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# **Current state:** Carers of people with health conditions or disabilities

BACKGROUND PAPER

# Executive Summary

The purpose of this paper is to provide information on New Zealand's working-age carers, including how their caregiving roles affect them, and to describe the supports currently provided as well as the challenges with the current carer support system. The Government is committed to ensuring that all New Zealanders are earning, learning, caring or volunteering.

Individual, family, whānau and āiga carers are crucial to New Zealand's society. They enable those who require additional help to develop, live and participate in their communities, allowing for greater independence, autonomy, quality of life and social inclusion.

Levels of informal care vary across time and jurisdictions, influenced by:

- whether and to what extent there is a legal obligation to support relatives with health or disability needs
- the types of services that the state provides or funds
- opinions about whether the state or 'the family' should in general be responsible for care and support and to what degree
- cultural obligations or customs and family expectations.

In New Zealand and other OECD (Organisation for Economic Co-operation and Development) countries, there has been a shift towards the care of people with health conditions and disabilities being provided in community-based settings rather than institutions. This trend is likely to continue. Concern has been expressed that the increased expectations of individuals, families, whānau and āiga to provide care are not accompanied by sufficiently resourced support services.

Caregivers are most likely to be family members, often women of working age who are caring for older relatives, partners or children with health conditions or disabilities. However, there is considerable diversity within the caregiving population.

The impacts of caring are varied and they are mediated by the intensity of care provided. High-intensity caring is associated with negative impacts on income, physical and mental health, family functioning and social networks. The impacts of care are felt disproportionately across different population groups. The impacts of caring and the costs associated with caring are more intense for those who are already disadvantaged.

Government agencies provide a range of supports and services for carers. Here are a number of challenges with the current system:

- The majority of supports are targeted to the people being cared for, meaning carers often access support consequentially.
- The interface between the supports provided by different government agencies is complex. The types of carer supports available depend on the age of the carer and the care recipient, the type of care provided, who the carer provides care for, and why the care recipient needs care. It is complicated and time consuming to access the various supports available from different government agencies that address the varying needs a carer may have. The fragmentation of supports across government agencies poses a barrier to accessing the appropriate services. In addition, the current system is set up to provide supports only to people who self-identify as carers. Many people do not self-identify as carers, and this may be more common within certain population groups, for example Māori, Pacific People and younger carers, and those with children with health conditions or disabilities.
- Many carers need or want support to remain in work with reduced hours or more flexible working arrangements, but this is not always possible.
- Most family carers in New Zealand are not paid. However, some are eligible for support from the Ministry of Social Development, the Ministry of Health or the Accident Compensation Corporation depending on whether the health conditions or disabilities were caused by accidents or not. Thus people with similar caregiving roles may have different access to resources and the degree of income support and other support varies across the agencies.
- There is a lack of accurate data on carers, who they care for within the welfare system and what their experience is. The population is broader than that receiving the Supported Living Payment Carers' benefit. Some people are likely to be underrepresented in the welfare system as carers (e.g. young carers, those caring for adult children and carers of people with intermittent conditions).
- Supplementary benefits are available to carers. This funding is particularly important for those on fixed and lower incomes. Anecdotal evidence suggests take-up is lower than expected.
- The diversity of carers, the range of caregiving relationships and the contexts in which caring takes place are not generally well matched to support services, thus negatively affecting carers and the people they are caring for.
- There is limited provision for urgent financial support for carers of people (including children) who experience a sudden significant health shock, such as serious illnesses or major injuries e.g. major organ failure, terminal illness, serious car crash, injuries in an earthquake, to prevent their losing their livelihoods at the time of crisis.

There is potential to make the system easier to navigate and more flexible and responsive in order to meet the diverse needs of carers and achieve more equitable outcomes. There are also opportunities to create new services or payments to support the specific needs of carers, for example to help carers meet the costs of caregiving.

### **Key questions:**

- To what degree should the state or 'the family' in general be responsible for care and support? What is it reasonable to expect families to do?
- What is the role of the welfare system in supporting carers of people with health conditions and disabilities?
- How should carers of people with health conditions and disabilities be supported financially? Who should have access to that support?

# Supporting the needs of informal carers

The purpose of this paper is to provide information on New Zealand's carers, including how their caregiving roles affect them, and to describe the supports currently provided as well as the challenges with the current carer support system. The Government is committed to ensuring that all New Zealanders are earning, learning, caring or volunteering.

This paper focuses on working-age 'informal' carers of people with health conditions or disabilities. Informal care is founded on an unpaid, non-professional, 'caring relationship' between a carer and the person whom they care for (i.e. people with long-term conditions, ill health, disabilities, mental illnesses or addictions). The caring relationship has both a social element (there is a bond or attachment of some sort) and a physical element (certain tasks or responsibilities are undertaken by one for or with the other) (Becker & Becker, 2008). An important consideration for the concept of caring is recognition that the care provided is above and beyond what would usually be expected within a relationship.

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## How we think about caring

Much of the literature on care constructs dichotomies of formal or informal, paid or unpaid care (Cass et al., 2009). Another approach is to conceptualise social care in terms of the interconnections of paid and unpaid care through the life course. Daly & Lewis (2000 in Cass et al., 2009) focuses on three interconnected aspects of care:

- *Care is labour – paid or unpaid, formal or informal.* The blurred and changing boundaries are influenced by public policies<sup>1</sup>, which are also subject to change. Viewing unpaid care as labour makes it more visible (Cass et al., 2009). The historical invisibility of informal caregivers has lessened as demographic and social changes have highlighted their role and led to their contribution starting to be more valued (Goodhead & McDonald, 2007).
- *Care is embedded within a normative framework of obligation and responsibility.* Informal care tends to be provided under conditions of social (usually familial) relationships and responsibilities, making it inappropriate to consider the labour aspects of care alone (Cass et al., 2009). The bonds of love and reciprocity between caregiver and care recipient can obscure the role and contribution of informal caregivers (Cass et al., 2009; Goodhead & McDonald, 2007). Pickard (2004) argues for the importance of understanding that informal caring takes place in a relationship. This leads to consideration being given to whose interests are being served by interventions – the carer or the care recipient – and where the balance should lie. Carers and care recipients may have the same interests but not always (e.g. a carer may need respite care but the care recipient does not want to go).
- *Care is an activity that incurs costs that extend across public-private boundaries.* These costs include direct costs (e.g. expenditure and costs to physical and mental health) and opportunity costs (e.g. impacts on education, training, labour force participation, income earning and participation in social and friendship networks). Key questions include: what are the costs and benefits of providing informal care?; who should provide it?; and what is an appropriate balance between informal and formal care?

1 For example, the move away from institutionalised care towards increased community care.

Those taking a disability rights perspective challenge the notion that disabled people requiring support are dependent. From their perspective, policy should underwrite the independence of disabled and older people. They argue that focusing on the needs of carers diverts attention from the core problem – that care recipients are not getting the assistance they need to live lives like everyone else (Goodhead & McDonald, 2007; Pickard, 2004). Some people need considerable support to live everyday lives in the community, for example people with severe physical and/or intellectual disabilities.

Some researchers have argued that the best way to support carers is to provide good-quality core services, along with other measures aimed at people with health conditions and disabilities, reducing the need for the provision of informal care. The existence of a carer should not lead to a failure to deliver a service to the person being cared for (Pickard, 2004).

## Levels of informal care vary across time and jurisdictions

In most countries, including New Zealand, a significant amount of physical, emotional and practical support for sick, disabled and older people has been delivered through informal caregiving arrangements (Colombo et al., 2011; Haberkern & Szydlik, 2010). Within public policy there has been an assumption that the principal care and welfare of dependants will be met by family members, as opposed to care being provided by others (e.g. the paid professional workforce providing care in various settings).

Levels of informal care are influenced by:

- whether and to what extent there is a legal obligation to support relatives in need
- the types of services that the state provides or funds
- cultural obligations or customs and family expectations. Research has demonstrated differing beliefs, levels of support and physical and emotional outcomes among caregivers from diverse cultural backgrounds (Goodhead & McDonald, 2007; Hirsch et al., 2011)
- opinions about whether the state or 'the family' should in general be responsible for care and support (Haberkern & Szydlik, 2010). Note that, in New Zealand, this conversation is currently happening in the context of Funded Family Care (FFC). The development of a Government position on this is important, and should take into account societal expectations of the 'natural supports'<sup>2</sup> reasonable for family members to provide and the conditions under which the state needs to provide support to ensure the wellbeing of carers and those being cared for.

The relationship between state and family support services can be conceptualised as some combination of substitution, complementarity and the joint responsibility of family and state (Haberkern & Szydlik, 2010).

Historically, greater numbers of people with disabilities or mental health conditions were cared for in institutional settings, in both New Zealand and other OECD (Organisation for Economic Co-operation and Development) countries. In the 1970s and 1980s the demand from families and care recipients for more responsive social-care systems and a greater recognition of the human rights of people with health conditions and disabilities, combined with concern about the rising cost of institutional care, saw a shift in focus towards care being provided in community-based settings. In New Zealand, deinstitutionalisation<sup>3</sup> coincided with the

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2 The term 'natural supports' is not always clearly defined or understood. 'Natural supports' often refers to the resources inherent in community environments, including personal associations and relationships, that enhance the quality, and security, of life for people. Natural supports usually involve family members, friends, co-workers, neighbours and acquaintances. Some people have few natural supports and may need help with developing these connections.

3 Deinstitutionalisation involved moving people out of long-term psychiatric and psychopaedic hospital care into the community. This occurred from the mid-1970s onwards.

contraction of the welfare state in the 1980s. Concern has been expressed that the increased expectations of individuals, families, whānau and āiga to provide care were not accompanied by sufficiently resourced support services, as significant levels of care may be required for some people to remain living at home.

The demand on and for individuals, families, whānau and āiga who are providing home-based care is only going to increase:

- as more people needing care are living longer and often with more complex or chronic health conditions or disabilities<sup>4</sup>
- as consumers continue to demand support for people to be cared for in their own homes or communities rather than in institutional settings
- as technological and medical advances enable more people with complex health conditions or disabilities to live in the community, where previously they would have required care in institutional settings or not survived
- as governments struggle to fund the rising costs of long-term care associated with an aging population.

