



Financial support for family carers

Providing financial support to family members who are caring for people experiencing ill-health, disability, mental illness or addiction, or frailty in their old age.



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INTRODUCTION

This paper responds to a request from the Minister of Labour in May 2007 for a think piece by the National Advisory Council on the Employment of Women (NACEW) on providing financial support to family carers.

Background

NACEW was established in 1967 as an independent advisory body to the Minister of Labour on matters related to women and employment, and charged with the following responsibilities:

- i. to advise the Minister of Labour on matters referred to him/her concerning the employment of women
- ii. to express views and make recommendations as appropriate to the Minister of Labour on matters relating to the employment of women
- iii. to make representations or submissions as appropriate to public bodies such as Commissions of Enquiry, subject to the approval of the Minister
- iv. to promote the dissemination of information on the employment of women in New Zealand and overseas.

NACEW's approach

Two-thirds of unpaid carers are women who are mainly, but not exclusively, family members. Enabling women to have meaningful choices about balancing paid work with participation in family and community life has been a focus of NACEW's deliberations over its forty years in existence.

Recognising the value, and contribution, of formal care services is essential to the support of informal carers. As the work of paid carers becomes recognised and more appropriately remunerated, the terms and conditions of the workforce improve, and workforce issues such as retraction, retention, and skills shortages are reduced.

Pivotal to supporting parents' work choices and parenting has been the valuing of childcare and improvements to the quality, quantity, and affordability of formal child care services. Affordable, quality formal care services are also the lynchpin for supporting meaningful choices for family carers.

Outline of this paper

The paper first discusses the number and characteristics of family carers and the drivers behind New Zealand taking a new look at its policies for care giving for people experiencing ill-health, disability, mental illness, addiction or frailty in their old age. It then looks at family care-giving in the international context of country policies on care. It identifies the principles that NACEW consider should underpin policies on family care-giving, the implications these have for paying for family carers, and makes recommendations for moving forward.

The Terms of Reference for this paper on providing financial support for informal carers is attached as Annex One. Annex Two contains the supporting analysis behind NACEW's recommendation to increase formal care services, and improve their quality as the key support to family carers.

THE EXTENT OF FAMILY CARE, AND CARERS' CHARACTERISTICS¹

Estimates for most other developed countries are that between 20-25% of all adults provide some unpaid care.

In the 2006 New Zealand Census, approximately 420,000 people aged 15 and over indicated that they had provided care to someone with ill-health or disability in the previous four weeks. The proportion of people reporting unpaid caring work in the previous four weeks was:

- 7.8 percent (6.3% of men, 9.1% of women) caring for an ill or disabled household member;
- 9.1 percent (6.5% of men, 11.5% of women) caring for an ill or disabled adult not living in their household;
- 16.2 percent (11.4% of men, 20.6% of women) caring for a child not living in their household.

Around two-thirds of all carers were women, and women aged 45-64 were the group most likely to be providing care to ill or disabled adults or children (38% of all carers in 2006).

Māori and Pacific people (both men and women) were significantly more likely to provide unpaid care. For example, 12.6% of Māori (9.7% of men, 15% of women) and 12.7% of Pacific people (10.5% of men, 14.7% of women) reported caring for a member of their own household who was ill or had a disability.

Analysis of the 2001 census data indicated that the proportions of Māori and Pacific family carers were particularly high for the 15-24 and 25-44 age groups². This is in line with United States research showing that carers from non-European back-grounds were on average younger, more likely to live with the care recipient and more likely to have multiple caring responsibilities including children and adults with disabilities³.

¹ Information in this section is largely sourced from an unpublished paper (October 2005) by the other carers working group that contributed to the development of the government's "Choices for Living, Caring and Working" plan of action updated with 2006 census data.

² Statistics New Zealand, data from the 2001 and 2006 Census of Population and Dwellings. There is no data on informal care provided by those aged under 15.

³ National Alliance for Caregiving and AARP, Caregiving in the U.S., Metlife Foundation, April 2004 (cited in the Other Carer's paper).

