

Financial Assistance

5.1 This chapter presents information on the financial implications of providing care for carers and their families. It also examines issues that have been raised in evidence relating to the:

- rates of income support and other government financial assistance available for carers;
- application and assessment processes for financial assistance for carers;
- the administration of income support and other supplementary payments through Centrelink;
- additional costs associated with disability and caring; and
- future and long term financial security for carers and care receivers.

Financial Implications of Providing Care

5.2 Carers make a significant contribution to society, often at significant costs to their own financial, physical and emotional wellbeing. Many carers have indicated that they are under serious financial stress due to their reduced capacity to participate in paid employment and inadequate government financial assistance. Many of these carers who report that they struggle to meet the every day costs of living including the costs of food and housing, are also faced with the increased costs associated with disability and the provision of care.¹

1 See for example: Mr N Faint, Submission No 20, pp 1-2; Name withheld, Submission No 22, p 1; Ms M Keep, Submission No 25, p 1; Mr J Thompson, Submission No 26, p 1; Ms A Seales, Submission No 52, p 1; Ms L Horsely, Submission No 123, p 1; Ms P Bastow, Submission No 161.1, p 1; Ms K Tucker, Submission No 321, 2; Ms N Green, Submission No 831, p 2; Ms C

- 5.3 For many carers the financial disadvantages go beyond the immediate difficulties in meeting daily expenses, as their reduced capacity to participate in employment, which sometimes extends over many years, also results in limited opportunities to save for the future and to build superannuation.²
- 5.4 Data from the 2003 Australian Bureau of Statistics (ABS) Survey of Disability, Ageing and Carers (SDAC) revealed that the median weekly gross income for carers was more than 25% lower than for non-carers. In the case of primary carers median weekly gross income is more than 40% lower. In addition, carers are over represented in the two lowest quintiles³ of household income.⁴
- 5.5 The Australian Institute of Family Studies' analysis of data from the Families Caring for a Person with a Disability Study provides another indication of the financial hardship that many carers face. This analysis reported that 30% of families with a carer receiving Carer Allowance, and 29% of families with a carer receiving Carer Payment, had experienced difficulty paying electricity, gas or telephone bills on time, compared with only 14.6% of the general population.⁵
- 5.6 As noted in the submission from the Millpark Schizophrenia Support Group:
- Economically, carers often have to factor in loss of income from both the people they are caring for and themselves. Many carers who previously worked full time are forced to
- reduce their work hours or even resign. The consequent economic pressures placed on carers and their families is enormous and not appreciated or recognized.⁶
- 5.7 The opportunity cost, that is the income forgone by carers spending time providing care, for families and for the Australian economy was estimated

Bortolot, Submission No 1124, p 2; Mr C Coleman, Transcript of Evidence, 12 August 2008, p 27.

2 See for example: Mr R G Spring, Submission No 49, p 1; Ms M Loyer, Submission No 61, p 1; Ms W L Cheung, Submission No 492, p 1.

3 Quintile: When persons are ranked from the lowest to the highest on the basis of some characteristic such as household income, they can then be divided into equal sized groups. When the population is divided into five equally sized groups, the groups are called quintiles.

4 Australian Bureau of Statistics (2004), *Survey of Disability, Ageing and Carers*, 4430.0, p 51.

5 Edwards *et al* (2008), Australian Institute of Family Studies Research Report No 16, *The Nature and Impact of Caring for a Family Member with a Disability*, pp 25-26. See also: Dr P Hill, Transcript of Evidence, 6 August 2008, p 76.

6 Millpark Schizophrenia Support Group, Submission No 573, p 2.

in 2005 by Access Economics at \$4.9 billion.⁷ The submission from Ms Fiona Anderson, a mother of two children, one of whom has physical disability illustrates the opportunity costs for an individual carer:

Due to my inability to continue my work, our family has lost my income of around \$900,000 over the last 10 years, excluding superannuation contributions. Simultaneously our family has paid nearly \$400,000 for equipment, therapy and services for their child with physical disability.⁸

5.8 The long term financial impact of providing care was also illustrated in evidence presented by Ms Lisa Humphries, a young carer for her (now deceased) mother who explained:

I resigned from my career in my early 20s and cared for her full-time through most of my 20s, probably for about four or five years. During that time my friends continued to grow in their careers and enjoy life in their 20s, whereas I moved away from Sydney to care for her. My financial situation suffered. I was not able to save money during that time. ... I still struggle now to catch up with everybody else. In my 20s I basically was not earning any money, so it is really difficult for me now financially. I am only just starting to get it together now in my early 30s.⁹

Government Financial Assistance for Carers

Base Rate of Income Supports and Supplements

5.9 Brief descriptions of the income support payments and supplementary payments for carers have been previously provided in chapter 2 of the report. As noted in chapter 2, the two major sources of Australian Government financial assistance for carers are Carer Payment and Carer Allowance. The current rationale for Carer Payment is that 'it is an income support payment for people who, because of the demands of their caring role, are unable to support themselves through substantial workforce participation'. The rationale for Carer Allowance is that it is 'an income supplement that is paid in recognition of the caring role'. Depending on

7 Access Economics (2005), *The Economic Value of Informal Care*, p 13.

8 Ms F Anderson, Submission No 979, p 8.

9 Ms L Humphries, Transcript of Evidence, 6 August 2008, p 43.

the specifics of the caring situation, carers may be on another pension (e.g. Age Pension, Disability Support Pension (DSP)) or benefit (e.g. Newstart Allowance or Parenting Payment). Additional information on payment rates and other payment features are at Appendices D to F.

- 5.10 The 2003 ABS SDAC found that approximately 40% of all carers, and 57% of primary carers, relied on a government pension or allowance as their main source of personal cash income.¹⁰ Many submissions from carers have stated that government financial assistance does not adequately compensate carers for the indirect cost of care (i.e. opportunity costs) or the additional direct costs associated with being a carer such as medical expenses, costs of accessing support services, provision of equipment, aids and appliances, and transport.¹¹ This in turn places many carers under significant financial stress as illustrated by the statements below which represent just a few of the many situations described in submissions from carers:

Mr Frederick Novak – carer for his wife with high care needs

As indicated earlier we are financially virtually destitute, just attempting to survive and keep up payments like our mortgage etc. There are a few days every fortnight, when we do not eat.¹²

Mr R Spring – a long term carer for his wife who has muscular dystrophy and is wheelchair bound

I find it difficult financially because of the rising costs of food – petrol - car service & repairs – house maintenance - etc. I have to cut back on so much to get through to the next Carers Payment. PLEASE HELP ME.¹³

Ms Margaret Jones – carer for her veteran husband who has a heart condition and post traumatic stress disorder

I find it difficult financially because we were in our 40s' when my husband became sick and could not work anymore. We were not able to work to retirement age and retire with superannuation,

10 Australian Bureau of Statistics (2008), *A Profile of Carers*, 4448.0, p 53.

11 See for example: Ms P Haldane, Submission No 41, p 1; Name withheld, Submission No 45, p 1; Ms T Camilleri, Submission No 48, p 2; Ms M Bartlett, Submission No 58, p 2; Mr I Morris, Submission No 162, p 2; Ms V Lynch, Submission No 334, p 1; Ms S Minutillo & Mr S Minutillo, Submission No 358, p 1; Mr P Alderton, Transcript of Evidence, 13 August 2008, p 3.

12 Mr F Novak, Submission No 1212, p 1.

13 Mr R G Spring, Submission No 49, p 1.

which was always our intention. I also had to give up my job to care for my husband. So we not only lost his wage but mine as well. I was earning more per week 12 years ago, than I get a fortnight now.¹⁴

Ms Lyn MacIver – carer for her husband following a stroke in 1999

I worry about the future EVERY DAY. The money we receive from Centrelink is pitiful, and well below the poverty level; given that, the cost of living a decent lifestyle is impossible without incurring debt.¹⁵

Ms Jenny Craven – carer for her elderly mother and for her husband who suffers from Huntington’s Disease

I am financially struggling because of obvious reasons. All pensioners are struggling. Trying to live in a place with no access to public transport means you have no choice but to drive everywhere.

