



Submission to the Pension Review

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This submission was prepared by: Ben Ilsley, Carers Victoria and Sue Aiesi, Carers Australia,
with assistance from Gill Pierce, Carers Victoria and
Toni Cannon, Carers Queensland

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Contact: **Ms Joan Hughes**
Chief Executive Officer
Carers Australia
Unit 1, 16 Napier Close
DEAKIN ACT 2600
Telephone: 02 6 122 9900
Facsimile: 02 6 122 9999
Email: caa@carersaustralia.com.au
Website: www.carersaustralia.com.au

Table of Contents

1	Executive Summary	1
1.1	Recommendations	3
2	Introduction	4
3	About Carers Australia	5
4	About Australia’s carers	5
5	Carers contribution to the Australian economy and society	7
6	Social inclusion and workforce participation	8
6.1	Social inclusion – a government priority	8
6.2	An under-utilised skill source	9
7	Caring and financial stress	11
7.1	Overview	11
7.2	Additional costs of care	12
7.3	Meeting the direct costs of caring for people with a disability	13
7.3.1	Carers’ concerns	15
7.4	Long-term financial impact of caring	16
7.4.1	Female carers aged 30-64 years	16
7.4.2	Female carers – taking on caring role at 50	18
8	Appropriate levels of income support and allowances	19
9	Frequency of payments	20
10	Structure and payment of concessions or other entitlements	20
11	The Case for Broader Welfare Reform	21
12	Conclusion	21
13	Bibliography	23

A carer's story

In 2007 Carers Australia commissioned the University of Canberra to undertake a qualitative analysis of open-ended responses to the Carer Health and Wellbeing Index Survey. This is one carer's story.

Surveys like this make me sad... then I just get on with life as usual ... expecting nothing different to happen. Why would things change? Never have before ... always the challenge to stay 'balanced' and be 'constructive within life' striving to be 'positive' despite 'overwhelming concern for a future for my disabled adult' which 'petrifies me'.

The future worries me so much ... what will happen to my disabled adult ... how to afford a 'safe and happy' life for her, where will she live, how can I afford her future, will I live long enough to do what I need to do, who will care enough???? I tell myself to keep focused and not worry just now ... and most days I am fine but I know there will be no funding for her ... I know of 'older' mums and days in their 80s and 90s who cannot get funding, they have their disabled children living with them ... some cannot go into aged care because of their situation. So who will help us???

I and a good number of my 'disabled' circle of mums often discuss the horrific choice we might make one day ... we do not want to leave our disabled loved ones here in this world without us. I am crying now because I know how shocking it is to say such a thing. I am a sane and rational person, not depressed or suicidal, or in danger of any self harm, just very stressed about the future.

In the meantime, we struggle to be 'normal'. I have recently taken on a 20hr part-time job which I am going to struggle to keep. I need the job to pay for 'respite/care' in order that my husband and I can go out to dinner or have some time to ourselves ... maybe an overnight break. I recently paid \$350 for a 48 hour respite break, it was lovely and just made me realise how 'not normal' we really are.

Wherever we go ... there is always the 3 of us ... and often our daughter simply does not want to be with us anymore ... she would like to do separate things too. Just to go to dinner We must pay for a carer first ... we have no 'normal' friends anymore They are all travelling and 'empty nesters'. A freedom we simply cannot expect to ever have.

Of course we love our special adult with all our heart ... but still long for some of the things we feel we are missing as a couple.

I also care for my 85 yr old mother who lives alone and has some dementia issues. I do all her cooking ... have an ACAT package for 5 hours per week ... we have a carer Monday – Friday for morning meds but I do the rest. We must pay \$120 per month for this service as my mother owns her own home ... that is her only asset, she receives a basic pension but is struggling to pay her household bills .. she has less than \$1500 in the bank. She does not want to move but she may be forced to do so soon.

My new job will be hard to keep due to all these demands ... Mondays I have to pay for a carer because the disabled daughter is home all day ... it actually costs me more than I earn for this day and I am having trouble finding carers. Working Tuesday – Friday would suit be better but that's not possible. Then there will be the days when I have to deal with sickness with both Mum or my disabled child ... I will not go on, but I feel I am not living ... not really.

I cannot see any real solutions on my horizon ... I am just doing my best.

Thank you for listening.

1 Executive Summary

Financial insecurity is a key issue for those people who provide care to a person with a disability, mental illness or disorder, chronic condition, terminal illness or who are frail. The base rate of all pensions and allowances currently does not provide for a decent standard of living or quality of life, particularly as prices of essential items and commodities increase sharply.

Australia has almost 2.6 million carers, from all walks of society and nearly 500,000 of these are primary carers. Carers are an integral part of Australia's health system and are the foundation of our aged, disability, mental health, community care and palliative care systems. Without family carers, these systems would collapse.

In 2005, carers in Australia contributed an estimated 1.2 billion hours of care. This is the annual equivalent of \$30.5 billion of formal aged and disability care services in Australia. However, the worth and value of caring extends way beyond the fact of it being cost effective to government and the community. Caring can prevent early or inappropriate entry to institutional care and is part of the reciprocity and mutuality that arises in families and other close relationships.

Despite public rhetoric acknowledging the need to help carers of the aged and people with a disability to balance their work and caring responsibilities, in reality tangible support is insufficient and ineffective. While social inclusion is a government priority, many carers feel socially and economically isolated because of their caring role – many are unable to work; many have lost friends, others imply cannot afford to participate in community activities; while others are simply exhausted.

Many carers who are currently on income support payments, would like to participate in the workforce but barriers such as a lack of alternative care and difficulty in organising flexible paid work, prevent this. The current income support system unintentionally contributes to low workforce participation by separating caring from paid employment. For example, the current 25 hour work, training and education threshold for Carer Payment recipients mean that caring and paid work can become an either/or proposition that does not fit for those wanting and needing to combine the two roles. To fully utilise this potentially large skill resource, the government should extend the Child Care Benefit and the Child Care Tax Rebate scheme to include care for adolescents and adults with disabilities or those who are elderly.

