chiriboga et al. 1990)

This psychometric instrument, developed in the USA, is weighted towards negative factors and relates directly to the context of filial care of parent. It may be culturally dependent and there are no studies testing its validity in New Zealand.

Collings and Seminuik highlighted the distinction between objective burden as the observable costs or disruptions, and the subjective burden, representing the individual's own view and the emotional reactions to caregiving. They undertook a series of focus groups with 40 caregivers recruited from Schizophrenia Fellowship in New Zealand. They confirmed a high degree of perceived burden and emotional stress in their groups, and this was closely related to the nature of the relationship with the person cared for. (Collings and Seminuik 1998)

Chappell and Reid demonstrated that well-being and burden are distinctly different concepts and therefore the quality of life can be improved even if burden is present. In their Canadian research of 243 caregivers, wellbeing was found to be directly affected by four variables: perceived social support, perceived burden, self-esteem, and hours of informal care. Perceived burden was related to behavioural problems and hours of care, inversely related to the frequency of getting a break and self-esteem, and was not related to perceived social support. (Chappell and Reid 2002)

Risk and resilience factors for distress and depression

A Canadian longitudinal study of stress in 330 informal caregivers of elderly over 30 months analysed a wide range of variables to see if predictors of caregiver stress could be identified. In order of importance, predictors found in this study were:

- caregiver financial difficulty
- lower age of caregiver
- care recipient being a spouse

- providing more hours of caregiving per day
- greater mental disability in the recipient
- higher levels of cognitive decline
- receiving more respite care (which may reflect dependency needs of recipient or may reflect caregiver not coping as well).

Together these variables accounted for 20 per cent of the variability in caregiver stress, suggesting there are many other factors which may contribute. (Armstrong-Esther et al. 2005)

Cameron and colleagues found 44 per cent of 94 Canadian caregivers of stroke patients were at risk of clinical depression. Depression scores were not affected by gender, education level, marital status, employment status, duration of caregiving, location or whether the caregivers lived in the same house as the recipient. However, those on higher incomes (more than $40,000 per year) reported significantly more depression symptoms than those on less. Using multiple regression analysis, 58 per cent of the variability in depression symptoms in caregivers was explained by being a female caregiver, more lifestyle interference, lower levels of mastery, providing less care to the stroke survivor, and the presence of more memory and comprehension difficulties in the recipient. Further analysis suggested that once the factors related to memory and comprehension and lifestyle interference is controlled for, there is actually a positive relationship between providing caregiver assistance and mental well-being. Researchers suggest this may be due to caregiving being a valued role and therefore enhancing the emotional well-being of the caregiver. An alternative explanation may be that those providing lower levels of care experience more depression symptoms. (Cameron et al 2006)

U.S. researcher Canning conducted a longitudinal study of caregivers of heart transplant patients which found the strongest predictors of distress shortly following the transplant were caregivers' employment status, perceived time constraints imposed by caregiving, and poor relationship with recipient. (Canning et al.1996)

Savage and Bailey in their review of studies on the impacts of caregiving on mental health identified financial stability, social support, coping strategies and sense of mastery or self-efficacy as factors that reduced the stress of caregiving. (Savage and Bailey 2004)

6.4 Financial implications

There is a recurring theme in the literature of the financial impacts for informal caregivers. These can be broadly categorised as direct costs incurred, the financial consequences of decisions around caregiving, and the constraints on choices arising from the financial status.

Parental caregivers of children with high and complex needs or children needing palliative care are commonly under financial pressure. This is exacerbated for sole parents and those on low incomes. Financial pressure adds to stress, places constraints on the manner in which they can care for their child and severely limits participation in normal activities for other children in the family. There are additional expenses arising from medical appointments, transport and parking, and home modifications (Carpinter et al. 2000; Horsburgh 2002; Horsburgh and Trenholme 2002)

A Canadian longitudinal study which assessed stress in 330 informal caregivers of elderly people over 30 months, found approximately 20 per cent of caregivers experienced financial difficulty. Many incurred additional expenses such as ramps and bath lifts, rails, transport, and medications. (Armstrong-Esther et al. 2005)

Research on informal caregivers in Hong Kong found that although the main financial impact is the loss of earnings, there are a number of other expenses commonly incurred. These include: incontinence products, medical expenses and medication, transport, additional heating, house adaptations, extra clothing or bedding, mobility aids, and special dietary requirements. (Petrus and Wing-chung 2005)

New Zealand research

Worrall found severe financial hardship for many grandparents raising kin children in New Zealand. It is noteworthy that over half of those in the study reported a change in employment status because of their caregiving responsibilities. This included those who returned to work to cover the costs of caregiving and those who gave up work to cope with caregiving. Over half received the Unsupported Child benefit but found this to be grossly inadequate to cover the large number of costs incurred. (Worrall 2005)

Low incomes are a major source of stress for all caregivers. The more dependent the disabled person, the more support needed by a caregiver. Level of income affects ability to purchase additional support. Nikora's study of Māori caregivers found asking the disabled care recipient to commit funds for medical or personal care is often a sensitive matter which may invite judgement or attack from other whānau members. The eroding of savings due to medical and personal care expenses for one spouse causes stress for both spouses. (Lungley et al. 1995; Nikora et al. 2004)

There are often significant costs incurred in caregiving, for both ongoing expenses (such as increased heating) and one-off payments (such as adapting a car for a wheelchair). Caregivers of those with schizophrenia reported subsidising household or person costs (such as phone calls or cigarettes) as the recipients seemed to have little comprehension of the costs or take limited responsibility for costs. Lungley and his colleagues also noted that informal caregivers are not used to thinking in terms of costs as they accept the expenses incurred as part of caregiving for their family member. The authors commented on the inequity of state provisions for a person with a congenital disability compared to a person with a disability resulting from an accident. The researchers concluded that caregiving can cause levels of poverty which potentially prevent the whole family from achieving acceptable standards of living. (Lungley et al.1995)

6.5 Impacts on family life

Caregiving for a family member occurs in the milieu of the wider family/ whānau context. The nature of the impact varies depending on the age of the recipient and their relationship to the caregiver.

Caregiving for a child or young person with a disability puts stress on the whole family system. The mother of a severely disabled child describes going to the beach and knowing one adult will be fully occupied with managing their child's inappropriate behaviours (for example delving into other families' bags and toys). Others' attempts to be nice and inclusive often had the effect of encouraging inappropriate behaviour:

> *How do we teach [child's name] society's rules and barriers when [he] is so often rewarded for breaking them? (Dixon 1994 pg75)*

Parental caregivers of children with high and complex needs struggle with balancing the needs of these children with of the needs of their siblings. Siblings commonly complain of double standards, while parents report difficulty maintaining consistent parenting while operating with different expectations between the disabled and non-disabled child/ren. Other children in the family may become a focus of guilt for parents who can not spend sufficient time with them, or a target of transferred frustrations. Children may miss out on normal sports activities, on inviting friends home and on just being with the parent. Holidays are rare due to the lack of energy to arrange it, the lack of discretionary spending, and the lack of safe environments for the high needs child. Respite care is not readily available. When respite care is available, difficulties arranging care can detract from the holiday. (Carpinter et al. 2000; Ballard 1994).

Many children are ashamed of, and embarrassed by, their high needs sibling. Parents need to manage the impact of the behaviours of the high needs child on siblings. Difficult behaviours may include aggression, violence, sexually inappropriate behaviour, and intrusiveness. Parents also worry that their other children have too much responsibility placed upon them too early. The needs of other siblings are highlighted in adolescence, and parents faced with the conflicting needs of children at this time may seek a permanent 'out of family' care situation for the disabled child. Support workers in the home can trigger frustrations for parents and siblings alike. Siblings often resent having strangers in the house and in turn may be the focus of criticism by support workers for not making a greater (and possibly age inappropriate) contribution.

Marital relationships can suffer due to stress and lack of quality time together. Many parents of disabled children are separated or divorced from their partners. While the separation is not necessarily attributed directly to the high needs child, it is always a contributing factor. Very few separated parents have formed new partnerships. Other family members were either not a significant support or their support diminished over time (Carpinter et al. 2000)

Paediatric palliative care also has major impacts for families. Common family problems include increased marital stress, negative impacts on family cohesiveness and relationships, and drastically curtailed social time for families, resulting in isolation. Psychological and emotional support needs are considerable, including for siblings, the child concerned and grandparents. Mothers have a range of responses to their child's terminal illness. Some mothers take pride and strength in being an advocate for their child to ensure the best possible care while others are overwhelmed by their emotional response to the situation. (Horsburgh 2002; Horsburgh and Trenholme 2002)

Grandparental caregivers who took up caregiving because of the breakdown of the parental commitments through neglect, abuse or incapacity, also often had to contend with the ongoing complications raised by contact between the grandchildren in their care and their biological parents. (Janicki et al. 2000; Worrall 2005)

6.6 Loss of social connectedness

Loss of social contact is a very common consequence of caregiving. This is particularly concerning as social support has been identified as protective against the strains of the role. Informal caregivers of elderly people with dementia are described as leading constricted lives with diminishing social contacts and friends (Opie 1990). Few people enter their world apart from immediate family and staff of day care centres. It becomes increasingly difficult to visit others and friends tend to shy away. Other studies of elderly recipients found the loss of social contact is the most prominent negative impact of caregiving. (Opie 1990; Patterson 1997; Petrus and Wing-chung 2005)

A study of caregivers for people with long-term health conditions, compared caregiver burden and social networks and found the most frequently reported consequences of caregiving were constraints in social activities, negative effects on family life, and a feeling of loss. Relatives of schizophrenics experienced greater barriers to socialising and received a lower level of emotional support than relatives caring for family members with physical conditions. While the level of professional support was similar for all groups, familial social support for crises concerning a relative with schitzophrenia was dramatically lower. (Magliano et al. 2005)

Grandparental caregivers, both in New Zealand and in New York, experienced a drastic curtailing of social activities. In one study, over a half stated they had no social activities and in the other study, over half were assessed as depressed due to social limitations and isolation. (Worrall 2005; Janicki et al. 2000)

6.7 Impacts on employment

Survey data on informal caregiving suggests lower participation in the workforce than the general population for the equivalent age range. Caregiving is harder if it conflicts with work and other activities. (Perkins 2006)

An Australian Bureau of Statistics survey showed that just over half of the caregivers participated in the workforce compared to two-thirds of a matched sample of non-caregivers. Of those in a primary caregiving role, only 39 per cent participated in the workforce. (Access Economics 2005)

These statistics show an association between caregiving and employment status but do not provide explanations for this relationship. A New Zealand survey by Worrall of 323 grandparents caregiving for their grandchildren found that over half the respondents reported a change in employment status linked to their caregiving responsibilities. This included both those who had returned to work to cover the costs of caregiving and those who gave up work to cope with caregiving. Respondents were predominantly aged over 50 years and drawn from a wide range of occupations. Other New Zealand studies report anecdotal evidence of changes in employment status due to taking on the caregiving role. (Worrall 2005; Carpinter et al. 2000; Opie 1990; Patterson 1997; Lungley et al. 1995; Nikora et al. 2004)

Perkins pointed out that caregiving is harder if it conflicts with work and other activities. (Perkins 2006)

A British study elucidates many of the issues that arise from combining caregiving and paid employment. Arksey and colleagues explored the relationship of informal caregiving and employment decisions based on a literature review and research with 80 caregivers from a range of occupations. They found an inverse relationship between the hours spent on caregiving and participation in paid employment (ie the more hours spent on caregiving, the less hours spent on paid work). Women were more likely to move from full-time to part-time paid employment than men, and co-resident caregivers were less likely to be in paid full-time employment. According to this study, being an extra-resident caregiver has no impact on male caregivers' paid employment but reduces the probability of women working full-time in paid employment. The literature review indicates most caregivers who are in paid employment prior to taking on the caregiving role give paid employment up reluctantly.

The literature review suggests people also try to achieve their desired mix of paid work and caregiving by:

- finding less demanding paid employment
- moving closer to the place of paid employment
- not applying for better jobs
- becoming self-employed
- working different hours
- using lunchtimes for caregiving tasks
- taking time off paid employment
- using holiday entitlements
- taking sick leave.

Dealing with crises and emergencies is particularly difficult for caregivers to accommodate and conflicts between the commitments of caregiving and paid employment can cause stress and guilt, impairing performance.

Paid employment brings benefits other than income. Socialising at work can alleviate the isolation caregivers often experience. Work can act as respite from the caregiving role. Caregiver-friendly workplace practices include:

- access to a telephone in private
- flexible working hours
- reduced hours
- availability of unpaid leave
- ability to work at home some of the time
- emergency care
- availability of career breaks
- supportive work colleagues.

The research component of the Arksey study involved 80 caregivers who were caregiving for at least 20 hours a week. The research was located in four sites: an area of high labour demand, an inner city area, a rural area, and a declining industrial area. Interviews with participants explored decisions around paid work and caregiving. The researchers found caregivers had to make complex decisions requiring constant review in response to to external factors outside their control. Decisions were often made in discussion with the recipient or other family members. Making decisions and planning ahead were often difficult because unknown factors such as the caregivers' and recipients' future health status created uncertainty about how long care would be needed for and what level of care and support would be required. (Arksey et al. 2005)

Those combining a caregiving role with paid employment of more than 30 hours a week were influenced by: the need to earn income, a belief that paid employment is important to health and wellbeing, a desire to maintain an identity beyond that of caregiver, a supportive employer and, for some, the availability of social services that allowed the caregiver to work.

The only New Zealand study examining the mix of work and informal caregiving is the research undertaken by Davey and Keeling. In a survey of employees of two city councils (Wellington and Christchurch) with a 31 per cent response, almost 10 per cent identified themselves as caregivers of older people. In general, these caregivers experienced the work environment as supportive but experienced work pressures which arose from the unpredictability of needs. They described some pressure for efficiency and productivity in the work place and valued flexibility to respond to the demands of caregiving. They valued the use of private phone at work to check on the recipient or to make appointments. Telephone use can be a source of guilt or embarrassment (for example, one woman described the embarrassment of shouting over the phone to her deaf father). Over the previous six months two-thirds of respondents had dealt with one crisis, a third had coped with more than one crisis, and of these 10 people had four or more crises. More than a third of respondents had some time off work to deal with one or more crises. Cognitive deficits in recipients are more likely to lead to the need for time-off for the caregiver. Many caregivers felt stressed over the combination of roles and felt guilty about letting work and colleagues down. The researchers noted that negative feelings towards caregiving are more likely when caregiving conflicts with work and other activities. (Davey and Keeling 2004)

An Australian literature review found that difficulties in maintaining employment consituted the major impact of being a caregiver. Caregivers often give up work to rely on income maintenance assistance yet found this insufficient. (Aoun 2004)

The research in this section suggests decisions about a work-caregiving balance are the result of a complex interplay of factors.

6.8 Lost opportunities

The time involved in caregiving can incur considerable opportunity costs for the caregiver. Time for work, social activity, leisure pursuits, health promoting exercise and normal freedoms of choice is reduced by caregiving.

Cochrane's survey of informal caregivers as part of the Ontario Health Survey found that 48 per cent of in-home caregivers reported a great or moderate amount of interference with their lives compared to 37 per cent of caregivers who lived separately from the recipient of care. (Aoun 2004; Carpinter et al. 2000; Cochrane 1997)

A study by MacLean and colleagues of 24 Dunedin caregivers of dementia patients found that three-quarters had experienced some loss of contact with friends and about half indicated that caregiving meant they could not keep up with previously enjoyed hobbies. (MacLean 1995)

One New Zealand thesis on caregivers specifically looked at leisure options for six women caregivers. Five of the six regarded leisure as important yet found caregiving constrained their access to leisure. They had a strong desire for physical and mental space with no immediate interruption or immediate obligations. Those who had previously established patterns of leisure were more likely to maintain them, particularly if they had access to respite care. The women who did take up leisure options reported it as vital to their sense of personal well being, supporting a sense of personal identity, self-actualisation, and temporarily shutting out caregiving from their minds. It enabled them to experience enjoyment, a sense of freedom, relief and replenished energy. Three of the six regarded it as absolutely essential to their survival in the caregiving role. (Carter1993).

6.9 Concern about the future

Parents of disabled children or children with high and complex needs have concerns about care provision for their child both in both the short and long term. Although to some extent, immediate crises with children with high and complex needs are ‘predictable’, this does not mean parents have undertaken, or have been enabled to undertake, planning to alleviate their concerns. Bray and others surveyed 53 Auckland families (including 10 Māori and five Pacfic families) about caregiving for their young person (under 25 years old) who had high and complex needs. Despite all the families knowing they needed a crisis plan to cover emergencies, only one in five had a plan in place and of these only three had written plans and only one had funding attached to it. (Ballard 1994; Bray et al. 2005)

The parental caregivers of disabled children are concerned not only about coping with the present but with their sense of responsibility for the future. In a study by Ballard, a parent of an intellectually disabled daughter struggled with vexed questions with regard to planning the future in anticipation of her being a dependent adult. Although some practical provisions could be made, ensuring caregiving individuals would be part of her life in the future was more difficult to plan for. This parent considered the best insurance is for that child to be independent and to form her own relationships.

In separate studies Worrall and Janicki highlighted the anxiety of grandparents to stay well and live long enough to see their dependent grandchildren through to adulthood. (Worral 2005; Janicki et al. 2000)

Informal caregivers of those with chronic health conditions feared growing older and not being able to look after the recipient. Where they were of a similar age to the recipient, the caregiver was worried about their own future health status. In Davy and Keeling's study, caregivers of elderly dependent recipients expressed concerns arising from uncertainty about what the future holds. (Lungley et al. 1995; Davey and Keeling 2004)

6.10 Positive impacts

Although many more studies examine the burdensome aspects of caregiving, there have also been a smaller number highlighting the positive impacts of caregiving.