- Our Neurologist is in Canberra, 2 hours away. \$\$\$
- Maintenance on our car is crippling. We struggle to pay for repairs and then get slugged with GST on top of the repair bill. Even a basic service is expensive. \$\$\$
- Utility bills continue to rise and the rebate for pensioners is swallowed up by the GST again. \$\$\$
- My husband's illness means that his appetite has increased four fold, meaning that he eats and drinks pretty much all day long. Metabolism is sped up with this disease so the eating is necessary to keep their weight up. Food costs are soaring. \$\$\$
- We have been on the waiting list for dental services here for years and now my husband needs 10 fillings because the high calorie (high sugar) foods he needs to maintain his weight have caused his teeth to decay. We can't seem to access the free dental scheme. Private dental work would involve us paying off our credit card for years. \$\$\$¹⁶

5.11 To reduce financial stress and adequately compensate carers for opportunity costs and the additional costs of disability and care, many submissions have recommended significant increases to the base rates of

14 Ms M Jones, Submission No 375, p 1.

15 Ms L MacIver, Submission No 191, p 2.

16 Ms J Craven, Submission No 754, pp 1-2.

income support for carers, including increases to the levels of Carer Payment and Carer Allowance.¹⁷

- 5.12 Some have also argued that it is inappropriate to view carers as 'welfare recipients', noting that carers do work in their caring role, often for many hours a day and without weekends off, holidays or sick leave.¹⁸ On this basis, some carers and organisations have suggested that financial assistance to carers should be paid at a level that is commensurate with employment and/or at least equivalent to the federal minimum wage.¹⁹ Yet others have suggested that Carer Payment and/or Carer Allowance should be awarded on a sliding scale which reflects the level of care required, with those providing support for care receivers with high needs receiving more than those providing support for care receivers with lower intensity care requirements.²⁰
- 5.13 The views expressed by many in relation to the rates of Carer Payment and Carer Allowance are illustrated by the following excerpts from evidence to the inquiry:

Ms Domenica Greenfield - carer for her husband with a mental illness

My role is just like a mental health worker but without the Degree. Supporting a mentally ill husband 24 hours a day is saving thousands of dollars for the Government because, 'I'm doing the work' and getting a pittance (Carers Allowance).²¹

17 See for example: Mr S Miljevic, Submission No 32, p 2; Ms P Haldane, Submission No 41, pp 1-2; Ms T Camilleri, Submission No 48, p 2; Ms J Small, Submission No 110, p 2; Mr N Kennedy, Submission No 183, p 1; Ms V Simpson, Submission No 260, p 5; Mr J Le, Submission No 364, p 1; Mr W de Goede, Submission No 366, p 1; Ms M Jones, Submission No 375, p 2; Ms D Stewart, Submission No 813, p 1; Ms R M Painter, Submission No 1143, p 2; Mrs M Bishop & Mr J Bishop, Submission No 1188, p 1.

18 See for example: Mr R Wells, Submission No 15, p 2; Ms K Stanley, Submission No 51, p 1; Ms D Edwards, Submission No 159, pp 1-2; Ms S Wilson, Submission No 371, p 1; Ms A Hewat, Submission No 866, p 6; Mr G Dwyer, Submission No 1093, p 1; Ms C Murray, Submission No 1134, pp 1-2.

19 See for example: Ms H James, Submission No 614, p 1; Carers NSW, Submission No 661, p 16; Ms N Hughes, Submission No 830, pp 4-5; Ms C Polak, Submission No 902, p 3; Ms V Evans, Submission No 1201, p 1.

20 See for example: National Carers Coalitions, Submission No 571, pp 23-25; Ms L Baker, Submission No 807, p 5; Ms C Murray, Submission No 1134, p 2; Ms M L Carter, Submission No 1291, p 6.

21 Ms D Greenfield, Submission No 111, p 2.

Ms Dagmar London – carer for her 86 year old husband

My carers allowance pays for window cleaners, small jobs I am unable to do - it is a great help but does not go far.²²

Ms Tania Hales – carer for her husband with limiting disabilities and mother to her young son

So it is a must that Government review all Centrelink carer income supports and eligibility tools to provide carers with adequate support to improve their financial situations. The carer allowance needs to be doubled to help cover some of the additional costs of caring and the Carer Bonus (that has recently been in the headlines) needs to be made an annual indexed payment for all carers in Australia, not to mention a superannuation scheme equivalent to the Federal Minimum Wage.²³

Name withheld – a couple caring for their intellectually disabled child

We feel the main issue comes down to the fact that we are just simply not compensated enough for our role ...Frankly...we need a lot more funding!!! ... We feel one of the key areas that needs to be revised is Carer Allowance and Carer Payment. It needs to be made more assessable. It needs to take into account the role of the carer not only caring for the individual, but the actual COST of caring.²⁴

Ms Marilyn Weller – aged pensioner providing care for her husband following a stroke

We would also really appreciate an increase in the small Carer Allowance paid to me, because rising costs in the necessities of day to day living are swallowing up the income we have from the Pension and Allowance, making it impossible to use the Carer Allowance for the purpose for which it was intended.²⁵

5.14 These concerns are also echoed by carer organisations, such as Carers Australia:

Our recommendations to the pension review include an increase in the base rate of pensions and allowances to be introduced as

22 Ms D London, Submission No 117, p 1.

23 Ms T Hales, Submission No 933, p 3.

24 Name withheld, Submission No 358, p 1.

25 Ms M Waller, Submission No 53, p 2.

soon as possible. We think there should be an increase in rental assistance, the utilities allowance and the pharmaceutical allowance.²⁶

Means Testing of Carer Payment

5.15 In addition to requests to increase base rates of income support payments, many submissions from carers and from organisations have recommended a review of the income and assets tests associated with the Carer Payment. Many carers questioned means testing of Carer Payment, observing that it often results in carers and their families being caught in a poverty trap.²⁷

5.16 For example, as a result of the assets test applied to income support Ms Lyn MacIver described how following her husband's stroke, they had both been required to live off savings, superannuation and liquidate assets to survive until they reached 'rock bottom'. Ms McIver concluded:

We now have no savings, and subsist on the 'benefits' from Centrelink.²⁸

5.17 Mr Terrence Hunter who, with his wife, provides daily and full time care for his grandchild with a disability said:

I am requesting that the greatest singular burden on us carers is the ability raise more income on top of our carers pension without being penalised by centrelink through asset [means] testing on our extra income that many of us are trying to earn to subsidize the immense financial burden that we have. ... We want to be able to contribute, but please remove this terrible obstacle, of asset [means] testing incomes.²⁹

5.18 Ms Carmen Polidano, who cares for her adult son with cerebral palsy noted in her submission that the means test was a disincentive for carers to earn additional income stating:

Currently we are treated like beggars and thieves. The meagre financial provision Centrelink gives us ensures we do not starve to

26 Ms J Hughes, Transcript of Evidence, 28 November 2008, p 11. See also: Carers ACT, Submission No 702, p 7.

27 See for example: Ms M Menegatos, Submission No 63, p 2; Ms V Simpson, Submission No 260, p 5; Ms L Krupjak, Submission No 365, p 1; National Carers Coalition, Submission No 571, p 5; Bathurst Carers District Voice, Submission No 1091.1, p 4.

28 Ms L MacIver, Submission No 191, pp 1-2.

29 Mr T Hunter, Submission No 7, p 1.

death while we care for the disabled and the means test makes sure we don't have any extra money to make our lives more bearable.³⁰

- 5.19 The argument presented by many carers is based on the premise that Carer Payment should be paid in recognition of the work that carers do and also in recognition of the savings to government as a consequence of the reduced need to provide formal care. As Ms Polidano proceeded to argue:

It is not unreasonable for Carers to be remunerated for their roles in a similar capacity to what they would otherwise receive in the work force. It is unreasonable for society and government to expect Carers to carry such a demanding burden for remuneration that is at or below the poverty line. It is unreasonable to expect that a Carer should continue their caring role and receive a greatly reduced Carer Payment or no Carer Payment at all because they have savings, assets and/or can be provided for by a husband or wife.³¹

- 5.20 Emphasising the case for the Carer Payment to be paid in recognition of the value of caring, rather than the financial status of the carer or their household, Mr Francis Horgan, who cares for his 80 year old wife with diabetes, suggested:

Ensuring that the tests used to determine eligibility for Carer's Allowances or Pensions not be based on financial income and asset tests (like age pensions) as the financial status of the Carer should not be the issue, rather the value of the voluntary contribution to the quality of life of the person being cared for.³²

- 5.21 Some submissions noted that because the income test is based on household income rather than income of the individual carer, those carers with partners earning above the income test threshold received either a reduced Carer Payment or no Carer Payment at all. In a society where households often rely on the contributions of two income earners, it was suggested that the loss of one income as a result of providing care should be acknowledged by receipt of the Carer Payment.
- 5.22 Commenting on both the base rate and means testing of Carer Payment, Mr John Halford who has been assisting his wife in providing care for his

30 Ms C Polidano, Submission No 259, p 4.

31 Ms C Polidano, Submission No 259, p 7.

32 Mr F Horgan, Submission No 513, pp 1-2.

elderly mother since the late 1980s stated:

[The Carers Payment] can only be acknowledged as a pittance. It is means tested on the whole family income, for anything extra that a partner earns, the Carer Payment reduces to make sure they remain second-class citizens.³³

5.23 Mr Philip Laughton who provides care for his wife who is on a DSP concurred:

Going out to work to try and maintain a reasonable standard of living and provide for your caree's needs compounds all the problems associated with caring. The whole situation is exacerbated by the demoralising and unjust effect of loosing half your income because of misguided punitive means testing. The low threshold at which the means testing cuts in means that the carer has to spend more time out at work, away from the caring role, to make up for the income withheld by Centrelink.³⁴

5.24 Writing on behalf of a group of mothers aged between 33 and 60 years, all with caring responsibilities for children with intellectual and physical disabilities, Ms Ruth Kyne suggested:

