

# Sharing the Care: The Future of Caring in Australia

Submission to the  
Inquiry into better support for carers

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Family, Community, Housing and Youth

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## ***About Carers Victoria***

Carers Victoria is the statewide peak organisation representing those who provide care. We represent more than 700,000 family carers across Victoria – people caring for ageing parents, children with disabilities, and spouses with mental illness or chronic health issues. Last financial year, Carers Victoria provided over 20,000 direct services to family carers.

Carers Victoria is a member of the National Network of Carers Associations, as well as the Victorian Carer Services Network. Carers Victoria is a non-profit association which relies on public and private sector support to fulfil its mission with and on behalf of carers.

Carers Victoria is a membership based organisation. Our members primarily consist of family carers, who play an important role in informing our work, contributing to advocacy and strategic aims, and distributing information more widely to other carers.

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## 1. Introduction

Across the lifecycle, Australians have always provided care and support to family members and friends who have a disability, mental illness, chronic condition, terminal illness or who are frail aged. Often overlooked or taken for granted, this informal care\* is a crucial lynchpin of strong communities, adding cohesion and creating social capital. With the right supports from governments and communities, it helps individuals needing care to live with independence, meaning and dignity.

Until recent decades, there was an expectation that the majority of care would be provided by women, supported financially by men in full time, secure work. Our submission argues that this paradigm of caring no longer applies in modern Australia. It is not economically or socially sustainable and, importantly, the community's expectations have shifted. In his book, *Weighing up Australian values* (Howe 2007), Howe describes current Australia as a society in which women are no longer confined to family caring roles, fewer people live in nuclear families and jobs are no longer for life. Furthermore, the number of people needing care is steadily rising and set to rise still further, and it is a preference of individuals and their families and of governments that they remain in the community while they receive care.

### 1.1 This submission

This submission will briefly outline the current and changing context of care in Australian society. We will outline the policy challenges likely to be driven by those changes, and will articulate a more useful paradigm for addressing them. Fundamental to our position is the belief that any successful enterprise to support informal care must also recognise and support the interdependent relationship with the person receiving care. Any successful measures or reforms must support and empower all of those affected.

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\* Informal care is distinguished from services provided by health and community sector employees ('formal care') because the care is provided free of charge to the recipient and is not regulated by government.

## **1.2 Current and Future Context of Caring In Australia**

### **1.2.1 Current Profile of Caring**

In Australia, the vast majority of people with a physical, sensory or intellectual disability, chronic or mental illness live within the community and not in institutions or paid care accommodation\*.

According to 1998 ABS statistics quoted in a report prepared for Carers Australia by the National Centre for Economic Modelling (NATSEM), only a small proportion (15.4%) of people with a severe or profound disability lived in paid care accommodation, while 69.2% were living with others and 13.2% were living alone in private dwellings (Percival & Kelly 2004 quoting ABS 1999). These figures refer to living arrangements only and do not reflect the full extent of informal care that is provided to people in all forms of dwelling. They do, however, point to the very high rate of people with care needs who are living in the community, a rate that is likely to be even greater when groups of people with less severe disabilities are considered.

This scenario is only possible because of the 2.6 million Australians who provide informal care. This figure represents 12.5% of the total Australian population. The Australian Bureau of Statistics (ABS) *Survey of disability, ageing and carers* identifies 500,000 primary carers, defined as someone who provides the most informal assistance for core activities and has been doing so for longer than six months. Most primary carers (78%) care for a person living in the same household (ABS 2004).

The increasing trend towards informal rather than formal care is likely to be due to several factors: deinstitutionalisation; the preferences of people with disability and their empowerment through disability rights' progress; and the preferences of their families. It is also important to recognise the ways in which policy and service contexts can impact on family circumstances and decisions. For example, families are more likely to provide higher levels of informal care if there is a lack of alternative services or if those services lack the quality or the level of care required to meet the needs of the person with a disability and their family.

The responsibilities of caring cut across all social, demographic and age groupings, although distribution is not equal. For example, 54% of all those caring are female but the percentage rises sharply to 71% when referring specifically to primary carers. Some of those caring do so for more than one person, including 'sandwich carers' who care for children as well as an elderly parent or other relative. There are 170,600 people under the age of 18 who provide care (ABS 2004).

Patterns of caring vary in duration and intensity. A child with a disability may need a high level of care for the remainder of their life. The role of an adult child caring for an elderly parent may change if the parent moves into an institutional setting, and will cease altogether when the parent dies. People recovering from an accident or illness, or those in palliative care, may need intensive care and support for a finite length of time, while those

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\* 'Disability' in the context of the *Survey of disability, ageing and carers* is an umbrella term for impairments, activity limitations and participation restrictions. The term is inclusive of people with physical, sensory and intellectual disabilities, chronic and mental illness (ABS 2004). We have used this broader definition of the term throughout this submission.

with a chronic episodic illness such as schizophrenia may need care at different times throughout their life course.

### **1.2.2 Contribution Made by Caring**

According to a report prepared for Carers Australia by Access Economics, informal caring in the community provided 1.2 billion hours of care in Australia in 2005.

There have been numerous attempts to quantify the financial contribution made to society by informal care, and to make a comparison with the value of equivalent formal care. One method is to calculate the cost to society if all current informal care was delivered through formal care systems. Access Economics conservatively estimated this figure to be \$30.5 billion per year. This is equivalent to 62.2% of the health and community sector budget for that year or 3.5% of annual Gross Domestic Product (GDP). To put this into perspective, the annual GDP contributed from the agriculture industry was 3.1 % (Access Economics 2005).

### **1.2.3 Future Projections of Caring**

A number of studies have predicted that the number of people needing informal care will steadily increase. This is because:

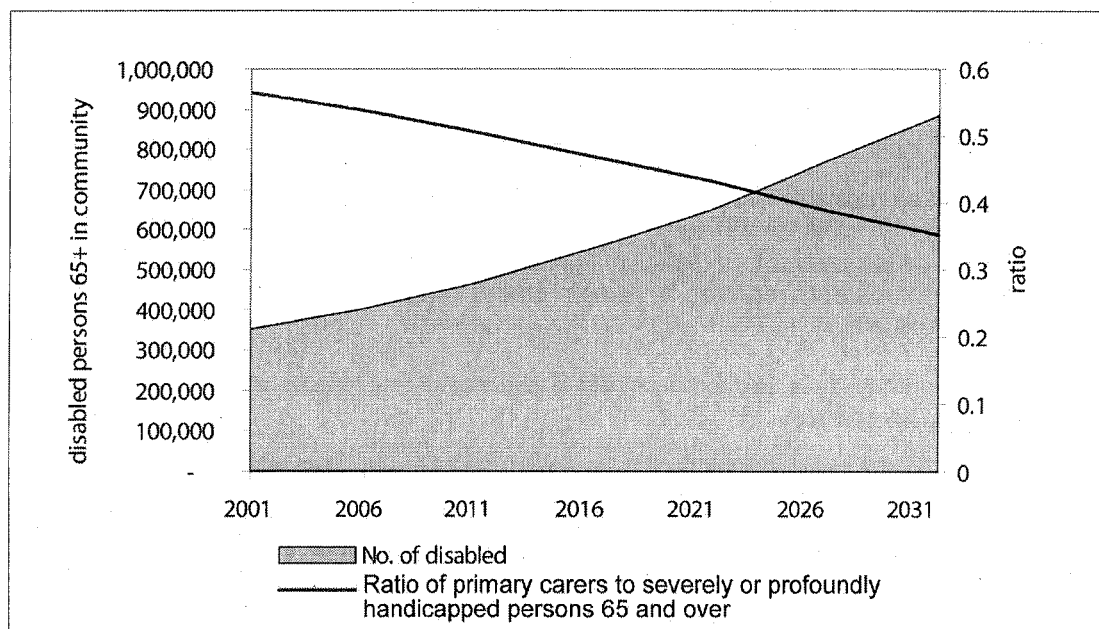
- Australia's population is ageing, with the number and proportion of people aged 65 years and over steadily increasing. This demographic change is widely accepted to be the result of lower birth rates and longer life expectancies.
- Although there is some debate about what longer life expectancies will mean for patterns of disability, there is some evidence that additional years of life will not mean that there will be more disability free years (Percival & Kelly 2004 quoting Davis et al 2002).
- It is estimated that that the numbers of older persons with a severe or profound disability in Australia will increase by 160% between 2001 to 2031 (Percival & Kelly 2004).
- By 2031, people over 65 years are projected to account for 62% of all profoundly or severely disabled people (increasing from 44% in 2001). Over the same period, people over 85 years are projected to account for 25% of all profoundly or severely disabled people (increasing from 14% in 2001) (Percival & Kelly 2004).
- The rates of people born with a disability, or acquiring a traumatic injury, mental illness are not expected to decline to any significant extent.
- It is assumed that older people and people with disabilities will continue to express a preference to live at home.