Other trends, such as declining family size, changing family composition and rising female participation in the labour market, are likely to lead to a reduction in the number of informal carers (Colombo et al., 2011; Fevang et al., 2008). At the same time the working-age population in OECD countries, including New Zealand, is expected to decline, constraining the supply of paid carers<sup>5</sup> at a time when demand is increasing.<sup>6</sup> The rising cost of paid care is likely to increase the expectation that informal carers (usually women) will combine paid work and caring. There could also be increased pressure on the state to provide residential care for people who do not have informal carers (e.g. people with disabilities currently cared for at home whose parents grow older and unable to care for them) (Colombo et al., 2011; Department of Labour, 2009). The contexts for caring are changing and it is important to consider the sustainability of formal and informal care in the context of growing and future demands. It is unclear what the ideal balance between formal and informal care is (Bauer & Sousa-Poza, 2015).

## In New Zealand, carers are a diverse group

Many New Zealanders will take on caring roles at some stage in their lives. Who ends up being a caregiver is often shaped by existing relationships, gender roles, cultural norms and expectations, and geographic proximity, as well as a host of other factors.

Caregivers in New Zealand are most likely to be family members, often women of working age who are caring for older relatives, partners or children with health conditions or disabilities. In 2013 there were around 430,000 unpaid carers<sup>7</sup>, making up 13% of the adult population. Of these:<sup>8</sup>

- 63% were women
- the median age was 49 years
- the largest age bracket was 50-54 years old.

4 Stats NZ estimates that by 2028 the proportion of the population aged 65 and over will increase from 15% to 19% – an increase of around 350,000 people. There is a correlation between age and the likelihood of disability and/or illness.

5 The OECD predicts that on average across OECD countries, the size of the working-age population as a share of the total population will shrink by about 9 percentage points, from 67% in 2010 to 58% by 2050 (Colombo et al., 2011). Added to this, caregiving jobs are typically lowly paid and therefore less attractive than others.

6 In absolute terms, by 2050 the demand for long-term care workers (on a full-time-equivalent basis) is expected to about triple in New Zealand (Colombo et al., 2011).

7 This includes people who provide help to others who are ill or have disabilities in their own households, and/or people who do not live in their households. The Census asks about caregiving in the previous four weeks only.

8 According to the 2013 Census and analysis from Infometrics.

Nevertheless, carers are a diverse group. Carers can be divided in a number of ways, including:

- by their own characteristics e.g. age, gender, ethnicity or cultural group, and socio-economic status
- by the characteristics of the people for whom they are providing care. Caregivers may be caring for their spouses, aged parents, children who have health conditions or are disabled (as children or adults), siblings or other relatives. The various types of care provided within these relationships can be complex, and this complexity may deepen depending on the reason for the care recipients needing care.

Overall, the ethnicity of carers generally reflects the ethnic mix of the wider New Zealand population, although among unpaid carers:

- Māori and European New Zealanders have the highest propensity to provide unpaid care in general
- compared to other ethnic groups, a higher proportion of European New Zealanders provides unpaid care for non-household members than for household members
- a lower percentage of Asian and other ethnicities provides unpaid care.

However, the data available provides an unbalanced and ad-hoc picture of the carer population. In particular, there are gaps in the data for specific population groups and their experiences of care. For example:

- young carers are likely to be undercounted – according to the Census in 2013 there were approximately 40,000 carers aged between 15 and 24 years (8%). However, the Ministry of Social Development (MSD) knows anecdotally that there are children younger than 15 years who provide care for family members, including grandparents (Enoka, 2015).<sup>9</sup> People under 15 years old providing care would not have been picked up in the Census. They will not be trained as carers
- older carers who look after partners, or grandparents who care for grandchildren (who disproportionately have health conditions or disabilities) may be undercounted as they do not self-identify as carers (e.g. in surveys) or know they can seek assistance (and hence be counted)
- patterns of caregiving amongst carers from culturally and linguistically diverse backgrounds are not well understood. Perceptions of caring, health and disability are culture-bound. Māori and Pacific People are more likely to choose family care and less likely to access formal supports and services. In this context Māori and Pacific carers may not self-identify as carers. However, informal caring amongst Māori and Pacific families may also occur due to the lack of culturally appropriate carer support services
- those caring for people with poor mental health may be underrepresented in carer statistics. Such carers may not self-identify as carers through fear of rejection and stigma (Van der Sanden et al., 2013)
- internationally, lesbian, gay, bisexual and transgender (LGBT) individuals are more likely to care or be cared for by non-relatives than non-LGBT individuals. We do not know how many LGBT individuals are carers in New Zealand.<sup>10</sup>

Friends, families, whānau and āiga support many people with health conditions and disabilities, including people with long-term physical or mental health conditions or disabilities and people with addictions. MSD does not have detailed data or information on the breakdown of the carer population in these areas.

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9 Australian research has found that young people under 15 years old are engaging in caregiving, but it is difficult to determine how many are undertaking such work. It estimates that 1.7% of children under the age of 15 years and 7.4% of 15- to 24-year-olds are carers (Warren & Edwards, 2017). The UK has also acknowledged that young carers are likely to be undercounted (Vizard et al., 2018).

10 See <http://www.rainbowwellington.org.nz/elders>.

## Caring has economic impacts for New Zealand

A recent study attempted to calculate the likely labour cost if care services were provided commercially rather than by families and whānau. Grimmond (2014:8) states:

*The estimates indicate that if unpaid care moved from the voluntary sector into the market economy, it would have a value of at least \$7.3 bn (or 3.4% of GDP) and could feasibly be as much as \$23.3 bn (or 10.8% of GDP). Our central estimate, based on the central scenario of the Time Use Survey and the carer wage is a valuation of \$10.8 bn (or 5.0% of GDP).*

It is important to acknowledge this, particularly given the costs placed on individuals, families, whānau and āiga carers.

The costs associated with caregiving can be categorised into:

- work-related costs, resulting from changed employment circumstances to provide care
- out-of-pocket expenses, which include direct payment for goods and services for caring
- carer time costs, related to the time investment required by carers.

## The impacts of caring on individuals are varied but they are mediated by the intensity of care provided

### **There are a variety of caregiving trajectories with variable impacts on individuals, families, whānau and āiga**

While there are common experiences across caregiving roles, there are a variety of caregiving trajectories (Schulz & Eden, 2016). For example:

- some carers engage in long-term care of people with significant but stable disabilities
- for some, the care trajectory may involve increasing care responsibilities punctuated by episodic events such as hospitalisations and placement in rehabilitation or long-term care facilities
- for others, the care trajectory may begin with sudden intensity, then gradually decrease as the care recipient's health improves
- other carers have a non-linear care trajectory (e.g. caring for someone with cancer)
- other long-term carers may need support to re-enter the workforce if the care recipient dies.

Informal caregiving most commonly stops when the recipient moves into residential care or dies, or their health improves – caregivers rarely choose to give up their role (Goodhead & McDonald, 2007).

The impact of caregiving on carers is influenced by a variety of factors. Schulz & Eden (2016) state: *“the diversity of families, the timing of entry into the caregiving role, the duration of the role in relation to the overall life course of the caregiver, and transitions in care experienced over time all shape the nature of the caregiving role”.*

The impacts are often greater for those undertaking prolonged and intense levels of care:

- More prolonged and intense levels of care can have negative impacts on the life-course trajectories of carers. Impacts include delaying education, moving to a smaller house, incurring significant debt and delaying medical care for other family members. The absence of appropriate support might exacerbate employment and health inequalities for certain groups of carers (Colombo et al., 2011).
- Those providing prolonged and intensive care differ from less intensive carers.<sup>11</sup> Intensive carers are generally older, less educated and poorer than non-intensive carers. Intensive care is predominantly provided to the spouse of the carer, but other groups include children with significant health conditions or disabilities. Intensive carers appear to face multiple disadvantages (Colombo et al., 2011).

## **A substantial commitment to caregiving has a marked impact on the life of the caregiver**

### **It has impacts on earnings for individuals and families**

New Zealand and international research indicates that many working-age carers combine paid work and informal caregiving (Grimmond, 2014; Colombo et al., 2011). However:

- households of unpaid caregivers in New Zealand typically earn 10% less than households that do not have care responsibilities (Grimmond, 2014)
- unpaid caregivers have fewer hours of paid employment than non-caregivers (i.e. a higher reliance on part-time work). Women are more likely to reduce hours of paid employment than men. Co-residential caregivers are more likely to reduce paid employment than those not living with the recipients (Department of Labour, 2011; Feinberg et al., 2011; Goodhead & McDonald, 2007; Colombo et al., 2011). It is not straightforward, however. Some caregivers may undertake more caring because they have lower-paid work commitments (Grimmond, 2014)
- caring activities may have negative impacts on career continuity and job choices (Colombo, et al., 2011:91). Data from Australia indicates that carers' careers are on average nearly three years shorter than those of non-carers. Without adequate support, carers may find it difficult to re-enter employment during care or when care ends
- some caregivers leave the labour force. In New Zealand the June 2018 labour market statistics show that for those not in the labour force, 13.9% have caring as their main activity.<sup>12</sup> New Zealand households with carers are more likely to receive forms of government assistance (Grimmond, 2014)

The OECD has reported that those undertaking long-term care at a high intensity (e.g. 20+ hours per week) are associated with a significant reduction in employment and hours of paid work. However, it found that caring does not seem to affect work decisions at low care intensity (less than 10 hours per week) (Colombo et al., 2011).

The OECD found that working-age carers are at a higher risk of poverty than non-carers (Colombo, et al., 2011:97). This is likely to reflect how caring affects earnings. Caregiving can lead to increased household expenditure, such as on heating, medication, telephone costs, medical aids and transport (Colombo et al., 2011; Feinberg et al., 2011).

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11 This is defined as those who provide more than 20 hours of care per week (Colombo et al., 2011).

12 Note that this includes caring for a child/children. See <https://www.stats.govt.nz/information-releases/labour-market-statistics-june-2018-quarter>

There is some international evidence that caring for grandchildren with health conditions or disabilities leads to greater attachment to the labour force, especially in skipped-generation families, for grandfathers, and among married grandparents (Wang & Marcotte, 2007). Data on the incidence and experience of grandparents caring for grandchildren in New Zealand is limited.

### **Caregivers at greater risk of poor physical and mental health**

In studies that compare caregivers to non-caregivers, caregivers often report poorer physical health and a higher use of medication (FaHCSIA, 2011; Goodhead & McDonald, 2007).

Carers, compared to non-carers, exhibit a higher prevalence of mental health problems across OECD countries for which data is available. Overall, the prevalence of mental health problems among carers is 20% higher than it is among non-carers. Female carers are more likely to suffer from poor mental health. Intensive carers and co-residential carers are more likely to have worse mental health outcomes as a result of their caregiving responsibilities (Colombo et al., 2011; FaHCSIA, 2011).