The tax rules relating to how much the carer's pension is reduced on the basis of income earned should be reviewed. Once a person earns above the tax free threshold (including the low income rebate) they are penalised twice - tax and a pension reduction per dollar. This is a disincentive to work, considering the extra costs of working (child care, transport, clothing) as well as the costs (time, stress and money) of caring well.³⁵

5.25 Noting that as a consequence of means testing some carers do not qualify for Carer Payment, the National Carers Coalition concluded:

The Means Testing of Carer Payment prevents thousands of full time carers from accessing this benefit because they are recipients of other welfare payments such as age/disability pension or who have a partner who is employed. This makes a mockery of the claim that the Carer Payment is a benefit for caring!³⁶

33 Mr J Halford, Submission No 250, p 5.

34 Mr P Laughton, Submission No 770, p 1.

35 Ms R Kyne, Submission No 873, p 4.

36 National Carers Coalition, Submission No 571, p 23.

Carer Bonuses

5.26 Since the 2004-2005 budget, eligible carers have been provided with 'one off' post budget bonuses to supplement Carer Payment and Carer Allowance. In 2008-2009 the bonus was \$1,000 for carers on Carer Payment³⁷ and \$600 for those paid Carer Allowance for each eligible carer receiver. Carers frequently urged that the one-off bonus become a confirmed annual payment.³⁸ The account provided by Ms Sonia Miles who provides care for her son who was born with a profound medical condition is typical and emphasises the importance of preserving the carer bonus:

I would just like to add the need and importance for the continuation of the Carer \$1000 and \$600 Bonus as this is a form of recognition and empowerment to us that the country does appreciate our hard work and the government actually recognises what we are saving them.³⁹

5.27 Some carers raised concerns relating to the difference in rate of Carer Bonus paid to those in receipt of Carer Payment versus those in receipt of Carer Allowance.⁴⁰ Others also noted inconsistency with bonuses received by carers in receipt of other forms of income support (e.g. Age Pension).⁴¹ Carers also debated whether it is preferable to receive bonuses as a one-off lump sum payment or spread across the year and paid fortnightly. In her submission Ms Marilyn Weller stated:

We appreciate that the Bonus has always come in a lump sum, rather than an increase in the fortnightly payment, as has been suggested by some in bureaucracy.

We ask that the Carer Bonus be maintained as a matter of necessity, and we would much prefer to have the Bonus paid as a lump sum annually.⁴²

37 The payment of \$1,000 was made to carers receiving Carer Payment, Department of Veterans' Affairs (DVA) Carer Service Pension, Wife Pension and Carer Allowance, and the DVA Partner Service Pension and Carer Allowance.

38 See for example: Ms P Jerrick, Submission No 6, p 1; Name withheld, Submission No 47, pp 2-3; Ms M Menegatos, Submission No 63, p 3; Ms N Kennedy, Submission No 183, p 1; Ms V Simpson, Submission No 260, p 6; Ms N Magnusson, Submission No 269, p 2; Ms S Hand, Submission No 322, p 5.

39 Ms S Miles, Submission No 452, p 2.

40 See for example: Ms G Hawthorne, Submission No 129, p 1; Ms S Shanawaz, Submission No 626, p 2.

41 See for example: Ms D Purcell, Submission No 2, p 1; Mr J Radford, Submission No 4, p 1; Mr C Dyer, Submission No 27, p 1.

42 Ms M Weller, Submission No 53, p 2.

- 5.28 Similarly, Ms Gina Wilson-Burns a mother caring for her son with multiple disabilities stated:

Mr Rudd spoke of his idea of spreading payments like the \$600 lump sum payment (one off) over the course of a year. This is a bad idea. We struggle to make ends meet as carers and so the act of saving up for the purchase of 'bigger ticket' items is difficult. A lump sum payment helps in this regard and should this type of payment continue, it should remain in its current lump sum format. The other consideration is that when you spread a payment such as this it has ramifications on those people who receive utility/rental/pension assistance based on their 'normal income'. Any small weekly increase to their income, such as Mr Rudd suggested, would not be beneficial to those carers most needing assistance.⁴³

- 5.29 Carers Australia suggested that there should be flexibility in relation to the payment frequency of the Carer Bonus that will enable carers to decide on the option that best suits their individual circumstances, stating:

People on income support payments should be given the option, we believe, of receiving their bonuses and other allowances as either part of their fortnightly payments or as a lump sum.⁴⁴

- 5.30 At the time of writing, the Government has given no indication that there will be further one-off bonuses for carers.

Reform to the Income Support Systems for Carers

- 5.31 A considerable quantity of evidence to the inquiry relates to the financial stresses experienced by many carers. On the basis of this evidence, the Committee concludes that the system of income support for carers is in need of significant reform. As noted in chapter 1 of the report the Australian Government is currently undertaking a review into pensions and taxation. The Pension Review, which included a review of the Age Pension, Carer Payment, Carer Allowance, DSP, Utilities Allowance and other allowances and benefits was completed in February 2009. At the time of writing, the Review's final report is not publicly available. However it is anticipated that the Review's findings will inform a reform package to income support and supplements, which may include reforms to Carer Payment, Carer Allowance, DSP and other allowances accessed

43 Ms G Wilson-Burns, Submission No 1080, p 18.

44 Ms J Hughes, Transcript of Evidence, 28 November 2008, p 11.

by carers. These reforms will be announced as part of the May 2009-10 Budget.

- 5.32 Nonetheless, in the absence of specific detail, the Committee is proceeding on the assumption that any change introduced by the Australian Government may only be incremental. On that basis, the Committee considers that the underlying principle of the income support system for carers still deserves to be reconsidered. Evidence to Committee suggests financial support for carers should relate to the activity of providing care itself, rather than to the financial circumstance of the individual carer or their household. In this sense, a carer would be earning a modest 'wage' as he or she is undertaking the caring role on behalf of the community – the more time the carer needs to spend to support the care receiver, the greater should be the carer's compensation or 'payment'. The Committee is encouraged in this regard by the new assessment process to be implemented for Carer Payment (child), which is based on a principle of the level of care needed by the care receiver and provided by the carer.⁴⁵
- 5.33 The Committee understands that this approach to the provision of financial assistance for carers would represent a significant and fundamental change. Reconfiguring Carer Payment and Carer Allowance to reflect this principle would be a long term task, but one that the Committee believes warrants detailed consideration. One implication, for example, might be changes to the income and/or assets testing that currently applies to Carer Payment.

Recommendation 17

- 5.34 **That the Minister of Families, Housing, Community Services and Indigenous Affairs examine how carer payments may be restructured to better reflect differences in the levels of care provided.**
- 5.35 In the shorter term there is a need to address the deficiencies in the existing system – firstly to the base rates of Carer Payment and Carer Allowance; and secondly, to the threshold and taper rates for Carer Payment income tests. The Committee understands that current restrictions force carers to reduce to a state of near poverty before they can receive support, which when received, is insufficient to lift them out of

45 See Australian Government (2007), *Report of the Carer Payment (child) Review Taskforce*, Recommendations 19-24, pp 16-17.

poverty again. Further, the income test thresholds and taper rates for Carer Payment, act as a disincentive to carers seeking to supplement the payment by gaining full or part time employment. Accordingly, the Committee makes recommendations to increase the base rates of both Carer Payment and Carer Allowance and to the threshold and taper rates of Carer Payment income test.

Recommendation 18

- 5.36 **That the Australian Government significantly increase the base rate of carer payments.**

Recommendation 19

- 5.37 **That the Minister for Families, Housing, Community Services and Indigenous Affairs examine and implement the most appropriate option(s) to reduce the disincentive for carers to earn supplementary income.**
- 5.38 The Committee acknowledges that the three preceding recommendations may well be affected by the Government's response to the Pension Review.
- 5.39 Evidence to the Committee indicates strong support for the continuation of Carer Bonuses, even if some prefer to receive them as an annual lump sum and others as a fortnightly supplement. At the time of writing the outcomes of the Pension Review have not been made available. However, if the Review recommends that Carer Bonuses be continued, then the Committee urges that carers be able to receive them as a lump sum or on a pro-rata basis.

Application and Assessment Processes for Income Support for Carers

- 5.40 As noted earlier in the report, Centrelink is the Government agency responsible for the delivery of a range of social welfare payments and allowances, including those provided by the Department of Families,

Community Services and Indigenous Affairs (FaHCSIA) for Carers. Submissions from a large number of carers outlined difficulties they have experienced in dealing with Centrelink.⁴⁶

5.41 The main issues that have been raised in relation to Centrelink relate to complex and inappropriate assessment procedures and application forms to qualify for benefits, inconsistent or incorrect advice from poorly trained or discourteous staff and concerns regarding frequent and intrusive review processes.

