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Who Cares ...?

Report on the inquiry into better support for carers

House of Representatives
Standing Committee on Family, Community, Housing and Youth

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Foreword

Carers – usually spouses, parents, grandparents, children, siblings and sometimes friends or neighbours – have asked to be heard – to have a voice of their own. So when the Committee embarked on this Inquiry into better support for carers, it clearly indicated that its objective was to learn more about the needs of carers from the experts – that is from carers themselves. And carers responded. Through written submissions to the Inquiry, and through participation in public hearings, more than 1300 carers shared their very personal and often distressing experiences with the Committee.

Many carers have observed that it is not possible for anyone to understand what caring entails unless they are, or have been, a carer – that reality is not disputed. However, thanks to the generosity and candour of so many carers, the Committee has been able to gain a degree of insight. The Inquiry's body of evidence clearly illustrates the profound physical, emotional and financial effects that providing care has on carers and on their families.

Becoming a carer is not a choice. Some people find that they are thrust into the role without warning after the birth of a child with an illness or disability, or following a traumatic event or accident involving a loved one. For others, becoming a carer is a more gradual process, though ultimately equally devastating. When does a husband, or a wife, recognise that they have also become a carer for their partner with dementia for example? While every caring situation is unique, the love, grief, guilt, fear, anger and frustration, coupled with sheer physical and mental exhaustion are all part and parcel of carers' lived experiences.

Despite the uniqueness of each caring situation described in evidence to the Inquiry, several consistent themes have emerged. The Committee has heard loud and clear from carers that they want choices – choices for themselves, for the people they care for and for their families. The Committee has also been reminded repeatedly that the needs of carers and those they care for are inextricably bound. While the carers are the focus of this Inquiry, the Committee has sought to achieve

a balance in the report that reflects the interrelationship of the needs of carers and care receivers without transgressing the Inquiry's terms of reference.

Over the years, the shift from institutional care to care in the community has greatly increased reliance on informal care provided by family and friends. In the absence of adequate support, carers are already in crisis. Emerging demographic and social trends are predicted to result in larger numbers of people requiring care and smaller numbers of people able and willing to provide it. Existing pressures on systems of support for carers which have been building over decades are therefore projected to increase. This means that action needs to be taken urgently.

With this in mind, the Committee has given consideration to diverse options for reform to address deficiencies in the current systems of support for carers. In some areas, such as respite care and in-home assistance, the Committee has recommended an increase in expenditure so that supply of services more closely matches demand.

Consideration has also been given to options for the more efficient use of existing resources. To this end, some recommendations have called for a reduction in the red tape associated with accessing some forms of carer support, and for greater cooperation across jurisdictional and portfolio divides to encourage the development of more coherent and coordinated systems.

The Committee has also considered the case for significant fundamental reform. Of particular note, is the recommendation for an examination of income support for carers to determine whether the system of carer payments can be restructured to better reflect the level of care provided. In addition, the Committee has also recommended consideration of increasing access to individualised or self-managed funding packages to provide carers with greater choice and flexibility to purchase the services they need.

Importantly, the Committee understands that with adequate levels of appropriate support in place, most carers wish to continue to provide care for as long as they feel able to do so. It is therefore in the best interests of all concerned – carers, care receivers, governments and society – to share the responsibility of providing care more evenly. If realised, this will allow carers and their families to participate more fully in society through engagement with education, employment and social activities.

In concluding, I would like to extend my sincere thanks to all those carers who have contributed to this Inquiry. It is your experiences, described in your own words that have provided the foundation for this report and its recommendations. I also thank the Deputy Chair, the Hon Judi Moylan MP, and the other Members of the Committee for their participation and commitment to the Inquiry.

As Chair of the Committee it is my view that many of the report's recommendations are a starting point only, providing a baseline for more fundamental and significant reforms to systems of support for carers. In considering the report, I urge the Australian Government and others to look beyond the specifics of the recommendations and to also consider their context and intent - that is to significantly improve the lives of carers and those they care for. Importantly, implementation of reform will be key to effecting meaningful change. It is my sincere hope that this report and its recommendations will act as a stimulus for action.

Ms Annette Ellis MP
Chair



Membership of the Committee

Chair	Ms Annette Ellis MP	
Deputy Chair	The Hon Judi Moylan MP	
Members	The Hon Tony Abbott MP	Mrs Louise Markus MP <i>(until 25/9/08)</i>
	Ms Jodie Campbell MP	Mrs Sophie Mirabella MP <i>(from 10/11/08)</i>
	Ms Julie Collins MP	Mr Scott Morrison MP <i>(from 25/9/08)</i>
	The Hon Sussan Ley MP <i>(until 10/11/08)</i>	Mr Brett Raguse MP
	Ms Kirsten Livermore MP	Mr Chris Trevor MP

Committee Secretariat

Secretary	Mr James Catchpole
Inquiry Secretary	Dr Alison Clegg
Research Officers	Ms Siobhan Carrigan <i>(from 8/9/08)</i>
	Ms Leila Jordan <i>(until 27/8/08)</i>
	Ms Belynda Zolotto
Administrative Officers	Ms Gaye Milner <i>(until 13/2/09)</i>
	Ms Tarran Snape



Terms of reference

Carers play a vital role in sustaining Australia's current system of community-based person-centred care. However, they are often at increased risk of becoming socially isolated from their peers and disconnected from mainstream employment. Many carers also have significantly worse health outcomes than the general population (both in terms of physical health and psychological wellbeing) and endure problematic access to services and support. Carers also often face increased financial pressures, having limited opportunities to accrue savings, accumulate superannuation and save for retirement.