Two studies noted that the quality of the prior relationship had a strong influence on how positively caregivers regarded the caregiving role. Patterson's study found positive impacts for most of the 11 women who were caregivers of elderly recipients. Daughters generally reported an improved relationship with parents, and at least one wife felt increased closeness with her husband because she felt needed. Other reported positives included: keeping the person out of residential care, being satisfied at doing a good job, undertaking caregiving as act of love, and for some, the opportunity to move out of the paid workforce. (Patterson 1997)

A UK study of 34 elderly caregivers conducted a follow-up interview after the recipient of care had died. Many caregivers identified a significant decline in the quality of their lives since their caregiving role had ended due to further reduced incomes, boredom, isolation and a sense of loss of both the person and the caregiving role. (Argyle 2001)

A Canadian study of 12 families with 38 family members focussed on parental caregivers of children with high and complex needs who require ventilator assistance to breathe. The study found parental caregivers experienced caregiving as deeply enriching and rewarding, despite the daily stress. (Carnevale et al. 2006)

Lopez and colleagues explored predictors of positive outcome for Spanish co-resident caregivers of elderly dependents. The sample included over 80 per cent women with an average age of 58 years who undertook 14 hours caregiving a day. Two-thirds were looking after an elderly parent and a quarter were caregiving for a spouse. The researchers found caregiver satisfaction was correlated with better previous relationship with recipient, being a caregiver by one's own choice, having leisure time, and not working outside the home. Together these factors explained 43 per cent of the variance in satisfaction ratings. The use of religion as a coping strategy was also helpful. Satisfaction with caregiving was unrelated to the characteristics of the recipient, despite many of these recipients being very dependent and some having serious memory and behavioural problems. (Lopez et al. 2005)

New Zealand research

A survey of employees from Wellington and Christchurch city councils found the majority of respondents who took care of older people said they provided care gladly, with even more of those who were caregiving for friends feeling positive. Caregivers of older people with physical health issues were more likely to be positive than those caregiving for someone with cognitive impairment. (Davey and Keeling 2004)

Other New Zealand research reporting positive outcomes is more anecdotal. Dixon, the mother of a boy with an intellectual disability observed it enriched the community to include her son. Bourgeois and Johnson case study found that family-based caregiving of a terminally ill person potentially gives families satisfaction from meeting difficult challenges together. Nikora and others' research with Māori caregivers of disabled people found that many reported giving as rewarding. For example, one person described their experience as a caregiver as a time of learning a lot and growing spiritually. (Dixon1994; Bourgeois and Johnson 2006; Nikora et al. 2004)

6.11 In summary

Caregiving almost always impacts on the life of the caregiver. Those heavily involved in caregiving experience profound and wide ranging changes to their lives.

In studies that compare caregivers with others, caregivers often report poorer physical health and higher use of medication than others. In many studies caregiving is associated with increased rates of depression and anxiety, less life satisfaction and a feeling of being burdened. There is some evidence to suggest cognitive impairment and mental illness in the recipient are more burdensome for caregivers than physical problems. In general, impacts on a caregiver's mental health become greater as the time spent on caregiving increases. Being a co-residential caregiver is a factor associated with increased mental health impacts.

Caregiving is associated with financial impacts including direct costs, the financial consequences of decisions around caregiving, and the constraints on choices arising from the financial status. There are often significant and multiple costs arising from caregiving. Depending on the nature of the recipient's disabilities, there may be increased heating, medical costs, transport costs and house modifications. Caregivers may choose to reduce hours or withdraw from paid employment to manage caregiving responsibilities. Those supported by income maintenance find it insufficient. Low income reduces the options for support with caregiving.

Caregiving most commonly occurs in the wider context of the family/whānau. The effects on others depend on the age of the recipient, although all caregiving affects the allocation of time and attention among family members, for example by reducing time for framily social activities. Parental caregivers of children with disabilities juggle the needs of other siblings with those of the child needing care. The recipient of care may also have behavioural problems which directly impact on other children. Strain between parents is reported to be common. Caregivers of older people sometimes come into conflict with other family members if they express disappointment with the contribution of others.

Caregivers commonly experience a loss of social contact with others which is concerning given that social support has been identified as protective against the strains of the caregiving role.

Caregivers have lower participation rates in the workforce compared to non-caregivers of the equivalent age range. Women are more likely to reduce hours of paid employment compared with men. Co-residential caregivers are more likely to reduce paid employment than those not living with the recipient. Caregivers used various strategies to try to undertake both paid employment and caregiving, including changing to a less demanding job, moving closer to work, and using lunchtimes, holiday or sick leave for caregiving purposes. Employers can make caregiver-friendly work-places by providing access to a private telephone, flexible hours, opportunities to work at home, career breaks, as well as through promoting supportive work relationships.

Parents of children with high and complex needs struggle to make plans for their child for the future, despite knowing this is necessary. Grandparent caregivers also worry about living long enough to support their grandchild through to adulthood. Other caregivers of adults with disabilities and of older people also worry about the future when they may no longer be able to care for the recipient.

Despite the demands of caregiving most caregivers gladly provide care and feel positively about the role. However, those who have heavier caregiving commitments are more likely to feel negatively. The quality of the prior relationship between caregiver and recipient influences how positively caregivers perceive their role. Caregivers of those with physical health problems are more positive than caregivers of people with cognitive issues, but caregiver satisfaction is otherwise unrelated to characteristics of the recipient. All caregivers are more positive when they have help from others.

7 Convergence and divergence

7.1 Caregiving among ethnic minorities

New Zealand research

The Social Development Council (SDC) produced a discussion paper on migrant families as part of its *Families in Special Circumstances* series in 1979. The paper was designed to stimulate discussion and awareness of the special issues arising for families of other ethnicities, but in practice there has been little attention to this topic. The paper reports that families often experience acute strain and loneliness. They have left behind the support of friendship, kinship networks and familiar values and cultural understandings. Emotional pressures are compounded by an incomplete knowledge of language and, in some cases, unfamiliarity with a money-based economy (SDC 1979).

A book published by the Skylight organisation noted that being of a minority ethnicity can create extra barriers for caregivers. Language barriers and unfamiliarity with the New Zealand system are compounded by lack of information about support services in languages other than English. Ethnic-specific experiences of stigma around illness or disability, and the nature of family tensions and expectations around caregiving can create further barriers to receiving assistance. (Irving 2005)

A study of social work practice with Chinese communities noted that family caregivers of those with mental health problems may withdraw from the care recipient because they are scared of dealing with them. (Ngai and Chu 2001)

A study of service delivery for children and young persons with terminal illness found that Māori and Pacific families are disadvantaged by:

- having difficulty accessing information about respite and palliative care
- communicating with health professionals
- insufficient financial support combined with low socioeconomic status. (Horsburgh 2002)

Caregiving among Pacific peoples in New Zealand

There are two New Zealand research studies that give some insight into caregiving within Pacific families.

Carpinter and her colleagues held focus group discussions with parental caregivers of children with high and complex needs. From the eight Pacific families out of the 54 participants, the researchers discovered that as well as the issues faced by all caregivers, Pacific families:

- did not know what help was available, how to find information or how to access it
- were proud and did not ask for help easily
- despite having a strong preference for fanau (extended family) providing support may have no fanau in New Zealand
- traditionally treat strangers entering their home as an honoured guest which means a paid support worker, previously unknown to the family, may not be an option for them unless they can be enabled to reach different understandings

- had fanau who rarely understood the level of care required for children with high and complex needs and who may not be willing to provide the support needed by the parents
- were under financial strain, particularly those who were not permanent residents and so not eligible for state support. (Carpinter et al. 2000)

Huakau and Bray conducted research on attitudes to disability among the Dunedin-based Samoan, Tongan and Cook Island communities. For Pacific people, disability is sometimes given religious or cultural explanations. This includes notions of disability being a punishment from God - possibly attributable to wrong-doing in the family or a negative relationship with high-status people, such as chiefs or ministers. As a consequence, there can be an element of shame, and concern with how others may gossip and interpret events negatively. These attitudes are gradually changing among the younger generation.

There is widespread belief that looking after one another, caregiving and sharing with the extended family is fundamental to family life. Care of a disabled family member is seen as the family's responsibility. The family encompasses extended family members as well as members of the wider community, which some study participants referred to as a strength. There is a strong cultural belief that issues concerning the family should be kept within the family system, making families reluctant to access formal support systems and more likely to continue to struggle with issues in silence. Involving a community leader or minister can also be problematic since the family is likely to feel obligated to give a gift that may strain the family budget. (Huakau and Bray 2000)

Huakau and Bray found that services would be more accessible to Pacific people if:

- information was provided in a culturally appropriate way
- a support person was available who spoke the same language
- support people had professional boundaries ie did not gossip about the family business
- needs assessments were holistic and led to culturally appropriate support for the family. (Huakau and Bray 2000)

Research from other countries

Pinquart and Sorenson defined ethnic or ethnocultural groups as follows.

> *Ethnic or ethnocultural groups are distinguished on the basis of a common history, a unique language or communication system, group-held values and beliefs as well as normative expectations and attendant customs and practices, the intergenerational transmission of these shared values, and a common locale or country of origin. (Pinquart and Sorenson 2005 pg 90)*

They found these groups in addition to the ethnicity that defined them are also likely to share common experiences of discrimination or other systematic bias in access to the health and welfare systems, for example, through language barriers.

The researchers hypothesised that different ethnic groups were likely to demonstrate different approaches to caregiving and experience different impacts undertaking caregiving. They undertook a meta-analysis of 116 studies of caregivers to draw out possible ethnic differences in stressors, resources and psychological outcomes between African-American, Asian-American, Hispanic caregivers and non-minority Americans.

Results showed that, compared to white American caregivers, caregivers from the ethnic minorities were found to be younger, had lower income, and lower educational attainment. All ethnic minorities demonstrated stronger beliefs about filial obligations. Overall, caregivers from ethnic minorities had better psychological outcomes but poorer physical health than other caregivers. However, Afro-Americans were less prone to depression whereas Asian-Americans were more prone to depression than other Americans. (Pinquart and Sorenson 2005)

Horsburgh, having reviewed UK and North America literature suggested ethnic minorities are less likely to use hospice care than the dominant ethnic group because of language and communication barriers, fear of losing control, distrust of white hospice workers, and lack of minority health care professionals. A longitudinal three-year study in the UK into the use of respite care for disabled children found access to services was inequitably distributed, with families from low SES and from ethnic minority communities having less choice of services. (Horsburgh 2002)

Three UK studies explored issues relating to caregivers from ethnic minorities. Hepworth examined the perceptions of Asian caregivers within the UK, and their contact with formal support services. According to these caregivers:

- health professionals have difficulty in sharing power and decision-making with ethnic minorities
- having a semi-informal connection with a community worker of their ethnic group is often important, whereas in the dominant culture any social contact between professional and client is seen as an inappropriate breach of professional boundaries
- being assertive about rights is difficult when using a language in which one is not fluent
- there is uncertainty about whether a support worker can be contacted when there is a need for further assistance
- families are disheartened by a lack of response when they request help
- regardless of the ethnicity of the support worker, qualities appreciated are reliability, being supportive, and being available
- Asian caregivers often rely on informal channels when they need support
- some Asian families feel uneasy about residential respite as it is a foreign concept to them, favouring outreach and befriending support, day respite and sitting support
- most are unaware of the assessment process or the link between assessment and accessing services
- their main contact with health services is with their GP, and there is a widespread lack of information about other services or support groups that are available. (Hepworth 2005)

Emerson and others in a study of over 400 family caregivers of intellectually disabled children in lower socio-economic areas found that while almost half of primary caregivers scored above the threshold for distress, this was as high as 70 per cent for caregivers of South-Asian ethnicity. (Emerson et al. 2003)

Summary: caregiving among ethnic minorities

Being from an ethnic minority accentuates the negative impacts of being a caregiver. Contributors include cultural unfamiliarity, language barriers, and isolation from family and community support networks. Cultural interpretations of illness or disability may add further barriers.

Research with Pacific people in New Zealand found significant language and information barriers to accessing health and support systems. Culturally-based attitudes may make it difficult to acknowledge the need for help or to accept a support worker into the home. Financial pressures are common. Some Pacific people attach shame to the presence of disability within a family, which can make it more difficult to ask for help. The support of a person with a disability is traditionally the responsibility of the extended Pacific family and community. However, in New Zealand, Pacific families may be isolated from that wider support network.

A meta-analysis from the USA found that overall, caregivers from ethnic minorities had better psychological outcomes but poorer physical health than other caregivers. UK studies found language barriers and differing attitudes to forming a relationship with support workers were both significant access barriers. Caregivers from ethnic minority groups may be uncertain about their rights and entitlements.

7.2 Caregiving and being poor

Few research studies examine the impact of income or socio-economic status on caregiver outcomes although some studies include income in the analysis as a potential confounding factor.

One UK study explored the impact of poverty on elderly caregivers, and the way ageing exacerbates the demands on caregivers due to reduced access to material resources and increased incidence of disability. This study recruited 34 older caregivers with an average household income considerably less than the national average. The research found that poverty interacted with care for the elderly in the following ways:

- disability incurs direct costs due to substitute care, aids, and adaptations
- those who are poor are more likely to turn down subsidised services such as respite care as they cannot afford them
- lack of transport increases indirect costs, such as buying groceries from a higher-priced local store rather than a cheaper, but less accessible one
- the option of the recipient going into care may be dismissed for financial reasons
- caregivers want, but struggle to afford, material assets
- having savings can mean recipients are means tested and therefore unable to access some services otherwise provided free
- caregivers adapt to their situations by being financially cautious, avoiding credit, and down-sizing – a strategy which may mean they choose not to pay for services that could make their caregiving role less burdensome
- all caregivers were found to be socially isolated, but the relationship between poverty and social withdrawal is complex as it is mediated by age (support network dying), disability (own health deteriorating) as well as financial expedience (reducing or shaping choices for social contact). (Argyle 2001)

In his study of caregivers of multiple sclerosis and schizophrenia sufferers, Lungley and his colleagues found the financial status of the caregiver and associates had a significant impact on the ability to cope. Caregivers of high socio-economic status have access to additional services, specialists, as well as home help and are being better informed. Those with more limited means are more dependent on state provision. Parental caregivers with higher socio-economic status can more easily set up a schizophrenic son or daughter in an independent living situation, addressing some of their worries about the future. (Lungley et al. 1995)

Horsburgh's study of paediatric palliative care found that while access to resources and support systems is generally difficult, parents who are articulate, confident and can afford to pay for additional support, have a greatest chance of accessing it. (Horsburgh 2002)

Cameron and colleagues researching the association between caregiving and depression for 94 Canadian caregivers of stroke patients, found 44 per cent achieved psychological scores suggestive of clinical depression. Depression scores did not significantly vary for gender, education level, and familial relationship, co-residential caregivers versus extra-residential caregivers, employment status, or duration of caregiving. However, financial status made a significant difference, with those making less than $40,000 per year reporting significantly more symptoms of depression than those making more than $40,000. (Cameron et al. 2006) While the association between depression and financial status is of interest, this does not demonstrate causality. A longitudinal study would be required to elucidate this.

Summary: caregiving and being poor

There are few studies exploring the impact of poverty on caregiving, although income is sometimes included as a potential confounding factor. The research that could be found suggests:

- poverty reduces the capacity of caregivers to cope with the impacts of caregiving
- having more income increases the choices open to caregivers
- poverty may distort choices about residential care if costs are involved
- poverty may increase social isolation
- those who are poor may have the most difficulty accessing services.

7.3 Women caregivers

There is a large volume of work reflecting feminist concern about the burden of caregiving falling on women due to societal expectations about women’s role as caregiver and nurturer.

Population surveys support the view that there are more women than men involved in caregiving. The New Zealand data, based on the census, indicates more women are involved in informal caregiving activities than men, but the way the data is collected does not easily allow comparisons between rates of caregiving in New Zealand and in other countries.

The British Household Panel Survey is a general purpose survey of the population in England, Scotland and Wales, and uses a nationally representative sample of around 5000 households. Data collected from 1990 onwards shows that women made up almost 60 per cent of caregivers and provided a similar proportion of caregiving hours. Ten years later, the UK General Household Survey for 2000 showed a very similar pattern of women's participation in caregiving. (Hirst 2005; Arksey et al. 2005)

The Australian Bureau of Statistics' 2003 Survey on Disability, Ageing and Caregiving indicated 54 per cent of caregivers are female. This is similar to the Ontario Health Survey of 1990 that found 59 per cent of caregivers were women. (Access Economics 2005; Cochrane 1997)

A group of New Zealand studies explored the reasons why more women are in a caregiving role than men. Some demographic reasons are that women live longer, there are more women than men, women tend to marry men older than themselves. However, the socially constructed and gendered nature of care informs familial ties and obligations, as well as creating social expectations of women (for example that caregiving is an extension of the maternal role). (Collings and Seminuik 1998; Milligan 2004; Winder and Bray 2005; Weaver 1999)

The studies that survey caregivers, report more women than men so consistently it is unusual to find an exception. Nevertheless, in research on caregivers of people with rheumatoid arthritis men are more commonly the spousal caregiver as women have a higher incidence of rheumatoid arthritis. (Brouwer et al 2004)

Differences between women and men as caregivers

Pinquart and Sorensen conducted a careful meta-analysis integrating results from 229 studies to examine gender differences in caregiver stressors, social resources and health.

Across these methodologically robust studies, caregiving women reported statistically significantly higher levels of caregiver burden, higher levels of depression, lower levels of physical health, and lower levels of subjective well-being compared to caregiving men. Analysis showed that gender explained 2.8 per cent of the variance on depression and 2.7 per cent of the variance of burden. Gender was found to explain 0.3 per cent of the variance in physical health once health differences between men and women in the general population were taken into account.

The authors concluded that the gender differences in caregiver depression and physical health are larger than those observed in the general population, in part explained by differences in caregiver stressors. Caregiving can be argued to increase gender differences in depression and physical health primarily because women experience more caregiving stressors.

A New Zealand research study of women found of the 12 per cent of caregivers in their sample who were depressed, the most significant factor was social support. Women who were dissatisfied with their network of social contacts were more likely to see caregiving negatively. The relationship between the two factors needs clarifying. (Knight et al 1998)

The longitudinal study by Hirst shows that men and women caregivers both experience distress beyond that of the rest of the population. Hirst's research showed that the prevalence of distress for both women and men was elevated prior to caregiving as compared to non-caregivers and that it rose steeply on taking on the caregiving role. There was some adjustment over the duration of caregiving so the prevalence rate declined, but the distress prevalence rose again at the transition out of caregiving. Women and men caregivers heavily involved in caregiving showed quite different profiles suggesting differences in response to caregiving between the genders. (Hirst 2005)

In a later study that included younger family caregivers, there appears to be a trend towards smaller gender differences in caregiving, which has been tentatively interpreted as reflecting social change in gender roles. Husbands and wives are reporting more similar caregiving experiences, although there is still a difference between sons and daughters. Sons are less likely to take on the role compared to daughters, and husbands are less likely to take on caregiving compared to wives. However once sons and husbands do take on the caregiver role, they experience the task in a similar way to wives and daughters. (Pinquart and Sorensen 2006)

Financial costs

Various researchers report that in a family caregiving situation, women are more likely to be the caregivers than men and more likely to give up work, or reduce the hours of work. The burden of caregiving therefore falls more heavily on women (Lungley et al. 1995; Carpinter et al. 2000; Carter 1993; Horsburgh 2002; Winder and Bray 2005)

Caregiving is likely to disadvantage a woman's long-term economic position due to the interruption in earnings. Davy found that women are five times as likely to retire from paid work when they are responsible for caregiving for a dependent spouse. Women already have disrupted work histories due to child rearing responsibilities in their early working life and then have an extra burden of eldercare in their later working life. This makes them less able to save adequately for retirement which – because of their life expectancy – may well be of longer duration than that of men. (Davey 2004; Collings and Seminuik 2000)

Mirfin-Veitch and colleagues observed that in families with a child with intellectual disabilities, mothers were usually the key family member to provide care and fathers frequently withdrew from caregiving and increased hours of work. (Mirfin-Veitch et al. 2003)

Summary: women caregivers

There is strong international evidence that women are more involved in caregiving than men. This includes the proportion of women caregiving, the proportion who are primary caregivers, and the number of hours women spend on their caregiving tasks. Women bear greater financial costs of caregiving as it often further interrupts their working life and reduces their opportunity to save for retirement, which in many cases is longer than that of men. New Zealand research is mostly anecdotal but is consistent with the view that women disproportionately carry the personal and financial costs of caregiving.