5.42 The experiences of many carers in dealing with Centrelink are summarised in the submission from the Carers Support Network of South Australia, which states:

The Centrelink system is a nightmare for many Carers. Most resent the condescending and suspicious attitudes they receive by Centrelink staff. The entire system of allowances, reviews and eligibility requirements is often referred to by Carers as 'insulting'. [Carers] are highly skilled in their own right, working 100 hours a week, have no sick or holiday pay – they work hard – and they rightly feel angry that they are treated as though they are trying to rip off the system. Many report that many Centrelink staff do not know how their own system works and Carers are then financially disadvantaged because they have not received correct information.⁴⁷

5.43 The views and experiences of carers in their dealing with Centrelink presented below are typical of many of those described in submissions to the inquiry:

Name withheld – carer for her son with autism

Sending us to Centrelink to claim carer's allowance was the most terrifying experience of my life with all the drug addicts and alcoholics pushing and shoving and screaming. No carer should ever have to do that walk of shame. I haven't done anything

46 See for example: Mr R Duley, Submission No 1, p 1; Ms B Kelly, Submission No 12, p 1; Mr G Ozols, Submission No 18, pp 1-2; Ms J Dajic, Submission No 56, p 3; Ms L MacIver, Submission No 191.1, p 4; Ms A Mitchell, Submission No 264, p 1; Name withheld, Submission No 353, p 1; Commonwealth Ombudsman, Submission No 511, p 3; Ms D Springett, Submission No 545, pp 1-2; Hunters Hill Ryde Community Services, Submission No 583, pp 1-2; Carer Support and Respite Centre Carer Group, Submission No 585, p 3; Ms A Hewat, Submission No 866, p 8; Ms A Robinson, Submission No 870, pp 4-5; Mr D Gill, Submission No 1136, p 2.

47 Carer Support Network of South Australia, Submission No 675, p 5.

wrong and shouldn't be treated like a moron. Treat me like a normal, working human being, please.⁴⁸

Ms Lynette Walker – carer for husband with partial paralysis

One of the things that stresses me most about being a carer is dealing with Centrelink. The attitude of this organization appears to be anti-carers; that we are trying to 'rip off the system'. I was made to feel that, because we are being financially supported by Centrelink, we are bludgers. The staff are rude and often unhelpful; the queues almost impossible and the office we have visited has poor disabled access. Every communication contains implied threats of penalties.⁴⁹

Ms Beulah Packham – carer for her elderly mother (now in residential care) with Addison's Disease

An important facet in the role of a carer who receives benefits from the Government is that the carer can often be the object of disdainful treatment by some members of the Centrelink staff. It is possible that they are overworked and therefore forget salient points in their training manual reminding them that the view that carers are just another drain on the resources of the economy is wrong.⁵⁰

Mr Rolf Regal – carer for his wife diagnosed with multiple sclerosis in 1984

Many carers voice their frustration with Centrelink. The impression that Centrelink staff assigned to deal with people with disabilities and their carers, do not know much about disabilities and are unsympathetic, is widespread. ... However, perhaps the most frustrating aspect is the number of times the same information about name, [date of birth], address, telephone numbers, etc has to be entered into forms afresh. With present day IT capabilities it should be possible to provide the necessary forms populated with the already held information, with clients asked to check what is there, and make corrections only when changes (or errors) have occurred.⁵¹

48 Name withheld, Submission No 19, p 2.

49 Ms L Walker, Submission No 470, p 2.

50 Ms B Packham, Submission No 1087, p 4.

51 Mr R Regal, Submission No 335, p 4.

Ms Dawn Springett - carer for her elderly mother

The application to Centrelink for a Carer's Allowance and / or Carers Payment is not only extremely difficult but humiliating. I found the cavalier attitude of Centrelink staff so patronising that I felt that they were grimly determined that I should never receive any payment.⁵²

Name withheld - carer for her mother who has multiple sclerosis

When we try to access support and information from peak bodies such as Centrelink and the Department of Human Services/Health and Ageing, we are often made to feel that we should be grateful for everything that we receive, the information is inconsistent and often incorrect and phone calls for assistance are often not returned. As a carer who works full time, I don't have this much time.⁵³

- 5.44 Submissions from some carers and organisations suggested that the complexity of the assessment processes and application forms that are required by Centrelink to gain access to income support present serious obstacles to many carers.⁵⁴ For example, Ms M Trehwella who cares for her quadriplegic husband suggested that:

The Centrelink system is so complex that it scares people and fails to simply address needs and issues in a manner that is clear and unambiguous. It should not be as I believe so complex that it is used as a mechanism to reduce welfare.⁵⁵

- 5.45 As noted by the National Ethnic Disability Alliance, complex assessment processes and application forms may make access to financial assistance even more problematic for carers from culturally and linguistically diverse (CALD) backgrounds who may have limited English.⁵⁶
- 5.46 The sheer volume of paper work required by Centrelink, coupled with the time and logistical effort required to complete the paperwork, attend and undergo the required medical and professional assessments were also major causes of frustration for carers. As explained by a mother who provides care for her intellectually disabled son:

52 Ms D Springett, Submission No 545, p 1.

53 Name withheld, Submission No 367, p 3.

54 See for example: Carers ACT, Submission No 702, p 17; Ms B Miller, Submission No 903, p 1; Mr K Gerachty & Ms K McCann, Submission No 884, p 2.

55 Ms M Trehwella, Submission No 154, p 5.

56 National Ethnic Disability Alliance, Submission No 1110, p 18.

Then there is the paperwork. Has anyone looked at the process of applying for Carer's Allowance or Payment? The paperwork alone and the requirements that go along with applying for these payments are so involved, that quite frankly, you just give up even trying to apply and really who has the time to get it all done? Then you question why you need to confirm that your child has a disability to Centrelink when he already is acknowledged as Disabled and registered with Disability Services? ... Honestly, panic sets in when we are sent forms for renewal of Carers allowance. It just takes forever and costs even more when a doctor needs to be involved in the process.⁵⁷

- 5.47 Also expressing her frustration with the carer income support claim and assessment processes, including the need for review processes, Ms Michiko Parnell suggested:

Can we please stop using GPs as the reference point for any paperwork associated with Centrelink ... It's very draining and expensive and why should Medicare pay for this form filling? If we have a letter of diagnosis, shouldn't that be enough! And why should I keep telling Centrelink every year or so, that my daughter's Cerebral Palsy hasn't been cured!!⁵⁸

- 5.48 For some carers accessing services from more than one agency, the onerous assessment processes were made worse by having to duplicate information for each agency and even undergo separate assessments. Ms Linda Symons who carers for her ex-RAAF husband who is now retired Totally and Permanently Incapacitated explained that they access services from both Centrelink and the Department of Veterans' Affairs (DVA). Despite DVA already having extensive information regarding her husband and Centrelink having access to that information, she described how they had to duplicate all of the information for Centrelink and how her husband had to undergo another medical assessment.⁵⁹

- 5.49 To address these issues, the Carers Support Network of South Australia called for a full review of the role of Centrelink with carers with a view to:

- creating a Department or Unit within Centrelink specifically for Carers.
- streamlining the current system, eligibility requirements etc.

57 Name withheld, Submission No 358, p 2. See also: Name withheld, Submission No 358, p 2; Ms G Parker, Transcript of Evidence, 12 August 2008, p 31.

58 Ms M Parnell, Submission No 849, p 14.

59 Ms L Symons, Submission No 1043, p 2.

- changing the attitudes of staff so that Carers are treated respectfully as contributors to our social system, not as bludgers.⁶⁰

5.50 One criticism repeatedly made in relation to the application and assessment processes for income support for carers is that they are biased toward physical disabilities and fail to adequately recognise carers who care for people with mental illness or challenging behaviours, particularly when these conditions are episodic.⁶¹

5.51 The Mental Illness Fellowship of Victoria provided the following illustration of how the claim form for Carer Payment/ Allowance discriminates against those with episodic illness:

Criteria for carer allowance and carer payments include an assessment of the level of disability of the person being cared for that principally focuses on physical mobility. Part C of the claim form asks the carer to assess the day to day needs of the person they care for. The explanatory notes state: *'Where the person's disability or condition is episodic or is only apparent at certain times, the question should be answered for when the person is not experiencing an episode or flare-up of the disability/condition'*.

Given that the nature of mental illnesses is episodic, the requirement to answer each question for when the person is not experiencing an episode is equivalent to excluding carers of people with mental illness by definition.⁶²

5.52 Ms Helen Charlesworth who provides care for her adult son who suffers from chronic paranoid schizophrenia explained:

I cannot access the Carers Allowance, even though I am his personal organiser, as most questions on the [Centrelink] form do not address mental health issues.⁶³

5.53 Similarly Ms Jan Wallent, a carer for her veteran husband observed:

The [Carer Allowance claim] form is very task orientated and doesn't take into account people with a mental illness, who can do

60 Carer Support Network of South Australia, Submission No 675, p 4. See also: Mr M Aldred, Transcript of Evidence, 12 August 2008, pp 57-58.

61 See for example: Ms D McIntyre, Submission No 187, p 1; ARAFMI WA, Submission No 578, p 2; Ms P Mason, Submission No 808, p 2; Horsham Family Advisory Committee, Submission No 1108, p 4; Ms G Parker, Transcript of Evidence, 12 August 2008, p 31; Ms S Matheson, Transcript of Evidence, 12 August 2008, p 52.