The number of people available to provide informal care is also expected to increase, but at a slower rate than that the number of people requiring care. Over the period 2001 to 2031 that the number of older people with severe or profound disability is expected to

increase by 160%, the number of people available to provide care is expected to increase by 57% (Percival & Kelly 2004).

The ageing population contributes to this trend, as do other social factors such as: fewer numbers of children per family; increased family breakdown and mobility; more people living alone and increased workforce participation by women.

Effect of improvements in age specific disability rates on projected numbers of severely or profoundly handicapped persons 65 years and over <sup>a</sup> and the ratio to primary carers, Australia 2001-2031



<sup>a</sup> Only includes persons living in private dwellings

**Table taken from Percival & Kelly 2004**

This decreasing 'caretaker ratio' creates an urgent policy challenge around how people with disabilities will be supported in the future. As we have previously shown, replacing informal care with formal care is likely to be prohibitively expensive for taxpayers and governments. The estimate of \$30.5 billion in 2005 is likely to increase dramatically as demand for services increases in line with demographic changes (Access Economics 2005). An ageing population is likely to result in a decreasing proportion of the population of workforce age and less revenue collection by government at current taxation rates. It is therefore unlikely that significantly more public money will be made available.

### 1.3 Costs of Providing Care

#### 1.3.1 Lost Opportunities and Financial Costs

Although informal care can result in some very tangible benefits for individuals, families and governments the costs can also be high, particularly for those providing the care.

A recent study by the Australian Institute of Family Studies (AIFS), 'Caring and women's labour market participation', showed that 53.6% of unemployed women who receive the Carer Payment want to work. The same study showed that, of this unemployed group of women, 47.4% had been employed just prior to commencing caring (Gray et al. 2008). This suggests a pattern where people who need to provide care find that they have to give up paid work to meet their caring responsibilities.

Unemployment is only one of a number of differences in employment patterns between those who are caring and the general population. Those who are combining paid work and caring are also much more likely to be working part time. The Access Economics report found that the full time employment rate of primary carers is less than half that of the general population (Access Economics 2005). A survey conducted by the Task Force on Care Costs (TOCC) also found that 44% of the employed carers surveyed were working in a role below their skill level because it gave them the flexibility they need to meet their care responsibilities (TOCC 2007).

Lack of workplace flexibility is one of a number of barriers making it difficult for carers to combine caring with paid employment. A separate AIFS report, 'The nature and impact of caring for family members with a disability in Australia' (Edwards et al. 2008), found that the most common barriers reported by female carers who are not in the labour force but would like to work are:

Main barriers to employment identified by female carers who were not in the labour force but would like to work, by payment type

	Payment type	
	Carer Allowance only	Carer Payment
	%	%
No alternative disability care arrangements available	22.4	21.6
Would be too disruptive to the person with the disability	12.7	17.6
Difficult to arrange working hours	23.0	15.7
Loss of skills from being out of the workforce	3.0	2.0
Age	6.7	17.6
Cost of paying for disability care while at work	2.4	2.0
Other	27.3	23.5
No difficulties expected	2.4	0.0
<b>Number of observations</b>	<b>165</b>	<b>51</b>

Notes: Excludes those aged 65 years or older. Of the 84 carers who indicated that there was an "other" barrier to employment, 27 (32.1%) indicated that their own health was a factor.

Source: FCPDS 2006

**Table taken from Edwards et al. 2008**

More attention will be given to these barriers later in the submission. It is worth noting, however, that they clearly reflect the interdependence of carers with the person they are caring for. They also range broadly across areas of formal service delivery, workplace policy and practice, and cost.

Not being able to participate in paid work means less household income. This 'opportunity cost' for those who provide care is estimated to be in the order of at least \$4.9



billion per year (Access Economics 2005). This figure does not include the value of superannuation foregone by those unable to accrue superannuation contributions because of care responsibilities.

For many households, caring responsibilities also add enormously to overall expenditure. There may be a need to pay for items such as aids and equipment, pharmaceuticals, housing customisation, additional heating and utilities and transport costs. A report by the Australian Housing and Urban Research Institute (AHURI) has also shown that the lack of workforce participation by people with disabilities and by those who care for them can mean that households are disadvantaged when attempting to enter or remain in the housing market. The difficulties can be particularly acute when there is a need to customise the home to make it appropriate for a person with a disability and the family are renting (Kroehn et al. 2007).

All of these factors contribute to a strong correlation between caring and low income. The ABS *Survey of disability, ageing and carers* found that the average income for carers was more than 25% lower than for non-carers. In addition, carers are over represented in the two lowest household income quintiles. (ABS 2004). A report produced jointly by Deakin University, Australian Unity and Carers Australia found that, even among carers who work full time, average earnings are \$7200 less per year than the general population (Cummins et al. 2007). All too often, lower incomes translate into financial hardship. The Edwards report showed that 30% of families including a person receiving Carer Allowance had problems paying utility bills on time. This rate is more than double the 14.6% rate of difficulty with utility bills experienced by the general population (Edwards et al. 2008).

The reduced capacity of carers to participate in the workforce comes, in turn, at considerable cost to society. The Access Economics report estimates that the Commonwealth government incurs costs in excess of \$2 billion per year through the Carer Allowance and Carer Payment, and loses in excess of \$1.36 billion in income taxation payments (Access Economics, 2005). Commonwealth, State and Territory governments also pay substantial sums for specialised carer support services.

### **1.3.2 Costs to Health and Wellbeing**

Caring can also have a negative impact on health and wellbeing. The Cummins report, commissioned as part of the 'Australian Unity Wellbeing Index', showed that carers have the lowest level of health and wellbeing of any group in Australia studied to date. In terms of mental health, the report posits that 'If this result (the rate of depression) is extrapolated to the whole population of carers across Australia, it is likely that carers account for a substantial proportion of the depressed people in Australia' (Cummins et al. 2007).

The Edwards report found that it is not only those providing care, but also their families who experience higher rates of mental health problems than the general population. The study found that over a four week period, 19% of female carers and 13% of male carers suffered clinical depression rates. This compares with 11% and 8% in the general population. In addition, 51% of female carers and 30.7% of male carers reported depressive episodes of six months or more since commencing their caring role (Edwards et al. 2008).

Studies have also shown that people who care are twice as likely to be in poor physical health compared to the general population. The Cummins report showed that those

caring had significantly higher incidences of chronic diseases than the general population (Cummins et al. 2007). A South Australian longitudinal survey of adult family carers supported this finding, showing that 70% of carers report chronic conditions such as diabetes, asthma, arthritis and cardiovascular disease. Carers are at least 40% more likely to suffer from a chronic health condition than the rest of the population (Gill et al. 2007). The burden of these chronic diseases comes at a massive financial cost to society. According to the Australian Institute of Health and Welfare the 12 most common chronic diseases cost the Australian tax payer \$11 billion in the year 2000-01.

### 1.3.3 Social Exclusion

Lower than average incomes, lower rates of workforce participation and poor health have all been shown to be indicators of social exclusion.

Numerous studies in recent years have explored the specific factors and circumstances that are important in determining the existence and extent of social disadvantage for people providing care. Such factors include: the duration of the caring period; the number of hours of caring per week; and the perceived level of support available. Those identified as primary carers are at particular risk of social disadvantage.

Factors influencing social exclusion are often compounded. For example, those who provide care for many years and have been unable to participate in paid work will then have little or no accumulated superannuation or assets, low rates of home ownership and are unlikely to have had opportunities to access the education or training needed to assist future workforce participation.

Those providing care have significant overlaps with population groups already at risk of social exclusion. In general, women are more likely to have lower workforce participation and lower accumulated superannuation than the population as a whole. As has already been mentioned, they are also more likely to be carers. The Human Rights and Equal Opportunity Commission (HREOC) report, 'It's about time' provides gender analysis on this issue and mounts a strong case for a more equitable sharing of paid and unpaid work across both genders (Squire & Tilly 2007). A report by the UK Institute for Public Policy Research, *Care in a new welfare society* found that 'caring (as defined across the life cycle) plays a crucial part in the concentration of women in low-skilled jobs and in the gender pay gap' (Moullin 2007).

Carers are themselves more likely to have disability (35.4%, compared with 22% of the general population) (ABS 2004). There is also a strong correlation between caring for a child with a disability and being a single parent, undoubtedly influenced by the high rates of separation associated with caring for a child with a disability.

It is also relevant to view social exclusion across a family or household context and not just an individual one. A household with someone caring will also include at least one person with a disability, and that person is also more likely than average to be unemployed and experience social exclusion. Young carers have been shown to be at risk of interrupted or shortened secondary education, so any children or young people with a caring role are more likely to experience social, educational and economic disadvantage. These factors suggest a possible correlation between caring and intergenerational social exclusion. Awareness of the possibility of the compound effects associated with caring families should be included in future work on monitoring and addressing social exclusion.