DRIVERS FOR A NEW POLICY ON FAMILY CARERS

The government is working with the New Zealand Carers Alliance to establish a New Zealand Carers Strategy (Ministry of Social Development and New Zealand Carers Alliance, 2007). This initiative reflects a number of imperatives.

As baby boomers age, the fiscal costs of providing care is a driver for countries, including New Zealand, to encourage home-based care. This trend is reinforced by both younger and older people generally preferring to receive care at home rather than in institutions. There is also evidence that earlier and less intrusive interventions make a difference to people being able to live independently at home, or in community settings.

Consumers want greater choice regarding care, and more equitable funding of care across different settings. While funding for home-based care has been increasing, demand has grown even more. The quality and reliability of formal services provided in the home has been compromised by the industry being low paid with poor employment conditions and high turnover (39% in 2005/06: NACEW, 2007). This, in turn, has increased pressure on family carers.

To a greater extent than ever before, women aspire to economic independence and full participation in society. This is reflected in the government's 10 year plan of action, Choices for Living, Caring and Working, which aims to enhance the choices parents and other carers have to balance paid work with care and other aspects of their lives (New Zealand Government, 2006).

Family carers face workforce disadvantage, particularly when they need to work short hours. Family carers who withdraw completely from the workforce face barriers accessing employment.

In the 2001 Census, people aged 25-64 who worked part-time were more likely to provide unpaid care than full-time employees. At all ages and across all ethnicities, people who identified themselves as unemployed were the most likely to report providing unpaid care in the last four weeks. The heavier informal care responsibilities carried by Māori and Pacific families are particularly concerning, given that this reinforces the wage and income disadvantage that these groups already experience.

The increasing labour force participation of the traditional group of unpaid family carers, namely female relatives, is placing a double burden on working age carers. While workforce participation tends to fall as hours of care increase, many people manage to combine paid employment with high levels of care. Pressures on individual carers are likely to intensify with the impact of ageing on the numbers of people needing care, and the shrinking of localised family and friendship networks (Davey and Keeling, 2004; HREOC, 2007). This is likely to increase multiple caring responsibilities for some family carers, which in turn makes them vulnerable to exclusion from other aspects of life.

Finally, there is growing recognition of the contribution of family care and the rights of family carers. Objective 15 of the New Zealand Disability Strategy (2001) is to "Value families, whanau and people providing ongoing support". Actions to achieve this include taking account of the needs of family in needs assessment processes, improving the

support and choices they have and providing education and information for families with disabled members.

The New Zealand Carer's Alliance has also stressed the importance of valuing and respecting the role and expertise of these carers. Without supports, family caregivers cannot maintain their caring role, their health, and a normal life (involving employment, leisure and time for other family) without stress.

A further equity issue for informal carers concerns their right to jobs. A recent, preliminary judgement by the European Court of Justice, in respect of a carer who was forced out of her job for demanding flexible hours to look after her disabled son, was that this was "discrimination by association" and that European Union laws that guarantee fair treatment at work for disabled people extended to those connected with them.

THE POLICY CONTEXT FOR SUPPORTING FAMILY CARE-GIVING⁴

International approaches

Internationally, the high level objectives of government policies on care-giving are similar and cover: the wellbeing of clients; supporting family and other relationships, and fiscal prudence. Specific country policies, however, tend to reflect assumptions around family and unpaid family work, as much as they reflect research on what works best.

Lundsgaard's (2005: 12) investigation into the long-term care of older persons, which explored five main country contexts for family care in OECD countries (New Zealand was not included in the study), showed the importance of cultural norms as well as financial incentives in different approaches to care. He identified:

- countries where long-term care primarily occurs informally within families even though nursing homes and other residential care is predominately publicly funded (Korea, Spain);
- countries where there are high levels of public funding used for formal services provided in homes as well as for institutions (Netherlands, Norway and Sweden);
- countries where a significant share of the funding for long-term care is used to fund family care through either granting allowances to care recipients who can then choose their carer (Austria, Germany and Luxembourg), or through allowances to family carers (Australia, Ireland, United Kingdom);
- in Japan, there is substantial family care, with no financial support. Formal care alternatives are growing as a result of mandatory long-term insurance;
- in the United States and Canada, an increase in consumer directed care has introduced limited arrangements where relatives can be paid.