62 Mental Illness Fellowship Victoria, Submission No 1104, p 10.

63 Ms H Charlesworth, Submission No 444, p 2.

many of their [activities of daily living] but no allowance for the time a carer spends trying to settle someone who is out of control, perhaps at midnight. After all if you ask anyone with a mental illness they will tell you that there is nothing wrong with them, just the rest of the world.⁶⁴

An Improved Approach to the Administration of Income Support for Carers

- 5.54 The Committee recognises the frustration experienced by many carers trying to access income support for themselves or for a care receiver. While the Committee understands that assessment to determine eligibility for income support is essential, it is concerned that so many carers have found the claim/application process and the associated assessments to be onerous and unnecessarily complex.
- 5.55 To a large extent the Committee is aware that the complexity of the Centrelink claim processes for income support is a reflection of the complexity of the associated assessment process. Although Centrelink is the agency responsible for the delivery of income support payments, it does so in accordance with legislation and policy guidelines that are developed by FaHCSIA. Therefore Centrelink's ability to streamline and simplify the claim processes is limited in the absence of a parallel review of associated policy which will need to be undertaken by FaHCSIA.
- 5.56 In this regard the Committee notes the outcomes of the Carer Payment (child) Taskforce and in particular those recommendations which relate to a new approach to assessment.⁶⁵ In response to the outcomes of the review, FaHCSIA has pointed to a number of changes to the assessment process for Carer Payment (child) that will be implemented from 1 July 2009. These include:
- a new, fairer and less restrictive assessment process, based on the level of care required by the care receiver and provided by the carer;
 - transitions between Carer Payment (child) and Carer Payment (adult) will be easier;
 - Carer Assessment Teams, staffed by health professionals, will undertake assessments of the complex assessments for Carer Payment (child);

64 Mr J Wallent, Submission No 834, p 2.

65 See Australian Government (2007), *Report of the Carer Payment (child) Review Taskforce*, Recommendations 19-24, pp 16-17.

- carers who provide short-term or episodic care for a child aged under 16 (for a minimum of three months and a maximum of six months) will be entitled to receive Carer Payment (child). Around 3,400 carers will benefit from this change in 2009-10;
- the current 63 day limit for hospital admission days will be removed and replaced with a 12 week review arrangement;
- the current requirement for a doctor to say that a child who has a medical condition will live no longer than 12 months has been replaced with an estimation of average life expectancy for a child with the same or similar medical condition, with a limit of 24 months; and
- by July 2010, a single assessment process for Carer Payment and Carer Allowance will be introduced.⁶⁶

5.57 The Committee is encouraged by these reforms to the assessment and anticipates that their implementation will improve access for those carers seeking to claim Carer Payment (child). Furthermore, the Committee is keen to ensure that similar considerations are also extended to assessment for Carer Payment (adult). In particular the Committee would like to see a thorough review of the assessment for Carer Payment (adult).

⁶⁶ Australian Government Departments (FaHCSIA, DoHA & DVA), Submission No 1109, p 45. See also: Social Security Amendment Bill 2009 introduced into Parliament on 19 May 2009.

Recommendation 20

5.58 **That the Minister for Families, Housing, Community Services and Indigenous Affairs direct the Department of Families, Housing, Community Services and Indigenous Affairs to review its assessment for Carer Payment/Allowance (adult) with a view to:**

- **extending the range of health and allied health professionals who are authorised to verify the applicant's claim;**
- **enabling acceptance of recent supporting documents that may already be held by the carer to verify the claim where these documents provide a sufficient level of detail regarding the care needs of the care receiver;**
- **developing a new assessment process that acknowledges the level of support provided by carers of people with intellectual disability, mental illness or with challenging behaviours. The assessment should also have regard to the episodic nature of some conditions; and**
- **reviewing the purpose and frequency of review processes, particularly in circumstances where it is evident the needs of the care receiver will not decrease over time.**

5.59 The Committee also believes that these reforms will need to be closely aligned to a review of Centrelink's management of income support delivery to carers and care recipients. Specifically, the Committee recommends that Centrelink review its claim forms to simplify their content and design. The evidence detailed above also suggests that Centrelink staff can do more to help carers, particularly those from CALD backgrounds, to navigate Centrelink's processes.

5.60 In addition, the Committee believes that Centrelink should review its data capture and management systems to reduce the need for carers to duplicate the same information on multiple occasions. While paying due regard to privacy concerns, Centrelink should improve its data matching with other government agencies in order to reduce the need for carers accessing services through more than one agency to undergo repeated assessments.

Recommendation 21

5.61 **That the Minister for Human Services, in consultation with the Minister for Families, Housing, Community Services and Indigenous Affairs, direct their Departments to review Centrelink's application processes for income support for carers and care receivers with a view to streamlining processes and simplifying the content and design of its claim forms.**

The review should also include consideration of how Centrelink's data capture and management systems might be improved to reduce the need for carers to provide the same information on multiple occasions.

5.62 The Committee is also particularly concerned by evidence from carers which suggests that Centrelink staff may poorly understand the legislation and policy associated with payments for carers and carer receivers. As a result carers report having received poor quality or inconsistent advice. The Committee understands that the provision of good quality advice requires consistent interpretation of complex legislation and policy. Therefore, the Committee believes there is merit in the suggestion that a dedicated Carer/Disability Unit be established in Centrelink.

Recommendation 22

5.63 **That the Minister for Human Services direct Centrelink to establish a dedicated Carer/Disability Unit with staff to provide specialist advice to carers and care receivers, including those with complex care and family issues.**

Costs of Disability and Caring

5.64 In addition to the forgone income associated with reduced capacity to participate in employment, evidence to the Inquiry indicated that the financial stress for carers and their families is amplified by the additional

direct costs associated with disability and care.⁶⁷ Additional costs incurred by carers and their families include:

- increased household utilities (e.g. electricity, gas, telephone etc);
- expenses associated with medical and specialist appointments;
- purchase of medication and medical supplies;
- provision of alternate care arrangements;
- purchase of specialist equipment, aids and appliances;
- costs associated with travel and transport; and
- home and vehicle modifications.

5.65 Many carers have indicated that they are either entirely responsible for meeting the additional costs of care and disability (e.g. carers of children with a disability) or that they heavily subsidise these costs. These additional costs can be significant as illustrated by Ms Fiona Anderson a mother of two children one of whom has a disability. Between 1996 and 2008, Ms Anderson estimates spending an additional \$400,000 on the purchase of disability aids, equipment and services for her child with a disability.⁶⁸ Some carers reported having to subsidise additional costs of disability and care even when the care receiver is living 'independently' or in supported residential accommodation.⁶⁹

5.66 Many submissions to the inquiry have highlighted the financial difficulties and stress for carers and their families as a result of the increased costs associated with disability and care. The excerpts below illustrate some of the many situations that carers and their families have described:

67 See for example: Mr R Smeaton, Submission No 69, pp 2-3; Mr N Sweeney, Submission No 133, p 1; Ms J Guilfiolo, Submission No 160, p 2; Mr K Sheedy, Submission No 276, p 2; Mr K McDonall, Submission No 518, p 2; Ms L Watkins, Submission No 551, p 1; Mr M MacDonald & Ms J MacDonald, Submission No 589, pp 2-3; Ms G Vines, Submission No 833, p 2; Ms C Paisley-Dew, Submission No 845, p 2; Ms C MacDonald, Submission No 947, p 1; Ms S Scrivener & Mr D Scrivener, Submission No 1113, p 3; Mr L Hudson & Ms A Hudson, Submission No 1141, p 1; Ms C McEachern & Mr R McEachern, Submission No 1171, p 2; Mr R Shaw, Submission No 1172, p 1; Ms L Aspinall, Submission No 1189, p 1; Ms T Shanahan, Submission No 1195, p 2; Ms K Duff, Submission No 1197, p 1; Ms T McLure, Submission No 1200, p 3; Ms K Clark, Transcript of Evidence, 6 August 2008, p 49; Ms H Johnson, Transcript of Evidence, 12 August 2008, p 47; Ms S Hodgson, Transcript of Evidence, 9 October 2008, p 38.