The financial stress associated with caring is linked both at a workforce participation level and through the additional ongoing costs associated with caring. For families where a person has had to give up work to care for a spouse who was also previously working, the reduction in income and living standards is particularly high. And the financial burden of caring will be even greater for those living in rural and remote areas of Australia. Carers are over-represented in the lower household income quintiles and under-represented in the higher quintiles.

Of increasing concern to carers is the additional costs involved in caring for a person with a disability, mental illness or disorder, chronic condition, terminal illness or caring for a person who is frail. These costs vary considerably between individuals and families and include expenditure for additional consumables, higher usage of utilities, increased health care and other service costs, additional transport and home modifications and equipment.

The income support system has an important role to play in mitigating the costs of caring, both through its influence on supporting workforce participation, and its potential to moderate the direct costs of disability and care. There are already precedents within the welfare system that recognise the additional costs of providing care to children with a disability. For example the (Child) Disability Assistance Payment provides an additional annual lump sum for people receiving Carer Allowance (Child), and the Carer Adjustment Payment is a one off payment to assist families following a catastrophic event where a child aged 0-6 is diagnosed with a severe illness, medical condition or a major disability. Neither of these payments are means tested, suggesting that their rationale is linked to the costs of care involved rather than the family's general financial circumstances.

There is a need to apply this broad principle to those caring for older children and adults with disabilities. Because the payments refer to and target the costs of disability and care, they should not be tied to eligibility for Carer Payment, Carer Allowance or Disability Support Pension.

Recent research commissioned by Carers Australia (2008) and undertaken by NATSEM confirms the negative long-term financial impact of caring. The study found that women carers pay a high price in terms of their health and financial well-being by taking on a primary carer role. The consequences of forgone income extend beyond the immediate ability of families to meet expenses. Inability to participate in the paid labour force has long-term implications for superannuation and the ability to invest toward retirement. Carers Australia is advocating for a government superannuation contribution at 9% of the Federal minimum wage for those carers who have been unable to participate in the workforce for two years or more because of their caring responsibilities.

Carers are particularly vulnerable to the recent sharp increases in the cost of essentials and there is an urgent need to develop and apply new mechanisms that benchmark payments according to the real costs that low income groups face rather than the current indexing linked to CPI and MTAW. People on low incomes spend higher proportions of their income on basic essentials such as food, medicines and health costs, utilities, services and travel. A budget standards approach is a more appropriate way to recognise these different needs.

Increases in the base rates of pensions and allowances should be introduced as soon as possible to enable carers and other receiving income support to have a decent standard of living and quality of life.

Carers Australia believes the Pension Review provides government with an opportunity to ensure the most vulnerable in our society are able to participate fully in community life and be part of a society that values all people. We also believe the Pension Review has an important role to play in acknowledging the role and contribution of family carers in sustaining the fabric of our community care systems. Increased investment in support for carers is an investment in strong families, healthy communities and a more inclusive and civilised society.

1.1 Recommendations

Carers Australia recommends:

- an increase in the base rate of pensions and allowances be introduced as soon as possible.
- an increase in rental assistance, the utilities allowance and the pharmaceutical allowance be introduced as soon as possible
- the introduction of payments to offset the additional costs of care, taking account of the precedents that currently exist within the welfare system
- the introduction of a superannuation scheme, paid at the rate of 9 per cent of the Federal minimum wage for those people who have been out of the workforce for two years or more because of their caring responsibilities
- people on income support payments should be given the option of receiving their bonuses and other allowances as either part of their fortnightly payments or as a lump sum
- a single concession card be introduced for people who receive income support and that entitles holders to similar concessions across Australia.

2 Introduction

Financial insecurity is a key issue for those providing care to a person with a disability, mental illness or disorder, chronic condition, terminal illness or who are frail. Current rates of pensions and allowances do not provide for a decent standard of living or quality of life.

Carers Australia welcomes the Pension Review and the opportunity to provide input. The financial difficulties of those with caring responsibilities raise issues that are considerably broader and more complex than can be covered by the particular terms of reference quoted. Of the 2.6 million Australians with caring responsibilities, 1 16,614 receive the Carer Payment and 393, 263 receive the Carer Allowance.¹ Many of those caring in receipt of income support receive other pensions and allowances such as the Aged Pension, Disability Support Pension, Parenting Payment Single or Newstart Allowance. The majority of those caring do not receive any direct income support. Some of the comments and recommendations made here necessarily refer to the broader population of those caring.

There are other important reasons for the breadth of our comments. The income support system has other functions, impacts and consequences for policy and society. Submissions to the Inquiry into Better Support for Carers reinforced that the low rates and patterns of workforce participation of those caring is a fundamental social and economic issue for governments, particularly as Australia's population ages. The income support system has a vital role in supporting transitions between work and caring and, consequently, supporting a more equitable sharing of care. Without reforms in these areas, caring will become increasingly unsustainable for individuals, families and the general population.

It is understood that some of these issues will need to be referred to the Henry Taxation Review, with its longer timeframes and broader scope.

3 About Carers Australia

Carers Australia is the national peak body representing carers. Carers are individuals who provide unpaid care to family members and friends with a disability, mental illness or disorder, chronic condition, terminal illness or who are frail.

Carers Australia seeks to lead change and action for carers through:

- being the national voice for carers
- research, policy development and advocacy
- carer services and programs
- education and training for carers and service providers.

The members of Carers Australia are the state and territory Carers Associations that deliver specialist information, advisory and counselling services to carers in communities around Australia. The state and territory associations also play an advocacy and policy development role in their jurisdiction and work closely with government and other partners to achieve support and change for carers and their families.

Carers Australia is informed about carer issues through its member Carers Associations, local and overseas research and its participation in national and international forums.

Carers Australia places great importance on the direct voices and experience of carers as well as relying on evidence provided through research and evaluation. The Carers Associations gather and analyse information from carer services and provide independent advice to government.

4 About Australia's carers

Australia has almost 2.6 million carers, and nearly 500,000 of these are primary carers – the people who provide the most care².