There is some evidence to suggest that women react to caregiving with a greater tendency to become depressed, distressed and to feel burdened by caregiving. This has been attributed to women experiencing more caregiving stressors, such as higher social expectations and lower social support for women than men. Gender differences in caregiving may be slightly decreasing. New evidence shows that both men and women are experiencing similar experiences of caregiving tasks.

7.4 Young caregivers

The situation where children and young people are providing care for a family member has recently gained increased recognition in New Zealand and other countries.

Much of the initial research and literature on this topic has come from the Young Caregivers Research Group based at the Department of Social Sciences at Loughborgh University, and more than 120 'young caregiver' projects now exist in the United Kingdom[5].

Research and services for young caregivers are also developing in the USA and Australia. Awareness is beginning to grow in New Zealand with the formation in 2005 of Young Caregivers New Zealand, a support and lobby group within the Caregivers New Zealand organisation.

Definition and prevalence

There is no agreed definition of young caregivers. The Young Caregivers New Zealand brochure says:

> *We are children and young people who support someone who has a chronic illness, or is disabled, coping with the effects of injury, or experiencing a mental illness . . . The care we provide can be physical, emotional, and social . . . We often help with tasks such as cooking and shopping, caring for other siblings, and household and personal care tasks such as bathing, dressing, assisting in the bathroom etc. . . Our responsibilities may be greater than those of others our age. Sometimes we feel isolated, restricted in our choices, and unsupported in our caring role. . . This can affect our physical and mental wellbeing, our social and our learning opportunities, and our development into adulthood. (Young Caregivers New Zealand undated)*

A number of UK projects have adopted definitions reflecting the restrictions the caregiving role imposes on the young person's life:

> *A young carer is a child or young person under the age of 18 whose life is in some way restricted because of the need to take responsibility for a person who is ill, has a disability, is elderly, is experiencing mental distress or is affected by substance misuse[6].*

Determining the numbers of young caregivers is difficult, both because of previous lack of recognition of young caregivers as a separate group and the current lack of agreed definition.

In the UK, estimates of prevalence have varied from 10,000 to 212,000. (Newman 2002) A general population sample of 12,000 households across Great Britain in 1996 suggested a figure of 0.2 per cent of the population. The 1999 Scottish Household Survey results indicated just over 5,000 children under the age of 16 (3 per cent of all caregivers) were providing care to people within their own home. (Banks, Gallagher et al. 2002) A USA estimate suggested 3.2 per cent of households with a child aged 8-18 years included a child caregiver. (Hunt et al. 2005)

The Australian Bureau of Statistics Survey of Disability, Ageing and Caregivers conducted in 2003, found that 2.56 million Australians (13 per cent of the population)

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[5] http://www.lboro.ac.uk/departments/ss/centres/YCRG/

[6] http://www.youngcarer.com

were providing informal care. The figures are broken down by age group, gender, and by primary or other caregiver. Primary caregivers only included persons aged 15 and over for whom a personal interview was conducted, hence the estimates of 0.1 per cent of under those under 18 being primary caregivers, and 3.5 of those under 18 being other caregivers are likely to be underestimates. (Access Economics 2005)

There are no robust statistics on the number of young caregivers in New Zealand. Caregivers New Zealand cites 2001 census data which found that 9 per cent between 15-18 years self-identify as caregiving for someone who is ill or disabled, as do 10 per cent between 19-24 years. Data was collected using a question asking whether, in the past four weeks, and without pay, the person had looked after a member of their household who was ill or had a disability, and/or helped someone who was ill or had a disability who did not live in their household. The question was not asked of those under 15 years, so the number of caregivers under 15 years is completely unknown[7].

The work of young caregivers

In the UK, the Young Caregivers Research Group has undertaken three national surveys in 1995, 1997 and 2003. These did not survey young caregivers directly, but were based on data from young caregiver projects providing services for young caregivers. In the most recent survey, 232 projects were contacted and 87 replied - a response rate of only 38 per cent, so the findings must be viewed cautiously. The projects which responded were supporting over 6,000 young caregivers. Girls made up 56 per cent of the sample and boys 44 per cent, with an average age of 12. The majority (59 per cent) of those being cared for were mothers, followed by siblings (33 per cent), fathers (16 per cent), grandparents (4 per cent) and others (3 per cent)[8]. Half of those needing care had a physical health need, 29 per cent had mental health problems, 17 per cent had learning difficulties, and 3 per cent had a sensory impairment. Young caregivers did domestic work, provided 'general care', gave emotional support, undertook intimate care and were responsible for childcare. Half the young caregivers spent 10 hours or less a week caregiving, one third spent 11 to 20 hours, and 16 per cent over 20 hours. Twenty-one percent had been caregiving for more than five years. (Dearden and Becker 2004)

In the USA, the National Alliance for Caregiving undertook two national studies of child caregivers. A random sample of 2,000 households were surveyed and from data collected, the authors found that 3.2 per cent of households with a child aged between 8-18 years included a child caregiver, although they believed this to be a conservative figure. Approximately half of these child caregivers were male and half female. A third was aged under 11, a third between 12 and 15, and a third between 16 and 18. Caregivers tended to live in households with lower incomes than non-caregivers, and were less likely than non-caregivers to be in two-parent households. The most common care recipients were parents or grandparents followed by siblings, other relatives and lastly non-relatives. At least three-quarters of the child caregivers reported someone also helped ie less than a quarter were the primary caregiver.

A second study was undertaken to learn more about child caregivers' roles and the impact of their responsibilities. Over half helped their care recipient with at least one activity of daily living such as bathing, dressing, getting in and out of beds and chairs, toileting and

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[7] http://www.caregivers.net.NewZealand/modules

[8] Note: figures add to more than 100 per cent because 10 per cent of the young caregivers cared for more than one person.

feeding. Nearly all helped with tasks such as shopping, household tasks and meal preparation. Methodological and ethical requirements affected the design of the study to such an extent that the authors noted that the study could only be considered representative of child caregiving households that were willing to discuss their situation, not of all households containing a child caregiver. (Hunt et al. 2005)

A research project undertaken by Caregivers Australia found girls are only slightly more likely to become young caregivers than boys, although two-thirds of those in a primary caregiver role were girls. Over half of young primary caregivers were caregiving for a parent (who is more likely to be a mother) and the family is also likely to be a sole-parent household. The person for whom care is provided most commonly has a physical disability or illness, and approximately one quarter of young caregivers provide care for someone with a mental illness. Most young caregivers provide emotional support as well as performing the same caregiving tasks as older primary caregivers, including assisting with mobility, medication, intimate care and housework. (Noble-Carr 2002)

A small research project was undertaken by a group of trainee interns in Dunedin in 2001 to try to determine the number of young people in that city who were caregiving for a relative who was ill or disabled. The information the project was able to gather about prevalence was limited, however the data suggested a slight preponderance of girls among young caregivers. Forty-five percent of young caregivers were estimated to provide a high level of care (involving daily responsibility), 38 per cent medium level (assisting when needed on an ad hoc basis) and 17 per cent low level (primary care provided by others and child helps out occasionally). Types of care being provided included domestic chores, companionship, physical assistance, supervision, communication, medication and nursing care and personal cares. (Ferguson et al. 2001)

A number of studies give greater detail about the caregiving role of young caregivers (Aldridge and Becker 1993; Frank 1995; Loose 2004) Aldridge and Becker note:

> *Most of the young caregivers started caring at a very young age, their responsibilities increasing as they got older. However, it is important to emphasise that the level and intensity of caring tasks is very much determined by the nature and severity of the care receiver's illness or disability. . . . the level of task performance was also determined by the availability of outside help . . .The level of tasks performed by the young caregivers ranged from basic domestic chores (washing up, making drinks) to personal intimate tasks including washing, toileting and dressing the care receiver. (Aldridge and Becker 1993 page 18)*

Young people's pathways into caregiving

An UK study interviewed 18 young caregivers, two former young caregivers and six parents to discover how children become caregivers. The study found that the situation evolved gradually and was accepted as part of lifel:

> *In most families, the extra responsibilities associated with having a member of the family who is ill or disabled have developed gradually. As an illness progressed or the disabled sibling grew from baby into child and teenager, the responsibilities became part of 'family life'. The child who is caring did not have or remember any alternative experience of family life. The children and young people had not necessarily chosen to become 'caregivers' but they had been constrained by the circumstances. It was a natural progression which had evolved to maintain the balance of the family. (Frank 1995)*

A significant factor in children becoming caregivers, was there being no one else to do the caregiving at the times it was needed. This may be particularly so in one-parent families, since in two-parent families, an 'able' parent can be the primary caregiver, leaving child/ren to take up support roles only. However, a parent's ability to care may be restricted if they are out at work, or not coping with their partner's illness/disability. The study found in some cases both parents need care. Other family and neighbourly support had often been available at the beginning of an illness or disability, but as the situation continued long-term this diminished, leaving a child in the caregiving role. (Frank 1995) A study by Banks found that in families with more than one child, a particular child may be 'elected' to the caregiving role, possibly on the basis of their gender or age. (Banks 2002)

The economic situation of the family is another important factor. Aldridge and Becker's study of 15 young caregivers found most experienced economic deprivation and this impacted on the choices both they and the care recipient had available to them:

> *. . . as the children could not contribute to the family income, then neither could they refuse to undertake a role which lack of money had forced on them. We found no evidence of young caregivers who had chosen to undertake the caring role or who were given any effective alternatives . . . Many of these young caregivers had been coerced – whether emotionally or practically – into caring. . . We can say that they have been 'socialised' into their caring roles .....This is not meant to imply that care receivers are exploiting child labour: they too have little choice in appropriating their children for caring duties. (Aldridge and Becker, 1993)*

Impacts on young caregivers

A wide range of impacts on young caregivers have been identified. There may be effects on young caregivers' own health, with both immediate and long-term impacts. (Frank 1999; Noble-Carr 2002; Cree 2003)

> *Young caregivers are at risk of poor physical health due to many factors including stress, limited sleep and inappropriate or incorrect lifting and carrying. Mental health can also be affected in the short and long term due to impaired psychosocial development, low self-esteem and unresolved feelings of fear, worry, sadness, anger, resentment and guilt. These feelings may contribute to depression and emotional breakdown later in life. (Noble-Carr 2002)*

Interruptions to education are commonly reported. (Aldridge and Becker 1993; Frank 1995; Frank 1999)

A UK study by Dearden and Becker reported 22 per cent of young caregivers were missing school or experiencing educational difficulties. However, an American study by Hunt et al. found little difference between caregiving and non-caregiving children in their experience of problems at school. Nevertheless, 20 per cent of these caregivers reported their caregiving activities had made them miss a school or after-school activity, 15 per cent that it had kept them from doing school work, and 8 per cent that it had made them miss doing homework. (Dearden and Becker 2004; Hunt et al. 2005)

Difficulties with schooling have important consequences for higher education and job opportunities for these young people. Australian data estimated only 4 per cent of young primary caregivers aged between 15 and 25 years were still at school compared with 23 per cent of the general population, and 60 per cent of the same group were unemployed or not in the labour force compared with 38 per cent of the general population. (Noble-Carr 2002)

The demands of the caregiving role may reduce the time and opportunity for young caregivers' own social life and leisure. There are a range of reasons for this, including parents being less able to transport their children to activities. (Noble-Carr 2002; Frank 1995; Aldridge and Becker 1993) In addition:

> *Young caregivers are also less likely to have meaningful friendships due to the demands of caring, their belief that they cannot trust people and talk to them about their caring role, the social stigma and misunderstanding in the community associated with illness and disability. (Noble-Carr 2002 page 8)*

Young caregiving may contribute to the formation of a strong bond between the caregiver and the recipient; however young caregivers may also feel embarrassment, resentment, anger, hatred or guilt, and some recipients may feel they are losing their parental role. Relationships with other family members may be negatively affected. Developing greater independence as an adolescent or young adult and leaving home may be complicated. (Noble-Carr 2002; Frank 1995; Aldridge and Becker 1993)

According to parents' reports of their child's behaviour in an American survey, child caregivers tend to show anxious or depressed behaviour more than non-caregivers, and/or more commonly behave antisocially. In the same survey, the caregivers' reports of self-esteem, sadness, loneliness and fun were similar to those of non-caregivers. However, boy caregivers were more likely to feel sad than boys who were not caregivers, and twice as likely to feel it was of no use to show their feelings. (Hunt et al, 2005)

Young caregivers may be limited in their access to employment or to social security payments. Their reliance on their family for financial support is compounded by the fewer financial resources available due to parental disability or illness. (Noble-Carr 2002)

Most of the impacts noted above are negative. However some commentators note the positive aspects of young caregiving too. These include the possibility of strengthened relationships, gaining a sense of self-worth and feeling appreciated for the help they give, gaining maturity and practical skills and developing knowledge about particular illnesses and disabilities. (Aldridge and Becker 1993; Hunt et al. 2005; Noble-Carr 2002; Thomas 2003; Tatum 1998; Banks 2001)

Perspectives on young caregivers

From the literature reviewed so far for this report, it seems that young caregivers may be at risk physically, emotionally and/or socially. However, some commentators take a different perspective. For example, a disability rights perspective views the issues from disabled parents' point of view. This perspective challenges the notions that disabled people requiring support are dependent and unable to parent. They argue that the real problem is not children taking on caregiving roles, but disabled parents not getting the assistance they need. (Keith and Morris 1995; Olsen 1996; Morris 1997; Prilleltensky 2004)

It is also possible to examine the social construction of young caregivers in relation to 'normal' childhood expectations of the amount and type of household help children give. As these expectations have changed over time and vary in different cultures, social constructivist analysis can reveal some of the pressures of social expectation integral to being part of our society today. (Olsen 1996 and 2000; Newman 2002)

Support for young caregivers

Australian research has identified a number of barriers to young caregivers receiving the support they need. Young caregivers are commonly referred to as being hidden or invisible. Lack of recognition by many caregiver, health or disability services and professionals, means there is little support provided and few services designed for them. They frequently do not have access to information transport, or money. Young caregivers face conflicting demands from work, school and caregiving responsibilities. They may need to rely on adults to navigate complex social service systems, but their parents may be reluctant to seek support or assistance for fear that child protection agencies may become involved, or because they believe their care requirements are a private family matter. Young caregivers may not be aware of respite care and if they are, they may not know how to access it. Social Security legislation in Australia limits entitlement to a caregiver payment to those who are working or studying for less than 20 hours a week which severely limits the ability of young caregivers of school age to be granted this payment or receive income support. (Noble-Carr 2002)

Recognising the existence of young caregivers is the first step to identifying their particular needs. Young caregivers and service providers have identified the following areas of need:

- greater community and professional recognition of the role of young caregivers, leading to inclusion in information and decision-making, and awareness of their needs and available supports (Noble-Carr 2002; Liddiard 1997)[9]
- greater understanding about illness and disability in general to reduce stigma for young caregivers and their families (Noble-Carr 2002)
- formal professional support for the person needing care, including: practical help and respite care, tailored and flexible services that consider the whole family (Aldridge and Becker 1993; Noble-Carr 2002; Frank 1995; Liddiard 1997)
- age appropriate, culturally appropriate, and internet accessible information on the recipient’s condition and needs, practical aspects of caregiving and benefits and services available to both the young caregiver and the care recipient (Aldridge and Becker 1993; Noble-Carr 2002; Frank 1995)
- professional or peer support from someone who understands the role of a young caregiver (Aldridge and Becker 1993; Noble-Carr 2002; Frank 1995; Liddiard 1997)
- flexible support options within the education system, support for transition to work and flexible work environments (Noble-Carr 2002)
- transport assistance to enable young caregivers in caregiving responsibilities as well accessing services, education, training and employment and social activities (Noble-Carr 2002)
- financial support for young caregivers (Aldridge and Becker 1993; Liddiard 1997)
- opportunity for young caregivers to be ‘just children and young people’. (Frank 1995)

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[9] Michael Gaffney of the Otago University Children’s Issues Centre has recently carried out a study to develop a recording tool for agencies to identify young caregivers (Gaffney 2006).

Aldridge and Becker argued the way forward for young caregivers is to:

> …acknowledge value and respect the reciprocal and interdependent nature of caring within their families and to support and nurture these relationships through a range of policies, services and procedures. The emphasis needs to be on the 'whole family' approach which locates caring by children in a wider social and economic context. Practical and emotional support for all family members, including ill or disabled parents, children and others is critical to the healthy living and development of individuals and of the family as a whole. (Aldridge and Becker 1999: 317)

Summary: young caregivers

Young caregivers are a sub-set of caregivers whose needs are only beginning to be recognised in New Zealand. Young caregivers may be offering substantial care as the sole caregiver, or lesser levels in a supportive role to the primary caregiver. The potential impacts on the lives of these young people can be immediate and longer term. Each will have unique needs depending on their family situation, but the need for a range of supports is clear.

7.5 Caregivers for people with mental illness

Some distinct issues arise for caregivers of people with a mental illness. Collings noted special features of the relationships between formal (mental health workers) and informal caregivers of people with mental illness.

- *triangulation*: Both caregivers care for the patient, but the informal caregiver also has his/her own need for care, support and education. All three parties will act as advocates for the patient's interests at different times but sometimes the interests of one may be in conflict with one or two of the others.
- *ongoing change:* The psychological and adaptive states of the parties are not fixed, in part due to the nature of the patient's illness.
- *role conflict:* The imbalance of authority and power between the parties contributes to the complexity. A parental informal caregiver and formal caregiver may conflict over the appropriate degree of autonomy and self-sufficiency for the patient.
- *negative perceptions:* Mental health professionals may make incorrect assumptions about informal caregivers' needs. Formal caregivers may interpret the familial caregivers' low rate of uptake of education or family support as resistance, unhealthy denial of the problems, lack of interest and motivation, whereas from the family's perspective they may be taking the course of action which best helps them cope psychologically in the face of severe stress.
- *unshared knowledge*: The formal caregiver has information about the patient which may not be shared with the informal caregiver due to the Privacy Act, whereas the informal caregiver may have an intimate and in-depth knowledge of the patient which they feel is not seen as significant by professionals.
- *token collaboration:* The current imperative to include caregivers into service and policy development has increased the complexity of relationships between informal caregivers and the professional caregivers. At an individual level there maybe token involvement and sometimes more genuine collaboration. (Collings 2006; Collings and Seminuik 1998)

Summary: caregivers for people with mental illness

Caregivers for people with mental illness have a complex relationship with health professionals. Their relationship with the care recipient and their possible contribution to the problems faced by the care recipient are assessed and monitored. Judgements about the role and interests of caregivers and health professionals in the care recipient's life can at times conflict.

8 The relationship between caregiver and recipient

8.1 The centrality of relationship

Caregiving brings about many life-changing impacts on the caregiver, including considerable 'cost' or negative impact. Despite this, it is unthinkable for many caregivers to contemplate not taking on the role because of their relationship with that person.