68 Ms F Anderson, Submission No 979, p 14.

69 See for example: Ms V Butler, Submission No 268, pp 1-3.

Mr Michael Aldred and Ms Honnie Aldred – parents of a severely disabled 16 year old girl

Money for looking after [our daughter] is an extreme issue in our family. Life revolves around it. It has caused more friction and problems in our family than anything else. There are a few examples. We get the \$470 from [the Continence Aids Assistance Scheme]; I pay \$250 a month for her continence programs. For wheelchairs we get \$3,000; a wheelchair costs us about \$8,000. We had to put a commode and a shower chair in; we got \$1,500 and it cost \$3,500. You spoke earlier about a car conversion. They are talking about giving us \$10,000. We bought a \$33,000 second-hand car. We paid \$25,000 on top of that for a conversion.⁷⁰

Ms Megan King and Mr Rob King – parents of two children including their son with disabilities

As Lachlan's disabilities became more challenging, we realized we would need to purchase lots of additional equipment to support him. We were lucky enough to have a fund raiser held for Lachie last year and the proceeds of this went towards several purchases, which included a van, floor matting, a bathroom stretcher, special low floor chair, a car seat, switch adapters and adaptable educational toys and many more incidentals. We have recently contributed \$4000.00 towards our home being modified to accommodate Lachlan and we are currently waiting on council approval to erect a carport out of the front of our home so that we can bring Lachlan in and out of the van in any type of weather, this will cost us \$5,500.00. We still need to modify our vehicle so that we can transport Lachlan in the rear whilst in his wheelchair. This is vital and needs to be done sooner rather than later as he is becoming far too big to be in a car seat. The reason why we haven't done this yet is due to the cost, which is approximately \$23,000.00. We will need to raise the majority of this money to have this done. We also need to purchase special formula for Lachlan and this costs around \$150.00 per month. The above mentioned goods have been paid for through our own means - be it from money raised or money we have had to find ourselves.⁷¹

70 Mr M Aldred, Transcript of Evidence, 12 August 2008, p 51.

71 Ms M King & Mr R King, Submission No 817, p 2.

Mr Ron Smeaton – cares for his wife with dementia

Adapting my home to accommodate my wife with her disability has cost in excess of fifty-six thousand dollars. The government contribution to this was approximately four thousand dollars plus whatever rebate was allowed on my income tax for these items. I think that a more realistic approach could be made in the level of assistance granted for this type of expense.⁷²

Ms M Hart and Mr R Hart – carers for their 17 year old son who has a severe disability

As equipment for disabled is limited it is quite expensive, the funding that is available for this does not go very far. As an example, for a basic wheelchair van we are looking at \$25,000 for the conversion alone. The Government is contributing up to a maximum of \$10,000. This leaves families having to buy a vehicle and then find another \$15,000 or more to modify. We also have to cope with funding for incontinence aids. We currently receive about \$480 per year which only lasts about 3 months.⁷³

5.67 Clearly the direct costs of disability and care will vary considerably from one situation to the next, depending on the nature of care required and on family circumstances. While there is limited data from Australia on the costs associated in disability and caring, research conducted in 2006 through the Social Policy Research Centre of the University of New South Wales reported that:

In income terms, the costs of disability are estimated to average around 29 per cent of (equivalised)⁷⁴ household income, rising to between 40 per cent and 49 per cent of income for those with a severe or profound restriction.⁷⁵

5.68 Based on the outcomes of this research, the author concluded:

... that there is an urgent need to review the adequacy of income support arrangements for those with a disability across all household types.⁷⁶

72 Mr R Smeaton, Submission No 69, p 3.

73 Ms M Hart & Mr R Hart, Submission No 1174, p 1.

74 Equivalised household income is adjusted to account for differences in household size and composition (eg number of adults and number of children in a household).

75 Dr P Saunders (2006), *The Costs of Disability and the Incidence of Poverty*, Social Policy Research Centre, Discussion Paper No 147, p 22.

76 Dr P Saunders (2006), *The Costs of Disability and the Incidence of Poverty*, Social Policy Research Centre, Discussion Paper No 147, p 22.

- 5.69 As noted by many carers, and summarised in the following statement from Carers Queensland, the current system of financial supports for carers and care receivers does not adequately address the additional costs associated with disability and caring:

A major deficiency in the current social support system is that it fails to address the costs associated with disability/illness and the costs of care. Very few families receive assistance to purchase the aids, interventions, therapies or support that they require.⁷⁷

Initiatives to Assist with the Additional Costs of Disability and Caring

- 5.70 The Committee acknowledges that the additional cost of disability and caring increases the financial stress of carers and their families who are already disadvantaged by a reduced capacity to participate in paid employment.
- 5.71 Before considering options for addressing the additional costs of disability and care, the Committee was interested to note that in Australia there appears to be a lack of information on the direct financial costs of living with a disability. Several surveys that have examined the financial impact of providing care have focused primarily on measuring lost opportunity costs, or the imputed costs of providing alternative formal care and the savings to government of the provision of informal care.⁷⁸ To address this deficit the Committee supports the need for a detailed survey of actual direct costs of living with disability, both for the person and their main caregiver(s).

Recommendation 23

- 5.72 **That the Minister for Families, Housing, Community Services and Indigenous Affairs through the Department of Families, Housing, Community Services and Indigenous Affairs fund a survey to measure the financial costs to households of caring for people with disability.**

77 Carers Queensland, Submission No 703, p 14.

78 See for example: Taskforce on Care Costs (2005), *Creating Choice: Employment and the cost of caring*; Taskforce on Care Costs (2007) *Creating Choice: Employment and the cost of caring*; Access Economics (2005), *The Economic Value of Informal Care*.

- 5.73 The varying circumstances of carers and their families will necessitate different strategies to assist them meet the additional costs of disability and care. The Carer Payment and the DSP are both income replacements payable to individuals who are deemed unable to support themselves through substantial workforce participation. Neither payments are intended to compensate for the additional costs of disability and caring. Similarly, the Carer Allowance, an income supplement paid recognition of the carer role, is also not explicitly intended to meet extra costs of disability and caring, although carers frequently report that they use it in this way.⁷⁹
- 5.74 The Australian Government does already provide some compensation for the additional costs of disability and care. For example, from March 2008 the Utilities Allowance⁸⁰ and the Telephone Allowance⁸¹ previously paid to Age Pension recipients only, were extended to people receiving Carer Payment and DSP. In addition the Department of Health and Ageing (DoHA) provides some assistance with the purchase of continence aids for people with permanent and severe incontinence aged 5 years and over through its Continence Aids Assistance Scheme.⁸²
- 5.75 The Committee heard repeatedly from carers that the purchase of continence aids was a significant cost for families providing care. Many carers also indicated that the current level of government financial assistance with meeting this cost is inadequate. While the purpose of Continence Aids Assistance Scheme is 'to meet some of the costs of continence products' the Committee considers that there is scope to increase the level of assistance for eligible clients.

Recommendation 24

- 5.76 **That the Minister for Health and Ageing increase the level of the subsidy available to eligible clients for the purchase of continence aids through the Continence Aids Assistance Scheme.**

79 Ms L Watkins, Submission No 551, p 1.

80 A quarterly payment to assist with regular household bills.

81 A quarterly payment to assist with maintaining the cost of a telephone service and internet connection.

82 Australian Government, Department of Health and Ageing website, viewed 25 February 2009 at www.health.gov.au/internet/main/publishing.nsf/content/continence-caas.htm.

- 5.77 The Committee also heard from many carers who are struggling to meet often significant additional costs associated with the purchase of specialist equipment, aids and appliances. In addition, carers are often required to arrange or provide transport for care receivers to enable them to attend medical appointments, therapy or to get to and from school, day care, employment or respite. In the absence of suitable and affordable public and community transport options for care receivers, many carers have indicated that they need to run their own vehicle or to rely on taxi services.⁸³ Given the financial difficulties experienced by many carers, these costs add to their financial pressures.
- 5.78 While the Committee appreciates that some financial assistance with the meeting the costs of disability and caring is offered by state and territory governments, the scope of assistance that is available and the eligibility criteria vary between jurisdictions.⁸⁴ The reality is that there is no nationally consistent framework of financial support to assist carers and their families with meeting the additional costs of disability and care.
- 5.79 In this regard the Committee is encouraged to note that among the priorities for reform identified in the National Disability Agreement (NDA), is the introduction of more consistent access to aids and equipment by the end of 2012. However the Committee is concerned that this will not include consideration of assistance with capital costs of disability and care, such as those associated with home or vehicle modifications.

Recommendation 25

- 5.80 **That the Minister for Families, Housing, Community Services and Indigenous Affairs negotiate through the National Disability Agreement to extend considerations in relation to developing more consistent access to aids and equipment, to also include consideration of a more consistent framework to assist with capital costs incurred as a result of disability and care, such as vehicle and home modifications.**

83 See for example: Mr M MacDonald & Ms J MacDonald, Submission No 589, pp 2-3; Ms K McCann, Submission No 751, p 4; Ms S Walden, Submission No 900, pp 3, 4; Ms G Hunter, Submission No 1090, p 1; Mr C Coleman, Transcript of Evidence, 12 August 2008, p 28.

84 For example: The Victorian Aids and Equipment Program (VAEP), the Community Aids Equipment Program (CAEP) in WA or the Patient Assisted Transport Scheme (PATS) in NSW.

5.81 To complement the commitment to introduce more consistent access to aids and equipment under the NDA, the Committee is also keen to investigate a range of options that might assist carers and their families with the additional costs of care and disability. As noted by MS Australia:

... there is no one size fits all solution as some carers work, some have private income and some rely on welfare payments. For employed carers, there are opportunities to utilise the taxation system to provide relief for these costs of care. ... Many people purchase items privately, or co-fund equipment with State and Territory schemes, and it is this that could be made tax deductible.⁸⁵

5.82 Evidence to the Inquiry has included considerable support from carers and from organisations alike for changes to the tax system which will provide tax concessions or rebates on the purchase of a range of services and items associated with disability and care (e.g. medication, therapy, aids and equipment, vehicle modifications, home modifications).⁸⁶ The Committee believes that detailed consideration of options for tax concessions or rebates to assist households with taxable income with the additional costs of disability and care should be undertaken as part of the Government's current review of Australia's future tax system.⁸⁷

Recommendation 26

5.83 **That the Treasurer ensure that the review of Australia's Future Tax System include consideration of options for tax concessions or rebates to apply to items associated with disability and caring such as medication, therapy, aids and equipment.**

Concession Cards and Allowances

5.84 Those receiving Carer Payment are automatically issued with a Pensioner Concession Card. The card entitles the holder to reduced cost medicines under the Pharmaceutical Benefits Scheme (PBS). Holders of the cards may also receive additional subsidies from state and local government

85 MS Australia, Submission No 692, p 22.

86 See for example: Australian Association for Families of Children with a Disability, Submission No 581, p 4; Young People in Nursing Homes National Alliance, Submission No 764, p 13; Ms F Anderson, Submission No 979, p 5.