Carers are from all walks of Australian society and come into the caring journey at various stages throughout their life. The Australian Bureau of Statistics has identified:^{3,4,5}

- 380,000 Australians under the age of 26 provide care to a family member who has a disability, or a mental or chronic illness
- 170,000 carers under the age of 18
- 31,600 Indigenous carers over the age of 15
- 620,000 of Australia's carers born outside Australia

- 366,700 of those born in other than main English-speaking countries
- 71% of primary carers are women
- 78% of primary carers care for a person living in the same household
- 26% of primary carers care for a child
- 42% of primary carers care for a partner
- 23% of primary carers care for a parent.

Carers are an integral part of Australia's health system and are the foundation of our aged, disability, mental health, community care and palliative care systems. Without family carers, these systems would collapse.

The impact of providing care on the carer's own health and wellbeing is well documented with many carers experiencing a significant decline in their own physical and mental health. In addition, there is a negative impact on carer's education and employment prospects, their financial position, and their ability to participate in social and community life.⁶

According to the ABS 2003 Survey of Disability, Ageing and Carers, there are almost 1.25 million people in Australia with disabilities that have profound or severe limitations and of those 1.07 million live in private households. 79 per cent of people with a disability living in households received care from relatives and friends; mainly partners, parents or children.⁷

64 per cent of primary carers over the age of 15 spend more than 40 hours per week caring for a person with a profound core activity limitation.⁸ Additionally, family carers sustain the fabric and operational effectiveness of mental health service systems across Australia with individual carers on average contributing 104 hours per week caring for a person with a mental illness. For many carers this time includes periods they are 'on call' or alert for early warning signs arising with the person with mental illness.

5 Carers contribution to the Australian economy and society

Carers in Australia contributed an estimated 1.2 billion hours of care in 2005. This is the annual equivalent of \$30.5 billion of formal aged and disability care services in Australia.⁹ However, the worth and value of caring extends way beyond the fact of it being cost effective to government and the community.

Caring prevents early or inappropriate entry to institutional care. People needing support can maintain their independence and quality of life in a familiar environment with assistance from people they know well. Caring, if supported well, can help keep families strong and hold neighbourhoods and communities together. It can be a truly rewarding personal experience for the carer, despite the difficulties they face when there is inadequate support and the circumstances are hard. Caring is part of the reciprocity and mutuality that arises in families and other close relationships. In short, increased investment in support of carers is an investment in strong families, healthy communities and a more inclusive and civilised society.

Carer Payment (child) Review Taskforce 2008

...The caring role is one of immense social and economic value. It cannot be overemphasised that the care provided is often the difference between life and death.

The importance of their contribution is not hard to describe:

- people needing care can remain at home in a familiar environment with people they love and who have their interests at the centre of considerations
- carers provide care in a highly individual and flexible way
- carers support family members with disabilities or illness to maximise their life and independence in the community
- family structures and relationships are preserved
- family members or friends experience a quality of care, not always possible in institutional settings.

Caring for a child with a disability

...However, the driving force of my caring experience is the ability to make a difference to the experience for my disabled child. This is limitlessly rewarding, though intangible. Unfortunately it is also sapping my resources very rapidly because I am so isolated in this experience.

The contribution of carers adds a dimension to Australian society that is not always valued or recognised.

6 Social inclusion and workforce participation

6.1 Social inclusion – a government priority

Social inclusion has been highlighted as a government priority. To support its agenda, a Social Inclusion Unit has been established in the Department of Prime Minister and Cabinet to assist in the development of a whole-of-government approach to social inclusion. Ministers have commented on the need to provide all Australians with opportunities to participate in all aspects of life.

Senator Stephens, in her address to the National Civil Society Dialogue said “To be socially included, we believe that all Australians must be given the opportunity to:

- secure a job
- access services
- connect with family, friends, work, personal interests and local community
- deal with personal crisis
- have their voices heard.”¹⁰

Further, the Australian Labor Party has outlined a number of issues around the importance of workforce participation and social inclusion:

- Labor believes that all Australians should be able to realise their full potential and have the opportunity to build a rewarding social and economic life.
- Labor believes that work, along with family and community gives meaning to life.
- Workforce participation is a foundation of social inclusion; it creates opportunities for financial independence and personal fulfilment.
- Labor believes that as well as being good for individuals, increasing workforce participation benefits local communities, regions and the broader economy. Communities are more prosperous and cohesive when those who can work are working.¹¹

However, many carers feel socially and economically isolated because of their caring role – many are unable to work; many have lost friends; others simply cannot afford to participate in community activities; while others are simply exhausted or too tired to participate in activities outside the home.

The rhetoric and the reality

The last report from the Taskforce on Care Costs (2007) summed up the situation well.

“... although public rhetoric acknowledges the need to help carers of the aged and people with a disability to balance their work and caring responsibilities, in reality tangible support is insufficient and ineffective. This is evident in relation to public policy (e.g. legislation, financial support and service provision) as well as workplace policy and practices.”¹²

The available evidence shows that carers face social and economic exclusion. The services and financial support that would enable greater choice and a better balance between caring responsibilities, work and other social engagement are simply not available to the overwhelming majority of carers.