Formal care services and family care in New Zealand

New Zealand's current policies are closest in approach to the Australia/Ireland/United Kingdom model of providing support directly to carers. Policies include relief care for family carers (which other family members from another household can be paid to provide at a reduced rate), an income and asset tested benefit (DPB for carers), and a non-means tested child disability allowance paid to families. Many countries provide more for family carers than New Zealand does. Small, non-means tested allowances are paid to family carers in Australia and Ireland, for example.

⁴ In broad terms, family care-giving refers to the unpaid care of children (including disabled children), and the care of other working age adults and older adults, arising from frailty, illness or disability. Typically family carers are relatives or partners, but sometimes are friends, or other close associates.

This discussion excludes the predictable care requirements of children for pre-school, after school and out of school care, along with the predictable needs of mothers and other parents for leave; that is, the bulk of unpaid care of children carried out by parents. Family care includes routine and non-routine and emergency care. Routine care is ongoing and anticipated, whereas emergency care arises with an event that cannot be predicted with any certainty and is likely to be sporadic and intensive. It can be long-term, as is the care of a disabled child or an older person who is chronically ill, or it can be short-term care.

The proportion of GDP spent on publicly-funded care services in New Zealand appears to be low; in a 2000 comparison on public expenditure on long-term care for older people, New Zealand had the second lowest (next to Spain) share of GDP spent on long-term care for the elderly. The expenditure was relatively low even when adjusted for different population profiles (OECD, 2005).

In 2005-06, NACEW estimated that there were around 40 - 50,000 formal carers in New Zealand with around 18,000 - 20,000 providing care for clients at home, and the rest working in residential institutions (NACEW, 2007).

Care services in the home are accessed in several ways: ACC provides services for people disabled by accidents; Disability Supports are provided to people with long-term needs through Ministry of Health Disability Supports (if aged under 65) and District Health Boards (aged over 65), usually following a formalised needs assessment process; and care services are provided when leaving acute care in hospital. While all processes refer to the need to take into account informal family carers, there is no explicit guidance on what this should mean in practice for formal care provision. There are only limited provisions within formal care packages to pay family carers. ACC, for example, sometimes employs family members to provide care.

Many people in need of care at home are not receiving comprehensive packages of formal services. This means a sizeable care load is being carried by family carers. Davey and Keeling's (2004) study of workers with eldercare responsibilities in two New Zealand City Councils found that while the vast majority of working carers were providing less than 10 hours' care a week, some were combining employment with more than 20 hours of unpaid care.

There are cases where almost all the care is provided by family carers and this is reflected in the DPB for carers, and relief care, being largely focused on the needs of full-time family carers.

Goodhead and McDonald (2007:25) argue that New Zealand views about where 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 family members.

NACEW'S POSITION ON FAMILY CARERS

To determine NACEW's view on financial support for family care giving, three possible policy approaches to family care-giving were considered (the full analysis is in Annex Two). They are:

- **mandated family responsibility** – the family is obliged to offer in-kind or monetary payment for services
- **government payments and supports to family caregivers** to provide relief, or to help them cope with the short and longer term costs of care-giving
- **increased formal care** so as to allow family members to stop or reduce care (adapted from Kane and Penrod, cited in Guberman, 1999: 63).

NACEW's conclusion is that the most important support base for family carers is the quality and quantity of formal care services available to clients at home.

Comprehensive quality services will give family carers the confidence to make normal life choices without worrying about the care their loved one is receiving. As we recommended in our report *Improving the Quality of Work for Women in the Homecare, Residential and Cleaning Sectors*, improving the quality of the formal services provided in the home requires the precariousness of employment to be addressed. Precarious work undermines the self esteem and wellbeing of workers, and is associated with low investment in skills, low morale and high turnover (NACEW, 2006).

Skilled, supervised and supported workers are critical to the provision of competent, safe, reliable and empathetic quality care services. Comprehensive packages of care, based on need, would legitimate family carers' rights to a normal life. The transition NACEW recommends occur is parallel to the transition that has occurred in relation to pre-schoolers where parents can now feel confident that early childhood services provide quality care and education. The majority of mothers of pre-schoolers, as well as fathers, now choose to undertake some paid work.