### **Family and social lives can be negatively affected**

Carers have roles and responsibilities beyond caregiving. Caregiving has different impacts at different times on caregivers' personal lives – as spouses or partners, parents, wider family/whānau members, employees, business owners or community members. Caregiving can overwhelm and undermine these other dimensions of caregivers' lives (Schulz & Eden, 2016). Some carers experience high rates of isolation and less attachment to their community and social groups. The risk of social isolation increases with the intensity of the care being provided (Colombo et al., 2011; FaHCSIA, 2011). Social support has been identified as protective against the strains of the caregiving role (Goodhead & McDonald, 2007; Jorgensen et al., 2009).

Little is known about the ripple effects of child health conditions and disabilities on families. However, there are indications that in families where children have chronic health conditions or disabilities:

- siblings may suffer because of a lack of normal attention due to the increased requirements of the care recipients (Collins & Doherty, n.d.; Wolfe et al., 2014). The importance of care and support for siblings, including access to primary mental healthcare, cannot be overstated
- relationship breakdown is reported by some to be more common (Expert Advisory Group on Solutions to Child Poverty, 2012), but the evidence is mixed (Hartley et al., 2010; Namkung et al., 2015).

### **Caregivers often have concerns about the future for those receiving the care**

Parents, especially older parents, of disabled children or children with high and complex needs have concerns about care provision for their children, in both the short and the long term (FaHCSIA, 2011; Goodhead & McDonald, 2007). Grandparents may have concerns about staying well and living long enough to see their dependent grandchildren through to adulthood. Where carers are of similar ages to recipients, the caregivers are worried about their own future health status (Goodhead & McDonald, 2007).

### **Sometimes the caring relationship is characterised by abuse, but data is limited**

Robust data on the prevalence of abuse perpetrated by caregivers and against caregivers in New Zealand is limited. However, international research indicates that both carers and the people they are caring for can be affected by abuse. For disabled people the power imbalance between them and their carers increases the opportunity for abuse (Baptcare, 2016; Beach et al., 2005; Lafferty et al., 2016). Disabled people, particularly disabled women, are up to twice

as likely to be victims of abuse and neglect as non-disabled people (Baptcare, 2016). Carers can be vulnerable to perpetrating abuse (Baptcare, 2016) or being abused (Erosa et al., 2010; Cooper et al., 2010). The risk increases where individuals, families, whānau and āiga are isolated, communication or relationships are difficult and they are not receiving appropriate support (for example, carers not having strategies for coping with challenging behaviours that may be associated with disability or dementia, and a lack of respite care).

## **The impacts of care do not fall evenly**

The impacts of care are felt disproportionately across different population groups.

### **Women face greater impacts from caregiving**

As providers of care are primarily women, they disproportionately face the impacts of caring. Women are also more often placed in situations where they are caring for children as well as older relatives. This dual role can come at a high cost to the caregivers.

Cultural norms that emphasise families taking responsibility for care may mean that Māori and Pacific People are more likely to be engaged in informal care at home. MSD suspects that as a result there is less awareness of and lower access to support for these population groups. There is also a lack of culturally appropriate support services.

### **Older carers and young carers face particular challenges**

An older carer may be in a caring relationship with a partner, where both partners provide some form of care and support for each other. This can have more serious implications when one person's condition or status worsens. This may also be the case for parents caring for adult disabled children or grandparents raising grandchildren.

For young carers, low school attendance due to caring responsibilities can affect both educational experiences and attainment, which in turn can have negative impacts on their transitions to further education and employment (Clay et al., 2016). The New Zealand Department of Labour found that at younger ages, "carers tended to have lower qualifications than similarly aged people in the general population" (Department of Labour, 2011). Young carers are also at greater risk of experiencing poor mental health and being socially isolated. There are barriers to young people identifying as carers (e.g. many young carers neither are aware of nor identify with this label; they may feel the need to keep their caring roles hidden for fear of being judged or misunderstood by their peers, teachers or service providers, or parental fear of child removal or familial disjunction) (Carers Australia SA, 2016). There are also people under the age of 15 who are providing care and are not regularly attending school due to taking on this role. MSD needs a better understanding of who young carers are and how caring affects their life trajectories and how this could be mitigated.

### **Carers with few economic, social and personal resources may be affected more by undertaking intense caring roles**

Economically disadvantaged families are more likely to engage in caregiving than those with greater financial resources, as they are less likely to be able to afford formal care and may have fewer labour market opportunities (Colombo, et al., 2011:93). These families are also more likely to struggle to meet the additional costs associated with caring. This means the impacts of caring and the costs associated with caring are felt more intensely by those who are already disadvantaged (Colombo, et al., 2011:93).

Carers with less support from extended family and fewer personal resources may face greater negative impacts from undertaking caregiving. For example, ill or disabled children with very similar needs may live in very different situations. A family with a strong marital relationship and four healthy, active and engaged grandparents is in a much better situation than a sole

parent whose own parents are unable or unwilling to help or are simply geographically distant. Money helps but it is not the only factor; wealthy carers can struggle too. An important aspect of personal resources that varies amongst carers is having the skills to understand and navigate 'the system' (Happell et al., 2017; National Advisory Committee on Health and Disability, 2010). It means having self-esteem, self-confidence, assertiveness without aggression and an understanding of how to interact with the system. Those without these resources are less likely than others to get the support they need. The complexity of system navigation is compounded when services are fragmented, excessively bureaucratic and uncoordinated (Funk et al., 2017).

### **The impacts of caring may be intensified for those in rural, isolated areas**

Carers in rural, isolated areas may have difficulty accessing timely and appropriate support for themselves and the people for whom they provide care. Failing to receive appropriate and timely treatment can place additional stress on the carer – especially if conditions worsen. Carers in rural areas are less likely than those elsewhere to receive training in how to cope with the challenges of caring, which can increase psychological distress. They may experience greater social isolation (Goodhead & McDonald, 2007; Winterton & Warburton, 2011).

## **A range of supports and services for carers exists but not all carers are eligible and the system is complex**

The range of supports and services provided should be considered in the context of the increasing demand for care due to demographic change and changes in policy settings (discussed above). The OECD argues that a continuation of informal caring roles will be essential given future demographic and cost pressures facing long-term care systems (OECD, 2011a). It is often the preference of both carers and care recipients that the majority of care is provided within families and communities. It is important to consider the sustainability of care, and to continue to seek ways to support and maintain the supply of family care. It is also important to provide care that meets the needs of people who do not have access to family carers.

There is a range of financial and non-financial supports for carers and the people they care for. For a detailed explanation of these supports, see Appendix 1. The majority of supports are targeted to the people being cared for, meaning carers often access support consequentially. While this may indirectly address the needs of carers, the support will not specifically identify or address any needs carers may have beyond those of the people they support. Research on the issue has emphasised the importance of carers being acknowledged and included when the needs of the recipients are being assessed (Goodhead & McDonald, 2007).

The interface between the supports provided by different government agencies is complex. The types of carer support available depend on the type of care a person provides, who they provide it for, and why that person requires care. The level of support provided varies:

- MSD's supports are aimed at carers who are unable to work and/or require income support.
- The health system's supports (the Ministry of Health [MOH] and District Health Boards [DHBs]) are targeted at carers of people with health conditions or disabilities. In addition, there are complex interfaces within the health sector for carers to navigate. For example, personal health, mental health and disability supports are complex systems within the health system. The complexity is exacerbated by differing definitions and eligibility criteria.
- If a person requires care because of an injury, the Accident Compensation Corporation (ACC) may be able to provide assistance, and this may be at a greater level than that provided by MSD or MOH.

## **The New Zealand Government provides some employment support to carers**

Many carers need or want support to remain in work, with reduced hours or more flexible working arrangements. The nature of the caring arrangement will affect the level of employment support required. For instance, support levels will vary depending on the intensity and length of care. Some carers may only need short periods of time off, for example to care for people with episodic conditions or people with terminal illnesses, while others will need more permanent arrangements.

Some carers will need to reduce their paid work hours drastically in order to take on the caring role. In many situations this will not be possible, and even where it is possible, managing work and care may place a high burden on carers, such as those caring for people with terminal illnesses. OECD research has shown that when carers have flexible working hours or the possibility of a leave of absence from work, their working hours tend to increase (Colombo et al., 2011:96).

New Zealand provides a statutory right to request flexible working arrangements.<sup>13</sup> However, this does not ensure that requests will be met favourably. Some employers are very supportive in meeting carers' requests to take time off to meet the demands of caring (e.g. to attend hospital appointments, provide care) but others are not and may even suggest that the people find more flexible employment. Parents of ill or disabled children can find it particularly difficult to find alternative care arrangements if they need to maintain paid employment.<sup>14</sup>

Some industry settings are not currently well suited to flexible working arrangements. In addition, many workplaces in New Zealand are small, and it can be difficult for them to provide flexible working arrangements. Employees in low-waged jobs may have less influence than those in higher-waged jobs over their employers in negotiating flexible working arrangements.

## **The New Zealand Government provides some income support to some carers**

Most family carers in New Zealand are not paid. However, some are eligible for support from MSD, MOH or ACC.

### **Some carers are eligible for MSD's Supported Living Payment**

Some people are eligible for MSD's Supported Living Payment (SLP) as carers. This is a means-tested benefit available to those who care for people who would otherwise need hospital-level, rest-home or residential care. This payment is not available for husbands, wives or partners who provide unpaid care.

The threshold for carers to access SLP is very high for parents of children with health conditions or disabilities. Someone caring for a child with a health condition or a severe and permanent disability would be unlikely to qualify if they had a working partner, because the benefit is subject to a joint family income test. Moreover, New Zealand no longer has long-stay hospitals for children. There is a need for a better way of defining when caregivers of children and young people are eligible for this benefit.

As at June 2018 there were 8,641 people receiving the SLP Carers benefit (Table 1). Most SLP carers were over 40 years of age and female (76%). Most (91%) carers did not have part-time earnings from employment. SLP carers made up a small proportion of all people receiving SLP (10%).

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13 Employment Relations Act 2000, Part 6AA.