In a recent study undertaken by the Social Policy Research Centre (SPRC) in conjunction with ACOSS, Mission Australia, Brotherhood of St Laurence and Anglicare, it was found that:

“Poverty is one of the most basic and enduring causes of social disadvantage. Those living in poverty face an increased risk of poor health, and experience low self-esteem and social isolation, all of which reinforce the hardship associated with not having enough to make ends meet.”¹³

6.2 An under-utilised skill source

Nearly 2 million carers are of workforce age, but many have had to leave the workforce, reduce the hours they work, or work below their skill capacity because of their caring responsibilities.¹⁴ The Australian Institute of Health and Welfare (AIHW) has projected that by 2013, 265,200 primary carers between the ages of 25-59 will be women. Of these 121,900 (46%) will be unemployed or not in the labour force. Of the projected 96,400 male primary carers in 2013, 43,400 will be unemployed or not in the labour force.¹⁵

Further, AIHW data indicates for carers and non carers of prime working ages 25-54 that:

- approximately 47 per cent of male primary carers in this age group were employed full time compared with 80 per cent of men who were not primary carers
- 18 per cent of female primary carers in this age group were in full time paid employment compared with 39 per cent of women who were not primary carers.¹⁶

Carers are potentially a large skill source. In 2003 it was estimated that 47.9 per cent of carers had a qualification at certificate level or above, only marginally below that of non carers (50.8%).¹⁷

2007 research by the Taskforce on Care Costs (TOCC) found that nearly half (44%) of working carers had selected a role at work below their skill level because it provided the flexibility they needed to balance their work and caring responsibilities.¹⁸

Research undertaken over the last decade has shown that carers are significantly disadvantaged in terms of labour force participation and social inclusion. Research has also shown that the majority of carers would like to participate in the workforce if there were suitable care arrangements and workplace flexibility.

The current income support system unintentionally contributes to low workforce participation by separating caring from paid employment. For example, the current 25 hour work, training and education (including travel) threshold for people receiving Carer Payment mean that caring and paid work can become an either/or proposition that does not fit for those wanting and needing to combine the two roles. Similarly, high taper rates for payments and pensions, income tax, increases in public housing rent and loss of concessions all contribute to high levels of Effective Marginal Tax Rates (EMTRs). This is a disincentive to those beginning or increasing hours of paid work.¹⁹ These effective tax rates are further increased when the alternative care costs necessary to allow a carer to work are factored in.

Additionally, there is insufficient flexibility to support those needing to transition from paid work to caring. The current system requires those who provide care to identify as a carer in order to receive the support they need.

A UK study²⁰ showed that 65% of people with a caring responsibility did not identify themselves as a carer in the first year of caring and a third took more than five years to do so. If a similar pattern occurs in Australia, as is likely, many people will not receive the income support they need when they need it. For those caring for a person whose care needs are primarily emotional for example, someone with a cognitive or mental health disorder, it is even more difficult to qualify for income support because of limitations in the design and application of assessment tools.

The current system's lack of support for employment/care transitions has the further effect of discouraging the sharing of care within families and the broader community. This contributes to the further social and economic exclusion of primary carers, particularly women. Current projected shortages of informal carers as the population ages can only be met by introducing measures that allow caring to be more sustainable and attractive to a greater proportion of the population. Changes that allow the splitting or sharing of payments must be considered. The current Carer Allowance can be split but the dollar amounts involved are small. The feasibility of dividing any future payment for costs of care between carers should be considered.

Increasing the workforce participation of those with caring responsibilities requires the availability of affordable, good quality alternative care for people with disabilities, mental health disorders and the elderly. Currently, such a system applies to the care of children and has had

success in allowing higher rates of workforce participation of parents, particularly women. Financial support for parents is administered through Child Care Benefit and the Child Care Tax Rebate. Such a scheme should be extended to include care for adolescents and adults with disabilities or are elderly, as recommended by the Taskforce on Care Costs (2007)²¹.

A report by Access Economics found that the full time employment rate of primary carers is less than half that of the general population.²² This is not because carers are unwilling to work - a recent study by the Australian Institute of Family Studies showed that 53.6% of unemployed women who receive the Carer Payment want to work²³. The main barriers to working were identified in this study as being a lack of alternative quality care and difficulty in organising flexible paid work. Additionally, carers are also concerned about gaining paid employment after spending time out of the workforce.

7 Caring and financial stress

The financial stress of caring is linked both at a workforce participation level and through the additional ongoing costs associated with caring and is often difficult to quantify. For families where a person has had to give up work to care for a spouse who was also previously working, the reduction in income and living standards is particularly high. If a single person on an average wage were to give up work to become a carer their weekly income would drop from \$1030 to \$294.²⁴ Carers Australia also believes that the impact of caring may be greater for those living in rural and remote areas of Australia.

7.1 Overview

The 2003 ABS Survey of Disability, Ageing and Carers indicates that carers are over-represented in the lower household income quintiles and under-represented in the higher quintiles, particularly primary carers.²⁵ This is linked to carers reduced levels of paid employment because of their caring responsibilities.

On average, their gross personal income is more than 25 per cent lower than for non carers. For almost half a million carers, the disparity is even greater at more than 40 per cent.

Carers who need to rely on the Carer Payment and the Carer Allowance for lengthy periods of caring can be particularly disadvantaged with their reduced capacity to save, accumulate superannuation and fund their retirements. AIHW indicated that 34 per cent of primary carers of children with a disability identified more financial support as their greatest need.²⁶

The Australian Unity Wellbeing Index (AUWI) on carers health and wellbeing highlights that carers reliant on Centrelink income as their main source of household income had lower wellbeing than carers who did not receive Centrelink income support. Low household income is considered a double jeopardy, as carers already have the lowest wellbeing of any large group surveyed for the AUWI.

This survey also found that carers' satisfaction with their ability to pay for household essentials, ability to save money, to have financial security, and to not worry about income covering expenses are all severely compromised compared with a general population sample.²⁷

Section 7.4 of our submission highlights the implications of lower levels of workforce participation on the ability to accrue superannuation and invest in retirement. For those not in the workforce for extended periods, this can continue financial hardship into old age even after caring responsibilities have come to an end. Whilst the position of Carers Australia is that reforms to income support, workplace regulation and support services are needed to prevent the continuation of these situations, it is acknowledged that such impacts of high intensity, long-term caring will continue in the short term for small numbers of those caring. It is proposed that the government pay superannuation for those who are out of the workforce for two years or more because of their caring responsibilities. This should be paid at a rate of 9% of the Federal minimum wage. Work is needed to arrive at a system that does not discourage workforce participation by adding to EMTRs. For those receiving government paid superannuation who can return to the workforce, a system that tops up employer contributions to 9% of the Federal minimum wage for a set period could achieve this.