The importance of the affection, support and contact with others that family carers provide to ill or disabled loved ones cannot be underestimated and cannot easily be replaced by formal services. In NACEW's view, this is the core role of family carers. Formal care is a complement to this core family role. British studies have found that the provision of complementary services to people needing care is an incentive for individuals to take on care responsibilities, because they know they will not be faced with the full responsibility (Woolley, 2001).

Assumptions that family members can provide large amounts, and sometimes 24/7, care, are unfair, because they:

- make it difficult for some carers, including young carers, to manage education or work as well as providing care,
- impose a double burden on carers who are in work, studying or have other caring roles, and
- take a toll on older carers who are nominally "retired".

Anecdotal evidence also suggests that some people advocate for comprehensive care packages more effectively than others. Some are also far more vulnerable to being persuaded into taking on a large informal caring role. Studies on family carers show they are at high risk of social exclusion – in other words, to limited social interaction, impoverishment, being out of job and not accessing services⁵.

There are substantial economic costs for these family carers, as they are often trapped in situations of low status and low or no pay, even after their caring responsibilities cease. Moreover, the economic costs are greater for Māori and Pacific populations than Pākehā populations. These problems are likely to get worse as the population ages and women's labour force participation continues to increase.

NACEW supports greater clarity around the expectations of family roles and formal care services, so that:

- transparent guidelines counterbalance the current incentives for many funders to reduce home-based services where there are strong supports available
- families and individuals who provide care are not unduly burdened
- the responsibility for providing personal care and specialist supports rests with funder or their agent, not with family carers.

There is scope within a framework like this to employ and pay family carers as part of the formal package of care. This occurs already in ACC and is common in countries where budget or direct payment approaches give consumers a greater choice over the specifics of care they receive.

Providing an option to employ family carers to perform substantive caring tasks is fairer and more efficient than having a separate stream of support for family carers. Separate support systems for family carers have a number of problems including:

- the appropriateness of legitimising some full-time caring roles, for example for young people and people over retirement age
- long-term, full-time caring roles, such as those supported through the DPB for carers, conflict with labour market objectives for women, as well as having risks of poor health and social exclusion
- carers who can only earn a low wage⁶ are likely to face disincentives to take on employment, which will entrench their labour market disadvantage (Lundsgaard, 2005)
- cultural factors, as well as physical and emotional needs, impact on the provision of family care, and make it difficult to identify the roles that should be paid for
- whether all carers should be paid, or just those not in employment (akin to the wages for housework dilemma).

⁵ These indicators are more fully discussed in Saunders 2007.

⁶ Of all recipients of the DPB (CSI), 58 per cent had been on this benefit for over twelve months, and 38 per cent for two years or more.

A new framework for supporting family carers

NACEW supports a framework for family caring that is based on the following principles:

- that the unique contribution of family carers is the provision of emotional and associative care and this needs to be recognised and valued as a priority
- that formal care packages are comprehensive responses to the intensity of a client's needs, and do not make assumptions about the family supports available
- that a client and their family members can opt for greater family involvement in care arrangements and negotiate the basis of their involvement within the care package provided
- that individual family members who are contracted into explicit service roles have similar protections and rights as other workers.

What does the NACEW position mean for financial support for family carers?

Would people who care for another family member receive financial assistance from the government?

Paid roles for family carers would need to be agreed by the client and the family carer as part of a comprehensive client care plan. Any paid role taken on by family carers would be explicitly included in this plan as a replacement for a service that would otherwise be provided formally.

Family members and friends would not be paid for the normal activities of relatives and friends, such as providing emotional support and helping people stay in touch with their friends.

Under what circumstances should the government provide financial support to such carers - e.g. short-time versus long-term caring situations; where a person has had to reduce or give up their paid employment to assume their caring responsibilities; or whether or not a paid, formal carer is available to support the family?

The payment would be made for explicit roles required within customised client care plans. Family carers could have other paid employment. The only requirement for a family member to receive payment for care work would be that they provide the designated services. The arrangement is most likely to occur when the care need is long-term and predictable, as in the case of a person with tetraplegia, or short-term and intensive, such as the care of someone who is terminally ill.