Caregiving nearly always arises out of a long-standing familial relationship. Nevertheless, there is a distinction between providing assistance involving caregiver tasks, that is, *taking on extra family responsibilities*, and being a primary caregiver, meaning *feeling responsible for that persons day-to-day well-being*. In this comment, Schofield notes that relationship commitments are overlaid with family and community expectations, giving a complex blend of reasons for caregiving:

> *We know that caregivers are emotionally, morally and culturally bound into their role. People enter into caregiving for a mix of reasons, including obligation and reciprocity. When beliefs have been built up over many years, they are deeply ingrained and persist during adversity. In these cases, family members continue to give care, whether they receive outside assistance or not. (Schofield 1999: 21)*

For many spouses, caregiving is a continuation of their previous relationship and they believe their partner would have done the same if the positions had been reversed. Caregiving arises out of joint history and mutuality. Opie found caregiving had a seamless quality about it and was embedded within the joint history of the couple'. (Opie 1992)

Caregivers believe they are in the best position to offer the care as they have the in-depth knowledge of their partner. Caregivers of elderly people with Alzheimers in Opie's Wellington sample sought to offer love, protection, continuity, dignity, stimulation, concern and a stable environment. Some spouses continued to include the recipient socially and to maintain physical affection. (Opie 1990; Campbell 1994; Collings and Seminuik 1998) Another motivator to adopt a caregiving role is dislike of institutional care as the alternative. Here too, the underlying dynamic is commitment to the recipient and a desire to monitor and safeguard their wellbeing (Opie, 1990; Collings and Seminuik 1998; Patterson 1997).

As caregiving demands become greater and the consideration of other options more pressing, choices are often complicated by family and community expectations which may be expressed by others or internalised into a sense of duty. This has been a particular focus of the feminist writers, who have been concerned to free women from undue pressure to be self-sacrificing. For example, Collings and Seminuik observed that notions of care and responsibility are central to a woman's morality. Women may feel little choice except to provide the care, both out of sense of duty and also because affiliation is central to relatedness to others. Some of Opie's caregivers expressed a sense of obligation and duty and some resentment and anger to the extent that they would have relinquished the role if they felt they had the choice. (Collings and Seminuik 1998; Opie 1992)

Opie, writing about older people with progressive dementia suggested both the historical and current relationship between the caregiver and recipient is at the heart of caregiving. She identified four elements to the commitment:

- the caregiver's belief their continued care will positively assist the recipient more than care by others could, because of their long and intimate knowledge of that person
- an acceptance that their relative's illness may be in a state of flux
- an acknowledgement of the stressful nature of caregiving and the ongoing grief and loss of the earlier relationship
- continuing to see the relationship as meaningful to help transcend moments of stressful and distressing interpersonal breakdown and the loss of other activities and interests for the caregiver.

According to Opie, the motivation and attitude of caregivers results from a complex and dynamic interplay between commitment, dissociation, obligation and repudiation. Within this matrix, stress is an integral part of caregiving, and caregivers move between these emotional positions as they seek ways to ameliorate stress. The past and present quality of relationship, and the extent to which caregiving challenges or undermines caregivers' perceptions of their identity, are key factors in ameliorating the stress generated. This dynamic positioning is precarious and lacks resilience.

Those caregiving out of a sense of obligation are less likely to define caregiving as central to their lives and are more likely to struggle with other commitments or competing demands, such as children, work, other family members, interests and hobbies. This is different from a dissociated caregiver, who gives other aspects of life priority. Dissociation may reflect a lower level of concern and a considerably reduced level of involvement. It may also reflect a higher degree of independence of the recipient and less disability, or a desire to sustain the recipient's independence for as long as possible. Where dissociation merges into repudiation, it may come close to neglect, lack of interest, and lack of knowledge or concern about a deteriorating situation.

Those caregiving from a position of repudiation experience very high stress and distress. They experience caregiving as undermining their dignity, self-esteem and identity. Their future may appear very bleak if there is an obligation to care and a sense of no real alternative. If there is no way to draw on the previous positive relationship with the recipient, and they are exhausted and angry over the enmeshment in caregiving, there is little resilience or reserves to draw on to cope with daily crises. Opie says:

> *A simple axiom seems to apply – the greater the guilt, the greater the impossibility of withdrawing from the caring relationship. The dynamic of the caring relationship is located in anger, depression and despair, leaving caregivers feeling increasingly alienated from themselves and from the wider social world. (Opie 1992: 117)*

Lungley and colleagues noted that the caregivers of adults with disability were predominantly parents or partners followed by children. The high personal costs mean that it is often only family that has the level of commitment required. Family members may also feel an obligation to provide this care. (Lungley et al. 1995)

8.2 The evolution of relationships

The relationship between caregiver and recipient is a dynamic and evolving entity. The study by Hirst suggests caregivers experience more distress than non-caregivers both during caregiving and, for those who were caregiving intensively, for as many as five years afterwards.

Hale gives us insight into the caregiver adjustment process when the recipient is an elderly person in a process of deterioration through analysis of discussions with primary caregiver wives in a support group for partners of patients of a geriatric service at Dunedin Hospital. As a group, the caregivers identified five stages of caregiving between a husband as care recipient and wife as caregiver:

- *onset:* At this stage full social networks are in place, the wife talks about '*we*' and the husband remains in charge of information regarding his illness, while the wife supports in practical ways.
- *increasing deterioration:* The development of an additional vocabulary around medical talk is evident. Anxiety around assessments can feature as well as labelling of the problems. Wives continue to use the '*we*' pronoun and the partners continue to attend activities and social occasions together.
- *transition:* This phase is marked by an increasing shift of decision-making to the wife as the husband continues to deteriorate, so that there is now a mixture of '*I*' and '*we*'. Discussion focuses on the future and managing ill health and disability. Health professionals more routinely inform the wife, rather than the husband alone. The professionals start to look to the wife to take responsibility for managing such aspects of care as medication. Within the group, this phase is often also marked by changing arrangements in the home as the couple may move to separate bedrooms or use different bathrooms, and a stock take occurs of who is able to offer support including personal support. Although the wife is still operating as a partner and her life is bound up with that of her husband, previously shared activities increasingly become individual.
- *relief care:* By now the wives are taking on more responsibility and use '*I*' more than '*we*'. There is more focus on the individual needing to find ways of looking after her own needs. Language includes respite care, home help, and support, and there is grieving for the loss of the marriage as it was. The caregiver may experience the severest isolation at this stage as informal networks have withdrawn, while the new networks revolve around attending to her husband and his needs.
- *Institutionalisation:* The final stage for some is the husband becoming a resident in an institutional setting. Pronouns are all '*I*' and '*he*'. The husband is now cared for by professionals who are the gatekeepers of information and providers of information to the wife, which is a complete reversal of the previous situation where the wife as primary caregiver gave information to the professionals. The wife remains a caregiver as visiting spouse, but is no longer co-resident. At home alone she has to rebuild (or build new) networks and friendships. (Hale 1999)

This process is echoed in other accounts of caregiving of elderly dementia sufferers. Opie’s caregivers described the difficulty of relating to a person who looks the same but may have lost their person-hood, may have had a disease-related change in personality or be given to outbursts of anger or aggression. This is often shocking and destabilising to the relationship. Ten of the caregivers spoke of times when they had raged, yelled or just restrained themselves from hitting. Uncertainty and unpredictability tended to characterise the relationship:

> *Most caregivers were living in a situation demanding enormous reserves of strength and fortitude, yet one where it was almost impossible for them to replenish their reserves. (Opie 1992:106)*

In situations where the informal caregiver is not the partner of the recipient, the context of the prior and ongoing relationship is still important. Collings and Seminuik note that each caregiver/recipient relationship is a dynamic and changing entity as the participants move through life phases and as the recipient's illness takes its course. The relationship is transactional with an ongoing process of adaptation to the caregiver situation by both participants. (Collings and Seminuik 1998)

A number of authors have drawn attention to how a relationship involves a reciprocal flow, rather than the one direction of exchange implicit in the labels *'giver of care'* and *'recipient of care'*. Georgeson argues that in the informal caregiving relationship, there is interdependence between the participants with caregiver and recipient neither totally independent nor dependent. The recipient may be reliant on others for certain needs to be met, but this does not mean they contribute nothing in terms of family life, education, or work both voluntary and paid. From this perspective of equal participation, any stress in the relationship is likely to affect both parties. If the caregiver is stressed, socially isolated or has limited life opportunities, then the recipient is likely to be experiencing this as well. The cost of this stress to the caregiving system may be borne by one or other party but each will be affected, as will the larger family/whānau system. If the consequence of inadequate support for caregivers is an increased likelihood of abuse or neglect, then that is a cost to the recipient and to the whole family system. (Georgeson 1994)

Munford draws attention to the care recipient who may at times feel oppressed by the caregiving situation or find it unsatisfactory yet find this difficult to articulate when the focus is on the burden or negative aspects of caregiving. Georgeson notes that if the person being cared for is aware of stress and strain on caregiver then they may 'choose' to go into institutional care to relieve the caregiver's stress. (Munford 1989; 1990; 1991; 1992; Georgeson 1994)

Some of Munford's writing also draws attention to the impact of socio-political pressures on the caregiving relationship. She says that the trend towards deinstitutionalisation over the last 20 years must not replace oppression of one group with oppression of another. Moving intellectually disabled people back into the community must not be at the expense of oppressing women who feel duty bound to pick up the responsibility of caregiving. She makes a plea for a needs assessment of all those involved in the caregiving situation - not just the recipient. Although the context is now historical, this example illustrates the way in which caregiving is dynamic relationship with a wider context and a reminder that analyses of costs and benefits need to be undertaken within a broad societal context. (Munford 1989; 1990; 1991; 1992)

Caregiving also needs to be seen in the context of the wider family situation. Some researchers have found that high demand caregiving situations often become relatively isolated from wider family support. Research hui with whānau of Māori with disabilities found a common theme was that extended family initially express sympathy and during the initial crisis period they are supportive and try to help. However as the long-term circumstances become apparent, often the whānau dynamics change as friends, spouses and whānau 'fade away' to their ordinary lives, leaving those in the caregiving role increasingly isolated and with a life which is dominated by caregiving. Alternatively, caregivers can be seen as boring and obsessed with their situation. As they grieve for the transformation of their loved one, they may also become less functional. (Nikora et al. 2004)

Parental caregivers of children with high and complex needs reported extended family are often the main source of support from others, including emotional support, but this was not so for all families and should not be assumed to be present. The reasons extended family are not involved may include: lack of acceptance of child, fear of the disability and not wanting to admit their fear, inability to provide support due to lack of skills or understanding, and lessened ability to provide support due to ageing. (Carpinter et al. 2000)

8.3 How caregiving affects relationships

The power imbalance implicit in the caregiver-recipient interaction can undermine and distort the relationship between the participants. Information held by the caregiver can be used to empower or disempower the care recipient. (Nikora et al. 2004) In addition, internalised societal attitudes to disability can be disempowering for the person with a disability, creating a barrier to equally contributing to the relationship, or asserting their rights. (Munford 1990)

A review of the elder abuse literature suggests there are five main factors that lead to elder maltreatment – intra-individual dynamics, transgenerational violence, social isolation, dependency, and external stress. Osborn compared caregivers who admitted physically abusing their elders, caregivers who neglected their elderly, and those who neither abused nor neglected. Although the results should be treated with caution as it relied on self-report by caregivers, it was found neglect was related to external stress, social isolation and elder dependency. Physical abuse is more related to intra-individual psychopathology of caregivers and possibly also of the elders. The research suggested strong attachment is a mitigating factor against the stress of caregiving. (Osborn 1996)

Caregiving for a spouse was found to have a higher level of risk of depressive symptomsassociated with it than caregiving for a parent, even though it could be assumed that similar tasks are involved. Possible explanations include grief and loss of relational reciprocity with a partner as well as other dimensions around intimacy, conflict, obligation, and shared life stage. (Cannuscio et al. 2004)

The financial implications of caregiving can cause relationship difficulties. Caregiving choices may be complicated by benefit entitlements or housing assistance. If the disabled person has substantial savings, then asking that person to commit funds for medical or personal care is often a sensitive (Georgeson 1994; Nikora et al. 2004)

Wrubel and others were able to identify three patterns of relating as ways of coping with caregiving among caregivers of HIV recipients – engagement, distance and conflict:

- *Engagement:* The engaged caregiver is strongly involved in caregiving as nurturing. Caregiving takes priority over work and any negative emotions are put aside to enable the caregiver to be more available to the recipient.
- *Distance:* Distanced caregivers emphasise the recipient taking care of themselves, use distance to support their partners' independence, and feel effective when they self-manage their emotions. Their caregiving is based on self-reliance.
- *Conflict:* The conflicted caregiver struggles with the competing demands of caregiving and taking care of themselves. Their involvement is based on obligation. They encourage the recipient to take care of themselves and deliver care on an as-needed basis, rather than proactively anticipating care needs.

Over time, the distanced caregivers fared best on depression or anxiety, showing no significant increases in these states. The other two groups had significant increases in depression, anxiety and anger. The engaged group fared best with regard to relationship satisfaction which increased significantly whereas other two groups did not change. The report recommended interventions to support caregivers take in to account the caregiving style that mediates the stress. Engaged caregivers may benefit from acknowledgement of their contributions and short breaks. Conflicted caregivers may benefit most from respite care. Distanced caregivers may fear their participation will strip their partners of autonomy. (Wrubel et al. 2001)

The relationship with the recipient has been found in some studies to alleviate the strain of caregiving. The quality of the previous relationship moderates the stress inherent in the task. (Lopez 2005)

8.4 In summary

Caregiving is strongly grounded in the relationship between caregiver and recipient. This relationship is dynamic and evolving. The relationship commitment means it is unthinkable for many would-be caregivers to do other than care for their family member, regardless of the personal cost involved. For caregivers of the elderly, caregiving commonly arises out of:

- continuation of relationship
- concern to make the best choice for the recipient, to safeguard their wellbeing
- a sense of duty reflecting cultural/ community/ family expectations which the caregiver has internalised.

Caregivers' motivations can be seen as dynamic, fluctuating between commitment, dissociation, obligation and repudiation, as caregivers respond to the inherent stress in the situation.

Positive previous relationship between the caregiver and recipient alleviate the strains of caregiving. Caregiver satisfaction is closely aligned to dimensions of relationship.

The relationship evolves as caregiving proceeds. For caregivers of elderly recipients with deteriorating health, this is complicated by the loss and grieving for previous relationship.

Caregivers of other recipients of care have relationships based on exchange and transactions, where both contribute. The caregiving relationship and the dynamics it generates can cause complications in the larger family context. Other relationship complexities caused by caregiving include:

- societal attitudes to disability which may be internalised by the caregiver and then act as a barrier to the recipient of care participating equally in the relationship
- power imbalance created by caregiving
- caregiver abuse and neglect arising out of caregiver stress, social isolation and (sometimes) psychopathology of the caregiver
- financial complexities
- increased risk of distress and depression in spousal care
- variation of coping styles with consequent implications for intervention.

9 Pathways into caregiving

There are few New Zealand studies which explore why people become caregivers. Abbott and Koopman-Boyden's study gives some indication in that over half of caregivers of older people said that if they did not provide the care the recipient would be cared for in a hospital or rest home. (Abbott and Koopman-Boyden1994)

Two international studies give more detailed information. A large USA survey of over 1000 family caregivers found the reasons for becoming a caregiver were:

- being the closest living relative (58 per cent)
- having the most time out of the potential caregivers (43 per cent)
- the recipient not wanting a stranger in the house (37 per cent)
- professional or formal care being thought unnecessary (44 per cent)
- the recipient being unable to afford care (40 per cent), and
- early hospital discharge (12 per cent). (Gould 2004)

Spanish research asked caregivers why they had taken on the caregiving role as part of a study exploring caregiver satisfaction. Respondents indicated the choice was made:

- on their own initiative (49 per cent)
- out of duty (30 per cent)
- because they were the only person who could do it (8 per cent)
- because they were asked by the relative (5 per cent)
- because nobody wanted to do it (4 per cent), and
- by family imposition (4 per cent).

Within this sample of 111 people, 25 per cent were looking after their spouse, and two-thirds were looking after a parent. (Lopez 2005)

Primary caregiving takes place within a more extensive network of family and social exchange but it is the strength of emotional commitment to the recipient that determines caregiver status. Comparisons across large population surveys indicate that studies where people are asked to self-identify as a caregiver find lower prevalence rates than studies that objectively analyse tasks undertaken. Conversely, people can readily identify with '*feeling responsible for*' as the defining feature of primary caregiver status. (Howe et al. 1997:10)

Hirst's analysis of data from the British Household Panel Survey found comparatively high distress prevalence rates for women with heavy caregiving responsibilities prior to taking on the caregiving role suggesting there is not a discrete transition to caregiving. (Hirst 2005)

The Victorian Caregivers Project also had a longitudinal aspect which allowed some exploration of when caregiving ended. One year after the main data collection about half of those who were not primary caregivers had ceased being caregivers, whereas primary caregivers particularly parental caregivers were unlikely to have ceased. Where caregiving had stopped, in four out of 10 cases this was due to the death of the recipient, in a third of cases it was due to improvement in the state of recipient’s health and in another third it was due to a change of care arrangements. Caregivers choosing to give up the role were a rare event. (Howe et al.1997)

9.1 Parental caregivers of children with high support needs

Two studies underpinned by discussions with family caregivers of young people with high and complex needs sheds some light on why families may stop providing care for their family member. (Bray et al. 2005; Carpinter et al. 2000)

In one study almost half of the caregivers had considered placing the recipient in full-time out-of-home placement, and in the other study, the families had either obtained or sought out-of-home placement. The same reasons feature across both studies, including:

- increased age and physical care needs of recipient
- increased behavioural problems of child and difficulty managing these
- increased age of the caregiver
- injury or illness of the caregiver
- insufficient availability of respite care and/or reduced support for primary caregiver
- decreased health and well-being of the caregiver
- desire to enhance the life of the disabled person through contact with peers, not just parents
- desire to attend more fully to the needs of other children in the family
- other family members, such as established or new partners, needing support or being unable or unwilling to accommodate the needs of the child
- separation from or death of the spouse of the caregiver
- the need for more expert care for the recipient.

Carpinter and colleagues held focus groups throughout New Zealand with primary caregivers who had made the transition to out-of-home care. They found there was usually no one trigger point, but rather a general pattern that emerged over time as the child's needs increased and the parents' capacity to meet their needs decreased, until the situation becoming unsustainable. Some parents said if they had high quality and timely support they would probably be able to cope better and for longer, but none envisaged doing so indefinitely. All wanted to maintain the relationship and to live in reasonably close proximity. This decision-making process was a difficult one for parents. Permanent out-of-family care is usually regarded as the last resort, and commonly follows many years of struggle. Anxiety about the standard of care is common, but parents are reluctant to complain about providers in case resentment is taken out on the resident child. Some expressed resignation that if they are unable to provide the care themselves, they have to accept what is on offer, provided the child's safety is not at risk.