It is possible that the relationship between caring and social exclusion is not a simple causal one. The Gray study posits that, because of informal decision making processes by individuals and within families, those who take on caring roles may have had reduced labour market earning capacity before taking on the role. Those with a higher earning capacity have a greater capacity to purchase the formal care supports that allow them to continue to participate in the workforce (Gray et al. 2008).

Compounding the effects of social exclusion by informally selecting already disadvantaged members of society to provide much of our caring is inequitable and unsustainable. This submission will argue that caring and paid work must be shared more equitably across society if we are to provide the quantum of informal caring we need now and in the future.

It is at this point that we arrive at the key policy dilemma that will guide the remainder of this submission:

***There will be a greater need for caring in the future but proportionally fewer people to provide informal care and limited financial resources with which to pay for that caring.***

#### **1.4 What Needs to Change?**

The current paradigm of caring is not sustainable from several perspectives:

- For many of those currently caring, the economic, health and social costs are too great.
- For society, the economic and health costs of allowing many caring families to be socially excluded are too high.
- In the future, there will be proportionally more people needing care and a shortage of people able to provide care. Substantially higher levels of formal care may not be affordable in the long term.

Australia urgently needs a policy framework that is able to maximise the supply of people to provide informal caring while minimising the costs to society. This broad aim will not be achieved without developing a coherent systemic approach that understands the ways in which different policies interact when applied to the realities of caring. The paradigm must have a dual and complimentary focus - recognising the interdependence between those caring and those receiving care. It must also address the changing needs of people across the lifecycle.

Current government policies aim to support an identified population group of 'carers'. This approach fails to encourage and support caring because it excludes those people who do not identify with the label and because it separates many of those who are caring from the workforce. Identifying a discrete population in this way precludes us from adequately meeting the broad range of individual and family needs, particularly for those families whose needs are greatest. A new paradigm must explicitly aim to support all and any individuals involved in the activity of caring.

An effective cluster of policies resulting from a new paradigm would need to achieve the following:

- Caring is seen to be entirely compatible with paid work. People providing care are supported to continue to participate in, rather than be separated from, the workforce. Workforce participation is a means of addressing financial hardship and social exclusion and can complement the need to increase carer availability.
- Transitions between work and care are supported so that they involve fewer risks for individual carers and their families.
- People, whether caring or not, are supported to participate in the workforce for longer. This will increase tax revenue to pay for the increased demand for services.
- Families are supported to share informal caring within and across family units. This will reduce the costs of caring for individuals and make caring more attractive for those considering caring.
- The negative impacts and disadvantages of high intensity, long term care are avoided or moderated.
- New models for sharing informal caring with formal services to allow both forms of caring to be more sustainable.
- Services for people with disabilities, chronic illness and people who are frail aged must be of sufficient quality and accessibility to provide real options and alternatives to family care and so make caring sustainable. This is an essential precursor to achieving all of the above aims.

## **2. Enablers of Change**

There is an urgent need for policy reform to address present and future care issues in Australian society. The new paradigm must make caring possible for a greater number of people and more sustainable for those already caring.

This submission will describe the following supports and enablers for a more sustainable approach to caring:

- Reform of the income support, taxation and superannuation systems to make caring possible for a greater number of people and more sustainable for those already caring;
- Reform of workforce policies and practices to support people to combine caring and paid work; and
- Reform of service systems to better support people with disabilities and their families so that caring arrangements are both more sustainable and offer real choices to families.

### **2.1 Income Support, Taxation and Superannuation Reform**

Welfare reform has a crucial part to play in meeting these policy needs. Our vision requires an income support system that:

- Supports caring by an increased number of Australians across the population and across the lifecycle;
- Encourages a more equitable distribution of caring and prevents long term financial insecurity and social exclusion; and
- Recognises and enhances the value of caring within society.

This section will briefly examine current relevant welfare and employment policies in the context of these aims before outlining an alternative framework.

#### **2.1.1 Current Welfare System**

The Commonwealth government currently provides financial support to people with caring responsibilities through two main welfare payments.

The Carer Allowance is a non-means tested, non-taxable payment made to people who provide daily care and attention at home to a person who has a disability or severe medical condition, or is frail aged. It is currently paid at the rate of \$100.60 per fortnight.

The Edwards report showed that one half of Carer Allowance recipients also received an income support payment such as Carer Payment, Age Pension, Parenting Payment or Disability Support Pension (Edwards et al. 2008).

The Carer Payment is an income support payment available to people who, because of the demands of their caring role, are unable to support themselves through substantial workforce participation. It is means tested and is targeted towards those most in financial need. It is currently paid at the same rate as other pensions, up to a maximum of \$546.80 per fortnight for a single person.

The Carer Payment is reduced once a person earns more than a prescribed level and recipients must not work, study or train for more than 25 hours per week (including travel time). It is a requirement that the needs of those receiving carer are assessed using the Adult Disability Assessment Tool (ADAT).

Both the Carer Allowance and Carer Payment have sub categories, with separate assessment criteria and processes, relating to those caring for a child or adult with a disability. A recent review by the Commonwealth government has recommended changes to this system as it applies to the care needs of children with a disability. The recommended changes aim to improve equity with the adult measures, to increase access, and to streamline transitions when a child with a disability becomes an adult (Carer Payment (child) Review Taskforce 2007).

While it is essential that income support is available for those unable to work because of their caring responsibilities, this is only part of the picture. The welfare system must play a broader role if it is to more adequately address current and projected caring contexts.

Firstly, to maximise the number of people available to provide informal caring, the risks and costs involved in making transitions from paid work into caring and vice versa must be minimised. Having caring responsibilities often means having to give up a job, reduce hours or take a position of lower responsibility and pay to provide flexibility. Over time, this reduction in paid work combined with additional caring costs means that those caring can endure higher levels of financial hardship. This continues even after caring has ceased because of decreased superannuation contributions. It is no surprise that, to many, the potential costs of caring are simply too high, and that these costs may be avoided by those with the means or opportunity to do so.

Howe describes Australian society as one in which women are no longer expected to provide all the informal care at the expense of working in paid employment (Howe 2007). The urgent need is for the community to understand that caring will be an increasingly commonplace part of all our lives. It is problematic that the current welfare, taxation and services system do not do enough to support this change of attitudes and expectation.

The Carer Allowance and Carer Payment do not aim to address the additional costs of providing care, to replace foregone income, or to recognise the replacement costs of formal care.

By identifying carers as a discrete population group rather than aiming to support caring as a role, the Carer Payment creates an artificial separation between caring and paid employment. The 25 hour maximum limit for work, training or study for those receiving Carer Payment reinforces the way in which the compatibility of paid work and caring is limited. This separation makes transitions between the two roles cumbersome and risky. Carer Payment cannot be divided between two or more people, meaning that the paid work and caring roles are commonly segregated. There is a disincentive for a single recipient of the Carer Payment to work more hours because it might mean loss of

benefits. The income and assets test is based on household rather than individual income and this can be a disincentive to leaving work to provide care.

It is well established that lack of paid work has a detrimental effect on health and wellbeing for all adult population groups. This is especially significant to those providing long term care because of paid employment's potential to provide respite and social participation in addition to income. The 25 hour limit for work, training or study for Carer Payment recipients reinforces the incompatibility between informal care and work. Carer Payment recipients are most likely to be primary carers providing long term, high intensity care. They are most likely to have the lowest incomes and levels of health and wellbeing. They have the most to gain by increased workforce participation.

A further barrier to workforce participation created by the Carer Payment is the way in which it interacts with the taxation system. When a Carer Payment recipient accepts paid work, their payments begin reducing as soon as they earn \$132.00 a fortnight. The value of the payment reduces even further when income tax is deducted, and the additional costs associated with participating in paid work reduce this still further. It is clear that the financial benefits of commencing or increasing paid work can quickly be compromised.

A recent NATSEM study into trends in Effective Marginal Tax Rates (EMTR's) showed that it is often those on the lowest incomes who are most affected by the ways that income support and taxation effects combine (Harding et al. 2006). Further work is needed to examine the specific ways in which unintended EMTR's can impact on those combining caring with paid work, especially for sole parent carers and household second income earners. A system that supports work/care transitions must reward paid work while also providing adequate income to those who cannot work because of their care responsibilities.