What would be the objective(s) of providing financial assistance to such carers – e.g. to compensate a carer for lost earnings where they have reduced or given up paid work to provide care; to offset the costs incurred from caring for another person; or as a payment for services provided?

The objectives of providing payments to family carers would be to:

- enhance the choices of people being cared for and the choices of their family carers
- extend the range of options in developing quality care plans through incorporating family carers
- value family carers and compensate them for designated roles beyond the things that family members normally do for their loved ones.

What level of financial support should be provided – e.g. should lost earnings be fully or partly replaced; should costs be fully or partly met; or should a family member be paid at the same level as a paid care worker?

As the family member would be contracted to undertake specific tasks, they would be paid the market rate for the tasks being performed. In other words, payment would equate to that received by workers delivering formal care services.

How would the provision of financial support interact with other entitlements available to such carers – e.g. should employees who have access to job-protected leave also be entitled to financial assistance; what other assistance is available to a carer including social assistance provided by ACC and Work and Income; or what other financial assistance might a carer need in addition to assistance the person being cared for already receives (i.e. the needs of carers separate to those of the person needing care).

NACEW supports the recent legislative provision which gives family carers the right to request flexible work arrangements to manage caring responsibilities. Because care needs can be short or long-term, and are not necessarily predictable, it would be unfair on employers to expect job protection arrangements to cater for every caring situation, particularly long-term arrangements.

Where family carers are involved on a long-term basis, NACEW supports continued improvements to provisions for leave and requesting flexible work hours to give more carers the opportunity to maintain their paid employment at the same time as being involved in care.

Where a family member is contracted to provide care, they would, in effect, be an employee or self-employed and receive training, ACC cover, Kiwisaver entitlements, and pay tax on the same basis as any other paid worker.

NACEW envisages that relief care arrangements and the child disability allowance would still be available.

RECOMMENDATIONS

1. The core role of family carers be recognised as providing emotional and associative care, which cannot be easily replaced by formal services.
2. The best way to support family carers is to complement their core role by ensuring there are comprehensive care services for clients at home, through increasing the quality and quantity of formal care services.
3. As recommended in our report *Improving the Quality of Work for Women in the Homecare, Residential and Cleaning Sectors*, improving the quality of the formal services provided in the home requires the precariousness of employment to be addressed.
4. That care plans and packages be based on the level of client need, not on assumptions of the availability of family care.
5. That clients and family carers, in consultation with funders, can opt for some aspects of care packages to be undertaken, for pay, by family carers.

BIBLIOGRAPHY

Davey, Judith A, and Sally Keeling (2004) *Combining Work and Eldercare*, New Zealand Institute for Research on Ageing, May

Department of Trade and Industry (2007) The third work-life balance employee survey: Main findings Employment Relations Research Series No 58 www.dti.gov.uk

Feinberg, Lynn Friss, Kari Wolkwitz, and Cara Goldstein (2006) *Ahead of the Curve: Emerging Trends and Practices in Family Caregiver Support* National Center on Caregiving Family Caregiver Alliance, March downloaded 15 September from http://assets.aarp.org/rgcenter/il/2006_09_caregiver.pdf

Fursman, Lindy, 2007 *Carers' Leave: A summary of the literature, research gaps and next steps* Unpublished paper, Department of Labour

Goodhead, Anne and Janet McDonald (2007) *Informal Caregivers Literature Review: A report prepared for the National Health Committee* Health Services Research Centre, Victoria University of Wellington

Guberman, Nancy (1999) *Caregivers and caregiving: New Trends and their implications for policy* Final report prepared for Health Canada Department de Travail social, Universte du Quebec a Montreal

Human Rights and Equal Opportunity Commission (2007) *It's about time: Women, men work and family* downloaded on 28 September 2007 from www.hreoc.gov.au

Lundsgaard, Jens (2005) *Consumer Direction and Choice in Long-Term Care for Older Persons, Including Payments for Informal Care: How Can it Help Improve Care Outcomes, Employment and Fiscal Sustainability?* OECD Health Working Papers No 20, May