14 Expert advice from Rosemary Marks, developmental paediatrician, Auckland DHB.

**Table 1: DPB-CSI<sup>15</sup>/SLP-Carer recipients reported June 2008 to June 2018**

SLP carers' ethnicity	Number of DPB-CSI/SLP-Carer recipients as at date										
	27 Jun 08	26 Jun 09	2 Jul 10	1 Jul 11	29 Jun 12	28 Jun 13	27 Jun 14	26 Jun 15	1 Jul 16	30 Jun 17	29 Jun 18
<b>Māori</b>	1,987	2,248	2,436	2,725	2,876	2,950	3,143	3,250	3,236	3,301	3,280
<b>NZ European</b>	1,732	1,989	2,185	2,323	2,399	2,622	2,793	2,760	2,634	2,621	2,599
<b>Pacific People</b>	883	1,047	1,208	1,321	1,431	1,465	1,509	1,502	1,549	1,477	1,431
<b>Other</b>	549	619	672	747	825	900	955	970	1,049	1,070	1,088
<b>Unspecified</b>	136	154	156	168	155	166	165	171	181	213	243
<b>Grand total</b>	<b>5,287</b>	<b>6,057</b>	<b>6,657</b>	<b>7,284</b>	<b>7,686</b>	<b>8,103</b>	<b>8,565</b>	<b>8,653</b>	<b>8,649</b>	<b>8,682</b>	<b>8,641</b>

**Source:** IAP Data Warehouse, prepared by Business Reporting, Insights MSD Group, Ministry of Social Development.

There are disincentives for those receiving carers' benefits to engage in paid work. Benefit stand-downs can affect carers' ability to test work opportunities. A stand-down is a period of up to two weeks when someone cannot receive a benefit payment following ceased employment. This may deter carers from pursuing and trialling work opportunities while caring, and may also have negative impacts for those transitioning from work to main benefits.

### **There are others on benefits caring for people with health conditions or disabilities**

While some carers access benefits in their own right, others access additional MSD supports, such as Accommodation Supplement, Child Disability Allowance (CDA), Disability Allowance (DA) and Temporary Additional Support.

### **Partners of people receiving health and disability benefits are likely to be undertaking caring**

Most people on SLP and Job Seeker – Health Condition or Disability (JS-HCD) benefits are single. If someone became unwell or disabled and could not work, but had a partner who was working, it is unlikely that either would be eligible for an MSD main benefit because the benefit would be subject to a joint family income test. However, where both people in a couple are not employed they can be on benefit as a couple. Some people on SLP and JS-HCD benefits have partners. The partners – especially SLP partners – are likely to be engaged in caring.

As at June 2018:

- 7,026 people were included on benefit as SLP partners and most were required to look for full- or part-time work (4,494 were subject to full-time work tests and 1,428 were subject to part-time work tests)
- 5,216 people were included on benefit as JS-HCD partners and most were required to look for full- or part-time work (2,657 were subject to full-time work tests and 1,466 were subject to part-time work tests)
- 852 SLP partners and 547 JS-HCD partners were exempted from work tests. For partners, the most common reasons for being exempted from work tests were that their own health would mean they qualified for SLP or JS-HCD or that they were caring for people with health conditions or disabilities

15 Domestic Purposes Benefit – Care of Sick and Infirm (this became SLP-Carer).

- the most common incapacities listed for SLP and JS-HCD recipients with partners were psychological or psychiatric conditions, musculoskeletal conditions and cardiovascular disorders
- long-term receipts of benefits were common among partners of SLP and JS-HCD recipients – 80% of SLP partners and 48% of JS-HCD partners had been receiving benefits as partners for two years or more
- some (18%) SLP partners and JS-HCD partners were earning while on benefit.

### **Caregivers of disabled children, including non-beneficiaries, can receive some financial assistance**

A caregiver may be eligible for a non-means-tested CDA<sup>16</sup> (\$47.64 per week) from MSD if they are a child's main carer. The CDA is only paid to caregivers of children with serious disabilities (these include serious health conditions). It is paid because of the extra care that may be needed by a child who has a physical, sensory, psychiatric or intellectual disability. Once the child turns 16 years of age they may be able to receive SLP in their own right if they meet the criteria.<sup>17</sup> Recipients of SLP payment may also receive DA.

Unlike the CDA, the United Kingdom Disability Living Allowance (DLA)<sup>18</sup> for children takes account of variations in experiences of disability by paying the allowance at a variable rate, with the lowest level being similar to our CDA. For example, DLA is able to recognise that the parent of a child with severe physical and intellectual disabilities, weighing 45 kilograms, doubly incontinent and having epileptic seizures daily, has a very high burden of care and is in need of more financial support than someone with a behavioural disorder who requires constant supervision for their safety.

As at June 2018 CDA was being paid to caregivers of 37,095 children with health conditions or disabilities (Table 2). The number of children receiving CDA fell from a high of 46,238 in 2009 to 34,085 in 2014 before increasing again. Most children receiving CDA had caregivers who were not receiving any benefits or additional supplementary assistance, which suggests inequity of access.

As at June 2018 there were 4,557 instances of DA being paid for children. This is a weekly payment to meet ongoing, additional costs incurred because of disability (e.g. doctors' visits, medicine). It is means tested. DA for children was most commonly paid to recipients of the Sole Parent Support (SPS) or SLP benefit.

16 Shared care/custody only applies when the parents or caregivers of a child are living apart, the child lives for at least 40% of the time with each parent and both parents apply for a Child Disability Allowance for that child. Only one parent/caregiver (defined as the principal caregiver) is entitled to receive the allowance. The parent or caregiver must meet the qualifications. Some people receiving this payment will be on SLP carer.

17 People may be able to receive SLP when they turn 16 years old if they are permanently and severely restricted in their capacity for work because of health conditions, injuries or disabilities or total blindness. SLP carers have to be at least 18 years old.

18 <https://www.gov.uk/disability-living-allowance-children/eligibility>.

**Table 2: Number of children paid CDA as at June 2018**

Benefit group	Number of children
Emergency Benefit	56
Emergency Maintenance Allowance	30
Jobseeker related	1,867
Jobseeker Support Student Hardship	8
New Zealand Superannuation, Veteran's Pension, Transitional Retirement Benefit	402
No financial assistance apart from CDA	20,304
CDA and other Non- Beneficiary assistance	3,680
Orphan's Benefit and Unsupported Child's Benefit	874
SLP related	
• SLP Carers	2,352
• SLP	1,478
SPS	6,020
Youth Payment/Youth Parent Payment	21
<b>TOTAL</b>	<b>37,092</b>

Source: IAP Data Warehouse, prepared by Business Reporting, Insights MSD Group, Ministry of Social Development.

### It is unclear if all eligible SPS recipient's take-up of CDA and DA

A number of sole parents are caring for children with health conditions or disabilities. As at June 2018 there were 58,563 people receiving the SPS benefit and:

- a small proportion (9% or 5,183) were receiving CDA or DA for a child (2% or 1,440)
- 6,020 children of SPS recipients were being paid CDA.

Disabled children in New Zealand are more likely to live in a sole parent household than are non-disabled children (Murray, 2018).

### Some people are caring for orphans or children not supported by their parents

Some caregivers receive the Orphan's Benefit (OB) or the Unsupported Child's Benefit (UCB).<sup>19</sup> Five per cent of OB/UCB children were receiving CDA as at June 2018. There were 365 OB children and 16,157 UCB children as at June 2018. As at June 2018, 271 caregivers were receiving OB and 10,631 were receiving UCB. Most caregivers with OB or UCB (74%) were over 45 years old and 27% were over 60 years old (e.g. grandparents caring for grandchildren).

<sup>19</sup> To receive UCB, a caregiver must not be the child's natural parent, adoptive parent or step-parent and because of a family breakdown there is no natural parent, adoptive parent or step-parent to care for the child. For OB the child's parents must be deceased, be unable to find, to be found, to find work or suffer from serious long-term illnesses or incapacity that make them unable to care for their child.

## **For caregivers, DA and CDA are important in offsetting additional financial costs associated with disability**

Supplementary assistance is important in offsetting additional financial costs associated with disability e.g. medication, equipment, therapy and transport. This funding is particularly important for those on fixed and potentially low incomes. Without the additional assistance of supplementary payments such as DA and CDA, some people could be less able to access appropriate health and disability services.

MSD is currently undertaking work to better understand the requirements, processes and challenges around the DA and CDA services. There are concerns that take-up of DA and CDA is less than ideal.<sup>20</sup> Anecdotal evidence suggests that the take-up of DA for a child and CDA is lower than expected. Given the link between poverty and poor child health, a higher take-up of DA and CDA would be expected amongst caregivers receiving main benefits. Some researchers have stated that more could be done to improve take-up (Murray, 2018; Suri & Johnson, 2016; Wynd, 2015).

Barriers to taking up DA or CDA for a child include:

- a lack of exposure to Work and Income services and awareness that the allowances are available
- a negative perception of Work and Income and reluctance to approach sites for assistance
- those without photo ID and permanent addresses not being able to enter and claim CDA, further disadvantaging those who are likely to be disadvantaged already
- a high administrative burden: the application process is considered daunting by some; there are sometimes difficulties in sourcing supporting documentation; and applying for relatively small claims is seen as burdensome by potential recipients
- medical practitioners being inconsistent in informing parents of CDA and in supporting applications. Given the complex welfare system it is not surprising that health professionals do not always have a good understanding of the support available
- most recipients of CDA only qualifying to receive the allowance for a period of time. Anecdotal evidence highlights a lack of understanding around maintaining eligibility over time, as eligibility can change as the requirement for care changes.

Some groups are more likely to be at risk of not knowing about DA and CDA as supplementary assistance, as they have little contact with the benefit system. This group includes grandparents who are not superannuitants but are caring for grandchildren with health conditions or disabilities, and working people not on benefit caring for children with health conditions or disabilities.

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20 There are limitations to this analysis and measuring the take-up of supplementary assistance payments. The key limitation is that agencies have limited knowledge of who is not applying. Additionally, it may be possible that the take-up levels are low because once people have moved into employment they are not aware that they are still eligible to receive this assistance.

## Some people are likely to be underrepresented in the welfare system as carers

Some people are likely to be underrepresented in the welfare system as carers. They include:

- young carers – for example, a young person caring for a parent on benefit with a health condition or a disability would not be eligible for a benefit in their own right
- carers of people with intermittent conditions (e.g. episodic mental or physical health conditions). People who are unwell intermittently may require intense periods of care, but as they are not permanently unwell their carers may not be eligible for carer benefits
- carers of adult children with disabilities. Some people may be on benefit providing care for adult children with disabilities, but not be receiving SLP as carers. Once a person is able to receive a benefit in their own right (e.g. SLP) it is often difficult to see in the system who is caring for them. As at June 2018, 982 SLP carers were caring for adult children – an increase from 307 in June 2008.<sup>21</sup> Those being cared for were typically aged under 40 years. Adult children who developed illnesses or disabilities after 18 years of age and were cared for by parents would not have been picked up in this analysis. Similarly, eligible adult children who did not access DA or CDA as children via their caregivers, but later came on to benefit in their own right, would not have been included in the analysis, and data is needed.