7.2 Additional costs of care

A second group of factors contributing to the long-term hardship of carers and of increasing concern, relate to the additional costs involved in caring for a person with a disability, mental illness or disorder, chronic condition, terminal illness or caring for a person who is frail. These costs vary considerably between individuals and families but may include:

- additional consumables
- respite and alternative care costs
- continence aids
- additional pharmaceutical and health costs
- aids and equipment
- additional heating and cooling costs because of health conditions
- additional wear and tear on white goods eg washing machines
- housing and vehicle modification
- additional transport costs.

There have been numerous attempts and methods used to quantify these costs^{28,29}. The SPRC research³⁰ and modelling into the costs of disability found that the average cost of disability was 29% of (equivalised) household income, rising to between 40% and 49% of income for those with a severe or profound restriction. It is important to note that these findings refer to the impacts of one adult with a disability on the entire household budget, reflecting the inter-

relatedness of people with disabilities and their families or carers and the ensuing cost relationship. The report goes on to evaluate the impacts of these costs on household poverty. With almost all household types, the risk of poverty increases when there is a disability present by between four and sixteen times.

The income support system has an important role to play in mitigating the costs of caring, both through its influence on supporting workforce participation, and its potential to moderate the direct costs of disability and care.

7.3 Meeting the direct costs of caring for people with a disability

There is an urgent need for government support to help meet the additional costs incurred by those with disabilities and those caring for them. The Carer Payment and Disability Support Pension, in common with other pensions, both have clear rationale of providing a basic level of income support for those unable to work. The aim of the Carers Allowance is to recognise the role of caring without it being intended to meet the cost of care. Currently Commonwealth payments that recognise the additional costs of disability and caring for an adult with a disability, are limited.

As discussed in the Pension Review Background Paper, the costs of disability vary considerably between different people with a disability. The Paper goes on to describe the theory and merit of adopting an approach that meets the needs and costs of people with disabilities through carefully targeted direct service provision rather than solely through cash transfers. Many such services exist provided by both Commonwealth and state/territory jurisdictions, and their role is crucial in the lives of people with disabilities and their families. However, there are shortcomings with relying solely on this approach. The reality is that these services are limited in their coverage of need and levels of funding, resulting in some people missing out on the levels of service they require. Alternatively, the necessary services are available but require financial top up and contribution from the client or their family. Even if levels of funding and coverage of such services were completely adequate, there remains a strong case for providing cash transfers because not all costs of disability and care can ever be met through in-kind services and providing cash to consumers increases their autonomy and empowerment. Many families want more control over the planning and delivery of services.

In the absence of any payments to meet the costs of disability and care, and where a caring relationship exists, it is carers who invariably end up trying to meet these costs. This is a reflection of the inter-relatedness and different capacities involved within caring relationships. As previously mentioned, studies show that disability costs, and the financial impacts of these, are shared within households or passed on to carers.

There are already precedents within the welfare system that recognise the additional costs of providing care to children with a disability. The (Child) Disability Assistance Payment provides an additional annual \$1000 lump sum for people receiving Carer Allowance (Child), and the Carer

Adjustment Payment is a one off payment to assist families following a catastrophic event where a child aged 0-6 is diagnosed with a severe illness, medical condition or a major disability.

Neither of these payments are means tested, suggesting that their rationale is linked to the costs of care involved rather than the family's general financial circumstances.

There is a need to apply this broad principle to those caring for older children and adults with disabilities. Because the payments refer to and target the costs of disability and care, they should not be tied to eligibility for Carer Payment, Carer Allowance or Disability Support Pension.

There are several complex aspects to consider in the design of a system aimed at meeting these costs. As previously mentioned, the magnitude of these costs varies enormously, according to many factors. Such factors are not confined to the specific condition a person has. One person with a specific disability or health condition may have quite different costs associated to another with the same condition. A study prepared by Dr Jack Frisch for the Physical Disability Council of Australia³¹ provided an analysis of the different methods and mechanisms available and recommended that an income support payment be supplemented by a Disability Cost of Living Allowance that is tiered according to assessed disability costs. This could be usefully generalised to other disability types such as intellectual, psychiatric and chronic conditions.

There are additional sensitivities and complexities to be observed when a person with a disability is dependent on their carer(s) for financial management and support. It is clear that there is considerable overlap between costs that could be considered to be related to caring and those related to disability. The distinction often relates to who meets these costs in practice. As mentioned before, in households where a person with a disability is living with a carer, it is common for these costs to be paid by a carer.

In cases, particularly where a person with a disability has limited capacity to manage finances, it is important to develop mechanisms that allow the person paying for the costs to be reimbursed. In the absence of such mechanisms that recognise caring relationships within families, any new payment will not achieve its purpose of meeting the costs currently incurred within families because of the costs of disability. The Frisch report explores the possibility and limitations of several different mechanisms, including the reimbursement of self assessed additional costs.

In short, further developmental work is needed to design a system that meets disability costs and encourages the autonomy of people with disabilities while also recognising the realities and inter-relatedness of caring relationships.

In terms of rationale as well as structures, there may be a useful precedent in the existence of Family Tax Benefit (A and B) for parents of young children. This payment recognises the necessity, social value and additional costs involved in caring for young children and may provide an alternative to introducing a new allowance if extended to those individuals and families with additional disability and caring costs. Consideration would also need to be applied

to any new payment's relationship to the existing Carer Allowance. It would be important that carers are not further financially disadvantaged by any new policies in this area.

7.3.1 Carers' concerns

Frequently, carers provide Carers Australia and the state and territory associations with stories that reflect the day to day financial stress of their caring role. Below are some excerpts from carers stories illustrating carers' concerns. Carers Australia believes that by highlighting these stories, a human face is put to the urgent need to address the inadequacy of income support payments and the associated costs of caring.

Caring for an aged parent with a disability

..“If I was paid more to care, it would go a long way to reducing my stress levels. Currently I worry about how bills will be paid. I worry about our declining health, and the inability to keep paying for vitamins and the things we need to keep well. I can't afford to see a specialist, or have specialist treatments. We are drowning in debt. .. My carer payment is a joke. I am on call 24/7 and my hourly rate is something like 0.2 cents. Paid carers (agency) who sleep over are paid \$30.07 an hour plus additional hourly costs for wakeups! Why is one type of carer regarded as an expert and paid accordingly, and the unpaid carer is viewed as a loser and remunerated as such. That is why our self esteem is progressively ground down.”