There were usually multiple trigger points for placing a child in care, including:

- the caregiver's own health
- economic stress reducing ability to care for the child
- time-limited availability of an acceptable choice
- the age of the child
- a 'last straw' trigger event, such as inappropriate sexual behaviour in front of younger siblings, or the death of a family member. (Carpinter et al. 2000)

An Australian review of policies to help support families with a disabled child to care for the child at home identified three key factors which influenced a family in their decision about whether they could continue to care for their child with a disability at home or seek alternative care. These were:

- a lack of congruence between the needs of the disabled child with and other family members
- a lack of integration of their disabled child into their everyday family life and the community more generally
- concerns about the effect of the disabled child on their siblings both now and in the future.

The researchers found that by the time the decision to seek out-of-home care is reached, it is difficult to provide effective intervention to change that decision as typically decision-making has occurred over a long time. (Llewellyn et al 1996 Nucleus Group 2002)

New Zealand researchers Mirfin-Veitch and colleagues talked with families whose family member had been relocated to the community as Templeton psychopaedic hospital closed down. In asking them to reflect on the decision-making processes that had led to the child moving to Templeton, they found themes in common between the families. A typical story was that it was never a spur of the moment decision, but was a process influenced by a range of factors including:

- a commitment to maintaining the family unit, which meant the decision to relocate their child to Templeton was actively resisted for a long time
- difficulty finding alternative community support for their child and failure of other options to meet the needs of the child and/or family as a whole
- increasingly intense challenges as children became older and harder to care for, parents became older, concerns grew about the detrimental impacts on siblings, until there was a sense of delaying the inevitable
- validation by health professionals that parental feelings of stress and inability to cope were normal and acceptable
- catalysing events changing the balance of family life, such as the birth of other children or ill-health in another child or family member.

A mothers' role was usually pivotal to the care needed to keep a disabled child in the family home. Without exception, they were committed to providing whatever was needed physically and emotionally by the child and did their utmost to keep the child within the home as long as possible. As the mothers were the major care providers, the mental health of the mother often determined the timing of the transition to permanent care and mothers usually made the final decision to seek out-of-home placement. The change itself was described as a very painful and difficult decision which left a legacy of enduring sadness and sense of failure.

Consideration of siblings was often a factor with parents expressing guilt that they were unable to spend more time with other children and have a more 'normal' home life. Yet in interviewing families it became apparent that siblings did not view the placement of their disabled brother or sister into permanent care as a positive thing. Although supportive and accepting of their parents' decision, they struggled to accept that their sibling had such a different life to themselves.

All parents and families interviewed were concerned and unsettled by the changes brought about by deinstitutionalisation. Interviews after resettlement indicated 86 per cent were positive about the change and 49 per cent had reversed their original negative attitude towards resettlement. Conversely, seven per cent felt positive about the change but then after the event were dissatisfied. Just seven per cent were negative before and after the resettlement. Families had definite views about what was important to the transition and communication with staff was a prevailing theme. Despite the family member having been institutionalised for many years, family involvement remained high. (Mirfin-Veitch et al. 2000)

9.2 Grandparental caregivers

Grandparents as primary caregivers have particular pathways through which grandchildren come into their care. For Māori, being a grandparental caregiver can be a traditional practice. Children in their care may be either blood relations or assigned to them because of needs or circumstances.

Walker conducted a study on the practice of maatua whāngai a particular form of adoption based on Māori concepts of family, kinship and shared responsibility. An adopted child, often called a tamaiti whāngai, was placed with those most able to provide. In this context the child is seen as not just the child of biological parents but as belonging to the whānau in a communal sense. In this study, a small sample of women who were primary caregivers of tamaiti whāngai felt the traditional practice of Māori which was based on their whakapapa had been used and abused by the state. Very little resourcing was attached to the placement of whāngai children, some of whom were special needs, when these children from state care were placed with whānau. This placed stress on the resources of other family members and affected family relationships. In 1991 the programme was shut down but the whānau continued to work with the children, demonstrating the long-term commitment involved in this informal caregiving. (Walker 2001)

Worrall found grandparents often assumed primary caregiving following neglect or abuse of the children. At this point, these children had high psychological and physical needs. The transition to caregiving often arises out of a family crisis with kin caregivers find themselves dealing with fractious family relationships, their own grief, custody disputes, and the problems of the children's parents in addition to the demands of caregiving itself.

Many survey participants identified multiple reasons for assuming care. Neglect of the child by the biological parents was either the sole reason or one of the reasons in almost half the cases. Grandparents assumed care when the child had been abandoned or there was parental drug or alcohol abuse, mental illness, domestic violence, gang associations, suicide, illness, intellectual disability or imprisonment. Other reasons included parents' inability to cope if it was a teenage pregnancy, they had another baby on the way, or new step-parents did not want the children. In this sample, there was a high frequency of problems amongst the children with as many as 85 per cent reported as having physical illness or disability. Psychological and behavioural problems were also common.

For about a third of the grandparents in the sample, care was assumed initially through an informal agreement with the biological parents. Almost half had a custody order under the Guardianship Act. Some grandparents preferred to leave it as an informal arrangement as they felt seeking legal custody or reporting concerns to a government agency may alienate the parents and endanger the safe haven the grandparents were able to offer. However, a third had faced legal challenges to their custody and guardianship status, and sometimes repeated challenges, with all the stress, financial strain and threat to permanency that involved. (Worrall 2005)

Mirfin-Veitch and colleagues found 'involved' grandparents were predicted by the culture of the family – *'we're just that sort of family'* – and having a positive relationship history with the parents. (Mirfin-Veitch 1997:306) Neither the nature of the disability nor the severity of it were predictive of grandparents as active supporters. (Mirfin-Veitch et al. 1996; 1997)

Two USA studies suggest similar pathways and problems for caregiver grandparents. (Burnette 2000; Janicki et al. 2000)

9.3 Caregivers of sick and disabled family members

Lungley and his colleagues made the point that informal caregiving incurs such personal costs that it is usually only family members who have the high personal commitment required. Caregiving is based on the pre-existing relationship and the events leading to the change in relationship are unforeseen and unwelcome. (Lungley et al. 1995)

Mothers are the most likely caregivers of children with schizophrenia according to Collings and Seminuik, and their commitment to caregiving remains strong despite high provocation. Five mothers who care for their adult children with schizophrenia shared their experiences with Soutar and described the physical strains and emotional stress. One was woken every two or three hours as the schizophrenic family member wanted to tell her something. Three of the mothers noted verbal abuse and insults. One son phoned the family church and falsely accused his mother of having physically and sexually abused him and his sister since the age of five the day after watching a film where that was the theme. One spoke of her realisation her daughter was dangerous and was going to pick up a jug of boiling water and throw it at her. In another case, the son smashed his way into the house by punching through a big plate glass window. (Collings and Seminuik 1998; Soutar 1997)

Discussions with Māori caregivers of people with disability indicated many whānau caregivers become so by default. There is a view that responsibility for the care of the elderly should fall on the eldest daughter, or the eldest grandchild, or to a child who is gay and perceived not to have other caregiving obligations. Whāngai are seen as obligated out of reciprocation, and those on government benefits are seen as more available for caregiving. A common factor is that the identified caregiver is perceived by others as having the time, energy, and being relatively free from commitments. Those who have been caregivers were quick to point out they did it for love. In practice, which person provides care and support depends on willingness, circumstances and resources available to a whānau at any one time. Nikora's informants noted how adaptable caregivers needed to be as circumstances, fortunes, whānau and disabilities change. Skilled whānau caregivers are seen as those able to marshal resources available to them to respond in practical and effective ways to change. Sometimes a disabled member needs to move to the home of caregiver, or else a caregiver spends time away from children and partners to provide care. (Nikora et al. 2004)

Nurses are placed under extra pressure to become informal caregivers for family members which can be stressful for them according to a study by Rochford. One nurse faced family expectations that she would become the caregiver because the family member would be more accepting of her physical care. A second participant described confused boundary issues arising when she was consulted by a health practitioner who saw her as a fellow health professional, rather than the emotionally involved family member she felt herself to be. The third participant was also looked to by the family as the one to relate to health professionals and take a lead role in decisions although she came from a well-functioning family who shared the caregiving load. (Rochford 2004)

9.4 Caregivers of the elderly

In Opie's study, informal caregivers of spouses with dementia unquestionably accepted the role of caregiver. Their description of their obligation was located primarily in a framework of love and reciprocity, with reference to long and significant marital relationships, although this was undermined in some cases by episodes of irritation, resentment and doubt.

Care is sometimes at high personal cost. Opie shares stories that detail the context in which decisions were made and the costs of these decisions. Opie found a common dynamic of caregiving was that the greater the dependency the less the caregiver felt able to move out of the caregiving role. Daughters commonly felt obligated, whereas sons seldom took the primary responsibility. The notion of 'capacity to care' – meaning the person for whom caregiving would cause the least disruption – was also influential. Filial caregivers noted it as a significant change when the elder relinquished separate accommodation and became co-resident, resulting in mutual loss of independence and privacy. Opie questioned how sensible it is for a caregiver to take on the caregiving role if the relationship history with the recipient was poor or there were major commitments in other directions. (Opie 1990; Opie 1992)

Informal caregivers experience the transition of the elderly person into residential care as very stressful, according to research by Milligan. Among a sample of 20 caregivers she found that the caregiver felt under pressure to make major life-changing decisions on top of worrying about the deteriorating health of the person they cared for and being exhausted from caregiving. In some cases a GP had encouraged them to visit a range of rest homes at an earlier stage – a proactive step which was in hindsight appreciated as good advice. All but one of the caregivers continued caregiving after the recipient moved into the residential care. Most spousal caregivers visited on a daily basis and most filial caregivers visited two or three times per week. The frequency of visits did not decline over time but eventually they felt able to take short breaks.

Choices for residential care may be limited by living in an area with few facilities or by the availability of public transport to the facility for caregivers who do not drive. One spousal caregiver was so distressed by the level of care in the only available place that it affected her mental health. Residential care that offers both rest home and hospital facilities causes the least disruption and upset to the lives of recipient and caregiver alike.

Some research participants found the transition to residential care had a detrimental effect on caregivers' physical and mental health. Some experienced physical ailments, guilt, worry and feelings of failure, whereas others spoke of relief. Many had to adjust to living alone after years of co-habiting. (Milligan 2004)

Petrus and Wing-chung researched caregivers of elderly Alzheimer's patients in Hong Kong where filial piety is central to family values and the caregiving responsibility traditionally falls to the eldest son. However, over time families have become smaller and there are fewer family members available to share the caregiving responsibilities making the burden of caregiving more acute. Since the 1970's health policy has emphasised community care for those with chronic illnesses and the costs of care have been passed onto the family, with public funding only when families are unable to provide care. (Petrus and Wing-chung 2005)

9.5 In summary

There is little New Zealand research exploring the reasons why caregivers take up the role.

Research suggests caregiving arises out of existing family and community ties with the primary caregiver status usually reflecting a long-standing emotional commitment. Primary caregivers are commonly helped by others, with spouse or partner caregivers being least likely to receive help. Caregiving most commonly stops when the recipient no longer needs the input due to death, improvement in health, or moving into residential care. Caregivers rarely choose to give up their role.

Parental caregivers of adult recipients with a disability are committed to caregiving as part of an ongoing relationship and often persist despite the difficult behaviours of the recipient and high costs associated with caregiving for them. However, parental caregivers may decide to relinquish the care of a child with high needs due to the child's increasing age and needs, a decrease in their own capacity due to ageing or ill health, the needs of others in the family, and/or the lack of respite care. Decisions to seek permanent residential placement are made over a long time and with great difficulty.

Grandparents caregiving for kin often take on the role due to the breakdown of the parental relationship, for reasons which include abuse of children, neglect, substance abuse in the parents, and abandonment. For Maori, being a grandparental caregiver can be a traditional cultural practice.

Caregivers are sometimes pressured into the role because they are perceived by others in the family as being available or having more time. Daughters more commonly feel responsible for elder care than sons. When an elderly recipient needs to move into residential care, the transition is often difficult for the caregiver and the caregiving role typically changes, rather than stops, at this point.

10 The interface with formal services

As a generalisation, there is little focus on the needs of informal caregivers in New Zealand and few services to support them. What little has been written emphasises the importance of informal caregivers being acknowledged and included when the needs of the recipient are being assessed.

Lungley and his colleagues stressed the need for health professionals to recognise the reciprocal relationship between caregiver and recipient, and the importance of health professionals sharing information with the caregiver. These authors suggested health professionals should promote the eligibility of caregiver for benefits, link caregivers with support organisations, and source respite care. (Lungley et al.1995)

A whānau caregivers training programme in the Waikato region, was evaluated by Ashwell and others. The main objectives of the training were to increase competence and confidence of whānau caregivers, to inform them about available services, to support their wellness and safety, and to increase the caregivers' support networks. Participants were largely positive about the course with suggestions for improvement reflecting caregivers' interest in even more information. (Ashwell et al. 2004)

The UK National Strategy for Caregivers and the Caregivers and Disabled Children Act 2000 are designed to improve outcomes for caregivers. These policy documents advocate incorporating caregivers in assessment and review processes and note that services are unlikely to meet recipients' needs if they fail to take account of caregivers' goals or strategies in caregiving. It argues regarding the caregiver as 'expert' can encourage a more facilitative model.. (Nicholas 2003)

10.1 Caregivers' use of health services

Longitudinal data offered by the British Household Panel Survey was analysed by Hirst to examine the effects of caregiving on caregivers' access to primary care health services. Women caregivers who cared for somebody in the same household for at least 20 hours a week showed reduced contacts with their GP over five years of caregiving, compared to a comparable sample of women not in a caregiving role. By contrast, men caregivers increased their GP contacts during the first three years of caregiving, before levelling off at a rate just slightly higher than that of a matched control group. Caregivers providing care for less than 20 hours care per week, or care to someone in another household had similar rates of GP contact as non-caregivers.

Hirst offered a range of explanations for the caregiving women's reduced use of services. The first set of reasons suggests taking on a caregiving role leads to

- increased support of a caregiver by family or friends
- indirect benefits to the caregiver from social and health services provided to the recipient
- support needs are met by caregiver support groups, or
- the sample is biased by caregivers withdrawing from the role as their own health needs increase. (Hirst 2005)

The second set of reasons provided by Hirst explores barriers to caregivers accessing services. A review of 20 studies identified the following as potential barriers to caregivers accessing services:

- *professional response*: Professionals may prioritise the needs of the recipient at the expense of the caregiver. GPs may see caregivers as a resource rather than as patients in their own right. Formal health professional care is mostly reactive, that is, only responding when asked, rather than proactive and preventative.
- *organisation of services:* Services may have inflexible appointment systems that do not fit well with caregiving and other responsibilities, or have lengthy appointments and waiting times that cut across routine care activities. Preventative health care, such as 'flu vaccinations, is not usually subsidised or provided free to informal caregivers although it is to other vulnerable groups or paid caregivers.
- *language or culturally held beliefs and practices:* Having English as a second language and lack of cultural understanding or sensitivity from service providers are further barriers. For example, some cultures highly value doctors of the same gender as the patient, particularly for women. Recent immigrants and refugee caregivers face wide-ranging access problems such as language, racism, lack of knowledge, uncertain status, limited means, and lack of social support.
- *characteristics of the caregiver or care recipient*: Caregivers who are overwhelmed by caregiving are less likely to seek help for themselves. Some researchers have suggested that an emotional response to caregiving might interfere with caregivers' ability to seek help. Young caregivers may not be assertive enough to ask for help in their own right.
- *lack of information and knowledge:* Studies have found caregivers are not routinely given information (by the primary care team or hospital staff) about the range of services available and how to access them.

Arksey and Hirst identified as the following ways to reduce access barriers to primary health care services for caregivers:

- training and raising awareness about caregivers' issues amongst members of the primary care team
- introducing systems to identify caregivers during new patient registrations or health checks and health consultations with elderly people and people with a mental illness
- keeping self-referral systems simple
- using systems and advertising support networks in languages appropriate to ethnic minorities
- promoting a caregivers' guide to good practice which suggests making contact with the GP before reaching crisis point
- providing information to caregivers. (Arksey and Hirst 2005)

A UK study by Kelly looked at service delivery to intellectually disabled children and their caregivers by canvassing the views of recipients, family caregivers and social workers about service objectives and preferences. The study found that parents:

- found it hard to access information and advice from service providers, often waiting long periods of time for their call to be returned
- were often confused about the roles of different professionals and agencies
- particularly disliked professionals having a negative attitude towards their child or his/her impairments

- were most supported when professionals demonstrated genuine caregiving for the child and family, recognised needs holistically, were adequately informed, referred them to relevant services, consulted with their family, and took the time to develop the rapport with their child
- wanted to be involved in discussing professionals' decisions about their child and, if necessary, to challenge or influence decisions about services
- wanted professionals to collaborate more so that services were better coordinated, transitions between services are smoother, and gaps or overlaps in the system were avoided[10]
- found multidisciplinary teams improved coordination but meeting with a whole team was tiring.

The research highlighted the need to involve intellectually disabled people in discussions and decision-making affecting them. (Kelly 2003)

Australian research by Girgis and colleagues suggests most informal caregivers of cancer patients have a poor knowledge of services and receive most of their information from family and friends rather than health professionals. Rural caregivers have less information than other caregivers. Although palliative care services have been found to benefit caregivers as well as patients, respite services are not well utilised and there is a need to research access and referral barriers. There is poor uptake and knowledge of the income support that is available to caregivers. The study found barriers to informal caregivers receiving full information about their family member included:

- family dynamics that get in the way of optimal communication with health professionals
- a mismatch between the patient's and caregiver's need for information, for example regarding prognosis
- caregivers' reluctance to disclose their needs because they do not want to put their needs first, they fear they will be perceived as an inadequate caregiver or they believe that distress in inevitable and cannot be alleviated. (Girgis et al. 2006)

10.2 Attitude barriers

Societal attitudes to the recipient and their disability may be influential on attitudes towards the caregiver.

Soutar reported that maternal caregivers of children with schizophrenia often experience an unsympathetic view of their position from health professionals. They have trouble being believed by health professionals, are treated by psychiatrists as over-anxious or to blame in some way, are seen as demanding if they ask questions or challenge points of view, and have trouble getting a diagnosis. On the other hand they are expected to take the primary caregiving role. This view is shared by Collings and Seminuik who point out families are often regarded as part of the pathology and this taints the relationship between the familial informal caregiver and professional caregivers. The recipient, professional and caregiver form a triangular relationship, brought together by the needs of recipient. Within this triad, covert and overt alliances form. Imbalances of authority and power contribute to the complexity, masking informal caregivers' needs for support, education and information in their own right. (Soutar 1997; Collings and Seminuik 1998)

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[10] There were perceived disadvantages of the key worker system as it meant other professionals backed off from providing services which they expected the key worker to provide.