If the welfare system is to be effective in supporting people to care, it must be accessible to those needing it. We know that there are 2.6 million people caring in Australia, almost 500,000 of whom are primary carers. However, fewer than 5% (116,614) of those caring receive the Carer Payment. The numbers are only slightly higher for the Carer Allowance, 15% (393,263). Since the majority of those receiving Carer Payment also receive Carer Allowance, these figures show that at least 8 out of 10 Australians who provide care are doing so with no support from government. There could be a number of reasons for this, including narrow eligibility and assessment criteria for welfare payments, a poor knowledge generally about the benefits available and a lack of identification with the label 'carer'.

Research done in the United Kingdom shows that 65% of people with a caring responsibility did not identify themselves as a carer in the first year of caring and that a third took more than five years to do so (Carers UK 2006). Though similar research has not been conducted in Australia, these findings again suggest the limitations of providing support for an identified 'carer' rather than for the role of caring. Lack of identification as a carer, and lack of information about supports, apply even more acutely to indigenous people, to young people or to people from culturally and linguistically diverse backgrounds, perhaps because the term carer has no cultural equivalent for these groups. The duties and responsibilities of caring are seen as extensions of family commitments and responsibilities.

The question of narrow eligibility and assessment may combine with systemic factors to make access inequitable across the care of people with different conditions. For example, there is anecdotal evidence that those providing care for someone with a mental illness are under represented amongst those accessing the Carer Allowance and the Carer Payment. While it is likely that the identification of a 'carer' is particularly problematic in a mental health context for both the person providing care and the person being cared for, it is also likely that the ADAT is limited in catering for those caring for people who have episodic conditions and for those for whom the bulk of support given is emotional rather than practical in kind.

One of the aspirations driving a reformed welfare system is to assist people to provide care by valuing and recognising the contribution of caring in the community. While the Carer Allowance is appreciated by those receiving it, its rationale and purpose remains publicly not explicit. While the allowance may be intended to provide a symbolic recognition of caring with a fixed monetary amount, we do not live in a society and context that equates the value of caring with that of paid work, and so this worthwhile aim is likely to be difficult to achieve through a single measure.

### **2.1.2 Using Welfare Reform to Encourage Caring**

The current welfare system cannot adequately support caring in the ways we need it to, in the present and the future. This section will recommend ways in which the welfare system can move towards meeting our aims better.

If we are to encourage caring across the life course and the sharing of care across a broader section of the population, access to financial supports must be more timely and must relate to the activity of caring rather than to an individual 'carer'. This aim is consistent with Moullin's recommendations regarding the development of a single income-replacement benefit to replace all other pensions (Moullin 2007). It is also consistent with Howe's application of Gunther Schmid's work on transitional labour market approaches in Europe to the Australian context (Howe 2007). This single income-replacement benefit would not require claimants to self-identify as carers but would value caring as a legitimate reason for being out of paid employment. By reducing the separation between caring and paid employment, such a system would normalise caring and provide support over the life course and across caring transitions. Eligibility based on the situation of individuals, rather than couples, would better recognise the financial independence of women and of those with caring responsibilities.

Considerable analysis would be required before employing such a universal approach, including economic modelling. Costs need to be understood within the context of the projected demand for informal care and would consider the benefits of facilitating the supply of care while helping those caring to maintain workforce participation. Advocates for transitional labour market approaches also point to improvements in workforce participation for older people, again meeting society's need to address the challenges of an ageing population.

A short term and much more immediate measure to address one of the current system's inequities would be to ensure that Carer Payment recipients are automatically eligible for Carer Allowance. Current eligibility inequities could be addressed by immediate attention to assessment procedures. This would include ensuring that those caring for people with episodic conditions such as mental health problems are not unfairly disadvantaged by the



assessment. Assessment needs to increasingly measure care load and to ensure eligibility for carers when their role focuses on supervision, emotional support and vigilance rather than on the physical requirements of care.

#### *Splitting Carer Payment*

The Cummins report showed long term caring to be an indicator of increased financial hardship and health problems (Cummins et al. 2007). We have previously argued that sharing the care would make caring more sustainable for many by mitigating the social and economic costs involved. We need to explore the feasibility of dividing the Carer Payment amongst more than one recipient.

#### *Carer Bonus*

Earlier this year, the possibility of the new Commonwealth government not continuing with the payment of Carer Bonuses was raised. The strong reaction of Carer Allowance and Carer Payment recipients demonstrated the reliance that families place on the bonus to help pay for one-off essential purchases or outstanding bills. Anecdotally, the bonuses were seen as having symbolic value and providing an enforced method of saving for families otherwise unable to do so. Political considerations may require that the Carer Bonus is legislated to become permanent with recipients having the choice and flexibility of receiving it distributed on a fortnightly basis or being able to draw down on it to provide a lump sum to pay for unexpected or larger expenditure items.

### **2.1.3 Reducing the Risks of Combining Work and Care**

It is important that we introduce other specific measures to reduce the barriers to taking on additional paid work experienced by those caring. In particular, income support and taxation rates must be adjusted to allow those caring to be more adequately rewarded for any paid work they do without encountering excessive Effective Marginal Tax Rates (EMTR's). Such measures would include application to second earners in a couple in the context of a single income replacement benefit.

The current 25 hour work, training and education threshold for Carer Payment recipients can act to increase EMTR's to extreme levels. Once someone works 26 hours, they lose their Carer Payment. Those providing care are already economically disadvantaged. This disincentive to work needs urgent attention.

As informed by the barriers to employment surveyed in the table on page 8, the high cost of formal substitute care can prohibit those caring from taking on paid work. There is an instructive parallel to be drawn here between government supports for those caring for young children without disabilities. Raising children is almost universally seen as a valuable social good that can restrict parents from participating in the workforce because of the need to provide care. Governments provide subsidised, universally accessible childcare services of good quality because this approach has been shown to facilitate the workforce participation of parents, particularly women. Current arrangements include provision of child care benefit through the taxation system and the sharing of out of pocket childcare costs between parents and government.

Caring for a person who is elderly or has a disability is also an essential social function that saves the taxpayer many billions of dollars but can restrict the workforce participation of those caring. Appropriate, good quality formal care services are not always available or

accessible to allow those caring to enter into, or increase their hours of paid work. Importantly, where these services are present they are frequently too costly to offer a real option (TOCC 2007). Issues in the quality and availability of formal care services will be addressed below in the section 'Reform to Service Systems' It is recommended here that the costs of formal care for those who have a disability or who are frail aged are shared more equitably between government and those caring. This will allow a better balance of formal and informal caring and provide the benefits of increased workforce participation by those who care.

#### *Changes to superannuation*

One of the specific financial effects of long term intensive caring is that any assets are diminished and there is no accrual of superannuation if a person has been shut out of the workforce. This can lead to ongoing financial hardship in old age even after the person needing care has died or made a transition into substitute care. Such a situation represents the failure by society to value the role of caring. Those caring in financial hardship do not have the capacity to participate in the current arrangement of government matching the superannuation contributions of people on low incomes. Urgent work needs to be done to test the feasibility of providing government superannuation contributions at the rate of 9% of the minimum wage to those unable to work over long periods because of their caring commitments. This concept presents a considerable challenge, not least because of the danger of providing a disincentive to work in the future when the circumstances of those providing care change. If government superannuation contributions were withdrawn as soon as those caring begin any part time work, this would act as a new form of effective marginal tax, thus defeating its intended purpose. One way forward would be to suggest that if a person began paid work after long term caring, the government would top up employer superannuation contributions to ensure that the total remained at 9% of minimum wage. Further consideration would be required to determine the longevity and criteria of such an arrangement for an individual.

#### *Providing skills development*

Another possible risk of long term, intensive caring is that individuals are denied opportunities to maintain or develop work skills. They are then disadvantaged further when looking for work becomes possible. Many of those caring take casual work either because of a lack of skills or so as to ensure flexibility of work hours. Casual workers also have reduced opportunities to undergo workplace supported training, thus compounding the problem. Howe promotes the concept of life long learning accounts for all people of workforce age so that resources are available for skills development or retraining. This idea would support the currently risky transitions across the lifespan in today's dynamic work/care environment. Howe argues that this approach would also have particular value in keeping older people in the work force for longer (Howe 2007). For those unable to work because of their caring responsibilities, government would provide learning account payments in the same way as for superannuation. Those coming out of long term caring will also need individualised supports to assist them back into the workforce. A lengthy period of adjustment is common in this situation and this should be reflected through the extent of Centrelink work related activity obligations.

#### *Recognition of caring*

Again, there is some merit in drawing a parallel with the way in which the taxation system treats parents caring for young children without a disability. Family Tax Benefits (A and B)

recognise the necessity, value and additional costs involved in caring for young children. While care needs vary from individual to individual in the case of people with a disability or people who are aged, there may be merit in considering parallel treatments for carers through the taxation system. In the shorter term, the purpose of the Carer Allowance must be clarified to achieve its aim of recognising the value of care.