Caring for a child with autism

..“Although I earned a good living until my boy was 16, his behaviour became such that I had to give it up to be there for him and now we are both welfare dependent. Not my dream, but I thank the government for Centrelink!”

Caring for a child with autism

..“As we live on a farm we can never have financial freedom and security and live in a broken down home always doing without – we do eat well (not steak and prawns) and do get basic clothing or household goods when essential and have to think long and hard about any spending.”

Caring for a child with a disability

..“Certainly the allowance of 90 odd dollars a fortnight only partly covers the costs involved in caring, by the time you take into consideration medications, extra washing, special diet, physio and other specialists, specialists' fees, costs of driving to appointments (time and petrol), parking fees, time spent at various doctors appointments, and implementing and following the programs. There is not anywhere you can access funding to attend seminars regard the caring role or information regarding the disabilities that the person you are caring for has. If you are unemployed, then you can attend lots of training to update your skills, or learn a new job. However, if you want to attend training as a carer, you have to find the money yourself.”

Caring for a child with an intellectual disability

..“Financial burdens on a weekly basis – eg for therapy, as part of a long-term plan to assist our daughter to develop more independence, life skills, resourcefulness are a constant concern. I do not feel any resentment for being 'given' my carers role or towards my child, but it has impacted on all other areas of my life, that are/were important to me, so I do feel loss.”

Caring for a partner

..“We have to go to Brisbane 4 times per year for doctor’s appointments for my husband. We are covered for the cost of rail which entails getting up at 3.30am for a 5am bus for a 6am train. We then arrive and see the doctor for about 15-20 minutes then have to stay around until 6pm for the train home. As my husband is diabetic it also entails meals which I cannot get out of for under \$100 so I have to budget weeks in advance just to keep doctor’s appointments.

Other carers have provided us with a snapshot of the actual dollars they have spent. For example one carer has spent \$180,000 over a 7 year period on aids and equipment and modifications to their home. This does not include items provided by government schemes. In addition their annual ongoing costs amount to \$13,165.00.

7.4 Long-term financial impact of caring

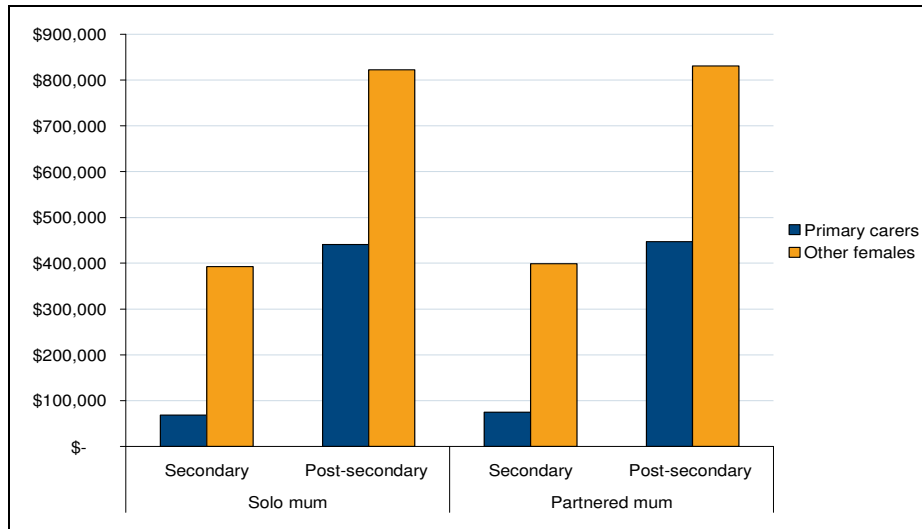
Research recently commissioned by Carers Australia confirms the negative long-term financial impact of caring. The study, undertaken by NATSEM, examined the impact of taking on a primary carer’s role on the health and economic wellbeing of women in Australia over the course of their ‘working’ life at two life stages – Women aged 30 with primary caring responsibilities and women aged 50 taking on a primary care role for their partner.³²

The study found that these two groups of women carers pay a high price in terms of their health and financial well-being for taking on a primary carer role. The impact of being a primary carer is significant and extends to the rest of the primary carer’s life - they experience a shorter period of good health over their working years; they are less able to participate in paid employment; receive lower income during their working years; and are less able to invest towards retirement.

7.4.1 Female carers aged 30-64 years

Findings from the research show that women, aged 30 years, with two or more children, caring for a child with a disability and whose highest level of education is less than or equal to completion of secondary school are expected to earn less than \$100,000 (2006 dollars) over their working life. Women sharing the same characteristics but without the primary caring responsibility will earn four times that amount over their working life. While women with post-secondary level education also show a difference in individual income earned over their working life, the difference between primary carers and other is double (about \$400,000 vs \$800,000) as opposed to the four fold difference observed with those with lower levels of education. Figure 1 highlights the difference in gross income for those females in a caring role compared to those without caring responsibilities.