### **The Ministry of Health provides Funded Family Care, which is currently being reviewed**

The Government has policies that enable specific family members to be paid to provide personal care and household management for the people they are caring for. There are two policies in the health system:

- MOH provides funding for some eligible disabled people to employ their parents or family members to provide FFC
- DHBs provide funding for carers of people with long-term chronic health conditions, mental health and addiction, or aged care needs. The employment relationships are with providers as opposed to with the people being cared for.

Table 3 shows a comparison of the two policies along with MSD and ACC payments.

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<sup>21</sup> This was determined by matching the names and dates of birth of care recipients with Social Welfare Numbers (SWN) entered with children's names in SWIFTT (the MSD administrative data base), then seeing if the matched children were or were not included in the carer (or their partners) benefit.

**Table 3: Comparison of caring payments**

	People ineligible to be funded for care	Pay rates for carer	Employment of carer
<b>MOH (Disability Support Services/ FFC)</b>	Spouses/Partners Parents of children under 18 years Anyone under 18 years	Adult minimum wage (\$16.50 per hour)	By disabled person
<b>DHB</b>	Spouses/Partners Parents of children under 18 years Anyone under 18 years	Pay rates comparable to contracted carers. This is the living wage	Contracted provider
<b>MSD</b>	Spouses/Partners	Someone single, 18 years or over: <sup>22</sup> <ul style="list-style-type: none"> <li>• \$269.15 (net per week)</li> <li>• \$303.40 (gross per week)</li> </ul>	NA SLP is paid to support a client while they are providing care, not to provide a wage  A person who needs care may receive funding from another agency such as ACC or MOH (e.g. FFC, Individualised Funding [IF]) to pay a carer directly. In this case the person may employ the client receiving SLP to provide care. While a client who is receiving payment for providing care is not excluded from receiving SLP, any payment they receive for providing care will be treated as income

22 <https://www.workandincome.govt.nz/products/benefit-rates/benefit-rates-april-2018.html#null>.

	People ineligible to be funded for care	Pay rates for carer	Employment of carer
ACC	Carers of people not eligible for ACC	<p>ACC does not have a flat hourly rate for Home and Community Support Services (HCSS)</p> <p>ACC pays two different rates:</p> <ul style="list-style-type: none"> <li>• <b>Contracted HCSS</b> are intended to be high-quality, flexible support services in a client’s home and community to support their rehabilitation and achieve and sustain their maximum level of participation in everyday life</li> <li>• <b>Non-contracted HCSS</b> give clients the ability to find their own services to support their rehabilitation. Non-contracted HCSS are for clients who want to have their services provided by friends, family members or agencies that do not have contracts with ACC (see Appendix 1)</li> </ul> <p>ACC has different hourly/daily rates depending on the services clients require</p>	<p>If a person’s injury has been covered by ACC and they require home help and/or attendant care, there are two ways they can use HCSS:</p> <ul style="list-style-type: none"> <li>• <b>Contracted HCSS</b> using one of ACC’s six lead suppliers, which have contractual obligations to deliver quality care</li> <li>• <b>Non-contracted HCSS</b> using a friend or family, or non-contracted agency</li> </ul> <p>A client can choose to have a combination or all of their services using contracted or non-contracted providers</p>

The FFC policy and related legislation have been subject to extensive challenge. The challenges include:

- part 4A of the New Zealand Public Health and Disability Act 2000 prohibits complaints to the Human Rights Commission or the courts about discrimination on the grounds of family status, and this is inconsistent with the New Zealand Bill of Rights Act 1990
- exclusion of adults from employing spouses/partners and exclusion of people under 18 years from employing family carers
- the requirement for employment relationships between disabled people and family members (this only applies to the FFC policy provided by MOH)
- lower pay rates under the FFC policy than those for contracted providers.

Take-up of FFC has been lower than expected. A recent report indicated that only 22% of the expected number of families took up FFC (Esplin et al., 2018).

FFC is currently under review. There is an opportunity to reconsider the Government policy on FFC. This needs to occur alongside the advancement of wider Government priorities and international obligations, as well as the development of the New Zealand Carers’ Strategy Action Plan.

## **The difference between the level of support provided by ACC and disability supports is a major issue**

People injured as a result of accidents in most cases receive greater financial and other support from ACC than is available through the health system (WEAG, 2019). Carers are also better supported under the ACC system. For example:

- a child funded by ACC may receive several hours of funded in-home care; the parent may, if they choose, go to work while the child is being cared for. A child funded by the Disability Support System support package through the Needs Assessment and Service Coordination service and MOH receives substantially less support and the parent is not permitted to work – if they do they may be penalised. Both primary carers are eligible to claim CDA
- the difference between a child receiving ACC and not receiving ACC in some cases is down to the quality of health professional note-keeping: the level of detail that clinicians provide in their reports to ACC, the persistence of the child's family in pursuing an ACC claim, and the family's resources to pay for a lawyer with expertise in ACC claims
- it is even more complex for an individual who has a disability and then has an injury causing further disability, or where there are clearly two contributing causes to the disability. ACC decides on the proportion it will fund
- in the health system there is a 'claw back' process e.g. for a child with cerebral palsy requiring hip surgery. If the child is funded by ACC where surgery is performed, the DHB will bill ACC for the service provided. If the child is not funded by ACC the costs will come out of the DHB budget.<sup>23</sup>

## **There are a number of challenges with the current system**

It is complicated and time consuming to access the various supports available from different government agencies that address the varying needs carers may have. The fragmentation of supports across government agencies poses a barrier to accessing the appropriate services. In addition, people self-identifying as carers is an important aspect of how the current system is set up to provide supports. Carers who do not self-identify as carers may not access support.

The diversity of carers, the range of caregiving relationships and the contexts in which caring takes place (for example within families, whānau and āiga, as opposed to with individuals) are not generally reflected in support services. There is a lack of culturally responsive services, and services may not be flexible enough to account for the variety of caregiving relationships, for example between partners, parents and children, and grandparents and grandchildren.

A lack of support services can mean carers are forced to choose between struggling to care for loved ones at home and placing them in residential care. This difficult decision could be prevented with the provision of timely and appropriate supports to enable people to remain in the community. Extra stresses occur when people have terminal illnesses.

The lack of accurate data on:

- carers and who they care for. Most people reliant on main benefits are single. However, supplementary assistance such as CDA can be accessed by non-beneficiaries. MSD knows less about these carers than others
- how many parents are caring for adult children with health conditions or disabilities within the welfare system due to a lack of household information
- children with health conditions and disabilities within the welfare system (Wynd, 2015)
- take-up rates for DA and CDA.

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23 Personal communication with Rosemary Marks.

There is potential to make the system easier to navigate and more flexible and responsive in order to meet the diverse needs of carers. There are also opportunities to create new services or payments to support the specific needs of carers, for example to help carers meet the cost of caregiving.

## What works for supporting carers?

Robust evidence of what works for different groups of carers and under what circumstances is limited. As carers are a diverse group, a variety of interventions will be required. There is evidence that suggests a way forward.

### Provision of cash for carers

A large number of OECD countries provide financial support to carers through cash benefits. These may be granted to either family carers or care recipients, allowing more choice regarding the services needed.

- *Direct payment to the carer.* The amount and the eligibility conditions vary across countries, but the two main approaches are the national provision of remuneration to family carers who are formally employed (e.g. in Denmark, Finland, Norway and Sweden<sup>24</sup>) and means-tested allowances (e.g. in Australia, Ireland, New Zealand and the UK).<sup>25</sup> Other options include flat-rate allowances and allowances at provincial level
- *Cash benefits for the care recipient.* Cash schemes allow the use of allowances to support family carers or even to hire family members formally. The amount a care recipient receives is based on their care needs. Most countries do not target allowances to income. The extent to which cash benefits are used by family carers is partly related to restrictions in the use of the allowances and to the degree of monitoring. The risks are that cash benefits will not always be used to pay family carers<sup>26</sup>, will create financial dependence in the carers, and will monetise family relations (Colombo et al., 2011)
- *Vouchers.* Sweden, Finland and Denmark have introduced voucher schemes that can be used by people in need of care to hire services that best meet their needs. While users have been satisfied, there are obstacles to voucher systems working effectively (e.g. users having insufficient knowledge to make informed choices, provider monopolies or no providers) (Colombo et al., 2011).

Cash-for-care policies come with trade-offs. The provision of cash may:

- discourage the emergence of private providers, as households will continue to rely on family carers or untrained, non-family members (e.g. migrant labour)
- trap family carers, especially women, into low-paid, unwanted roles (Colombo et al., 2011; Hoffmann & Rodrigues, 2010)
- act as a disincentive to paid employment (Colombo et al., 2011; Hoffmann & Rodrigues, 2010).

24 Compensation constitutes a relatively low wage, so there is still an incentive to work. Access to remuneration is restrictive and tends to be granted to keep the care recipient at home instead of moving to an institution, and when the care performed is very intensive. Care allowances are costly (Colombo et al., 2011).

25 Allowances are limited to those most in need, with heavy and regular caring duties that result in forgone earnings. Care recipients must be on disability benefits. Eligibility is tightly controlled and reciprocity rates are low. There is concern that means testing and eligibility conditions may result in disincentives to work.

26 In Germany, Austria, the Czech Republic and Italy, for example, there is little control over the use of the benefit.

## Improving work-life balance for carers in paid employment

International research indicates that carers can be supported by promoting a better work-life balance through more choice and flexibility. Examples include:

- *care leave*. For example, Canada provides the Compassionate Care Benefit programme, under which employment insurance benefits and job protection are provided to eligible family members for up to 28 weeks while caring for someone
- *tax incentives*. Design and implementation are crucial. The Canadian Disability Tax Credit<sup>27</sup> has had low take-up. Low awareness and a burdensome application process are likely key contributing factors (Dunn & Zwicker, 2018) (see Appendix 2)
- *payments to cover costs*. Australia has recently announced an annual \$600 payment for carers to help them meet the additional costs associated with care. However, payments to caregivers should take into account the possible economic incentives for certain groups to leave the labour market.

## Better identification of and support for carers

In the UK, the Carers Social Action Support Fund was established to invest in projects that use social action to support carers. An evaluation of the Fund found:

- indicative evidence that carer identification services can help carers gain access to a range of well integrated support<sup>28</sup> (Babudu et al., 2016)
- strong evidence that peer-support services can slow, prevent or reverse a decline in carers' social isolation and carer-related stress (Babudu et al., 2016)
- indicative evidence that respite services can reduce carer-related stress and reduce the likelihood of a carer having a breakdown (Babudu et al., 2016)
- a positive association between carers' employment and receipt of paid services by cared-for people (Pickard et al., 2014)
- more limited evidence that practical support services can improve carers' wellbeing and/or reduce the likelihood of their breaking down (Babudu et al., 2016).