Minister for Disability Issues (2001) *The New Zealand Disability Strategy: Making a World of Difference Whakanui Oranga* Ministry of Health, Wellington

Ministry of Social Development and NZ Carers Alliance (2007) *Caring for New Zealand Carers*, July

NACEW (2006) *Improving the Quality of Work for Women in the Homecare, Residential and Cleaning Sectors* downloaded on 17 January 2008 from www.nacew.govt.nz/publications/quality/background/

National Health Committee (1998) *How should we care for the carers? Better support for those who care for people with disabilities*

New Zealand Government (2006) *Choices for Living, Caring and Working: A ten year plan to improve the caring and employment choices available to parents and carers* downloaded on 20 September 2007 from www.dol.govt.nz

OECD (2005) "Ensuring quality long-term care for older people" Policy Brief *OECD Observer* March

Other Carers Working Group (2005) *Enhancing Parents' and other carers' choices* unpublished contribution to the development of "Choices for Living, Caring and Working" plan of action, October

Saunders, Peter (2007) "Towards New Indicators of Disadvantage Project: Bulletin No 3: Social Exclusion in Australia" *Social Policy Research Centre Newsletter* November

Woolley, F. (2001) 'The strengths and limitations of the voluntary sector' *ISUMA: Canadian Journal of Policy Research* 2 (2), pp. 21–27.

ANNEX ONE: TERMS OF REFERENCE

Scope the possible policy approaches that could underpin the provision of financial support to unpaid family members who care for a person(s) experiencing ill health, disability, mental illness, addiction or old age. This will include the implications of the different principles that might underpin approaches to the provision of financial support and identifies the strengths and weaknesses of the different approaches.

In scoping the possible policy approaches, the report will consider the following questions:

- Should people who care for another family member receive financial assistance from the government?
- Under what circumstances should the government provide financial support to such carers - e.g. short-term versus long-term caring situations; where a person has had to reduce or give up their paid employment to assume their caring responsibilities; or whether or not a paid external carer is available to support the family?
- What would be the objective(s) of providing financial assistance to such carers – e.g. to compensate a carer for lost earnings where they have reduced or given up paid work to provide care; to offset the costs incurred from caring for another person; or as a payment for service provided?
- What level of financial support should be provided – e.g. should lost earnings be fully or partly replaced; should costs be fully or partly met; or should a family member be paid at the same level as a paid care worker?
- How would the provision of financial support interact with other entitlements available to such carers – e.g. should employees who have access to job-protected leave also be entitled to financial assistance; what other assistance is available to a carer including social assistance provided by ACC and Work and Income; or what other financial assistance might a carer need in addition to assistance the person being cared for already receives (i.e. the needs of carers separate to those of the person needing care).

ANNEX TWO: ANALYSIS OF POLICY APPROACHES TO FAMILY CARE-GIVING

NACEW considered three possible policy approaches to care-giving to assess its position on financial support for informal care giving. They are:

- ***mandated family responsibility*** – the family is obliged to offer in-kind or monetary payment for services;
- ***payments and supports to family caregivers*** to provide relief, or to help them cope with the short and longer term costs of care-giving; and
- ***increased formal care*** so as to allow family members to stop or reduce care (adapted from Kane and Penrod, cited in Guberman, 1999:63).

Mandated family responsibility

Some family responsibilities are mandatory; there are legal requirements on parents to provide care for their non-adult children and on spouses to care for each other. NACEW is concerned that interpreting these obligations as a responsibility for extraordinary care places an overly large burden on individuals, mainly women, who are required to care for severely disabled family members. This, in turn, restricts the opportunities for those family carers to have a normal life. There is also evidence that heavy obligations to care trigger breakdowns in care arrangements and in wider family arrangements⁷.

Historically, care responsibilities taken on by other family members (such as children caring for parents, and parents caring for adult children) have reflected obligations and expectations more than legal requirements. These obligations are more common in some cultures and families than others, but appear to be on the decline across the population as a whole, and do not sit comfortably with contemporary views on individual rights and independence.