## **2.2 Workplace Regulation Reform**

Changes to the income security, taxation and superannuation systems which aim to encourage the combination of caring and paid work need to be accompanied by changes in workplace regulation which ensure flexible work arrangements.

### **2.2.1 Right to Request Flexible Work**

Having the right to request flexible work arrangements ('right to request') is an important measure for those who care for children, adults and older people. It provides a right for employees to request variations in their work arrangements and an obligation for employers to seriously or reasonably consider the request. Employers can only refuse the request based on 'reasonable business grounds.' Successful requests for flexible work can make it easier and more viable for those who care to combine caring and working roles and for two or more people to share the responsibilities of caring. The 'right to request' extends the opportunities for those who provide care to take up or remain in paid work. This in turn provides social and economic benefits for families and contributes to the economy.

The 'right to request' includes an array of flexible arrangements, tailored to what is feasible within the work setting. It may include, for example, changes to working hours including working fewer days or a reduction in daily hours; hours compression; starting or finishing early or late; changing rosters or changing hours for break times; job share or job redesign; and working from home. Extending unpaid leave when leave entitlements have been exhausted can be considered, together with options for making up periods of time taken off work to address care responsibilities. In addition, the 'right to request' can address the need for flexibility in the timing of meetings, or to reduce the need for overnight stays. It can provide access to the use of an office phone for calls relating to family responsibilities, or provide access to a room where children or other family members can wait. The 'right to request' is about making reasonable attempts to create a more flexible workplace for those who provide care. It will provide significant assistance, helping those who provide care to both work and accommodate day to day care demands and episodic changes in the health and well being of the person receiving care.

### **2.2.2 International Context**

Internationally there has been considerable emphasis on regulation of the 'right to request', particularly in the United Kingdom, Netherlands, Germany and New Zealand. The United Kingdom's flexible working laws have progressively extended the 'right to request' from parents of children up to the age of 6, to parents of disabled children up to the age of 18 and in 2007 to carers of dependent adults (Charlesworth & Campbell 2008). The laws are essentially focused on affirmative action for carers in the workplace.

The 'Employers for Carers' initiative (Carers UK website) is a partnership of major corporate and government employers who want to assist their staff with caring responsibilities. Their research into the business benefits of offering carers flexible ways

of working has demonstrated impressive business results. These include lower staff turnover, reduced recruitment and training costs, greater productivity and higher staff morale, reduced absenteeism, higher levels of trust in working relationships as well as improved recruitment and improved company image. Fears among employers in the United Kingdom that the 'right to request' would open the floodgates were not realised.

In other countries such as the Netherlands and Germany all workers, those with care responsibilities and those without are covered by the 'right to request'. There are some limits to eligibility related to length of service and size of workplace (Charlesworth & Campbell 2008). Universal models have the potential to reduce the resentment that workplace peers may express in more limited 'carer friendly' models. They can improve the take up of flexible work by both men and women and can contribute to addressing gender equity (It is noted that the take up of the 'right to request' in the UK is greater for women than men, and that there is a higher rate of refusal of requests from male workers). In addition, universal 'right to request' systems can reduce tensions that may arise from the need for disclosure and issues of confidentiality. Older workers have much to gain from the 'right to request' and the economy can benefit from the improved and ongoing workplace participation of older people.

A staged approach to the implementation of the 'right to request' for all might progressively extend the right from parents of young children, to parents and carers, and then to all workers, as implemented in the United Kingdom. It is understood that a staged approach may be favoured by the Australian Industrial Relations Commission.

### **2.2.3 Australian Context**

The recently released *National Employment Standards* reflect the commitment of the current Commonwealth government to replace the five Australian and Fair Pay Conditions standards with ten National Employment Standards (Australian Government 2008). They are firmly and desirably based in the Industrial Relations arena. Relevant provisions in the *National Employment Standards* include an annual allowance of 10 days paid personal /carer leave and two days of unpaid leave and compassionate leave relating to care responsibilities; and the 'right to request' for parents of children under school age who are either permanent or casual employees and whose employment is likely to continue. Eligible employees must have 12 months service. The provisions, however, are weak in relation to the duty of the employer. Requests can only be refused on 'reasonable business grounds' and this has no clarity of definition. Importantly also there is no grievance procedure or process to provide redress if requests are unreasonably refused. The employer only has to provide reasons for refusal in writing.

In addition, parental leave provisions in the standards allow one member of a couple to take leave for 12 months with their partner taking a further 12 months up to a maximum of two years per child.

### **2.2.4 What Needs to Change?**

The Commonwealth government has clearly worked to meet its election commitments in the Industrial Relations arena with the introduction of the *National Employment Standards*. To further encourage the participation and retention of those who provide care in the workforce and to encourage the sharing of care, the Commonwealth government must work towards:

- Removal of the inequity in the 'right to request' provision by extending eligibility to include people who care for older dependant children, as well as those who care for children or adults with a disability or chronic illness or people who are frail and aged. This will increase the options for people who provide care to either continue to participate in paid work or to avoid a premature withdrawal from employment.
- Incorporating policy guidelines concerning what constitutes 'reasonable grounds for refusal' of the 'right to request' in the *National Employment Standards*.
- Extending and modifying parental leave provisions to become care leave. This will ensure eligibility for those who care for older dependant children, adults and older people with a disability or chronic illness. It will provide flexibility for employed workers to take leave at the onset of high intensity care situations which frequently lead to withdrawal from work and will accommodate many periods of care which require only a one or two year commitment. It will assist in promoting a sharing of care between partners or other relatives and friends. Shared care could involve two people taking a consecutive year of care leave; alternatively two people taking half time or other periods of leave.
- Ensuring the development and inclusion in the *National Employment Standards* of a compliance regime and a grievance mechanism concerning the 'right to request' provisions. This will extend the grievance mechanisms that are in place for the other nine National Employment Standards to the 'right to request' standard. (Charlesworth & Campbell 2008). This would provide protection against unreasonable refusal of flexible work or leave and would safeguard employees against any unintended consequences of requesting flexible work, such as poorer quality employment, pay reductions or intensified workloads (Charlesworth & Campbell 2008).

#### *Other legislative options*

The incorporation of the 'right to request' as regulation in the Industrial Relations arena through the *National Employment Standards* can be complemented by legislation in the anti-discrimination arena. Examples include the *Equal Opportunity Amendment (Family Responsibilities) Act 2008* in Victoria which introduces family responsibilities as grounds for discrimination for all parents and carers and makes it unlawful discrimination for employers to unreasonably refuse to accommodate the parental or carer responsibilities of an employee. Essentially, this provides a retrospective 'right to complain'. In addition, the recommendation by HROEC for a national Family Responsibilities and Carers' Rights Act may provide additional safeguards, particularly in relation to employer compliance (Squire & Tilly 2007).

There is value in the Commonwealth government examining the eligibility, scope and outcomes of a variety of national and international "right to request" provisions in the workplace to modify and extend the *National Employment Standards* for the future. Policy development work should explore the potential benefits of extending the 'right to request' to all employees and should ensure gender equity is included as a pillar of all provisions. It will be essential to avoid the 'right to request' becoming a mechanism for enshrining

gender inequity, rather than addressing it. This is a feature of robust debate in the United Kingdom (Lewis & Campbell 2007).

#### *Resources for employers and employees*

Extensive public education will be required to precede and accompany the implementation of broader 'right to request' provisions in Australia. This might include a government sponsored 'Work-Life Balance' marketing campaign to help employers and employer bodies to afford the right to flexible work to their employees. It would involve peak union bodies and employer bodies working in collaboration and consultation on the detail. It would encourage the sharing of best practice. Leadership training programs for Human Resource Managers together with education programs to inform the workplace and promote cultural change will be required. The development of simple employer and employee guidelines, and simple forms for employee requests and employer decisions would also be required. Much can be drawn from the experience of the United Kingdom.

### **2.3 Reform of Service Systems**

This section outlines a new paradigm for our services system. It describes a series of changes that aim to ensure better support for people with disabilities and their families, to offer real choices in relation to caring, and to make caring more sustainable over the long term.

It discusses current features of the community services system and flags effective features that need to be retained. It describes a number of new services initiatives which are needed to support the increased workforce participation of carers, and puts forward areas of current services that require further investment. It outlines a number of strategies to develop greater efficiency, responsiveness and improved coordination of services, and suggests ways that we can redevelop program policies to improve carer recognition and the responsiveness of services to their needs. It also recommends a number of practical measures to support transitions in care.

All of these measures will contribute to improving social inclusion, health and well being for those providing care.

#### **2.3.1 A Robust Community Care System**

An effective community care services system must guarantee the availability, accessibility, affordability, flexibility and quality of the services needed to support each individual care situation. It should supplement the work of those providing care and ensure they have a variety of options and choices in their life, including being able to participate in employment, and to take part in family and community life while providing care.