The attitude of mental health professionals was very significant in increasing or soothing distress in caregivers in another study that researched the reactions of four primary caregivers of young adults diagnosed with schizophrenia for the first time. Parental caregivers revealed they experienced considerable emotional trauma as they adjusted to their young adult child being diagnosed with schizophrenia. The shock and emotional turmoil as well as any other physiological impacts were exacerbated by the impact of hospitalisation, by the changes in their child and by their fear and uncertainty about the future. Hospital staff were able to positively or negatively influence the level of trauma experienced by caregivers by involving them in care planning for their child. Caregivers expressed a need for continuity of care after discharge and information about available community supports. When health professionals are more forthcoming with information, supportive and encouraging towards caregivers, the overall trauma is reduced. (Wheeler 1994)

Caregivers of children with Downs Syndrome often need to advocate for their inclusion in society. Munford says that a common experience for caregivers to have to come to terms with the way society devalues those they care for, especially since the caregiver identifies with the child and feels their exclusion intensely.

> *In a society that has socially constructed disability as a problem ... people with intellectual disabilities, and those who personally assist them, are continually devalued. (Munford, 1994 pg 278)*

Health professionals may use the power of their position to control access to information and resources, or make assumptions about what is best for the care recipient. However, if they are subject to the same fears and prejudices as the rest of society, they may not have the best perspective on the needs and rights of the people they are dealing with. (Ballard 1994; Munford 1994)

10.3 Lack of recognition and insensitivity

Services can fail to offer caregivers information and training that would facilitate adjustment to the caregiver role.

Gould reported on a survey of over 1000 family caregivers throughout USA. Many who were delivering care had received no appropriate training despite working with care recipients who needed skilled handling. Almost one in five caregivers indicated that they had tried to get help over the previous year but had been unable to. Over half reported unmet medical needs and two-thirds had unmet non-medical needs such as home care. (Gould 2004)

Oyebode reviewed the interface of the formal and informal care systems in the UK and highlighted the range of ways caregivers are viewed by health professionals. The caregiver may be treated as a co-therapist, an informant, a proxy for the patient, and/or as a patient themselves. They may seen as requiring support, education or training. Services tend to react to caregivers rather than proactively enable them to cope effectively with their caregiving role. Follow-ups checks of the recipient by health service workers may not even assess the caregiver, particularly if that person is not co-resident. (Oyebode 2005)

10.4 New Zealand research

The few New Zealand studies researching the access of caregivers to services suggest caregivers generally lack knowledge of services available to them.

Taranaki whānau caregivers received little training or information regarding safe and appropriate ways of delivering personal cares to their stroke-afflicted family member. Instead, they learned by observing nurses deliver care. Whānau received little information to prepare for discharge, including information about, or referral to, appropriate services. Whānau would have liked more guidance on strategies to deal with impairments arising from the stroke. Assumptions were made about the whānau caregiving for the family member and delivering the care but with no supervision of the in-home ongoing physical therapy rehabilitation programmes. There was considerable disappointment that the post-discharge outpatient rehabilitation services were limited to six weeks. There was widespread failure to tell whānau what services they were entitled to, including income maintenance benefits, orthopaedic and podiatry services, and installation of mobility aids and ramps. Services were either not forthcoming or were much delayed. (Corbett 2003)

Opie found that caregivers of elderly people with dementia felt unsupported by formal services. She made a distinction between not knowing about services and not choosing to take up services on offer, finding both dimensions relevant. Day care was considered important as timeout for the caregiver, as well as providing activities for the recipient. There was a low uptake of meals on wheels and similar services. Only one caregiver used a laundry service and some were not aware of the availability of incontinence pads. In Opie's study 'a number' were unclear about financial benefits available to them, and respite care was only used by seven out of 28 caregivers. The need for such care is frequently based on a medical assessment of the recipient which only rarely takes into account the psychological and physical state of the caregiver. Opie observed some caregivers only requested help after the crisis point had passed, or else used it with considerable concern and anxiety about the welfare of the person. Professionals had a tendency to describe the caregiver as over-involved, rather than being sympathetic to the caregiver's perspective. (Opie 1990)

Nikora and her colleagues found whānau caregivers are often the communicator with professional support and health service delivery people which may place them in a gatekeeper role. Caregivers often also determine the activities the recipient is involved in, which may include contact with community or wider whānau. This may also include saying 'no' and then being the object of abuse from the disabled person or other whānau members. Caregivers report both physical and verbal attacks. The whānau caregivers in this study complained that medical professionals acted as if they were invisible, or else treated them as a support person or friend, but not as an important source of information on the health and well-being of the recipient. Nikora found caregivers reported a strong need for Māori-appropriate service providers who were responsive to the needs of whānau. Whānau caregivers felt guilty about asking for assistance, and feared being seen as a failure. Caregivers described interactions with providers as characterised by racism, powerlessness, a lack of control and invisibility. There was also resentment at inadequate, inappropriate, inefficient or insensitive treatment by income support and health services. (Nikora et al. 2004)

Davy's work on caregivers of the elderly found some participants reported difficulties arising from the interaction with formal health care services, for example, inconvenient scheduling of appointments, cancellation of appointments, early discharge from hospital, and lack of communication with services such as meals on wheels or home care. Relationships with GPs can be difficult as they do not always pass on information and elderly people are not reliable in their memory. Being excluded from information was particularly difficult when they were the ones expected to be responsible for medications and managing care at home. Several people in this study felt elderly parents are not treated well or with little understanding of the difficulties elderly have in negotiating the health system. (Davey 2004)

10.5 In summary

Informal caregivers receive little direct attention by service providers in New Zealand. By contrast, other policy regimes make better provision for caregivers and have researched their access to services. Despite increased risk of health problems, it is not clear that caregivers use primary care services more than non-caregivers. It could be that there are systematic barriers limiting caregivers' access to services which may include health professionals failing to recognise caregivers as patients in their own right, services not keeping a record of caregivers, services not fitting around caregiving demands, or barriers of language, culture and lack of appropriate information.

Parental caregivers of children with intellectual disability are particularly sensitive to the attitudes of the professional caregivers. Poor service co-ordination and responsiveness as well as lack of clarity about who is the main case worker can make services seem impenetrable.

New Zealand research suggests cultural attitudes can be a barrier to receiving information and support. This includes lack of cultural sensitivity in developing relationships with the whanau and lack of information about appropriate methods of care. At an organisational level, lack of awareness of the needs of the caregiver may mean health professionals do not ensure appointments fit with the caregiver’s time commitments.

Part of the caregiver’s role is to advocate for their recipient and to monitor the adequacy of the formal care delivered. The role of the informal caregiver fills any shortfall left by the formal caregivers. Health professionals may view the caregiver as an informant, as a proxy for the patient, as a patient themselves, or as co-therapist who requires education and training.

11 Supporting informal caregivers

11.1 Respite care

Respite care can be very important for caregivers. However, the quality of respite care must be acceptable to the primary caregiver. In some cases where respite care arrangements are in place over a long time, there is a real sense of care being shared. For example, a parent of a severely handicapped daughter is appreciative of an IHC scheme which arranges one night a month respite care when the daughter goes to stay with a volunteer caregiving couple, referred to as a ‘shared care family’. (Ballard1994)

Respite care can be an important component of paediatric palliative care to allow the usual caregiver to have a complete break from caregiving. Researchers have found that respite care needs to be provided by appropriately trained people for a specified time, and that services must be coordinated between agencies, of a high standard, flexible, accessible, culturally appropriate and not financially constraining. Among Auckland families there was considerable variation between caregiving families and their children with regard to what they needed and wanted from respite care. (Horsburgh 2002; Horsburgh and Trenholme 2002)

Among Māori, whānau caregiving for a family member with disability, respite care or time out was used infrequently. Key informants noted difficulties in finding the right person to often the recipient did not want others involved and sometimes the caregiver did not trust anybody else to do the job. For the same reasons, formal caregivers were often considered not to be an option. Although time out can be very positive, caregivers can also feel a sense of neglect, guilt or shame for turning attention away from the person cared for. (Nikora et al. 2004)

A review of respite care by Scottish researcher Chesson revealed a range of understandings of what is meant by the term. Respite care may refer to residential or home-based and can include befriending, a sitter service, nursing, shared care or day care. He found respite care can be a positive experience for both the caregiver and the recipient. As well as enabling caregivers to do things most people take for granted, respite is also sometimes used as an opportunity for the recipient to develop new social skills. Sometimes short-term admission to a hospital, for example to adjust medication, has been used as an indirect way to achieve respite care. However, if the use of such admissions as respite is not transparent, then these respite beds may be lost when hospital resources are trimmed for other reasons. Chesson promotes the use of the '*short term care*' meaning '*any short term service that is intended to provide temporary care of an impaired person, including respite care services for the family caregivers.*' However, he cautions against using the term 'short breaks' which may undermine the seriousness of the caregiver and recipient need, and may undermine the emerging emphasis on respite being constructive for the recipient. 'Breaks' suggest episodic care rather than the continuity and may not encompass the range of respite provision needed, including planned respite, holiday respite, emergency respite, care at home, community and family respite. (Chesson 2001)

Respite care should be a positive experience for both caregiver and recipient. The Scottish Office Social Work Services Group established the following indicators for quality respite care. Good quality respite care:

- is needs-led
- is planned

- is flexible
- forms part of a continuing programme of care
- provides feedback to the caregiver
- takes account of information and support the primary health care team can provide
- is accessible
- is provided in a range of settings
- incorporates arrangements to ensure that both groups benefit where respite and long term care users mix
- is affordable and provides value for money
- has benefits for both users and caregivers, and
- is forms a partnership with caregivers. (Scottish Office Social Work Services Group 1996)

In New Zealand, the majority of families caring for children and young people with high and complex needs preferred respite care to be provided out of the home. In particular, it was valued by single parent families, families where the child has severe or multiple disabilities or families of children with challenging behaviour. Carpinter suggests there should be a database of approved caregivers, a family/caregiver matching service, more trained caregivers, training available for people to become caregivers, and closer supervision of paid caregivers by agencies. (Carpinter 1995; Carpinter et al. 2000)

11.2 Formal care services

Good relationships and communication between professionals and families, and continuity of care, are important for caregivers.

Caregivers of family members with schizophrenia are assisted by experiencing a rapport with the health professionals delivering treatment. Collings and Seminuik found that consistency of information, being treated with respect, and being believed by professional caregivers were important elements in establishing trust between professional staff and caregivers. Similarly, Soutar found caregivers of adult children with schizophrenia identified professionals as helpful when they treated the child with respect and made themselves available. Having a supportive GP was also important. (Collings and Seminuik1998; Soutar 1997)

When good communication is established between health professionals and families looking after a dying child, the families' cultural and spiritual needs can be understood and responded to, according to Horsburgh. (Horsburgh 2002)

In Tucker's study, parental caregivers of children with high and complex needs identified continuity of care from formal supports as important. (Tucker 2004)

A small study showed that being taken seriously by health professionals, and having professionals respond more quickly to cries for help would have helped rural women taking care of terminally ill husbands. (Campbell 2004)

11.3 Provision of information

Caregivers report they need and are helped by the provision of information.

Whānau caregivers of Māori with disabilities perceived information as the key to better decisions about care, better access to resources or networks, better understanding of the whānau member and being better prepared for medical crises. Often caregivers needed to be assertive and determined to obtain the information. A steep learning curve was often involved when technical information was included. (Nikora et al. 2004)

Ashwell and others found that provision of information was important to those involved in the whānau caregivers training programme in the Waikato region. At the beginning of the course, evaluators observed a high level of stress among whānau caregivers due to misunderstanding and misinformation regarding the availability and accessibility of services, funding entitlements and respite care entitlements, but this was allayed as participants were given information and were able to clarify issues. (Ashwell et al. 2004)

Schizophrenia Fellowship was helpful to caregivers as it gave information about the latest research, medication and therapies for people with schizophrenia. Caregivers also found it supportive to have access to others in a similar situation. (Soutar 1997)

Parental caregivers of children and young people with high and complex needs require information and guidance. This is particularly so at the outset of caregiving, but is also ongoing. Families want information to be provided by a liaison person who is personally knowledgeable, understands their situation, whose information is reliable, and who can provide them with the facts they need. (Carpinter 1995; Carpinter et al. 2000; Bray et al. 2005)

11.4 Extended family and community

Caregivers often need assistance with transport. Whānau caregivers greatly appreciated help with transport from relatives, friends and neighbours. Free or reduced-cost transport is only available to some care recipients and not all of the time. (Nikora et al. 2004; NHC 2007)

Opie found that among her sample of 28 caregivers of elderly family members with dementia, most had only limited family support available to them and often from only one family member, but it was still important. Caregivers felt supported when they could phone that family member and get a warm and empathetic response. Visits, providing help with tasks, legal advice, taking caregivers away on holiday, and helping with meal preparation were all appreciated. Support, both practical and emotional, reduced the sense of burden and reassured them that there was somebody they could call on in an emergency. Caregivers felt valued when their work was acknowledged by the supportive family member. (Opie 1990, 1992)

Emotional support is important for maternal caregivers of children with schizophrenia, in particular the opportunity to talk freely without being judged. One participant reported deliberately setting up that opportunity by arranging for six women from the church to each give 20 minutes where she could just talk. Practical support is appreciated, for example, a church that unexpectedly sent a Christmas hamper, and a neighbour who agreed to come immediately if the porch light was turned on – a pre-arranged signal indicating the caregiver felt threatened. One friend offered to share her house with a mother and her schizophrenic daughter, which was helpful in modelling appropriate behaviour to the daughter. (Soutar 1997)

Extended family (often grandparents) is important for providing respite care. With children who have high and complex needs, some grandparents have had to learn to clear tracheotomies, administer medication, catheterise and undertake other specialist roles. The support may be for the other children in the family rather than for the child needing care. For example, one family set up bedrooms at the grandparents' house when the parents had to spend long periods at hospital for a high-needs sibling. (Tucker 2004)

While extended family are often the main source of support for parental caregivers of young people with high support needs, Carpinter cautions that this should not be assumed. Reasons extended family are not involved at times include a lack of acceptance of the child's illness, fear of the disability, an inability to provide support due to lack of skills or understanding and limited ability to support due to getting older. (Carpinter et al. 2000)

11.5 Support groups

Whānau caregivers often benefited from talking about their experiences but found others did not always want to listen to them. However, in some cases caregivers felt that caregiving issues so dominated the conversation of support groups that it was as if the caregiving role had consumed the caregiver's social existence. (Nikora et al. 2004)

A parental support group was helpful for parental caregivers of children with high needs. The parents enjoyed the reciprocity, information sharing, advice, emotional support, advocacy, and practical support they got from the group. (Tucker 2004)

The Grandparents Raising Grandchildren Trust is a national support organisation for grandparents and other kin caregivers, with 36 support groups across New Zealand. In Worrall's work, members said they found the Trust helpful. (Worrall 2005)

Oyebode critiqued four studies which looked at the efficacy of interventions with caregivers. The studies showed mixed reports but some evidence for positive gains for caregivers and recipients when caregiver needs were addressed. In one study caregivers had reduced distress, increased knowledge, and improved mood of recipient. Other studies found institutionalisation had been delayed after intervention. Psychosocial interventions with caregivers showed significant small to moderate benefits in caregiver mental health and aspects of social functioning. Interventions tailored to the specific needs of the caregiver and recipient may include intensive case management, cognitive-behavioural family intervention, and cognitive rehabilitation. Group interventions have the advantages of reducing social isolation of caregivers, and being cheaper and more efficient with regard to professionals' time, but they do not show such positive impacts. (Oyebode 2005)

11.6 Caregivers' coping strategies

In two studies parental caregivers were well aware that support is limited and that assessment based on need can be quite subjective. All had put aside any hesitancy about asking for help and had become assertive in asking for care. (Tucker 2004; Ballard 1994).

Caregivers who juggled work and caregiving for older people used a range of coping strategies. Those most commonly employed included:

- discussing care arrangements with other family members
- making sure the older person's affairs were in order

- seeking information about community services for seniors
- modifying the older person's home to make home care provision easier
- exploring options for long-term care
- putting money aside to help with the older person's needs
- finding ways for caregiver and recipient to live closer together
- considering reducing paid work commitments
- looking for paid work closer to where they live. (Davey and Keeling 2004)

Lopez and others investigated the coping strategies used by caregivers and found that religion was associated with caregiver satisfaction, whereas emotional venting and self-blame were negatively correlated with satisfaction. (Lopez et al. 2005)

Lungley and colleagues, who researched caregivers for people with multiple sclerosis and schizophrenia, found the relationship dimensions to be important. Where the relationship was positive and was based on love and affection, then there was a greater willingness and ability to solve difficulties, and to cope with sadness about the effect of the illness on the person they cared for. It was also helpful to be at centre of a supportive network of family and friends. Being able to continue in paid work was important for some, as was maintaining hobbies or exercise. Holidays (even brief ones) and respite care, were coping strategies for some. Access to services and information was also important, since caregivers who understood the system or who had a strong advocate tended to cope better. (Lungley et al.1995)

A New Zealand book written by a geriatrician for caregivers of those with dementia suggests a number of useful coping strategies. These include the caregiver accepting feelings, taking care of themselves and accepting help, involving family and friends, using support groups such as Alzheimer's New Zealand, looking after their own health, and maintaining a sense of humour. (Perkins 2006)

Opie observed caregivers using various coping strategies, including allowing themselves to cry, reminding themselves the spouse was not acting intentionally, talking with another family member, and recalling strong mothers who had continued against all odds. Moments of recognition, a smile, responsiveness and physical affection from the confused person were all important for sustaining caregiving under duress. (Opie1990) Spiritual understandings are important for some caregivers. (Soutar 1997)

Caregivers of stroke patients are less likely to become depressed if they feel some mastery and can maintain their leisure pursuits. Memory and comprehension difficulties in the recipient are associated with depression in caregivers. Cameron and colleagues suggested three types of intervention to reduce the risk of depression in caregivers:

- informing caregivers about the different types of behavioural and psychological symptoms, and teaching them strategies to manage these
- promoting strategies enabling caregivers to participate in valued activities and interests including respite opportunities
- enhancing clinical management of the behavioural and psychological symptoms of the recipient to decrease their frequency or severity. (Cameron et al. 2006)

Identifying caregivers with high stress and designing interventions to improve their internal locus of control, is a way to proactively help caregivers of the elderly and reduce the chance of the recipient's admission to a rehabilitation unit. (Caradoc-Davies and Dixon 1991)

11.7 What caregivers find unhelpful

Collings noted the relative paucity of New Zealand research on informal caregivers for people with mental illness, although there is some information available through the Mental Health Commission. Available research suggests that caregivers of mental health patients find the legislation around mental health and the services to be a major source of stress. In particular:

- privacy laws sometimes prevent caregivers knowing about medication or potential risk
- informal caregivers are still not regarded as a productive part of the health system, despite the Mental Health Strategy requiring the integration of care with family and whānau. (Collings 2006)

Parental caregivers of children with high and complex needs struggle with a lack of understanding and acceptance from others, according to research by Carpinter and her colleagues. Most families, including the Māori and Pacific families included in this research, experienced little support from extended family. Support workers were reported to be of variable use, with parents finding it difficult to locate a caregiver with integrity and common sense who was also adequately trained. Parents were frustrated by the high turnover due to poor pay – as the effort of training a new caregiver was a huge investment for little return. Some found the disruption and effort of a support worker to be *'just not worth it'*. Respite care out of the home was what the majority of families valued most and few had access to quality respite care frequently enough. (Carpinter et al. 2000)

Focus groups with caregivers of people with schizophrenia revealed caregivers were frustrated by difficulties getting information out of professionals regarding the patient's illness, prognosis and care. Receiving inaccurate or vague information was experienced as unhelpful and distressing. Some caregivers felt they were seen as a nuisance. Often caregivers found their input was not listened to or taken seriously when they tried to point out when their family member was unwell. Caregivers felt distrusted when professional staff dismissed what they had to say. . (Collings and Seminuik 1998)

Mental health services are often difficult to access and poorly resourced, which angers many caregivers who feel abandoned by treatment providers and current social and health policy. Caregivers are very aware of the stigma and discrimination experienced by the mentally ill, and this is hurtful to caregivers who strongly want to treat that patient as a person rather than a label. (Collings and Seminuik 1998)

In his study of paediatric palliative care Horsburgh found familial caregivers:

- were hindered by a lack of coordination between agencies
- experienced difficulty accessing resources and support
- were burdened by having to monitor and train respite caregivers. (Horsburgh 2002)

A UK survey of 76 families of families caregiving for children and adults with severe or profound learning disabilities, found fewer than half the families had been through a needs assessment despite that being mandatory, only half had had their support package reviewed within the last year, and most did not receive respite care. The majority had never been offered a choice of service. (MENCAP 2003)

Research with whānau caregivers found that caregivers experienced difficulty with:

- knowing services are needed but not being able to readily access them

- being unable to receive information they believed could help their caregiving (because of the Privacy Act)
- lack of coordination amongst providers of formal supports
- lack of practical support (leading to frustration, arguments and stress)
- the combination of invisibility and lack of acknowledgement of the caregiver role, and perceived race-based discrimination (leading to caregivers feeling disrespected, dismissed and isolated)
- whānau members and friends being both a great source of support and a source of criticism, painful and spiteful behaviour. (Nikora et al. 2004)

11.8 In summary

Research with caregivers shows that actions they find supportive of their role include:

- good quality respite care
- respectful relationships with formal services based on good communication
- good quality and readily available information
- practical assistance and emotional support from extended family and the community
- caregiver support groups.