Existing welfare payments broadly reflect an expectation of family responsibility. The Domestic Purposes Benefit (Care of sick and infirm) (DPB (CSI)), is available where the care recipient would otherwise be in hospital, receiving 24/7 care. The DPB is income and asset tested and not available to full-time carers who have other family income from wages, working partners, or National Superannuation. Carers who are married to an invalid receive a benefit due to their partner being eligible, rather than as recompense for the care they provide. This benefit is also abated against other income, such as employment earnings.

The mandated family responsibility approach would have the lowest direct costs to government in terms of providing care, but high indirect costs in terms of the costs for carers and costs due to poor quality care. The costs to carers are documented in research – and include stress, poor physical and mental health, loss of employment, poverty, loss of social connectedness, and negative impacts on leisure and family life. These impacts can flow on to clients; for example a New Zealand study of employees

⁷ For example there are children in CYFS care due to the breakdown of family care as a consequence of high needs rather than abuse or neglect.

involved in eldercare found that seven in ten carers who spent 20 hours or more providing care had negative feelings about their caring role (Davey and Keeling, 2004). In its pure form, this model assumes that families will be the best carers for their family members and does not provide any funding for alternative care. Under this model, a choice to have an alternative care arrangement depends on a person's ability to pay. The model does not come from a carers' rights perspective; it rather assumes that care is a natural task of families and is arguably somewhat blind to the often negative long-term consequences for the carer, as well as to the quality of care.

Overall, the family responsibility model is archaic in its expectations of most family situations, is not sustainable into the future, and out of step with contemporary views on individual rights as well as government policies promoting economic independence at the individual level. It does not align, for example, with government policy on *Choices for Living, Caring and Working* aiming to enhance the choices of parents and other carers.

Payments and supports to family caregivers

Recognition of family carers can be provided through tangible contributions to costs, employment-type benefits and payments for tasks. In New Zealand, the non-means-tested subsidies available for family carers to purchase respite care, and the ability to take sick leave to care for family members, are the main examples of such payments and supports. New Zealand's payments are less generous than those of Australia and Ireland where non-means tested allowances are paid to family carers.

In Sweden, France and Italy, family carers accrue social security entitlements (paid leave, pension etc), and similar legislation is being considered in Germany. Leave and/or flexible work are other provisions that can assist family carers to maintain employment whilst caring⁸.

One benefit of paying family carers is that it assists the sustainability of what is often a preferred care arrangement. For example, it can be difficult for lower paid workers to combine caring and employment work. Payments can also be a lever for ensuring family carers undertake specific training (such as learning to lift an adult safely). Contracting arrangements around the care provided can be instituted to set parameters.

Where they are in place, direct payments to family carers tend to be set at a minimal level. This is no doubt linked to budget issues, but also reflects a number of dilemmas around such payments, including:

- paying carers not in employment is inequitable with respect to carers in employment who have similar care responsibilities (akin to the wages for housework dilemma⁹)
- cultural factors, as well as physical and emotional needs, impact on the provision of family care, and make it difficult to identify the roles that should be paid for

⁸ There is evidence to suggest that employees do not generally uplift unpaid leave and that flexible work arrangements and paid provisions are therefore more useful (Fursman, 2007).

⁹ In this regard, some European countries provide pension credits or equivalent to all parents, regardless of whether they are in or out of the workforce, as a recognition of the time demands of raising children.

- carers who can only earn a low wage¹⁰ are likely to face disincentives to take on employment, which will entrench their labour market disadvantage (Lundsgaard, 2005)
- the appropriateness of legitimising some full-time caring roles, for example for young people and people over retirement age
- long-term, full-time caring roles conflict with labour market objectives for women, as well as having health and isolation risks.

Legitimising family carers through paying allowances, providing more “leave”, improving respite arrangements and providing recognitions with arrangements such as Kiwisaver, is not likely to be cheap. Current provisions (primarily the DPB (CSI)) are minimal and do not, for example, include payments to full-time family carers who are receiving National Superannuation or have an earning partner.

The payment to family carers model lends itself to the idea of payments based on the caring “work load”. If this approach is taken, setting the payment within a client-managed (or client-professional – managed) budget would provide for clients to choose between a family carer or a service. It would also provide for the review of arrangements and for purchasing care from a number of sources, so that family carers are not overburdened. In this scenario, the payment would approximate the wage of a care worker, rather than bearing any relationship to opportunity cost of wages foregone.