The system should provide support at a level that makes sure that care is sustainable. This will minimise social exclusion and the costs to carer health and well being. It means complementing informal care with formal services that help sustain people with disabilities in their homes and communities, and prevent the premature use of costly institutionalised and supported accommodation options.

A robust community care system that successfully combines the resources of family, friends and formal care and support services will contribute to a reduction in the costs of the burden of disease. It is the preferred option for people with a disability and their

families. The cost will also be significantly lower than the cost of depending heavily on institutionalised care (Access Economics 2005).

A recent survey by Allen Consulting found that 85% of people with a disability and 87% of people providing care believed that community care services were necessary for sustaining independent living at home. The response identified a number of difficulties with the current system, including:

- Obtaining relevant and timely information and accessing services;
- Negotiating the complexity of the system, particularly in relation to the need to deal with many providers and to experience many separate assessments;
- Understanding the specifics of various programs, how to access particular services, and how separate programs interact to meet the needs of care situations;
- Lengthy waiting periods to access specific community care programs; and
- Lack of access to support as and when it is needed.

Both those who provide and those who receive care found the majority of community care services to be too inflexible, with few providers tailoring their services to the specific needs and circumstances of the individual care situation.

To be most effective, community care services must be provided in relationships of trust and respect, and provide a positive and meaningful experience for both the person who provides and the person who receives care. Services need to be provided in a way which empowers the people receiving formal care services. The ideal for most people interviewed would be a service that is consistent, personalised and individual – provided by the same worker(s) on a regular basis (Allen Consulting Group 2007).

### **2.3.2 Supporting Increased Workforce Participation**

The ability to participate in the workforce, on a limited, part time or full time basis, is an expressed preference of many primary carers of workforce age (Access Economics 2005; Edwards et al. 2008). Workforce participation will also address the financial hardship and social exclusion currently experienced by many people with caring responsibilities.

The community care system must provide opportunities for those who care to pursue their preferred options in terms of balancing paid work with their caring responsibilities, and in balancing formal care services with informal caring.

#### *Current Services Barriers to Workforce Participation*

The limited availability of appropriate, affordable and quality support services to provide alternative care arrangements creates many barriers for carers who want to join, or to continue to participate in, the workforce experience (ABS 2004). The Edwards report found that for 22.4% of non working carers who wanted to work, the lack of alternative care for the person they cared for was a disincentive (Edwards et al. 2008).

There are significant gaps in the availability of services that support carers to participate in employment. In particular, these impact on people who care for an adolescent or adult with a lifelong disability, people who care for an adult with a neurological condition, an acquired disability or chronic illness and people who care for an older person with a disability or chronic illness. It is likely that the limited availability of alternative care arrangements has a much greater impact on those who care for children and adults with high intensity physical care needs or with challenging and difficult behaviours. Access to quality alternative care arrangements can also be more difficult for those who care in rural and remote areas, or those who care for people from CALD backgrounds.

Any factor that makes it difficult to access regular, consistent alternative care arrangements creates a barrier preventing those with caring responsibilities from choosing to participate in the workforce, or to increase their participation. Current service barriers include:

- The non existence of alternative, appropriate care services for particular target groups.
- The inability of available services to ensure quality and continuity of care. People who provide care wish to ensure that alternative care arrangements are available in a timely fashion and provide positive, meaningful and socially relevant experiences for the person they care for. Any reluctance shown by the person needing care can make it difficult for the carer to continue to use a particular service.
- Long waiting periods for access to available services.

Issues in the affordability of alternative care are a significant disincentive. Work by the Task Force on Care Costs has demonstrated (across child care, disability care and care of older people) that there is a clear relationship between employment participation and the costs of care.

- In 2006, the costs of care influenced the departure of 64% of people with care responsibilities who were interviewed from the workforce;
- 35% of people with care responsibilities would increase their work hours if alternative care was more affordable;
- 60% of unemployed carers would re-enter the workforce and 52% of part time employees would increase their hours of employment if care was more affordable; and
- 72% of participants in the News Poll survey believed care costs should be shared equally between families and the Commonwealth government to ensure greater affordability and a fairer sharing of the costs. (Taskforce on Care Costs 2007).

The Edwards report also found that potential carers with good labour market earning capacity are better able to support their continued participation in work by purchasing care rather than providing it themselves, while low income earners were unable to afford



alternative care arrangements (Edwards et al. 2008). This applies particularly to in home care. With a per hour cost of \$30 - \$35, the purchase of additional in home care is an option available only to families with a significant income.

#### *What Needs to Change?*

Australia needs to increase investment in the development of recurrently funded programs which support the workforce participation of all people providing care. Investment should be based on the identification and promotion of effective models and practices. Good practice models should demonstrate a capacity to support the continued workforce participation of those who provide care, and should provide quality, personalised and meaningful experiences for the person requiring care. Such models may be drawn in part from the experience and evaluation of the Commonwealth government's Employed Carers Programs for Carers of Older People, and may include:

- Small locally based cottage care or host homes/family day care for older people with a disability or chronic illness. Such services provide meaningful activities and opportunities for social inclusion;
- Out of centre hours and vacation care programs for adolescents and adults with life long disabilities. Programs may be built onto existing infrastructure and developed to maximise social inclusion and community participation;
- Innovative day care models for adults with high care needs who require personal care and assistance;
- In home peak period support and emergency care services;
- Drop in services to monitor the well being of the person needing care;
- An expansion of the availability of the Home and Community Care (HACC) program, and of packaged care programs in the aged and disability care sectors, to allow clients to combine informal care with home and centre based formal care. In aged care for example, this might involve developing an increased number of bands of aged care packages between CACP's and EACH to ensure greater continuity of care as care needs change. Currently, differences in the level of support between CACP's and EACH packages is extremely wide; and
- An expansion of community based psychiatric disability support services to provide meaningful alternative care and support in the community.

Formal support services have a key role in supplementing informal care. Better access to formal support services will help to normalise and value caring, and will provide incentives that help families to share the responsibilities more equitably. When meshed with informal care, formal services can extend the choices available to carers to participate in paid work.

To assist families with the affordability of alternative care, the Child Care Rebate requires development into a Care Rebate. It should be extended to recognise the costs of alternative care for people who have a disability, chronic illness or who are frail and aged.

The Taskforce on Care Costs recommended that the Commonwealth government fund a 50% reimbursement, up to \$10,000 per year for the care costs in disability and aged care as a tax rebate. This will support the workforce participation of care giving families and encourage a better balance between formal and informal caring. (Taskforce on Care Costs, 2007). Introduction of such a scheme will require careful consideration of the range of services which used in combination can be regarded as 'approved' care services.

The limitations of the current community care system indicate that the Commonwealth government must:

- Urgently address gaps between the demand and supply of services with the aim of ensuring that appropriate levels of support are available to those who provide care and wish to participate in employment. Accessible, responsive and quality services will ensure the engagement and trust of both those who care and those who need care.
- Explore the introduction of a Care Tax Rebate as recommended by the Taskforce on Care Costs, which extends the Child Care Tax Rebate to elder and disability care. This will contribute to normalising care across the life course and to ensuring that the high costs of alternative care are shared.

### **2.3.3 Supporting Care Transitions**

Transitions and changes are an important feature of the experience of those providing care. Transitions can relate to the onset or end of caring; changes in the health, wellbeing or care needs of the person needing care; changes in the health, wellbeing or capacity to care of the person providing the care; and changes in access to formal or informal resources.

Access to appropriate services and supports during a transitional phase can help caring families to plan approaches to new circumstances and to identify their additional support needs. It can help to prevent 'knee jerk' reactions, such as a premature withdrawal from the workforce, to changing circumstances. A range of practical support measures can help to strengthen the resilience of those who provide care through difficult transitions in their individual caring journey:

#### *Carer education and capacity building*

There is considerable evidence showing that investment in educational and psychosocial interventions is beneficial for those providing care, especially for carers of people with dementia, mental illness or disability. A synthesis by the University of Wollongong has reviewed a number of studies that demonstrate the benefit to carers when they acquire skills relating the management of care, improved problem solving skills, stress management, and reduction of depression (Eager et al. 2007). Educational intervention can also help those providing care to maintain their health, improve their wellbeing and to safely undertake the practical tasks involved caring, such as transfers and lifting. A study prepared by Access Economics for Alzheimer's Australia has shown that when early identification and pharmacological intervention is accompanied by social support programs for people with dementia and their families, the progress of the disease and the need for institutional care can be effectively delayed (Access Economics 2003).

It is important to expand current carer education programs to cope with increasing demand. Measures to improve collaboration between disability specific consumer organisations, carer organisations and front line agencies such as hospitals, community services agencies and respite programs will also raise awareness of educational services and improve carer access to programs tailored specifically for their needs.