Caregiver coping strategies include:

- being assertive in asking for support
- have a religious practice or spiritual philosophy
- adjusting paid work arrangements to fit more easily with caregiving
- involving other family members
- checking out formal support options
- active coping and reframing strategies
- (for some) continuing in paid work
- looking after their own health.

Caregivers are hindered by:

- lack of knowledge of services
- lack of information about the care recipient (for example, the recipient’s illness prognosis)
- lack of support, including from extended family and from formal services
- the high turnover of formal support workers resulting from the low pay and status
- health professionals of mental health patients viewing the family as part of the pathology
- power imbalances impeding relationship with health professionals.
- mental health services that are poorly resourced and hard to access
- stigma and discrimination towards the recipients of care
- lack of coordination between agencies and provider organisations.

12 Other ways to support informal caregiving

12.1 A public health issue

Advocates for informal caregivers argue that their contribution to the health and welfare systems should be recognised, and that they should be protected from any disadvantages or costs arising from their caregiving. Maintaining the health of caregivers supports the motivation to care, can reduce health inequalities arising from caregiving, may avert the recipient's use of health services, and in some cases can delay or avoid admission to residential care for the recipient. Hirst concluded additional resources should be allocated to developing caregiver support services in Britain. (Hirst 2004; 2005)

Montgomery and Feinberg undertook an international review of policy regimes and identified the following initiatives to alleviate the costs and difficulties for caregivers:

- equity of access to information
- assistance with seeking long-term care services
- routine assessment of caregivers' needs
- provision of training, respite care, counselling and other caregiver support
- compensation for caregivers who need to take time off work
- pension credits for caregivers who cannot work due to heavy caregiving demands
- wider availability of tax incentives
- cash payment options to offset the higher cost of goods and services that are associated with illness and disability. (Montgomery and Feinberg 2003)

Hooyman challenges the assumption that caregiving is a private duty. Arguing for caregivers' welfare to be a central goal of social and health policy in the USA, she puts forward the need for policy makers to use criteria other than efficiency and cost-containment to assess policies to support family caregivers. Taking compassion as a primary value, she says policies should reflect shared responsibility for care between family, public and private domains. Policies should also allow choice about the extent of informal caregiving and provide tangible relief from demands. Although informal caregivers are not motivated by financial considerations, the financial cost of caregiving should not be ignored and monetary compensation for caregiving should be considered. Traditional values of family responsibility must be given equal footing with market place values in shaping the building of society around human needs. (Hooyman 1990)

Howe and colleagues undertook research in Australia and made comparison with Canadian and UK findings. They highlighted the policy dilemma over whether policies should provide support across the network of those who provide help to care recipients, or whether support should be targeted to those experiencing a significant burden of care. Broad-based policies would assure caregivers that support was available as caregiving became more intense. Without this assurance and support, there is a risk that caregivers could lose motivation and capacity for further caregiving. This would also work in the interests of keeping down the numbers of people admitted to residential care as there are lower rates of admission to residential units among those with caregivers. Howe's paper shows that motivation and capacity in caregivers are both independently and significantly inversely associated with admission to residential care among highly dependent recipients. Howe suggests a multi-faceted public health approach to slow down the progression of burden and promote the well-being of caregivers. (Howe et al 1997)

Aoun recommended these policy changes for Australia in the area of palliative care:

- changes to taxation, social security and income maintenance to ease financial burdens of caregivers
- more caregiver friendly workplaces offering flexible employment arrangements and improved workforce opportunities -
- coordinated service funding and service provision across all levels of government to ensure equitable social and geographical distribution of services
- a comprehensive and coordinated approach to the evaluation of services, to ensure closer links between policy and practice, and to develop standards for service quality for caregivers
- education at a community level to promote the social value of caregiving and an awareness of the demands and impacts of the caregiving role
- educational materials in a range of forms geared specifically for caregivers
- improved communication and timely access to support services
- focused strategies addressing the barriers caregivers experience
- specialised strategies addressing the needs of special groups such as younger or older caregivers, those from indigenous and ethnic minority backgrounds, those living in rural areas, and those with chronic disabling conditions
- multi-disciplinary research leading to evidence-based practice approaches to home-based palliative care
- partnerships and collaborations between government, service providers, GPs, families and researchers to meet the needs of families for good palliative care. Aoun (2004)

12.2 Support for particular groups of caregivers

Caregivers of children and young people with high and complex needs

To alleviate stress and support parental caregivers of children with high and complex needs, Bray and colleagues recommended:

- assessment of needs focused on the caregiver and the family context, not just on the disabled person
- services which are well coordinated
- each family is helped to develop a written crisis plan with funding attached
- needs assessment and service co-ordination agencies are resourced and trained and able to deliver flexible packages of care to meet families' needs
- there are competent support or respite workers to offer overnight or weekend stays, care to cover family emergencies when urgent care is needed, appropriate after school and holiday care, and care that does not require the rest of the family to move out of the house to have a break
- an intersectoral approach is taken to address the transition of young people with high and complex needs to adulthood
- quality out-of-home care offered as a real option without this being seen as a failure of the caregivers when they request appropriate support.

When the parental caregivers were asked what types of help would make their caregiving easier, the types of support requested (in priority order) were: better information, help with gardening and other home maintenance, training in areas relevant to caregiving for that family member, help with other children, support and understanding from other caregivers, and counselling or a listening ear. (Bray et al. 2005)

By contrast, Carpinter's discussions with parental caregivers of children with high and complex needs found that:

- respite care is the number one priority for most, if not all, families
- parents want support in their own right
- several parents felt families caregiving for a child with very high support needs should be assigned an advocate who could work with them to help secure assistance they were entitled to and from which they could benefit
- around the clock emergency support to cover crises
- planning to cover any emergency situation where the primary caregiver is not available
- long-term planning for permanent placement options. (Carpinter et al. 2000)

Nucleus Group emphasised building resilience over the long-term to reduce the need for more intensive services. Nucleus Group noted that resilience is related to the family:

- communication skills
- capacity to be flexible
- degree of commitment to maintaining the family unit
- problem solving abilities
- extent to which they maintain their social networks
- the relationships they build with professionals.

They argued support should be proactive and delivered through early intervention as family caregivers may not seek assistance until they reach a crisis point. (Nucleus Group 2002)

Caregivers of people who are terminally ill

Ways to assist those caregiving in a palliative care situation should include:

- information and open communication
- skills training
- emotional support
- respite care, and
- the provision of grief support. (Charlton 1992)

Christakis and Iwashayna looked at caregiver burden as reflected in the death rate of spouses after their terminally ill partner died. They did this by examining whether the subsequent death rate of caregiver spouses was reduced when the terminally ill patient used a hospice. In this USA study, hospice care includes home-based, supportive terminal care which incorporates nursing care, physician visits, homemaker assistance, social services and bereavement counselling. They found that the use of hospice care did reduce the risk of death in the surviving spouse. This effect was large and statistically significant in bereaved wives. (Christakis and Iwashayna 2003)

Caregivers of people with mental illness

Focus group discussions with caregivers of family members with schizophrenia, indicated sensitive early intervention was seen as 'extremely important', but not used often enough. (Collings and Seminuik (1998)

Women caregiving for an adult child with schizophrenia identified respite care and support for the family caregivers as important. Family reported often feeling ignored or irrelevant to the treatment process. (Soutar1997)

Laidlaw and others emphasise the importance of including primary caregivers in assessment and treatment programmes (including teaching stress-reduction strategies even when they are living apart from the patient). Family interventions that train families to work collaboratively have been shown to reduce major recurrent episodes by at least half. The vulnerability-stress model provides a theoretical base for these programmes. This model suggests environmental stresses interact with biological vulnerability to produce major episodes of schizophrenic psychopathology. The overall goal is therefore to train patients and their caregivers to apply problem-solving strategies to enhance their management of major stresses. Laidlaw suggests that education and cognitive-behavioural strategies need to be trialled to demonstrate their effectiveness in reducing family caregivers' burden. He suggested all caregivers could benefit from this approach, not just familial caregivers. (Laidlaw et al 2002)

Caregivers of adults with disabilities

Hirst underlines the importance of early identification of caregivers, monitoring high-risk groups, and timing appropriate interventions. Caregivers are likely to benefit from advice, information, training in care tasks, support around the start of caregiving and at regular intervals throughout heavy caregiving. Recurrent episodes of distress indicate a need to review the factors underlying caregivers' emotional health and enhance their coping skills and resources, including respite care options. Emotional support may also be beneficial when care giving comes to an end. (Hirst 2005)

A study of long-term caregiving in Italy suggested clinicians should help families by addressing relatives' psychological reactions to patients' illness. Ways to assist families to respond more effectively to the family member's illness include:

- providing information about the expected course of the illness
- educating about how to monitor symptoms and recognise early warning signs
- encouraging use of a problem-solving approach to deal with practical consequences of physical disabilities
- reinforcing relatives' social resources. (Magliano et al. 2005)

Caregivers of elderly people

Opie suggests services to support caregivers for elderly people with dementia should be:

- available without a waiting list
- timely and appropriate
- acceptable to the family
- accessible (for example, transport to collect the elderly person if necessary)
- coordinated with other services
- convenient (or it won't be used)
- dependable
- treat patient and caregiver with respect and dignity
- equitable
- flexible (able to meet the changing needs of family)
- family-centred

- professionally directed
- cultivated climate of trust between providers and caregivers. (Opie 1992)

Research with caregivers who had recently relinquished care of an elderly person indicated that to ease the transition of an elderly person into residential care and to integrate the caregiver into the ongoing care, the following aspects are important:

- information given by rest home staff
- treating the caregiver as a partner in the ongoing care
- including caregivers in care planning and access to medical care records
- good communication between caregivers, health professionals and formal caregivers
- integrating the informal caregiver into the residential setting (for example, having a small kitchen may help the caregiver to undertake small tasks such as making a cup of tea or light snacks)
- more support for caregivers in coping with the transition which for many was emotional, traumatic and had been taken as an option of last resort. (Milligan 2004)

Williams observed that when formal caregivers work to build partnerships with families it helps families with any feelings of worthlessness, guilt and frustration. Nurses need to understand the immense strain on these families and the grieving involved in relinquishing care. (Williams 1991)

Grandparental caregivers

Worrall recommends the following to support grandparental caregivers in New Zealand:

- an adequate income for kin caregivers equivalent to the Foster Care Board payments, and financial support that reflects the needs of the children
- extending all support services to caregiving kin
- educating income support workers to ensure income entitlements are given where appropriate
- governemnt payment of legal expenses to clarify guardianship and custody where the child has been under the care of Child, Youth and Family (CYF)
- a higher priority on placement stability by judicary
- respite care, day care, and after school care are offered routinely to kin caregivers and the costs covered by income support
- free medical care is available to all children
- free counselling is available to grandparent caregivers
- CYF staff are given specific training on the issues involved in placing children with kin
- government provision of suitable housing for grandparents or kin who assume long term care for children. (Worrall 2005)

12.3 In summary

Advocates of informal caregivers seek to have informal caregiving raised as a public health issue and caregivers recognised as a productive part of the health system. A scan of international policy regimes suggests routine assessment of caregivers' needs, provision of caregiver support services, compensation for caregivers who take time off work, superannuation credits, access of information about other options, and reimbursement for costs incurred through caregiving all help alleviate the impacts of caregiving. Health professionals could be educated to become more aware of caregivers and their issues.

Caregivers of children with high and complex needs value a holistic assessment of family, well coordinated services, flexible support packages, a reliable supply of competent and well-trained respite care workers, a planned approach to the transition of the young person into adulthood and quality out-of-home options. Caregivers of people with mentally illness indicated early intervention, respite care, and involvement in treatment programmes would reduce negative impacts of caregiving. Caregivers of adults with disabilities would be helped by improvement of coping strategies, information and social support. Services for caregivers of elderly people should be available, appropriate and accessible. Services need to be well co-ordinated, maintain the dignity of the recipient and caregiver, and flexible. Caregivers coping with the transition to residential care need to be integrated into the new environment and their ongoing caregiving status recognised by inclusion. Adequate income support and access to services are important for grandparental caregivers.

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Appendix A Databases, search terms and other sources

A range of databases were systematically searched:

- CINAHL
- IBSS
- Medline
- OCLC
- Proquest
- PsycINFO
- Te Puna
- Science Direct
- Scopus
- Web of Knowledge and Web of Science

The search terms used included:

- Carer AND home
- Carer* (within some search systems this can be used as a generic prefix)
- Caregiver NOT nurs*
- Informal caring
- Home support
- Respite care
- Unpaid care

The librarians or relevant policy worker of these government organisations were also asked to check for additional material:

- Ministry of Social Development
- Office for Disability Issues
- Ministry of Women's Affairs
- Te Puni Kokiri
- Statistics NEW ZEALAND

These NGOs were asked to source any material held by their libraries and to check for any research undertaken by their organisation:

- Caregivers NEW ZEALAND
- Age Concern
- CCS
- IHC
- Social service agencies (e.g. Presbyterian Support)
- Donald Beasley Institute
- Tautoko

Appendix B Prevalence of caregiving in other counries

	Country	Prevalence	Co-resident	Primary caregiver	Other caregiver	Gender balance
Australian Bureau of Statistics 2005	Australian National Survey of Disability, Ageing and Caregivers, 2003	12.9 per cent Of these, providing to partner 42 per cent, parent 23 per cent, child 26 per cent		2.4 per cent (1.7 per cent female, 0.7 per cent male)	10.6 per cent (5.3 per cent female, 5.3 per cent male)	54 per cent female But 71.3 per cent of primary caregivers
Arksey (2005b)	UK General Household Survey, 2000	16 per cent of those aged over 16 18 per cent of women, 14 per cent of men	Approximately one third of caregivers			58 per cent female
Gould (2004)	US National Survey of Family Caregivers*	21.8 per cent				
Cochrane (1997)	Ontario Health Survey, 1997	15 per cent of those aged 15-64				59 per cent female

* Conducted collaboratively between Henry J. Kaiser Family Foundation, Harvard School of Public Health, and the National Opinion Research Centre at the University of Chicago

Appendix C Access Economics' approach to valuing informal caregiving in Australia

In a survey conducted by the Australian Bureau of Statistics in 2003 (cited by Access Economics, 2005), one in eight Australians, or 12.9% of the population, are estimated to be providing informal care to a person needing assistance due to disability, chronic illness or old age. Of these, approximately one fifth are primary caregivers. On average caregivers contribute an average 9 hours per week or 470 hours per year. However this caregiving is heavily weighted towards the primary caregivers who provide 54% of the caregiving but represent 20% of the population of caregivers.

An Australian economic valuation for Carers Australia (Access Economics, 2005) drew on the above reported prevalence and scope of informal caregiving to estimate the contribution of informal care being in Australia to the economy as a whole. Both opportunity cost and replacement cost methods were used.

The opportunity cost of informal care, measured by the reduction in paid employment, was estimated at Aus$4.9 billion (equivalent to 0.6% of forecast GDP and 9.9% of the value of formal health care). Although some informal some informal caregivers continue to work, there is also evidence that the rates of employment and labour force participation among caregivers are substantially lower than the equivalent age and gender cohorts of non-caregivers. The age standardisation of labour force participation (including those unemployed looking for work) for primary caregivers is 45 per cent, compared to 62.7 per cent of the Australian population.

The alternative replacement valuation method focuses on the resources that would otherwise need to be diverted from the formal economy to replace the work of informal caregivers, should their services become unavailable. If all hours were purchased from formal care service providers, the replacement value is equivalent to 3.5 per cent of forecast GDP and 62 per cent of other formal care.

To put this in context, the following sectors added to the Australian economy gross value, as a percentage of GDP for 2003-2004: forestry and fishing (0.2 per cent); textile, clothing and footwear (0.3 per cent); wood and paper products (0.7 per cent); accommodation, restaurants and cafes (2.0 per cent); communication services (2.7 per cent); agriculture (3.1 per cent); and mining (4.2 per cent) (Access Economics, 2005, pg.17, citing Australian Bureau of Statistics, 2004)

Currently these productivity losses are largely carried by the individuals involved. However there are wider macro-economic implications as there is a lower personal income tax collection and some payment of income support payments to caregivers. The authors point out these are transfer payments but there are associated efficiency losses.

The costs to health and well-being were acknowledged as substantial and additional but were not calculated. Interestingly the cost of sleep deprivation arising from informal caregiving was tentatively estimated, based on a comparable study which did place a cost-value on sleep disorders (citing Access Economics, 2005) as greater than one billion dollars, compared for example with their $4.9 billion opportunity-cost of the reduced productivity of informal caregiving. The cost estimate contribution of sleep derivation used the data from the 44 per cent of primary caregivers whose sleep is interrupted due to the requirements of the caregiving role.

The economics of using different delivery of care models were compared, for the Australian economy. According to the Access Economics economic valuation and the average costs of care, combinations of informal care and community-based formal care services are generally lower cost than institutional care, based on an opportunity cost valuation of the informal caregiver’s time, but excluding health impacts, and including some allowance for a housing cost.