A further option is to provide paid leave from employment for family caregivers. While paid leave on the birth or adoption of a child is common in developed countries, paid leave to provide family care for disabled or frail people is generally quite limited. The wage-related schemes that do exist are time-limited and only available to people who have employment. Sweden has the most generous provision of a statutory right to take up to 60 days leave at 80% of salary to care for a terminally ill relative. In Ireland and Canada, there are schemes providing 47% of average earnings and 55% of employment income respectively (Lundsgaard, 2005: 19).

In summary, there would be considerable and significant additional funding needed to legitimate and properly support family carers. The approach of paying carers directly is less robust than providing for the payment of family carers as part of a client budget, e.g. direct payments, especially through a different funder, cannot ensure family carers are educated for, and supported in their role. The wage paid would relate to the wage of care workers. The long duration of many caring arrangements appear to make wage-related payments, similar to those available in Sweden, unrealistic in the short to medium-term.

¹⁰ Of all recipients of the DPB (CSI), 58 per cent had been on this benefit for over twelve months, and 38 per cent for two years or more.

Increased formal care

Formal care has had bad press as a consequence of its past emphasis on institutional services. Even today, home-based services, whilst much expanded, offer highly restricted services, and the low wages in the sector are associated with high staff turnover and some difficulties in achieving continuity of services.

Recent literature emphasises the role of formal care as a complement to family care. This can be in a relief capacity, and also in undertaking more complex support tasks, and particularly the tasks that can undermine the personal relationship between a family carer and the client. British studies have found that the provision of complementary services to people needing care is an incentive for individuals to take on care responsibilities because they know they will not be faced with the full responsibility¹¹.

Formal services may also reduce carer stress, rather than substituting for informal care. Some surveys have found that family carers were not likely to significantly reduce their hours of care when formal care was provided, but instead spend this time on other caring or household tasks. Services, such as day centres, can also provide respite for family carers and enable them to take on some employment.

An emphasis on increasing formal care services is consistent with a move to managed budget holding by clients or their representatives, where budgets reflect the level of need. Such arrangements are not yet widespread in New Zealand. A comprehensive supply of formal home care services is also essential if family carers are to maintain their labour force attachment.

Greater consumer choice via budget arrangements often, but not always, leads to a preference for family care. In Germany, where people with long-term care insurance can choose cash or services, 73% opt for cash, and even at the highest level of support, 64% opt for cash. A frequent motive behind the choice was receiving care from family members (Lundsgaard, 2005:27). Studies in the United States similarly found that consumers valued the freedom to hire a family member, friend or neighbour (Feinberg et al, 2006: 15).

Adopting this approach would have significant budget implications due to the relatively small, though growing size of the budget for non-institutional care services. A more comprehensive approach may not be sustainable solely through publicly funded services. Insurance arrangements and part-charges for those with higher levels of wealth may need to be part of the solution.

While care costs are likely to increase under this model, they are likely to be offset by greater productivity through higher employment participation. Lundsgaard (2005) found that countries with extensive provision of formal home care, but only limited support for informal care (such as Scandinavian countries), had higher employment rates for women aged 50-59 than countries such as the United Kingdom, Germany, Austria and

¹¹ Luxton, M, "Families and the Labour Market: Coping Strategies from a Sociological Perspective," in D. Cheal, F. Woolley and M. Luxton, *How Families Cope and Why Policymakers Need to Know* (Ottawa: CPRN, 1998), p. 65. cited in Woolley, F, 2001.

Luxembourg, which had limited or average provision of formal home care but extensive financial support for informal care via cash allowances.

Overall, a greater emphasis on formal services that complement family care, and potentially enable the funding of family care within a managed arrangement, is likely to provide for better client care, and improved carer welfare and social inclusion.

Any payment for family carers would then fall out of their explicitly recognised role in providing care, as would other employment like responsibilities (tax) and benefits (Kiwisaver contributions, training, health and safety). Flexible work and leave arrangements for family carers would then be addressed as a separate issue from payment for providing care.

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