There is also a significant need to invest in community awareness programs about demographic change and the need for care. Encouraging and supporting families to engage in discussions about intergenerational family care for older people will encourage the development of flexible, shared informal care arrangements that in combination with formal care can ensure social inclusion and economic participation for those who care.

#### *Counselling support*

Evidence shows that investment in counselling and psychosocial interventions is beneficial to those providing care (Eager et al. 2007). Programs such as the National Carer Counselling Program (NCCP) support those providing care through personal health transitions, such as periods of anxiety and depression; help carers to make decisions about their capacity to continue to care at home; provide objective assistance with difficulties in the care relationship or in family dynamics; suggest strategies for managing challenging behaviours; and provide emotional support for the complex processes of loss and grief which are a feature of caring relationships.

The NCCP provided 19,109 counselling sessions for carers in 2006-7, including a wide range of language specific counselling for carers of CALD backgrounds. The rapid growth of the NCCP, its growing waiting lists and the number of requests for an increased number of sessions demonstrates the value of accessible, responsive and affordable counselling services to those providing care. Future expansion of the program is needed.

#### *Respite Services*

While research evidence on the value of respite services suggests they provide some benefits, anecdotal reports from carers emphasise the value of such services (Eager et al. 2007). Respite care services support those who provide care, and those who receive it, through emergencies, key transitions in the care situation, and changes in family circumstances. Respite helps to improve carer health and wellbeing, and provides carers with opportunities to focus on other areas of their lives. It must also provide positive and meaningful experiences for the person needing care.

The Commonwealth government has undertaken considerable investment in the development and delivery of respite services over the past decade, supplemented by investment from State and Territory governments.

The current system of respite service provision suffers from fragmentation and duplication of services. Respite programs, each with separate target groups, eligibility criteria, and access processes are delivered by a wide variety of auspice agencies, including the National Respite for Carers Program, local government, non government organisations, disability services and residential aged care providers.

This fragmentation means that accessing appropriate respite care is often costly and inefficient. Resources are wasted by duplication in assessment, and the transaction costs

of providing brokered episodic and short term respite arrangements that need to be purchased from a variety of agencies are likely to be significant.

Improved access to quality and continuous respite support is very much demanded by caring families. Planned program growth should focus more on recurrent funding of good practice models for a variety of target groups. It should also promote the development of quality services models that target and support high needs care situations, and encourage the development of improved emergency respite opportunities.

#### *Improving carer health*

The health and wellbeing needs of those who provide care are often overlooked. Medical practitioners, in general, lack awareness of the impact of caring on carer health and wellbeing, and carers may themselves concentrate on the needs of others to the extent that they ignore their own health problems. The health needs of those who provide care should be identified and explored in their interactions with General Practitioners and with other medical practitioners. Strategies to address this issue may include:

- Developing and promoting accredited self training modules to enhance the knowledge and practice of medical practitioners about carer needs and health issues.
- Extending the MBS preventative health care check item to carers.
- Raising medical practitioner awareness of MBS items that may be used to assess and manage carer health needs, including the items for Chronic Disease Management, Enhanced Primary Care, and mental health.
- Raising awareness about the importance of self care among those who provide care.

### **2.3.4 Increasing Key Services and Supports**

Some practical and achievable changes to current services may include:

- Increase the real annual funding growth of the HACCC program from 4 to 8% over the next 10 years. This will help to accommodate growing numbers of older people and people with a disability with low care needs (Victorian Community Care Coalition 2006).
- Modify the current Aged Care Planning Ratio from 20 to 24 care packages per 1000 people over 70. This will increase the number of care packages by one third. It is also important to develop an increased number of bands of care package to ensure there is greater continuity and responsiveness in the support and assistance provided to families when care needs change.
- Increase investment in the development of disability accommodation support packages and expand the number of community support packages for high needs care situations.

- Commission the development of Disability Care Planning Ratios based on available disability data sets, and formulating a disability care needs formula for low and high care situations. This would provide achievable targets for the allocation of disability accommodation support packages and community care packages to support the care of people with a disability. It would also improve the range of choices available to their carers.
- Strengthen the psychosocial community support and housing systems available to people with a psychiatric disability. This will provide better support to families and clients, as well as reducing episodes of illness and the high cost of 'blocked' inpatient beds.
- Improve the services and supports available to young people with caring responsibilities. Improved peer, school and economic supports will minimise the social exclusion experienced by young carers. Strengthening the services available to the family will help to maintain the family situation.

Particular priority must be given to addressing the needs of the burgeoning numbers of ageing parent carers. They need increased investment to help with the transition of their son or daughter into care outside the home or, through packages of support, to sustain care at home for as long as possible.

In a response to a Commonwealth government inquiry, Carers Australia have emphasised the need to ensure that ageing parent carers and their families are supported with future planning for their son or daughter. Planning may relate to accommodation support, financial and legal planning, transition planning and the development of psychosocial supports for the future (Carers Australia 2005). In a response to a Commonwealth government discussion paper on disability supported accommodation, Carers Australia also emphasised the need to develop practice models to engage with and support families and people with a disability to plan and develop supported accommodation options consistent with their means, family preferences and friendship networks (Carers Australia 2007).

### **2.3.5 Improving Efficiencies**

For those caring and those who receive care, fragmentation and duplication of services are a common experience in the current community care services system. This can cause confusion and access difficulties and result in significant wastage of resources, particularly in relation to transaction costs. A lack of effective coordination of government funding and planning policies between the Commonwealth, State and Territory governments, and the impact of competition policy have all contributed to this problem.

The following strategies would contribute to efficiency gains and improvements in the continuity of community care services, thereby strengthening the system as a whole and ensuring that available resources are better used to support those caring and those who receive care:

- The development of linked Low (HACC) and High (Community Options, CACP's and EACH) community aged care tiers through joint Commonwealth and State and Territory government planning processes. The strategic allocation of additional high care packages could assist in reshaping

community care architecture for older people and strengthening the capacity of services providers to deliver a comprehensive range of support program within defined geographical areas.

According to the Victorian government *Submission to the review of subsidies and services in Australian government funded community aged care services*, this would facilitate timely access into the system, ensure continuity in the levels of support available to older people and those who care for them, assist in smoothing client flows and help to ensure greater continuity in formal caring relationships (Victorian Government 2007).

- The creation of efficiency gains through the development of optional models for consumer directed care, for a selection of care situations in the disability and aged care sectors. International experience suggests this option is attractive to some carers. It ensures empowerment and choice, and reduces administration costs (Allen Consulting Group 2007).
- Improving access to information and advice about community aged care to older people and their families. The impact of the demonstration 'Access Points' collaboratively developed through the 'Way Forward Initiative' will need to be appraised. The implementation of a 'No wrong door' policy among all services providers (including those involved with key transition points such as GP's and hospital discharge workers) will further assist carers to receive the right information at the right time.
- Strengthening community care services for people with a psychiatric disability by improved collaboration and joint planning between Commonwealth and State and Territory governments. This approach will facilitate the development of more seamless community care services, particularly in relation to recently initiated Commonwealth government funded programs, such as the Personal Helpers and Mentors Program and Respite Care for carers of people with a mental illness/psychiatric disability. Strategic allocations from funding rounds and re tendering have the potential to reduce system fragmentation by integrating new programs with the existing community care infrastructure for people with a psychiatric disability.
- The introduction of a national equitable and comprehensive no fault personal injury scheme, tailored to address current system differences in State and Territory compensation systems. The recommendations, tabled in a report by PricewaterhouseCoopers, concerning the extension of eligibility for traumatically injured people will improve equity for people with traumatic injury and free up high cost care packages within current CSTDA services. These can be reallocated to support other high need care situations (PricewaterhouseCoopers 2005).
- The integration and coordination of separate initiatives targeted at ageing parent carers. A lack of cooperative planning between Commonwealth and State and Territory governments has led to new programs being superimposed over existing state disability and mental health services

infrastructure. This has added to system fragmentation, duplication and inequitable distribution of services.

A coordinated Commonwealth, State and Territory government approach could:

- Map identified ageing carers and the purpose, scope and capacity of available specialised services in each region.
- Use new funding to enhance and reshape existing services architecture to improve the availability of a range of comprehensive supports for ageing parent carers within regional areas.
- Develop policy, protocols and procedures for a state coordinated and regionally implemented national Register of Ageing Parents which can operate on an interagency basis. The register would maintain key consistent planning data about family needs and circumstances, identify key contact workers or case managers who work with individual families, and monitor key outcomes in relation to planning for the future.
- Create a registration and outreach system that will systematically target ageing parent carers, helping them to identify their needs, to acquire the supports they need and to begin planning for the future.