Appendix D Media references to informal caregiving

In order to get a picture of how informal caregivers are presented and the kinds of issues they may face, New Zealand media sources were searched using the 'Newztext Plus' database. This indexes articles from major New Zealand newspapers, and magazines with a business or industry orientation. The database was searched from 1 January 2006 to 6 November 2006 using the terms care, caregiver, caregiving, caregiver and caregiving. Fifty-seven articles considered relevant were retrieved. A much larger number of articles contain the keyword/s, but refer to such things as general parental caregiving for children, foster care, childcare/early education and formal caregiving.

Of the articles retrieved, 32 gave perspectives on informal caregivers. Twelve articles referring to formal caregiving were included because they reflect issues that would also impact on informal caregivers. Five articles covered both formal and informal caregiving, and there were eight references to grandparents caregiving for grandchildren which also falls within both classifications. This shows immediately the close interface between informal and formal caregiving.

Many of the articles about caregivers are 'human interest stories', often occasioned by lobbying for a particular cause (e.g. Alzheimers' Awareness Week; Autism Week; Schizophrenia Week; Stroke Awareness Week) or reflecting particular difficulties for an individual caregiver. Some issues raised may be pertinent to a particular situation, but many raise general issues for caregivers. They are set out in three sections below: informal caregiving, formal caregiving and grandparents as caregivers.

INFORMAL CAREGIVING

- The boundary between the usual reciprocal care within a relationship and 'informal caregiving' is blurred. A woman caregiving for her husband who has Alzheimers disease comments, 'He tells me I'm not his caregiver, I'm his wife…And we're happy together…we look after each other'. ('Illness robs couple of conversation', Taranaki Daily News 24/7/06 p2)
- Jim Anderton. speech notes: 'In many cases it will be family members, who provide care (sic). And often, their care is a life-long commitment. Families of people with mental illness often become caregivers by default. They often give their support without payment and so it's sometimes difficult to tell the difference between caregiving … and ordinary support for family and friends.' ('Anderton launches Schizophrenia Awareness Week', Government Press Release 7/3/06)
- Family caregivers express a desire to care for their family members at home and do not want to see them institutionalised, or view this as a last resort. ('Little interest in dementia care', Stuff: Kaikoura 13/9/06; 'Couple hoping for some respite', The Timaru Herald 1/3/06 p3)
- At the same time, family may already be stretched by caregiving and unable to offer more. 'In these situations the family usually helps, but the family I have is helping. What next? Because we're not coping.' ('Who will care for us?' The Dominion Post 7/1/06 p1)
- Changes in society may also mean family members are less available to care, with more women in the workforce and grandparents often not close by. ('Caregivers plea for desperate families', The Dominion Post 9/1/06 p2) A woman who cared for her elderly mother says, '… I was still feeling incredibly guilty that I wasn't doing enough for her. Society has an expectation that you will look after aged parents and there is guilt of (sic) you don't…She says it can be harder these days

because people have smaller families and the responsibility often falls on one person.' ('Course aims to help those caregiving for elderly relatives', Stuff: The North Shore Times 18/5/06)

- Caregivers can also experience stress from their caregiving role and from lack of support. 'The branch [of Autism New Zealand] is so concerned about the stresses facing families who can't get the funding, the caregivers or the quality help they need …' ('Autism still hell for families', Manawatu Standard 23/9/06 p3)
- '… the boys' own father left the family and returned to Canada, providing no financial support and little contact. 'He had a breakdown and became delusional, possibly because of the stress' [his partner] said.' ('Who will care for us?' The Dominion Post 7/1/06 p1)
- A study of family caregivers of people with schizophrenia showed they often suffer high levels of stress and anxiety. ('Schizophrenia week acknowledges family assistance', Taranaki Daily News 8/3/06 p2)
- Other emotions experienced by caregivers may include grief about the family member's illness/disability or at change or loss of relationships; frustration; and loneliness. ('Illness robs couple of conversation', Taranaki Daily News 24/7/06 p2; 'Who will care for us?' The Dominion Post 7/1/06 p1; 'Charge dropped against man who had body in car', The Dominion Post 3/11/06 p3)
- Caregivers may experience harm in their caregiving. 'The 73-year-old widow, who was the sole caregiver for her 41-year old schizophrenic son, had her finger bitten off and her eyes gouged and may lose her sight.' ('Schizophrenia group says Rotorua attack shows families' vulnerable' Radio New Zealand Newswire 29/3/06: 16:26)
- Caregivers may have no choice but to ignore their own needs in order to care for another. A woman whose daughter has autism reports having major surgery and being advised to have six weeks recovery time, including three weeks 'complete rest from the daily physical stress of caregiving for her autistic daughter' but getting 12 days. ('Daily struggle with little help', Manawatu Standard 25/9/06 p1)
- Caregiving impacts on the whole family. For example, parents caregiving for a child with an illness or disability comment on the impact on siblings and on the marital relationship ('Autism Week highlights problem', The Nelson Mail 7/6/06 p3; 'Hit hard by pneumococcal disease', The Dominion Post 7/8/06 p10).
- Family members, as well as a person with illness or disability, may experience stigma. Grandparents caregiving for their grandson who has autism say they have become 'social outcasts' since taking on his care and attribute this to people's ignorance and fear. ('Autism – a different way of thinking, Stuff: Northern News 8/6/06)
- Nor do caregivers want to be patronised or sanctified for their role. ('Good care needed', The Nelson Mail 25/5/06 p11)
- Respite care is essential for informal caregivers. 'For many parents, good respite care can mean the difference between feeling on top of a demanding load, and going under.' ('Good care needed', The Nelson Mail 25/5/06 p11)
- However many report difficulties with getting respite care. People may have an allocation of respite care days, but be unable to find suitable caregivers. ('Good care needed', The Nelson Mail 25/5/06 p11)
- The low pay available for respite caregivers makes it difficult to attract and retain them. ('Hit hard by pneumococcal disease', The Dominion Post 7/8/06 p10; 'Schizophrinics' caregivers 'alienated, stressed'', The Press 7/3/06 p7) 'Over the years, there have been more than 100 [support caregivers]. Some of them have

been great, she says, but others she wouldn’t be confident leaving in charge of the dog.' (‘Daily struggle with little help’, Manawatu Standard 25/9/06 p1)

- People caregiving for those with Alzheimers report a lack of daycare options and respite beds. Therefore although they may have respite days allocated, they are not able to use them. (‘Shortage in respite beds, care’, The Press 20/7/06 p4) Inability to get respite time adds further stress to caregivers who may already be ‘at the end of their tether’. (op cit)
- A family with very high needs (two high needs children, a four month old baby and a grandmother with terminal cancer) tell of their struggle to get help. They have had assessments by various agencies who then fail to coordinate assistance because of 'arguments around budget boundaries.' The family themselves were paying additional wages to cover support costs of $100 a day (‘Who will care for us?’ The Dominion Post 7/1/06 p1)
- There is a call for more flexible respite services – 'At the moment, they run from 8.30am to 5pm and five days a week. People aren’t sick from 8.30am to 5pm.' ‘Schizophrenics’ caregivers 'alienated, stressed'’, The Press 7/3/06 p7)
- Institutional respite care needs to be 'good-quality…, close to home so [family] could visit and ideally with the same home each time so dependent relative could build a relationship with staff.' (‘Shortage in respite beds, care’, The Press 20/7/06 p4)
- Family caregivers may not wish or be able to continue caregiving for ever. 'I don’t intend to have Jayden at home all the time as he get older. I do believe it would be good for him to get into the community a bit more and we’re not going to be able to lift him forever.' (‘Hit hard by pneumococcal disease’, The Dominion Post 7/8/06 p10)
- 'As Ben was getting older and stronger, the need for respite care was greater, she said. ‘I am getting tired and my sense of humour is waning’'. (‘Couple hoping for some respite’, The Timaru Herald 1/3/06 p3)
- Many caregivers of the elderly are themselves frail and elderly, have their own needs and find it increasingly difficult to care for another. (‘Shortage in respite beds, care’, The Press 20/7/06 p4)
- On the other hand, caregivers may so strongly wish to continue caregiving that they seek ‘treatment’ for the person with a disability in order to facilitate their ability to care. The ethical dilemmas posed by this situation are raised in an article reporting parents have sought medical help to halt the growth of their 6 year old daughter who has profound developmental disabilities in order to make her care easier for them in the future and delay the need to 'hand care to ‘strangers’'. (‘Disabled girl’s growth halted’, The Dominion Post 3/11/06 pB2)
- Informal caregivers are contributing an enormous amount of care which would otherwise have to be provided in some other way. For example, 70 per cent of people with Alzheimers disease are said to be being cared for at home. (‘One day at a time’, Stuff: Central Leader 21/7/06) In addition, with an aging population, the need for caregiving can be expected to increase in the future. (‘Little interest in dementia care’, Stuff: Kaikoura 13/9/06) Policy has moved to encouraging care at home and in the community rather than in institutions. However there needs to be community support to match (‘Shortage in respite beds, care’, The Press 20/7/06 p4) A speech by Jim Anderton during Schizophrenia Awareness Week acknowledged the positive side of deinstitutionalisation, 'But alongside the success, we need to talk about the increased burdens that have been imposed on

caregivers, and on families in particular.' ('Anderton launches Schizophrenia Awareness Week', Government Press Release 7/3/06)

- Adaptations to housing or provision of equipment or a modified car assist with caregiving, encourage independence and relieve caregivers of some responsibilities ('Special-needs house built to measure', The Press, 19/7/06 p47; 'Holding fast to hope for dream home', The Timaru Herald 4/1/06 p1-2)
- Information and training for caregivers may be helpful. 'Karen and John have both attended a training course run by Autism NEW ZEALAND to help parents and caregivers understand autism and learn ways to help their child.' (Autism Week highlights problem', The Nelson Mail 7/6/06 p3)
- Support groups can also be helpful to address caregivers' own needs and concerns ('For dear life', The Nelson Mail 6/5/06 p15)
- Caregivers would appreciate professionals giving them information about where to go for support. ('Schizophrenia group says Rotorua attack shows families' vulnerable' radio New Zealand Newswire 29/3/06: 16:26) One article outlined care and support options that are available for older people. ('Care and support service options for the elderly', Waikato Times 2/6/06 p10) Another noted the lack of community support for people who have suffered a stroke after they leave hospital. ('Stroke Awareness Week', Stroke Foundation Press Release 12/9/06)
- Families may make financial sacrifices to care. 'She says a recent survey found most caregivers of those with chronic mental illness are women, and many give up paid jobs to look after a relative.' ('Schizophrenia group says Rotorua attack shows families' vu' [sic], radio New Zealand Newswire 29/3/06: 16:26)
- A study of family caregivers of people with schizophrenia showed more than half were forced to leave their usual employment. ('Schizophrenia week acknowledges family assistance', Taranaki Daily News 8/3/06 p2) In addition, caregivers spent on average $64.96 per week on medical and other expenses. ('Counting the costs of caregiving for sick', The Southland Times 10/3/06 p2)
- One article lauds a 14-year old 'young caregiver' who cares for a sick aunt along with household tasks, school, sport and church activities. She had previously cared for her now-deceased mother. For her efforts, she has been awarded a Child Development Foundation Youth Award which includes an Outward Bound course. There is no discussion of whether her caregiving role is appropriate, or whether she receives any support. ('Tribute to teens with right stuff', NEW ZEALAND Herald website 24/3/06)
- Caregivers may contribute to the success of treatment for an ill family member. 'Treatment for mental illness is often more successful when families and loved ones are involved. So it is even more critical that we look after our caregivers. Better care for caregivers will improve the prospects for recovery of the ill, and improve the quality of their care.' ('Anderton launches Schizophrenia Awareness Week', Government Press Release 7/3/06)
- One woman expresses gratitude for respite and realism about its limitations. 'Ms Carmichael says she's grateful for all the help she does get, and knows here is not an unlimited budget for around-the-clock care in the home'. At the same time, she is frustrated by repeated reassessments which make her anxious that her entitlement to support will be reduced. ('Daily struggle with little help', Manawatu Standard 25/9/06 p1)
- A very recent debate raises issues about the value of the lives of people with disabilities, and the 'burden' they may impose on families. The NEW ZEALAND Herald (www.New Zealandherald.co.New Zealand 6/11/06) briefly referred to a

British newspaper report in which doctors are calling for consideration of euthanasia of seriously disabled newborn babies. 'The college is arguing that ‘active euthanasia’ should be considered for the overall good of families, to spare parents the emotional burden and financial hardship of bringing up the sickest babies. ‘A very disabled child can mean a disabled family,’ it says.' (‘Doctors: let us kill disabled babies’, The Sunday Times, Britain, 5/11/06) This also raises questions about the views of society about the role of caregivers and how much can or should be expected of them.

- Informal caregiving may sometimes impose risks for the recipient. Three articles report on ‘elder abuse’, including physical and financial abuse, noting 70 per cent is carried out by family members. (‘Call to bring elder abuse into the open’, Stuff: The Press 1/4/06; ‘Elder abuse not acceptable, says Dyson’, New Zealand Government Press Release 16/6/06; ‘Elderly abuse victims on rise’, Stuff: North Shore Times 26/6/06)
- Another story reports the difficulties of two sisters, Susan, who has cerebral palsy, and Theresa who has cared for her. Susan moved into a supported living situation 18 months earlier, and has recently taken out a trespass order against her sister. From Theresa’s point of view, she is worried about the care her sister is getting and believes she has been manipulated by the formal caregiving services; from the perspective of an advocate of Susan’s, she is 'getting excellent care and…blanking her sister was her own choice'. (‘A sister’s struggle’, The Press 17/6/06 p5) A human rights commissioner says the key issue is disabled people making their own choice. 'Sometimes they need support to be able to make the choices that are right for them and sometimes their family members might not like it, but they may be part of the problem too.' (‘Disabled woman bans sister’, The Press 17/6/06 p2)
- Child, Youth and Family Minister Ruth Dyson paid tribute to caregivers during ‘Foster Caregivers Awareness Week’, saying 'Caregivers hold a unique place in our society, which is often not fully recognised, valued or appreciated'. She mentions nearly 3000 caregivers for Child, Youth and Family, but also recognises '…thousands of other caregivers around the country, working for non-government organisations and in less formal arrangements such as relatives looking after extended family members.' (‘A time to remember caregivers’, New Zealand Government Press Release 29/10/06)

FORMAL CAREGIVING

- There are a number of references to the lack of training, poor pay and conditions for formal caregivers, and the flow-on effects of these for recruitment and retention. (‘Dyson taking up the cause of caregivers’, The Timaru Herald 26/7/06 p3; ‘Drumming up support for aged care sector’, Stuff: Taupo Times 19/7/06; ‘Home caregivers count the cost of working’, The Press 25/5/06 p5; ‘Disability support workers consider strike action’, Radio New Zealand Newswire 3/11/06 at 06:02:36) This has been exacerbated by the higher wages offered by District Health Boards compared with the private aged care sector. (‘Staffing crisis risks lives of the elderly’, The Press 16/9/06 p1)
- Provider Rhyder Cheshire is reported to pay significantly more for people with seniority and experience, and to support its caregivers with training. Most caregivers are women, who are generally paid less than men. (‘Suffrage Day: Ending Pay Discrimination’, Council of Trade Union Press Release 20/9/06)
- A particular issue for some community caregivers is the cost of their travel for work. Although some funding had been made available to reimburse this, it was slow to be passed on to the workers, with concerns it would go to administration

instead. ('Dyson taking up the cause of caregivers', The Timaru Herald 26/7/06 p3; 'Lengthy wait for caregivers' pay rise draws criticism', The Timaru Herald 20/8/06 p3; 'Caregivers' contracts agreed', The Timaru Herald 5/10/06 p2)

- Offering short-term respite is not 'attractive' to providers, who would rather fill a bed permanently. ('Shortage in respite beds, care', The Press 20/7/06 p4)
- All these things impact on informal caregivers, limiting their options for respite care and home help support. Inevitably, the responsibility for care falls back on family members. A woman reports keeping her teenage son home to help when the paid caregiver did not turn up. ('Home caregivers count the cost of working', The Press 25/5/06 p5)
- Concerns about the care being provided by Focus 2000 led to an independent review. ('Focus still short of answers', New Zealand Herald 24/6/06; 'Full review of care agency as complaints rise', The Dominion Post 24/2/06 p2) Again this has major impacts for informal caregivers – if they cannot be confident about the care their family member will receive in formal services they will be reluctant to use them.

GRANDPARENTS AS CAREGIVERS

- An estimated 4000 grandparents in New Zealand are caregiving for grandchildren. They may receive a weekly Unsupported Child's Benefit, but this is $20-30 per week less than non-family foster caregivers receive. The Government had agreed in 2005 to remedy this inequity and grandparents were lobbying for action on this promise. ('Grandparent-caregivers count the cost of a broken Budget pledge', Scoop: The New Zealand Herald 30/5/06; 'Grandparents suffer from broken Budget promise', United Future New Zealand Party Press Release 31/5/06; 'Grandparents Deserve Fair Go', National Council of Women Press Release 6/6/06; 'Grandmother joins plea for support', The Dominion Post 23/9/06 p3; 'Time for equity for grandparents', Joint Media Statement by Grandparents Raising Grandchildren/Age Concern New Zealand /Grey Power New Zealand Federation/National Council of women of New Zealand, 16/10/06)
- If grandparents or other kin caregivers did not undertake this role, it would fall to, and cost, other social agencies. ('Grandparents suffer from broken Budget promise', United Future New Zealand Party Press Release 31/5/06) Indeed, grandparents may be requested to take on this responsibility by Child, Youth and Family. ('Grandparents continue to suffer', United Future New Zealand Party Press Release 29/8/06)
- Grandparents caregiving face financial pressure, particularly as they may be on a pension and have limited employment options. ('Grandmother joins plea for support', The Dominion Post 23/9/06 p3) Low income also disadvantages the grandchildren being cared for ('Grandparents Deserve Fair Go', National Council of Women Press Release 6/6/06)
- Grandparents' own health may be declining. ('Grandmother joins plea for support', The Dominion Post 23/9/06 p3)
- Grandparents are committed to the care of their grandchildren and believe care by family members is superior to out-of-family foster care. ('Grandmother joins plea for support', The Dominion Post 23/9/06 p3) At the same time, they may feel they have no choice but to care for these children ('Grandparent-caregivers count the cost of a broken Budget pledge', Scoop: The New Zealand Herald 30/5/06)
- Respite care in various forms would also help grandparents who are caregiving. 'The toughest part was not being able to take a break. A subsidy for a school

holiday programme or after-school care would be a big help, she said.' ('Grandmother joins plea for support', The Dominion Post 23/9/06 p3) A weekly support group for grandparents caregiving for grandchildren is reported to be held at Omaka Marae. ('Grandparent caregivers day at marae', Stuff: The Marlborough Express 19/4/06)

- Non-kin foster caregivers are also recognised to need some respite as their role can be stressful, particularly when they are looking after children with behavioural difficulties. ('Turner: Labour talk is cheap on foster care', United Future New Zealand Party Press Release 31/10/06)