## Improving carers' coping strategies

There is evidence that supporting carers by providing education interventions combined with psychological support and specific, tailored and skilled advice can help to reduce the risk of carer burden and depression by assisting carers with coping strategies and problem-solving. This is especially helpful for those caring for people with mental health conditions (Kishita, et al., 2018; Sin et al., 2017; Nicholson, 2010; Yesufu-Udechuku et al., 2015) and/or challenging behaviours<sup>29</sup> (Social Care Institute for Excellence, 2011). Supporting families can also improve outcomes for the people being cared for e.g. in mental health (Nicholson, 2010; Yesufu-Udechuku et al., 2015).

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27 <https://www.canada.ca/en/revenue-agency/services/tax/individuals/segments/tax-credits-deductions-persons-disabilities/disability-tax-credit.html>

28 MSD and the Health Research Council funded a study of the cost of disability to inform Government planning and the allocation of Government resources related to disability. The research investigated individual costs and examined how those costs varied by type of disability and personal circumstances. The reference group participants advised the researchers that one of the most important types of support needed was a 'navigator', someone to assist an individual in accessing the resource options efficiently and effectively. They stated that this type of support was beyond the scope of medical professionals and needs assessors. The report suggests that the advice and guidance of a 'navigator' would "encompass the totality of what is needed to fully participate and contribute to the community and to a meaningful life" (Travaglia et al., 2010:25).

29 Caring for someone with challenging or changing behaviours: <https://www.carergateway.gov.au/caring-for-someone-with-changing-or-challenging-behaviours>.

### Targeting support to specific categories of carer

Targeting support to specific categories of carer might work best in supporting carers (Colombo et al., 2011). For example:

- *young carers*. Recognising the existence of young caregivers and identifying who they are is the first step to identifying their particular needs. Policies that support young carers include:
  - access to age-appropriate information pertaining to the young caring role, and material outlining possible services for the young carer and their care recipient. These are key supports identified in the literature (Cass et al., 2009)
  - services and support in their own right (as carers) at the same time as the people they support need dedicated services and support. A ‘whole family’ approach is recommended (Becker & Becker, 2008)
  - assistance in managing the transition to adulthood. Helping young carers stay connected with education is likely to be useful. In Australia, young carers are less likely to complete high-school education and to be engaged in either work or study compared to those not undertaking caring<sup>30</sup>
  - improved linkages between services targeting young carers and adult care services
- *addressing the needs of grandparents as caregivers*. Grandchildren cared for by grandparents often have greater challenges due to the family circumstances that lead to these arrangements. The children may have health conditions or disabilities. There is a need for improved resources and services for custodial grandparents, including increased financial aid, education support, counselling services, support groups, treatment for children’s behavioural disorders, and initiatives aimed at helping grandparents to reduce their social isolation, seek treatment for health problems and increase their access to health services (Carlini-Marlatt, 2005). Some countries have explicitly recognised the role that grandparents play in the provision of informal childcare (OECD, 2011b).

### Strengthening the formal care sector is important

The OECD states that an over-reliance on family carers is not desirable, and many countries need to strengthen the formal care services (Colombo et al., 2011).

### Providing greater choice and control over supports and services

In the United States an intervention tested the impact of giving care recipients and carers more choice and control over their supports and services. Through the Medicaid Cash and Counselling Demonstration, participants managed a monthly allowance to purchase assistance with routine daily living activities from sources other than traditional home care agencies. Participants typically hired relatives, but about one-third hired only unrelated individuals. Counsellors provided oversight and support to ensure that consumers developed reasonable spending plans and followed them. Checks were typically written by fiscal intermediaries, based on consumers’ invoices.

Researchers found large, statistically significant, favourable effects on unmet needs, satisfaction with care, and quality of life in all three states where the Demonstration took place, for both elderly and non-elderly adults, and for children with developmental disabilities in Florida. Family

30 Overall, rates of Year 12 completion have been increasing in the past decade among all young people, including young carers. However, in 2016 young carers were still less likely to have completed Year 12 or its equivalent (75%) than those of the same age who did not provide unpaid care (79%). In 2016, 68% of young carers were fully engaged in work and/or study, compared with 78% of those without caring responsibilities. Almost one in five (18%) young carers were not engaged in either education or work in 2016, unchanged since 2006 (18%). Young carers were almost twice as likely as non-carers (9.8%) to be unengaged in either work or study (ABS, 2018).

caregivers of programme participants experienced a much higher quality of life and lower levels of physical, emotional and financial stress than the control group caregivers, in all three states (Brown et al., 2007; Foster et al., 2007).

However, a UK study found that while having personal budgets enabled carers to undertake different activities and better juggle care and employment, they did not relinquish their direct involvement in care provision. Some carers supporting direct-payment users experienced higher levels of stress, which appeared to be linked to the additional responsibilities involved in administering the direct payments (Woolham et al., 2018).

### **Protecting carers' rights**

In 2014 the UK established the Care Act to protect carers' rights. The Act provides for an assessment of carers' needs, support to help carers meet their eligible needs, and information and advice. This includes providing a clear right to respite services and putting a cap on the care costs for which an individual is liable. It is too early to determine how effective the Act has been in supporting carers.

## **Work is underway within MSD to update the Carers' Strategy Action Plan**

The New Zealand Carers' Strategy was launched in 2008 in a partnership between government agencies and the NZ Carers Alliance, to improve support for individuals, families, whānau and āiga carers who assist friends and family who need help with everyday living because of health conditions, injuries or disabilities.

The Strategy's vision is that "New Zealand Aotearoa is a society that values individuals, families, whānau, or āiga who support others who, need help with their everyday living". The Strategy also has four guiding principles, which are 'recognise diversity', 'be proactive', 'enable carers' and 'be inclusive'.

The New Zealand Carers' Strategy Action Plan (the Action Plan) is the vehicle for achieving the Strategy, and for coordinating action across Government to support carers. The current action plan expired at the end of 2018. MSD is working to develop the 2019-2023 Action Plan. This will be the third Action Plan to support the Strategy.

Previous action plans have focused on the provision of information, including increasing the accessibility of resources. The new action plan will aim to build on the momentum of the previous two action plans in order to deliver material impact for carers. Previous action plans have not been formally evaluated for effectiveness, and this is something MSD is hoping to improve on for the new action plan. MSD is currently exploring options for measuring the impacts of the new action plan.

The action plan targets all New Zealand carers. However, MSD recognises that there is an information gap when it comes to the issues faced by specific groups of carers. These include Māori, Pacific People, younger and older carers. MSD is considering whether the action plan needs to have an emphasis on the particular issues faced by those groups of carers.

The development of the new action plan is supported by a wellbeing framework, which will inform how we prioritise and develop actions for the action plan. The wellbeing approach has two key goals. The first is a focus on improving the wellbeing outcomes of individual, family, whānau and āiga carers. The second goal is about sustainability and family choice to ensure carers are supported to meet growing and future demands.

MSD anticipates public consultation will be carried out on the draft action plan in early 2019.

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# Appendix 1: Current supports available to informal carers, and those who they are caring for

## Financial support

Table 4: Income support for carers

Need	Provider	Name	What/eligibility
Income support for carers	Ministry of Social Development (MSD)	Supported Living Payment (SLP)	<p>SLP is a weekly payment for carers providing full-time care and attention to people (other than their spouses or partners) at home who would otherwise need hospital care, rest-home care, residential disability care or care of an equivalent kind.</p> <p>A partner can only be included in SLP if it is granted on the grounds that the client is permanently and severely restricted in their capacity for work or totally blind. Partners cannot be included in SLP if it is granted on the grounds that the client is caring for a person who requires full-time care and attention.</p> <p>To get SLP a person must be:</p> <ul style="list-style-type: none"> <li>• 18 years or older if they are caring for a person and do not have dependent children, or</li> <li>• 20 years or older if they are caring for a person and have dependent children.</li> </ul> <p>SLP is paid to support a client while they are providing care, not to provide a wage.</p> <p>People who are receiving SLP-Carer are not required to apply for Child Support for any of their dependent children.</p>
		Special Disability Allowance	<p>This is a weekly payment for people who have spouses or partners who are in residential care or have been in a public hospital for more than 13 weeks.</p> <p>It is paid to the spouse or partner who is not in care to help with the extra costs of having their spouse or partner in care.</p> <p>The person must be on a benefit or pension.</p>
	ACC	Caring for someone with an injury	<p>If a person's injury has been covered by ACC and they require home help and/or attendant care, they can choose to have a friend or family member provide that support. ACC can either pay the carer directly or pay the person receiving care, who will pay the carer.</p> <p>However, there are tax and legal obligations that need to be considered as this is an employment relationship.</p>
	Ministry of Health (MOH)	Carer Support subsidy	<p>Carer Support provides reimbursement of some of the costs of a support person to care and support a disabled person.</p> <p>A person must be an unpaid full-time carer of a disabled person; a 'full-time carer' is a person who provides more than four hours per day unpaid care for a disabled person.</p>

Need	Provider	Name	What/eligibility
	MOH	Funded Family Care (FFC)	<p>In certain circumstances a person will be able to get FFC if:</p> <ul style="list-style-type: none"> <li>• they are over 18</li> <li>• they are caring for a parent and/or other disabled family member</li> <li>• that parent and/or family member lives with them.</li> </ul> <p>Note: MOH is currently undertaking a review of FFC.</p>

The following table outlines the current rates payable to non-contracted agencies and family or private carers.