87 Australian Government, Treasury website, viewed 25 February 2009 at taxreview.treasury.gov.au/Content/Content.aspx?doc=html/home.htm.

authorities although these are the responsibility of the providers and may vary from state to state, but typically include:

- reductions in property and water rates;
- reductions in energy bills;
- a telephone allowance;
- reduced fares on public transport;
- reductions on motor vehicle registration; and
- one or more free rail journeys within the state each year.⁸⁸

5.85 Those carers receiving Carer Allowance are not entitled to a Pensioner Concession Card, although those receiving Carer Allowance (child) are issued with a Health Care Card in the child's name. The Health Care Card entitles the holder to reduced cost medicines under the PBS for the person named on the card and to some extra concessions from state and local government authorities (although not to the same extent as on the Pensioner Concession Card). Given the low income thresholds and taper rates of the Carer Payment, many carers find that they are significantly disadvantaged financially by their responsibilities without receiving any assistance from concessions.⁸⁹ This applies particularly to lower paid carers who just miss out on the Carer Payment. While recommending above that the base rates, thresholds and taper rates of Carer Payment be raised and that the base rate of Carer Allowance also be raised, the Committee still thinks that those lower income carers not on Carer Payment should have access to reduced cost medicines and other concessions in their own right – particularly as carers as a cohort suffer poor health outcomes in comparison to the rest of the community.⁹⁰

88 Australian Government, Centrelink website, viewed 2 March 2009 at www.centrelink.gov.au/internet/internet.nsf/payments/conc_cards_pcc.htm.

89 See for example: Parkside Foundation, Submission No 673, p 10; Ms M Cardamone, Submission No 799, p 5; Ms M Parnell, Submission No 849, p 7; Ms K Ingram & Mr G Ingram, Submission No 865, p 3; Ms L Coyte, Submission No 868, p 4; Ms C Rowntree, Submission No 1299, p 1.

90 Issues pertaining to the health and wellbeing of carers are considered in more detail in chapter 8 of the report.

Recommendation 27

- 5.86 **That the Minister for Families, Housing, Community Services and Indigenous Affairs advocate for Health Care Cards to be issued under the same means test as Carer Payment to those receiving Carers Allowance.**
- 5.87 An option that has been raised to help ease one of the frustrations of caring is the introduction of a National Carer Card for carers receiving Carer Payment and/or Carer Allowance.⁹¹ Such a card could be used to verify a carer's responsibilities for a care receiver by government agencies (such as Centrelink), health professionals or other service providers when the carer is acting on behalf of the care receiver. A national carer card could ultimately also provide the vehicle to replace pensioner concession or health care cards for carers eligible for those concessions. Another use would be as a discount card to allow carers to access the range of informal discounts offered to other groups such as students or seniors. On the basis of these potential benefits, the Committee, without becoming embroiled in debate about the privacy implications of a national identity card, makes the following recommendation.

Recommendation 28

- 5.88 **That the Minister for Families Housing, Community Services and Indigenous Affairs direct the Department of Families Housing, Community Services and Indigenous Affairs to investigate the benefits of introducing a national carer card for recipients of Carer Payment and Carer Allowance in order to verify the relationship between a primary carer and a care receiver.**

91 See for example: Ms B Kelly, Submission No 12, p 1; Name withheld, Submission No 559, p 4; Carers WA, Submission No 566, p 6; Carers Support and Respite Centre Carers Group, Submission No 585, p 7; Carers NSW, Submission No 661, pp 17-18; Carers Support Network of South Australia, Submission No 675, pp 4, 10; Ms P Mason, Submission No 808, pp 2-3; Ms M L Carter, Submission No 1291, pp 5-6; Mr C Coleman, Transcript of Evidence, 12 August 2008, p 70; Ms D Stewart, Transcript of Evidence, 13 August 2008, p 27; Ms J Hughes, Transcript of Evidence, 28 November 2008, p 11.

National Disability Insurance Scheme

5.89 Finally in relation to addressing the costs of disability and care, the Committee also received evidence from a number of sources identifying support for a National Disability Insurance Scheme (NDIS).⁹² The concept of a NDIS was discussed at the 2020 summit as an innovative model of reform to funding of disability services (excluding income support) for people under the age of 65 years, including those born with a disability. Giving her support for the introduction of a NDIS, Ms Liz Kelly, mother of a child with severe disabilities urged the Committee to:

Support the 2020 submission for the National Disability Insurance Scheme (NDIS) to cover the growing costs of disability, which is a risk faced by everyone in the community. This should be a fully-funded universal National Disability Insurance Scheme (NDIS). It could be funded from a number of sources, including as a special supplement to the Medicare levy, third party car insurance and/or workplace insurance.⁹³

5.90 Ms Kelly also observed:

The models for a NDIS already exist, as there are already fully-funded no-fault insurance schemes to meet the needs of people injured in the workplace in NSW, Victoria, SA, NT and the Commonwealth and in car accidents in NSW, Victoria and Tasmania.

The costs would be modest (as little as an additional \$20 per annum on third party car insurance premiums in Victoria to cover all catastrophic injuries) and the benefits significant because a National Disability Insurance Scheme would be much more equitable than current arrangements (where a few can get multi-million dollar payouts and many others with similar disabilities nothing) and enable people with disabilities and their carers to be in control, make choices and plan their lives with confidence.⁹⁴

92 See for example: Carers Australia, Submission No 699, p 31; MS Australia, Submission No 692, p 23; Name withheld, Submission No 883, p 5; Ms A-M Newbold, Submission No 1942, p 3; Ms H Johnson, Submission No 1178, p 8; Developmental Disability Council of WA, Submission No 786, p 4; Association for Children with a Disability, Submission No 750, p 4; Disability Services Commission, Submission No 1039, p 9; Ms K Clark, Transcript of Evidence, 6 August 2008, p 49; Mr B Bonyhady, Transcript of Evidence, 5 March 2009, pp 1-11.

93 Ms L Kelly, Submission No 1173, pp 1-2.

94 Ms L Kelly, Submission No 1173, p 4.

- 5.91 While supporting a NDIS, MS Australia identified the need for further development of the model, particularly the need for cooperation across levels of government:

The model for such a scheme needs to be designed carefully, requiring the Commonwealth and States to work together to achieve a workable scheme. A disability insurance scheme with a capacity to fund rehabilitation and lifetime care is a necessity for Australia's health system from both a financing and service delivery perspective.⁹⁵

- 5.92 A NDIS would represent a significant and fundamental transformation to the way in which support is provided for people with disabilities in Australia. The reality is, however, that addressing deficiencies in the current system of support may require a new and innovative approach. On the basis of evidence to the inquiry and the success of existing no-fault insurance schemes in Australia and internationally⁹⁶, the Committee believes that the principles and practice of implementing a NDIS should be further investigated.
- 5.93 Even the proponents of a NDIS recognise that it would require a detailed financial evaluation to confirm its viability and determine the finer details. Currently, the possibility of a NDIS is being considered by the Disability Investment Group (DIG) established in 2008 by the Parliamentary Secretary for Disabilities and Children's Services. The DIG is due to report to the Parliamentary Secretary later in 2009. The Committee looks forward to the DIG's findings.

Future and Long Term Financial Security

- 5.94 Many carers have raised concerns about their longer-term financial security and ability to plan for the future. The main concerns relate to their own longer-term financial security as carers, and also to the longer term

95 MS Australia, Submission No 692, p 23.

96 In Australia no fault insurance already exists for employees injured at work through workers compensation schemes (e.g. NSW WorkCover) and for people injured in a traffic accident (e.g. Victorian Transport Accident Commission's no fault insurance scheme). Internationally, since 1974 New Zealand has had a nationalised, no fault disability service insurance scheme, which provides on going support services for people acquiring permanent personal injury.

financial security of care receivers, particularly when the carers are no longer able to provide assistance.

- 5.95 A reduced capacity to participate in employment has resulted in many carers having limited opportunity to accumulate savings or contribute to superannuation.⁹⁷ Further, a number of carers have reported needing to use their savings or access superannuation early in order to meet the additional costs of disability and care.⁹⁸ As summarised by MS Australia:

Part of the financial security issue for carers is the poor retirement saving outcomes. Carers' ability to accumulate retirement savings is directly related to their ability to participate in the workforce. In many cases carers leaving employment access their superannuation balances early on compassionate grounds, and use these lump sums to settle debt, pay for equipment and home modification, and once this money is exhausted it does not grow back. Ageing carers need to contribute significant amounts each year to even manage a subsistence level of superannuation, and this is currently out of reach.