Figure 1 Gross individual income over the working life from wages and salaries for 30-year old women with two or more children – primary carers of a child a disability versus other females, 2006

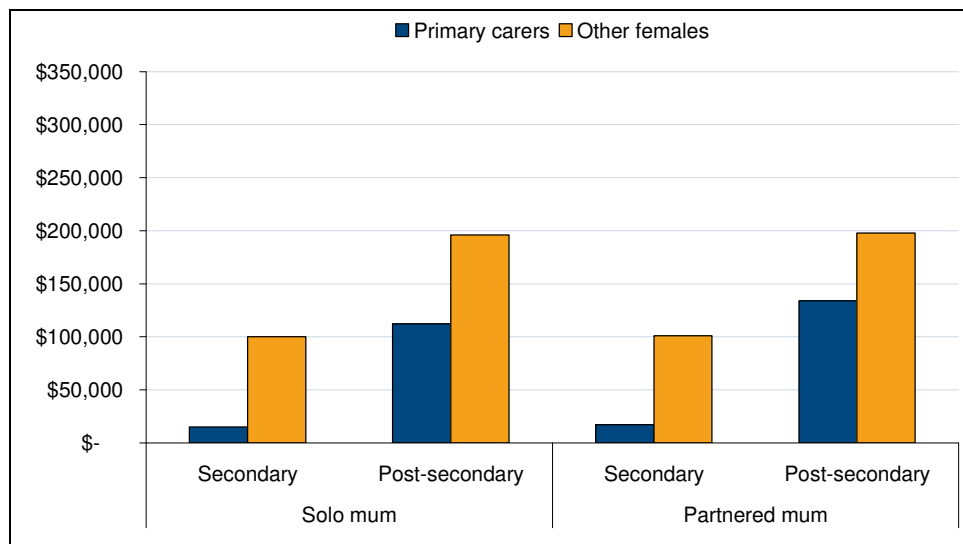


Source: Model estimates using HILDA Wave 6 data file.

Superannuation

The consequences of forgone income extend beyond the immediate ability of families to meet expenses. Inability to participate in the paid labour force has long term implications for superannuation and the ability to invest toward retirement. Figure 2 highlights the long-term disadvantages for those females in a caring role for the majority of their working life.

Figure 2 Prospective personal superannuation at age 65 to mothers currently aged 30-34 years - primary carers of a child with a disability versus other females, 2006



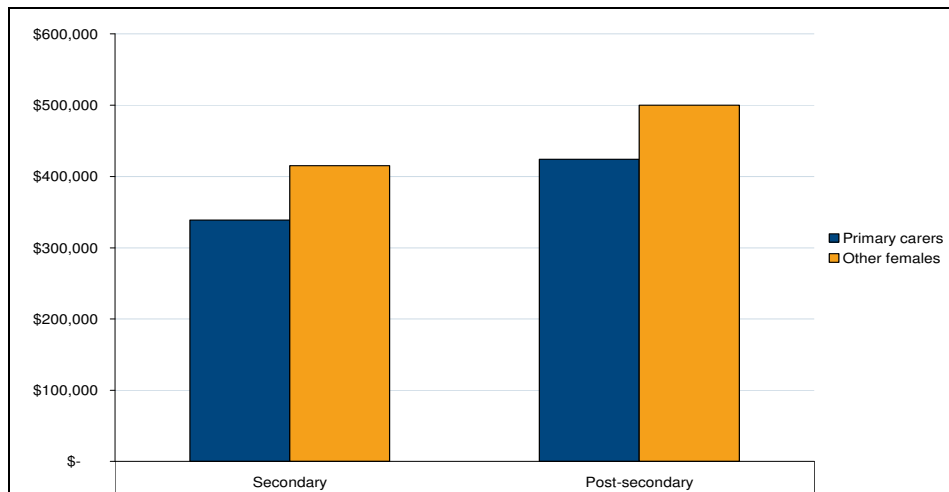
Notes: Superannuation was calculated by assuming 9 per cent super contribution and 5 per cent return rate. Mortality has not been adjusted in these calculations. Figures are rounded to nearest thousand.

Source: Model estimates using HILDA Wave 6 data file.

7.4.2 Female carers – taking on caring role at 50

The study also found that women aged 50 years taking on a caring role would expect to earn approximately 80 per cent of the income that would be earned by women that have the same characteristics but without the caring responsibilities, resulting in a deficit of approximately \$85,000 (2006 dollars) over the remaining working life.

Figure 3 Gross individual income from wages and salaries over the remaining working life of 50-year old working females – primary carers of a partner with a disability versus other females, 2006



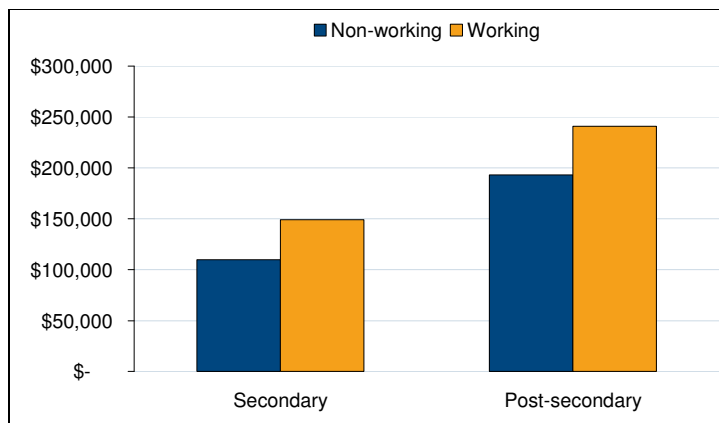
Note: An insignificant amount of income for non-working females could be due to reporting error or their involvement in paid job outside the reference period.

Source: Model estimates using HILDA Wave 6 data file.

Superannuation

The study found that there is over a two fold difference in the superannuation that a 50 year old female primary carer of a male partner who is no longer able to work because of the caring role and who has secondary school qualifications only can expect to access at 65 years of age compared to women who have post-secondary schooling, who continue to work up to retirement at 65 years of age and who do not have the same caring responsibilities.

Figure 4. Prospective personal superannuation available at age 65 years to females currently 50-54 years of age – working and non-working primary carers of a partner with a disability, 2006



Source: Model estimates using HILDA Wave 6 data file.

8 Appropriate levels of income support and allowances

The base rate of all pensions and allowances currently does not provide for a decent standard of living, particularly as prices of essential items and commodities increase sharply. There is an urgent need to develop and apply mechanisms that benchmark these payments according to the real costs that low income groups face rather than current indexing linked to CPI and MTAW. Current mechanisms are not specific or relevant enough to the needs and spending habits of those in receipt of income support. People on low incomes spend higher proportions of their income on basic necessities such as food, medicines and health costs, utilities, services and travel. A budget standards approach is a more appropriate way to recognise these different needs, although there has been little work done to date on comparing the “shopping baskets” of different low income groups. It may be the case that many of those with caring roles will have different needs because of their different stage in the life cycle. The need to address the additional costs of caring has been addressed separately in our submission under Section 7. As discussed in SPRC’s paper, *“The cost of disability and the incidence of poverty”*³³ caution is needed when developing methods of cost measurement. Levels of income support should reflect necessary costs of living rather than current spending habits or preferences.