**Table 5: ACC current rates payable to non-contracted agencies and family or private carers**

Code	Description	Pricing unit	Prices from 1 July 2018 (gst excl)
HBRN50	Home Help – non contracted	per hour	\$23.92
HBRN51	Attendant Care Level 1 – non contracted	per hour	\$23.92
HBRN52	Attendant Care Level 2 – non contracted	per hour	\$25.36
HBRN53	Sleepover – non contracted	per night	\$159.47
HBRN54	Childcare – non contracted	per hour	\$23.92
HBRN55	Support for client training programmes – non contracted	per hour	\$20.25
HBRN56	Oversight Supervision – non contracted	per hour	\$9.83
HBRN60	Sleepover – CPI – non contracted	per night	\$159.47
HBRN61	Attendant Care Level 1 – CPI – non contracted	per hour	\$23.92
HBRN62	Attendant Care Level 2 – CPI – non contracted	per hour	\$25.36

**Table 6: Support for the person being cared for**

Need	Provider	Name	What/Eligibility
<p><b>Income support for the person being cared for</b></p>	MSD	Supported Living Payment (SLP)	<p>This is a weekly payment to a person who is not able to work because they are permanently and severely restricted because of a health condition, injury or disability, or totally blind (requires medical certificate).</p> <p>To get SLP the client must be 16 years or older if they are permanently and severely restricted in their capacity for work because of a health condition, injury or disability or total blindness.</p>
		Jobseeker – Health Condition or Disability (HCD)	<p>Jobseeker support is for people who would like to work but are not currently working, or are working fewer hours, because of health conditions, injuries or disabilities.</p> <p>To qualify, a person must be 18 years or older if they have no dependent children, or 20 years or older if they have dependent children. They also need to have a medical certificate and complete a self-assessment and a Work Ability Assessment.</p> <p>Jobseeker support HCD is income and asset tested.</p>
		New Zealand Superannuation	<p>These are paid to New Zealand citizens once they have reached age 65 years.</p>
		Veteran’s Pension	<p>There are some limitations if the person is also receiving ACC weekly compensation, depending on how long they have been receiving or have been eligible for weekly compensation.</p>
	MOH	Individualised Funding (IF) – Respite	<p>IF can be used to:</p> <ul style="list-style-type: none"> <li>• purchase Household Management and Personal Care provided by support workers (employees, contracted personnel or organisations) and pay costs relating to the employment of support workers</li> <li>• purchase Respite care through support workers or other opportunities where a full-time carer is able to have a break (including school holiday programmes or facilities).</li> </ul> <p>IF cannot be used to employ or contract support workers who are:</p> <ul style="list-style-type: none"> <li>• the spouses/partners or parents of the disabled person, or</li> <li>• family members who live in the same house as the disabled person. A family member is defined as a grandparent, grandchild, daughter, son, sister, brother, aunt or uncle.</li> </ul> <p>IF doesn’t cover costs related to medical supplies, equipment, home renovations, leisure, recreation and personal or family costs, and cannot be used to increase the personal income of an individual or family.</p>

Need	Provider	Name	What/Eligibility
	ACC	Weekly compensation	If a person's injury is covered by ACC, they can receive 80% of their income while they recover. This payment stops when the person is assessed as able to return to work.
Additional costs	ACC	Help at home	<p>Help at home is paid to cover:</p> <ul style="list-style-type: none"> <li>assistance with cleaning and looking after a person's home</li> <li>assistance with personal activities such as showering and dressing.</li> </ul> <p>Once ACC has agreed to cover an injury, this support can be requested directly through ACC or a doctor.</p> <p>Note that:</p> <ul style="list-style-type: none"> <li>depending on recovery time, an assessment may be needed</li> <li>a person can choose who provides the support (i.e. a professional, friend or family member, or a mix) and they can receive payment from ACC to pay a carer, or ACC can pay them directly.</li> </ul>
	MSD	Disability Allowance (DA)	<p>This is a weekly payment to meet ongoing, additional costs incurred because of a disability (e.g. doctors' visits, medicine).</p> <p>To be eligible for DA a person must:</p> <ul style="list-style-type: none"> <li>have a disability that is likely to last at least six months</li> <li>have ongoing, additional costs because of a disability</li> <li>meet an income test.</li> </ul>
		Child Disability Allowance	This is a weekly payment to the principal caregiver of a dependent child who has a serious disability, to meet the costs of extra care. This payment is not income or asset tested. Recipients of this payment may also receive DA.
		Hardship Assistance	<p>There is a range of special assistance options (Special Needs Grants) if a person is struggling with accommodation, bills, food, school costs, etc.</p> <p>The person must already be receiving a benefit to be eligible.</p>

Need	Provider	Name	What/Eligibility
<b>Medical</b>	Pharmacists	Prescription Subsidy Card	A person is eligible for this subsidy once they have paid for 20 new prescription medicine items from 1 February each year. This can be a combination of items for a partner and dependent child 13 to 18 years.
	MSD	Community Services Card	This card provides subsidies for a range of health costs. A person may be able to get a Community Services Card if they are:  16 years or over (not a dependent child)  on a low to middle income (defined by income thresholds for different living situations/family types).
	GPs	High Use Health Card	This card offers the same benefits as a Community Services Card.  To qualify a person must have received 12 health practitioner consultations within the past 12 months for a particular ongoing medical condition.
<b>Housing/ Transport</b>	MSD	Accommodation Supplement	This payment helps clients with rent, board or housing costs. To be eligible a person must meet a cash asset test and an income test and have accommodation costs.  The amount the person can receive depends on the zone they live in, the benefit they receive and their age and living situation.
	Local government	Rates Rebate Scheme	This is a rebate for low-income ratepayers. To apply a person must be: <ul style="list-style-type: none"> <li>the person who pays the rates on the property that is their home</li> <li>be living in that home</li> <li>be listed as the ratepayer in the local council's Rating Information Database</li> </ul> The person cannot receive the rebate if the property is used for commercial activities or is a rental property/holiday home.
	MOH	Vehicle modification	This is funding for a person with a serious disability to enable them to purchase or modify a vehicle – to obtain full-time employment, look after dependent children or attend study/training.  The person must complete a needs assessment from MOH, provided by different contractors via occupational therapists.  Funding is subject to income and cash asset testing for the person with the disability and their partner.

Need	Provider	Name	What/Eligibility
	District Health Boards	National Travel Assistance Scheme for health and disability services	<p>This provides financial assistance for travel (and accommodation costs) for people who need to travel long distances. Eligibility depends on the DHB areas they live in, how far and how often they need to travel, and if they have Community Services Cards.</p> <p>People may not be eligible if they are already receiving assistance for travel from another part of Government (e.g. ACC or MSD).</p>
	NZ Transport Agency	Total Mobility Scheme	<p>The Total Mobility Scheme provides subsidised taxi services to people who have impairments that prevent them undertaking one or more of the following five components of a journey unaccompanied, on a bus, train or ferry, in a safe and dignified manner:</p> <ul style="list-style-type: none"> <li>• Getting to the place from where the transport departs</li> <li>• Getting onto the transport</li> <li>• Riding securely</li> <li>• Getting off the transport</li> <li>• Getting to the destination.</li> </ul>
<b>Extra help – over-65</b>	MSD	SuperGold Card	This is a discount and concession card for all New Zealanders over age 65.

## Non-financial support

Need	Provider	Name	What/Eligibility
Information / coordination	MSD/Carers NZ	A Guide for Carers	This provides information on a range of financial/ non-financial supports available to carers and how to access them. The guide is accessible online through the Carers NZ, MSD and MOH websites.
	MOH	MyCare	This is an online care matching service that aims to help carers access relief carers.
	Carers NZ	cares.net.nz/ phone line	The Carers NZ website provides information, advice, learning and support.  There is a 'Find Services and Support' tool that lists a range of support types (including Carer Retreats, Carer Support Groups, Pen Friends, Shuttle Services and Whānau Accommodation) by region and by city.
	Carers NZ	Time Out Guide	This provides ideas, guidance and planning assistance to help carers take a break.
	Care Matters	carematters.org.nz	Care Matters provides a National Carer Learning and Wellbeing Resource Service including: <ul style="list-style-type: none"> <li>• free phone service</li> <li>• published resources</li> <li>• facilitated workshops and courses around New Zealand</li> <li>• a network of carers who can offer leadership to carers regionally.</li> </ul>
	Mental Health Commission	<i>When Someone You Care About has Mental Health or Addiction Problems: A Guide for Family, Whānau And Friends</i>	This provides information, guidance and a list of support services available to friends and family when a person close to them requires support with their mental health.
Transport	CCS Disability Action	Mobility Parking Permit Scheme	The Scheme provides a Mobility Parking Permit card, which allows holders to use mobility parking spaces, which are wider than standard parks and closer to venues.  The Scheme is available to people of all ages if they: <ul style="list-style-type: none"> <li>• are unable to walk, and rely on the use of a wheelchair</li> <li>• have a severely restricted ability to walk due to a health condition or disability</li> <li>• have a health condition or disability that requires them to have physical contact or close supervision to get around safely, and cannot be left unattended.</li> </ul>

Need	Provider	Name	What/Eligibility
<b>Assessment and assistance</b>	Needs Assessment and Service Coordination (NASC) (MOH)	Needs assessments	<p>There are two types of NASC services for different populations:</p> <ul style="list-style-type: none"> <li>For younger people (those generally under 65) with: <ul style="list-style-type: none"> <li>physical, intellectual and/or sensory disabilities that are likely to last for six months or more, or</li> <li>chronic health conditions and high ongoing needs.</li> </ul> </li> <li>For older people (aged 65 years and above) and people aged 50-64 who have similar needs as listed above.</li> </ul> <p>There are also assessment services for mental health and alcohol and drug dependencies, although they are dependent on DHBs.</p>
	MOH	Respite services	<p>Eligibility for these services is determined through NASC assessments – and a person would need to be eligible for Disability Support System services.</p> <ul style="list-style-type: none"> <li>Facility-based respite provides care for a disabled person out of their home (usually overnight in a dedicated respite house or other facility, which provides care for a group of about five people at one time).</li> <li>Respite, through which disabled people or their families directly purchase their own respite supports.</li> <li>In-home support or one-on-one 'buddy' support, which may be provided in the home, in the community or through after-school, before-school or holiday programmes (paid at an hourly rate).</li> <li>Host-family respite, which provides an overnight break in the home of another family. The host family receives payment through Carer Support or through a provider contracted to MOH. Children and young people are more likely to receive host-family respite.</li> </ul>
		Home and Community Support Services	<p>These services provide help for a person who needs personal care, generally aged 65 and above.</p> <p>A NASC assessment is required for access to these services, and the person who requires the support must have a Community Services Card. Assessments are carried out through InterRAI (see below).</p>

Need	Provider	Name	What/Eligibility
	InterRAI	Comprehensive Clinical Assessment for Aged Care	<p>This provides a comprehensive clinical assessment of a person’s medical, rehabilitation and support needs and abilities, such as mobility and self-care. In addition, it:</p> <ul style="list-style-type: none"> <li>• provides information to help nurses write tailor-made care plans that, when implemented, benefit both older people and staff</li> <li>• allows an older person’s family to be part of the assessment process, so they know that their family member’s needs have been identified and catered to by the rest-home facility</li> <li>• allows for comparing data on residents with similar needs within a facility or within a chain of facilities, so a standardised ‘best practice’ approach to providing care can be used</li> <li>• allows MOH to access data on how older people are doing in rest homes and in the community, to identify any trends or gaps so that health policy can be developed that addresses healthcare needs.</li> </ul>
<b>Assistance for children</b>	Ministry of Education	Learning support services	<p>Special education services are free for all those who are eligible. An individual assessment may be needed to determine a child’s individual needs and supports needed.</p> <p>Learning support services include:</p> <ul style="list-style-type: none"> <li>• advice/information</li> <li>• speech language therapy</li> <li>• education support workers</li> <li>• special resources (e.g. communication aids)</li> <li>• coordinating physiotherapy, occupational therapy, equipment etc.</li> </ul>

## Appendix 2: What are other countries doing?

A recent report provides a summary of the literature on what other countries are doing in terms of carer payments.