### **2.3.6 Redefining Policy Objectives**

Policies, programs and services which are directed at those who provide informal care should connect seamlessly with policies directed at those receiving care. They should recognise the different needs and interests of different care situations and acknowledge their different degrees of interdependence. Care is based on relationships, and achieving better outcomes for people needing care is symbiotically tied to securing better outcomes for those who care for them. This level of integration may require a systematic review of relevant program policies at Commonwealth, State and Territory levels.

The policy objectives of all community care programs should ensure a balanced focus on:

- Using person and family centred approaches to empower all those in a care situation. This will improve the capacity for choice, allowing people to select the services and supports which are most helpful to their individual care situation and life choices.
- Making sure that services have a dual focus and that they address equally the needs, health and well being of those who care and those who receive care.
- Making sure that those providing care are recognised and respected as providers, partners and experts when decisions are made regarding supports and interventions.
- Supporting the sustainability and well being of each individual care situation.

With demographic change likely to result in increased demand for formal support services, only partnerships involving strong support from family, friends and funded services can effectively sustain community care for people with disabilities and chronic illnesses. There are many ways in which program policies and practices can be reshaped to improve recognition of the important role played by those who provide care:

- Resource allocation in HACC programs, Aged Care Packages and disability support packages should explicitly target the needs, choices and priorities of both those who give and those who receive care. Carers should be seen as partners in needs assessment, goal setting and care planning for the needs of the family. They would contribute their expertise to how care can best be managed by combining formal and informal care. They would participate in the planning of services and in quality assurance processes.
- Acute and community support services systems should view carers as partners and experts in the treatment and care of people with a mental illness or psychiatric disability. Those providing care should be involved in assessment, services delivery, discharge planning and monitoring decisions. This approach can be facilitated through the development of carer engagement policies and practices, in particular policies that better balance the confidentiality rights of clients and the right to know of those providing care. In addition, the needs, expertise and circumstances of carers would guide decisions about immediate care needs and how ongoing care can best be managed.
- Medical practitioners should be encouraged to develop policies and practices concerning their duty of care to those who provide care. Carer inclusive policies and practice would aim to improve communication and engagement between medical practitioners and carers, fostering a partnership approach that respects carers concerns and expertise, choices and priorities. They would also facilitate a better balance between patient confidentiality rights and the right to know of those providing care.
- Policies and practices in the acute and sub acute health care systems should recognise and make explicit the role of those providing care in needs assessment, treatment, care planning and implementation, and discharge planning. Carer inclusive policies and practices should explicitly enhance the work of specific health programs, such as post acute care, hospital in the home, continuing care, and rehabilitation services.
- Policies and practices in accommodation services should ensure recognition and respect for care relationships, even when formal support services play the predominant role in day to day care. Carer inclusive policies and practices would explicitly outline expectations regarding the participation of carers in ongoing care, acknowledge those providing care as partners in goal setting and care management, recognise and respect their expertise, and engage them in quality assurance processes.

Commonwealth, State and Territory governments must consider the development of a national, whole of government 'recognising and supporting care' policy which outlines a



vision for the future of care in Australia by government, business, families and the community. The strategy would encourage coherence across the policy and program initiatives of different government portfolios with the aim of better supporting people who receive and provide care. Supported by successive three year strategic plans for implementation, it would be complemented by the development of action plans within relevant government portfolios.

### **2.3.7 Building a Strong Workforce**

The ability to sustain and expand community care services remains dependent on the recruitment and retention of an adequate, skilled and robust workforce. Recruitment and retention issues are apparent in the current community care service system. This may be attributed, in part, to low pay, lack of career path, and the isolated nature of the work. The ageing of the current community care workforce is a further concern. Shortages in the availability of community care workers will become an increasing problem as the workforce shrinks and competition for workers increases. It is likely to become increasingly difficult, and more expensive, for community care providers to recruit the workforce they need to meet growing demand.

The Commonwealth, State and Territory governments must work with the community care sector to urgently address the issue of sustaining the community care services workforce. An analysis of strategies to address issues such as remuneration, recruitment and retention of workers, greater recognition and continued service improvement is required.

### **2.3.8 Sustainable Community Care Services**

Sustainable community care for both those who give and receive care will require an injection of funds. Debate, largely in the aged care sector, about how to ensure the sustainability of funding for long term community care has included proposals about new hypothecated taxes or levies, increased government contribution, increases in the Medicare levy and long term care insurance arrangements.

The Commonwealth government needs to commission work exploring options for sustaining the costs of long term care of all people with a disability or illness and their families.

### 3. Conclusion

Our submission argues that providing care, whether for young children, or for adolescents, adults and older people with a disability or chronic illness, should be seen as a normal and valued activity in Australian society. Most people will provide some form of care across their life span. For most people of workforce age who care, providing care must be seen as entirely compatible with paid work, although varying levels of participation will result from the demands of and intensity of the care that is required. Participation in work is desired by many of those who provide care, and can protect them against financial hardship and social exclusion.

Reforms to income support payments, taxation provisions and care benefits can be developed in ways which ensure greater equity between the valued roles of caring for young children and equally valued and normative roles of caring for adolescents, adults and older people with a disability or chronic illness. Income support and taxation arrangements can be modified to promote a sharing of care within and between families, to improve workforce participation and to improve gender equity for those who provide care. This in turn will help to protect those who provide care from social exclusion, financial hardship, poor health and disadvantage.

#### ***Suggested Reforms***

- Consider the introduction of a single income replacement benefit to normalise caring and provide support for care transitions into and out of employment;
- Consider arrangements for dividing Carer Payment (or a single income replacement payment) between more than one recipient;
- Exploration of reforms to Effective Marginal Tax Rates for income security recipients to reduce the impact they have as a disincentive to participation in paid work;
- Introduction of a Care Tax Rebate, to replace the Child Care Tax Rebate. It would be accessible to all those who provide care. This will assist in ensuring that alternative care to support participation in paid work is affordable, with the costs being shared equally between those who provide care and government; and
- Consider extending the Family Tax Benefits (A and B) to recognise the necessity, value and additional costs of caring for adolescents, adults and older people.

Immediate, short term reforms would ensure that Carer Payment recipients are automatically eligible for Carer Allowance and that Carer Bonus payments are legislated to become permanent. Recipients would have the choice to access the bonus in regular fortnightly installments or to be able to draw down on it to provide a lump sum for large expenditure items.

For high intensity, long term carers who are at risk of workforce exclusion for long periods, government sponsored superannuation provision will ensure they have access to better financial well being and social inclusion at retirement age. Careful modeling of superannuation arrangements may also encourage the limited workforce participation of

this group in paid work. In addition, the introduction of learning account payments to ensure that resources are available for skills development and training for those able to re enter paid employment are essential. These need to be accompanied by programs of individualised support to encourage workforce re-entry.

Workplace policies and practices must also change to support the combination of caring and paid employment, and to support shared care arrangements. They are needed to prevent Australia lagging behind in the Industrial Relations arena. The reforms required include changes and progressive extensions to the *National Employment Standards* to ensure that the 'right to request' is incrementally made available to all employees, with appropriate compliance guidelines for employers, and the development of grievance mechanisms. Reforms must also include progressively ensuring that all those who care have access to two years unpaid care leave (equating to current provisions for Parental Leave) which can be used to support various family arrangements to share the care while continuing to participate in employment.

Further government investment into the development of specific ongoing alternative care services for adolescents, adults and older people will be essential to support the increased workforce participation of those who care.

The submission includes a number of practical suggestions concerning how key community care services can be extended and improved; about increasing the efficiency of current services; and how increased carer recognition and support can result from work to redevelop the policy and practices guidelines of various community care programs.

The development of a national 'recognising and supporting care' policy is recommended as a means of outlining a vision for the future of care in Australia by government, business, families and communities. The commissioning by the Commonwealth government of work to explore options for the sustainable financing of long term community care is also recommended.

### ***Benefits of Reform***

Improving the recognition of and support for those who care requires reform across a broad range of interrelated policy areas; income security policy; taxation policy; superannuation policy; workforce regulation arrangements and services and supports for community care. However, the progressive development of reforms across portfolios has the potential to ensure:

- Considerable benefits to individuals. Caring will be shared more equitably across families and the population. There will be less financial hardship, fewer health impacts and reduced disadvantage for those who provide care.
- Considerable benefits to government. These will result from an increase in the workforce participation of people who provide care, and of older people. Increased workforce participation will generate increased tax revenue. While governments will be supporting a greater number of people to provide care, more of these people will be participating in paid work.

- Considerable benefits to people with a disability or chronic illness. Sharing the care across families and communities results in greater social inclusion, the potential for reduced dependency on one family member, and reduced household stress.
- Considerable benefits for society resulting from greater connectivity, less net social exclusion, better work life balance, and greater opportunities for sharing the rewards of caring.

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