There is a current inequity between the way that allowances such as Newstart and Youth Allowance are indexed as compared to pensions. This has resulted in an increasing difference between the rates of these payment types. The Pension Review Background Paper describes the rationale for the lower rate of allowances as to increase incentives of people of workforce age to seek employment. This structure must be carefully monitored in the light of the efficacy of this rationale and the negative unintended consequences on workforce participation of those receiving pensions at a higher rate than allowances. It may be necessary to overlay this mechanism with reference to additional poverty benchmarks.

There are other growing inequities between different population groups receiving income support. Significant decreases in housing affordability in many parts of Australia have led to very high rents for those who do not own their own home and large mortgages for those who have bought their house in recent years. For people who rely on income support solely, these costs are unsustainable. Carers and people with disabilities are over represented within the groups of those renting in private and public housing compared to other groups receiving income support. There is an urgent need to raise rental assistance to levels that reflect the increase of rents beyond CPI. The need for broader policies and measures to increase housing supply and affordability have been well documented and covered within public debate. Families can be at particular risk of losing their housing when a member becomes disabled or chronically unwell unexpectedly, resulting in the double loss of income of the person with the disability and a second income earner because of caring responsibilities.

There is strong evidence that single people relying on income support are even more vulnerable to increasing cost of living pressures. This includes single aged pensioners, people on DSP,

Parenting Payment (single), single carers and those on Newstart and Youth Allowance. Single people relying on income support need a higher proportion of payment relative to couples than the current ratio, particularly if they are renting.

People on low incomes spend a greater proportion of their income on energy and water bills than the general population and so are particularly vulnerable to price increases and the impacts of climate change policies. An increase in utilities allowance and compensation through the Emissions Trading Scheme is required. Low income and vulnerable groups will also need specific financial and practical assistance to increase their energy efficiency because they currently have fewer resources to do make the necessary improvements to their housing and appliances.

The Pharmaceutical Allowance of \$2.90 per week, paid to recipients of Carer Payment is inadequate to meet the often high costs of health care associated with caring for a person with a chronic condition or terminal illness. Carers often neglect their own health and wellbeing because of additional health care costs associated with the person for whom they are caring.

There is considerable divergence of financial need between different individuals receiving income support. For this reason, it is recommended that the base rates of payments, both of pensions and allowances, are increased in line with a budget standards approach. Differences between the needs and costs of individuals could be catered for through increases to rental assistance, utilities allowance and pharmaceutical allowance. Further reforms are urgently required through the introduction of new payments to mitigate the costs of disability and caring as outlined in Section 7.

9 Frequency of payments

With advances in technology and banking transfers, people on income support should be given the option of receiving their bonuses and other allowances as part of their fortnightly payments or as a lump sum.

10 Structure and payment of concessions or other entitlements

There is a need to simplify the structure and payment of concessions and entitlements. Carers identify the complexity around these payments as one of their major areas of concern. There are also the added inequities of different concessions being available through different state/territory jurisdictions. The current system of concessions does not have in place adequate indexing to ensure the value of concessions is not eroded over time. Consideration should be

given to developing a single concession card for people on income support that entitles holders to similar concessions across Australia.

11 The Case for Broader Welfare Reform

There are limitations with the existing income support structure in supporting transitions between caring and employment. Without strong supports for these transitions, caring will be viewed as carrying too many financial, social and health risks for many to take on such a role. Current and projected costs to society and governments due to a lack of people to provide caring for an ageing population are unsustainable³⁴. There is a strong case to be made that more substantial reform of the income support system is required to encourage a broader sharing of care responsibilities and prevent the systemic economic and social exclusion of caring families.

At the heart of this problem lies the artificial separation of caring and paid work, requiring people to identify as carers to receive support from a system that then can make it difficult to re-enter the workforce. The current system creates entitlement distinctions between prescribed groups that are not necessarily based on their circumstances, resulting in increased system complexity and opacity and unintended behaviours by recipients. Much work has been done to develop and analyse systems that provide a single working age benefit for all groups with different activity requirements for different situations, such as caring. There are benefits for all groups in adopting such an approach, not just those caring. In the UK, the Institute of Public Policy Research has been heavily involved in this³⁵ while S. Moullin³⁶, from the same institute, has applied it to those with caring responsibilities. Both the United Kingdom and New Zealand have progressed towards such systems. In Australia, Brian Howe³⁷ has adapted the transitional labour market approaches developed by Gunther Schmid and argued for their application to Australia.

12 Conclusion

There is an urgent need to address the inadequacy of the base rate of pensions and ensure that allowances such as rental assistance, utilities allowance and pharmaceutical allowance are increased to a level that would assist people on income support to have a decent standard of living and quality of life. An increase in these payments should be introduced as soon as possible.

A financial package to assist carers with the additional costs of caring is also urgently required. This package should take account of the extra use of utilities, the higher costs of transport, the additional health care and service costs, the cost of equipment and aids as well as the additional expenditure to ensure that homes and vehicles are equipped appropriately.

When examining the long-term financial impact of caring, evidence clearly shows that caring has a negative impact on the ability to contribute to superannuation and invest in retirement. Carers Australia, as outlined in Section 7, has proposed that the government pay superannuation at the rate of 9% of the Federal minimum wage for those carers who are unable to participate in workforce for two years or more because of their caring responsibilities.

The Pension Review provides government with an opportunity to ensure the most vulnerable in our society are able to participate fully in community life and be part of a society that values all people. We also believe the Pension Review has an important role to play in acknowledging the role and contribution of family carers in sustaining the fabric of our community care systems. Increased investment in support for carers is an investment in strong families, healthy communities and a more inclusive and civilised society.

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