Key search terms used in the paper were:

- carers
- caregivers
- payment for caregivers
- family caregiver payment
- funded family care
- Eurocarers
- caregiver compensation.

The report states that “direct compensation programs are a common aspect of caregiving policy in a number of countries. Australia, the United Kingdom, France, Germany, the Netherlands, Sweden and Norway all maintain some kind of program that can be accessed by family caregivers. The programs vary significantly in terms of the monetary value of the payment, the eligibility requirement for benefits, and the framework within which they are situated. Some programs are framed as social assistance and income security measures; others are aspects of health and home care policy (the latter is usually the case with payments to care recipients for caregiving services which may be used to fund informal family care or professional assistance)” (Esplin et al., 2018).

Jurisdiction and responsible entity	Support available	Payment rate
<b>United Kingdom</b> <b>Department for Work &amp; Pensions</b> <b>Local authorities</b>	<b>Carer’s Allowance.</b> A person could receive the allowance if they care for someone for at least 35 hours a week and they get certain benefits. For each week they get Carer’s Allowance they will automatically get National Insurance credits. The person they care for must already get a particular benefit	Up to £64.60 a week <a href="https://www.gov.uk/carers-allowance">https://www.gov.uk/carers-allowance</a>
	<b>Carer’s Credit.</b> A person could get Carer’s Credit if they are caring for someone for at least 20 hours a week. Carer’s Credit is a National Insurance credit that helps with gaps in their National Insurance record. If they are eligible for Carer’s Credit, they can get credits to help fill gaps in their National Insurance record. This means they can take on caring responsibilities without affecting their ability to qualify for the State Pension.	
	<b>Direct payments.</b> A direct payment is the amount of money that the local council/trust has to pay to meet the needs of the carer or the person being cared for, and which is given to enable either party to purchase services that will meet their needs (as assessed by the local council/trust).	This payment is “generally” not available for family members providing care. It is an ‘employer-employee’ (cared for-caregiver) arrangement.

Jurisdiction and responsible entity	Support available	Payment rate
<p><b>Canada</b> <b>Department of Employment and Social Development</b></p>	<p>Financial assistance from the Government for caregivers in Canada is mainly in the form of <b>federal tax credits</b> and <b>insurance benefits</b>.</p> <p>NB: For 2017 and subsequent taxation years, the budget proposes to consolidate the infirm dependant credit, the caregiver credit (for in-home care of a relative) and the family caregiver credit as part of the new Canada caregiver credit.</p> <p><b>Compassionate Care Benefit program.</b> Employment Insurance benefits and job protection are provided to eligible family members for up to 28 weeks while caring for someone.</p>	<p>Employment Insurance compassionate care benefits.</p> <p>The basic benefit rate is 55% of the recipients' average insurable earnings, up to a yearly maximum insurable amount (\$51,700 in 2018). This means that, in 2018, a eligible person can receive a maximum payment of \$547 per week. A person's Employment Insurance payment is taxable income, meaning federal and provincial or territorial taxes, if they apply, will be deducted.</p> <p>People could have a higher benefit rate if their family includes children, and if they earn a low family income – less than \$25,921 per year. If they or their spouse receives the Canada Child Tax Benefit, they may then be entitled to the Family Supplement, which means a higher benefit rate. However, the benefit payments will never be more than \$547 per week.</p> <p><a href="https://www.canada.ca/en/financial-consumer-agency/services/caring-someone-ill/benefits-tax-credits-caregivers.html">https://www.canada.ca/en/financial-consumer-agency/services/caring-someone-ill/benefits-tax-credits-caregivers.html</a></p>
<p><b>Canada</b> <b>Nova Scotia</b> <b>Department of Health &amp; Wellness</b></p>	<p><b>Canada Caregiver Credit.</b></p> <p><b>Disability Tax Credit.</b> A person with a "severe and prolonged" impairment in physical or mental function may claim the disability amount once they are eligible.</p> <p>Caregivers of dependants or spouses/ common law partners may be eligible to have the Disability Tax Credit amount transferred to their own tax returns.</p> <p>Take-up is low (Dunn &amp; Zwicker, 2018).</p> <p>Currently, Nova Scotia is the only province in Canada that has a monthly income or allowance available (known as the Caregiver Benefit Program).</p>	<p>If the caregiver and the care recipient both qualify for the Program, the caregiver will receive \$400 per month.</p> <p><a href="https://novascotia.ca/dhw/ccs/caregiver-benefit.asp">https://novascotia.ca/dhw/ccs/caregiver-benefit.asp</a></p>

Jurisdiction and responsible entity	Support available	Payment rate
<p><b>Australia</b></p> <p><b>Department of Human Services</b></p>	<p><b>Carer Payment</b> supports someone if they can't work in substantial paid employment. This can be providing full-time daily care to:</p> <ul style="list-style-type: none"> <li>• someone with a severe disability or medical condition, or</li> <li>• someone who is frail aged.</li> </ul>	<p><a href="https://www.humanservices.gov.au/individuals/enablers/how-muchcarer-payment-you-can-get">https://www.humanservices.gov.au/individuals/enablers/how-muchcarer-payment-you-can-get</a></p>
	<p><b>Carer Allowance</b> is an income supplement for parents or carers.</p> <p>You need to provide daily care for someone:</p> <ul style="list-style-type: none"> <li>• with a disability</li> <li>• with a medical condition, or</li> <li>• who is frail aged.</li> </ul> <p>There is no income or assets test for Carer Allowance. The same rate is paid no matter what someone earns or owns.</p>	<p>If someone is providing care to a person who is aged 16 or older, Carer Allowance (\$129.80) is paid each fortnight.</p> <p>If a person is providing care for a child aged under 16, with high needs they receive the allowance every fortnight and a Health Care Card for the child. If they have a child with lower needs they receive a Carer Allowance Health Care Card for the child.</p> <p><a href="https://www.humanservices.gov.au/individuals/services/centrelink/carer-allowance/eligibility/payment-rates">https://www.humanservices.gov.au/individuals/services/centrelink/carer-allowance/eligibility/payment-rates</a></p>
	<p><b>Carer Adjustment Payment</b> is a one-off payment. It helps families when children up to six years of age are diagnosed with:</p> <ul style="list-style-type: none"> <li>• severe illnesses</li> <li>• medical conditions, or</li> <li>• major disabilities.</li> </ul>	<p>The most any family can get is \$10,000 for each child for one catastrophic event.</p> <p>How much they get depends on their family's circumstances.</p> <p>The recipient won't pay tax on this payment.</p>
	<p><b>Child Disability Assistance Payment</b> is a yearly payment to help parents with the costs of caring for a child with disability.</p>	<p>Each year someone can get up to \$1,000 for each child who qualifies for Carer Allowance. If they are getting Carer Allowance for two children, they will get two payments.</p>
	<p><b>Essential Medical Equipment Payment</b> is a yearly payment to help with increases in home energy costs. These can be from the use of essential medical equipment to help manage disability or a medical condition.</p>	<p>The most they can get is \$157 each year.</p>
	<p>The <b>National Disability Insurance Scheme</b> aims to support people with permanent and significant disabilities and will pay for some aids and equipment.</p> <p>Each state and territory has its own equipment schemes.</p>	<p>Provides support to people with a disability and their families and carers. Supports may be funded in areas such as education, employment, social participation, independence, living arrangements and health and wellbeing.</p>

Jurisdiction and responsible entity	Support available	Payment rate
US	<p>In 15 states, Medicaid offers a <b>Cash &amp; Counselling</b> programme that provides an allowance that can be used for various services, including paying family members for care.<sup>31</sup></p> <p>In some communities across the US, veterans who are at risk of nursing home placement can enrol in the <b>Veteran-Directed Home and Community Based Services</b> programme, which allows veterans to manage their own care, including hiring and paying their own caregivers.</p> <p>Also available to wartime veterans and their spouses is a benefit called <b>Aid and Attendance</b>, which helps pay for in-home care, as well as assisted living and nursing home care. This benefit can also be used to pay family caregivers (means tested).</p>	Medicaid eligibility criteria apply.
Sweden	<p>The Swedish Care for the Elderly law entitles caregivers to an allowance and social security protection comparable to what exists for care personnel in the formal caregiving sector.</p> <p>The municipality reimburses the caregiver of an elderly dependant with a salary equal to that of a municipal formal home care worker. This salary is subject to income taxes. In addition, the Attendance Allowance is an untaxed cash payment to a care recipient to compensate a family caregiver.</p> <p>Eligibility is usually based on the level of dependence/amount of caregiving (calculated care hours per week) and payment is around kr.5,000/month. Each municipality has authority over the Attendance Allowance and whether and how it is offered is within their discretion – there is no federal or state regulation – and availability, payments, eligibility criteria and maximum payment vary by municipality.</p> <p><a href="https://www.bcli.org/sites/default/files/Family%20Caregiving%20-%20Chapter%206.pdf">https://www.bcli.org/sites/default/files/Family%20Caregiving%20-%20Chapter%206.pdf</a></p>	The maximum charge for home help, daytime activities and certain other kinds of care is SEK1,772 per month (2016).

31 An evaluation found that family caregivers of programme participants experienced a much higher quality of life and lower levels of physical, emotional and financial stress than control group caregivers, in all three states examined (Brown et al., 2007; Foster et al., 2007).

Jurisdiction and responsible entity	Support available	Payment rate
<b>Norway</b>	<p>The Care Wage is a taxable wage available to caregivers who are providing extraordinarily burdensome care to severely disabled persons. The amount of the wage is based on care needs but the average pay is kr.4,600/ month. However, this salary would purchase one month's groceries plus seven train tickets in Oslo, but is not adequate to cover the cost of rent in Norway. <a href="https://www.bcli.org/sites/default/files/Family%20Caregiving%20-%20Chapter%206.pdf">https://www.bcli.org/sites/default/files/Family%20Caregiving%20-%20Chapter%206.pdf</a></p>	