A way needs to be found to address this exclusion from the mainstream retirement savings system, and protect carers from the double disadvantage of losing income as well as their retirement savings.⁹⁹

- 5.96 Clearly, the financial situation for carers (and their families) will vary considerably depending on the age at which they left the workforce, the duration of their absence, the level of previous superannuation contributions and whether they can have early access to that superannuation. However, there is little doubt that carers and their families are disadvantaged. In a 2008 report from National Centre for Social and Economic Modelling on *Women Carers in Financial Stress* found that the capacity for women who were also primary carers to accumulate

97 See for example: Mr N Kennedy, Submission No 183, p 1; Ms M Major, Submission No 1163, p 1; Mr S Dodd & Ms H Dodd, Submission No 1196, p 1; Ms J Rollo, Submission No 1246, p 1; Mr M Forty, Transcript of Evidence, 12 August 2008, p 42; Mr T Stroud, Transcript of Evidence, 12 August 2008, p 50; Ms K Logan, Transcript of Evidence, 9 October 2008, p 20.

98 See for example: Ms L McIver, Submission No 191, pp 1-2; Ms G Vines, Submission No 833, p 2; Ms J O'Connor, Submission No 1003, p 2; Ms J English, Transcript of Evidence, 12 August 2008, p 62; Ms K Pritchard, Transcript of Evidence, 28 November 2008, p 5.

99 MS Australia, Submission No 692, p 3.

superannuation is likely to be severely compromised and unlikely to provide sufficient income to support them in retirement.¹⁰⁰

- 5.97 To address the shortfall in retirement savings and superannuation, carers and organisations alike have urged the Australian Government to consider ways of assisting carers to build their superannuation savings.¹⁰¹ The Committee has received various suggestions for the form that this assistance might take. Some have recommended that carers who are not in the workforce should still be eligible for the Government superannuation co-contribution.¹⁰² Carers Australia and others have recommended the establishment of a national carers superannuation scheme for recipients of the Carer Payment and for sole parent carers on other income support with a Government contribution of 9% of the Federal minimum wage.¹⁰³

Improving the Long-Term Financial Security of Carers

- 5.98 The Committee understands that the limited opportunities many carers have to accumulate savings or superannuation causes stress to many carers and their families. Those without any superannuation at all or with inadequate superannuation are likely to be left behind financially and rely on the Age Pension as a last resort. One option for improving the long-term financial security for carers is to make it easier for carers to participate in the workforce. More detailed consideration of measures that might help are discussed in chapter 7.
- 5.99 Carers and carer organisations that have urged for a national carers' superannuation scheme have been, understandably, short on the detail on how such a scheme could work, given the complexity of the current superannuation regime. However, the retirement income system is

100 NATASEM (2008), *Commonwealth Financial Planning: Women Carers in Financial Stress*, pp 21, 26-27.

101 See for example: Mr W de Goede, Submission No 366, p1; Ms D Hayes, Submission No 952, p 21; Mr D Galbraith, Submission No 967, p 1; Ms A Pfaller, Submission No 976, p 2; Perth Carer Forum Group, Submission No 983, p 4; Mr R Shaw, Submission No 1172, p 1; Ms H Johnson, Submission No 1178, p 8; Ms V Evan, Submission No 1201, p 1; Ms G Pierce, Transcript of Evidence, 12 August 2008; pp 36-37.

102 See for example: Mr J Halford, Submission No 250, p 6; Special Kidz Special Needs, Submission No 567, p 17; Ms C Phillips, Submission No 755, p 2; Disability Services Commission, Submission No 1039, p 6; Ms J Cooper, Submission No 1194, p 3; Ms W L Cheung, Transcript of Evidence, 12 August 2008, p 41.

103 See for example: Association for Children with a Disability, Submission No 750, pp 4-5; Sutherland Shire Disability Accommodation Action Group, Submission No 846, p 4; Australian Association of Gerontology, Submission No 915, p 2; Ms J Hughes, Transcript of Evidence, 28 November 2008, p 11.

currently under review as part of the Government's major review of Australia's Future Tax System. A consultation paper released in December 2008 sought community input and included the following consultation question:

As the SG [superannuation guarantee] system matures, it will become a greater part of an employee's retirement income. What are the implications for individuals partially or fully excluded from the mature SG system (the self-employed, individuals with broken work patterns such as carers, women and migrants), and how can the retirement income system best accommodate these groups?¹⁰⁴

- 5.100 Public contributions relating to the retirement income system closed in February 2009 and the outcomes of the consultation are due to be reported to the Government by the end of March 2009. The Committee is keen to support any initiatives to assist carers to improve their long-term financial security and looks forward to the findings of the report on the future tax system being released.

Improving the Long-Term Financial Security of Care Receivers

- 5.101 Throughout the Inquiry, the Committee has frequently been reminded that it is not possible to adequately address the needs of carers without also considering the needs of those for whom they care. In addition to the concerns of carers about their own financial security, many reported that the financial security of the care receiver was also a major concern. In particular, many carers worry about the future of their care receiver should the carer's health fail or should the carer die.¹⁰⁵
- 5.102 One way in which the Australian Government has sought to address this need was through the introduction of Special Disability Trusts (SDTs) in 2006. The purpose of SDTs is to encourage immediate family members and carers who have the financial means to do so, to make private financial provision for the current and future care and accommodation needs of a family member with severe disability. To achieve this SDT

104 Australian Government, The Treasury, *Australia's Future Tax System – Retirement Income Consultation Paper*, (2008).

105 See for example: Ms K McDonnal, Submission No 518, pp 2, 4; Ms I Stockfeld, Submission No 554, pp 1, 4; Ms Y Graham, Submission No 716, p 2; Ms S Goodman, Submission No 879, p 2; Ms J Rodighiero, Submission No 934, p 1; Ms M Wells, Submission No 1034, p 8; Ms G Hunter, Submission No 1090, p 1; Name withheld, Submission No 1175, p 2; Ms N Cummings, Submission No 1181, p 3.

legislation creates exceptions to the ordinary means test rules applying to Trusts for a person with severe disability. These means test exemptions apply where family members and people with severe disability rely (or may rely in the near future) on social security or veterans' affairs entitlements.¹⁰⁶

- 5.103 The Committee received limited comments about SDTs, although those which were received were critical of the restricted eligibility requirements, the taxation regime and the limited uses allowed for the trust.¹⁰⁷ As explained in the submission for Special Kidz Special Needs, a charity established to assist families caring for children with special needs:

It seems that these trusts have been set up with the intention of assisting future planning for the disabled, however somewhere along the way there was such a fear that these trusts would be exploited that they were created with so much reporting, and the addition of capital gains on property that they are under-utilised and have not achieved what they set out to.¹⁰⁸

- 5.104 The Committee also heard from Ms Stephanie Maxwell, who provides care for her husband and for her daughter, about the restrictions associated with SDTs:

The previous government made a big hoo-ha about how wonderful special disability trusts were going to be for carers to succession plan and make sure that the person was looked after in their absence. ... I have a huge life insurance policy on myself so as to provide for him and my daughter to be looked after if something happened to me. But he is not eligible for that money to go into a special disability trust because he is able to work at the minimum wage. That does not take into account that his cost of care is so far beyond even a decent salary in Australia today. If a person with a disability can work at or above the minimum wage then they are ineligible to have a special disability trust. It would be lovely if the government could work at making it possible for there to be recognition that a person's cost of care might far exceed

106 Australian Government, Department of Families, Housing, Community Services and Indigenous Affairs website, viewed 2 March 2009 at www.fahcsia.gov.au/internet/facsinternet.nsf/disabilities/carers-special_disability_trusts.htm.

107 See for example: Ms M Walsh, Submission No 752, p 5; Ms N Brown, Submission No 951, p 14; Ms T Keith, Submission No 960, p 1; Ms F Anderson, Submission No 979, p 12; Ms S Maxwell, Transcript of Evidence, 26 September 2008, p 28.

108 Special Kidz Special Needs, Submission No 567, pp 8, 17.

their earning capacity, and therefore it would be beneficial for them to have a special disability trust to be able to meet their care needs.¹⁰⁹

- 5.105 In response to a lower than expected take-up, SDTs became the subject of an inquiry by the Senate Standing Committee on Community Affairs in 2008. The Senate Committee's report, *Building Trust: Supporting Families through Disability Trusts* contains 14 recommendations intended to increase awareness of SDTs, and improve the operation of the SDTs by reducing the complexity and costs associated with establishing and maintaining a Trust.¹¹⁰ On the basis of these recommendations the Committee anticipates that reforms to the structure and operation of the SDTs will make Trusts a more attractive option for some carers for improving the longer term security of people with a disability.

109 Ms S Maxwell, Transcript of Evidence, 26 September 2008, p 28.

110 Parliament of Australia, Department of the Senate, *Building Trust: Supporting Families through Disability Trusts*, viewed 22 February 2008 at www.aph.gov.au/Senate/committee/clac_ctte/disability_trusts/report/c01.htm.