To obtain an improved understanding of the challenges facing carers and their support needs, the committee will inquire into and report on:

- the role and contribution of carers in society and how this should be recognised;
- the barriers to social and economic participation for carers, with a particular focus on helping carers to find and/or retain employment;
- the practical measures required to better support carers, including key priorities for action; and
- strategies to assist carers to access the same range of opportunities and choices as the wider community, including strategies to increase the capacity for carers to make choices within their caring roles, transition into and out of caring, and effectively plan for the future.

In examining each of these issues, the committee will also inquire into the specific needs of particular groups within the caring population including new carers, younger carers, older carers, Indigenous carers and those with multiple care responsibilities.

For the purpose of this inquiry carers are defined as 'individuals providing unpaid support for others with ongoing needs due to a long-term medical condition, a mental illness, a disability or frailty'.



List of abbreviations

ABS	Australian Bureau of Statistics
ACAT	Aged Care Assessment Team
ACT	Australian Capital Territory
ACTU	Australian Council of Trade Unions
AIHW	Australian Institute of Health and Welfare
ATAPS	Access to Allied Psychological Services
CACP	Community Aged Care Package
CALD	culturally and linguistically diverse
CAP	Carer Adjustment Payment
CENA	Carer Eligibility and Needs Assessment
COAG	Council of Australian Governments
CSTDA	Commonwealth State Territory Disability Agreement
CYCLOPS	Connecting Young Carers to Life Opportunities and Personalised Supports
DEEWR	Department of Education, Employment and Workplace Relations
DIG	Disability Investment Group
DoHA	Department of Health and Ageing

DSP	Disability Support Pension
DVA	Department of Veterans' Affairs
EACH	Extended Aged Care at Home package
EACHD	Extended Aged Care at Home Dementia package
FaHCSIA	Department of Families, Housing, Community Services and Indigenous Affairs
GP	general practitioner
HACC	Home and Community Care program
HCDSMC	Health, Community and Disability Services Ministerial Council
HREOC	Human Rights and Equal Opportunities Commission
NATSEM	National Centre for Social and Economic Modelling
NDA	National Disability Agreement
NDIS	National Disability Insurance Scheme
NDS	National Disability Strategy
NES	National Employment Standards
NNAAMI	National Network of Adolescent and Adult Children who have a Mentally Ill Parent
MND	Motor Neurone Disease
NRCP	National Respite for Carers Program
NSW	New South Wales
PBS	Pharmaceutical Benefits Scheme
PCA	Palliative Care Australia
PM&C	Department of Prime Minister and Cabinet
SA	South Australia
SDAC	Survey of Disability, Ageing and Carers

SDT	Special Disability Trusts
SPP	Specific Purpose Payments
TOCC	Taskforce on Care Costs
WA	Western Australia



List of recommendations

Recommendation 1

That the Treasurer direct the Australian Bureau of Statistics, either through an extension to its Survey of Disability, Ageing and Carers or through the development of an alternative carer specific survey, to expand the information it collects on carers to include information on:

- secondary carers;
- carers providing episodic care;
- carers providing palliative care; and
- carers aged 15 years and under.

The Australian Bureau of Statistics should also consider increasing the frequency of the Survey of Disability, Ageing and Carers to three yearly intervals.

Recommendation 2

That the Australian Government, through the Department of Families, Housing, Community Services and Indigenous Affairs and the Department of Health and Ageing support a national community education campaign to promote a better understanding of the role and needs of carers, and an appreciation of the contribution that carers make to society.

The campaign should also include components to promote increased awareness of their role among 'hidden' carers who may not readily self-identify and to address the concerns of carers who may be reluctant to disclose their role to others.

Recommendation 3

That the Minister for Families, Housing, Community Services and Indigenous Affairs and the Minister for Health and Ageing propose to the Health,

Community and Disability Services Ministerial Council (HCDSMC) that the Australian Government and each jurisdiction review existing legislation and policy relating to health and community care to ensure that carers are adequately recognised.

If legislation affecting carers falls beyond the jurisdiction of HCDSMC then it should be referred to the appropriate ministerial council for review.

Recommendation 4

That the Minister for Families, Housing, Community Services and Indigenous Affairs seek the Health, Community and Disability Services Ministerial Council to develop a nationally consistent carer recognition framework, comprising:

- national carer recognition legislation, which complements state and territory carer legislation; and
- a national carer strategy which builds on and complements state and territory carer policies.

Recommendation 5

That the Department of Prime Minister and Cabinet establish a national office for carers, either within the Office of Work and Family or as a new office within the Department.

That the Australian Government nominate a lead Minister to be responsible for overseeing the development of nationally coordinated carer legislation, policy, programs and services so that these are effectively linked across all levels of government and portfolios.

Recommendation 6

That the Australian Government consider consolidating portfolio responsibility for people with disabilities, people with mental illness, the frail aged and their carers into a single Australian Government department.

Recommendation 7

That the Minister for Families, Housing, Community Services and Indigenous Affairs and the Minister for Health and Ageing, seek agreement through the Health, Community and Disability Services Ministerial Council to extend the Access Points Demonstration Projects to include disability services and community mental health services.

Recommendation 8

That the Australian Government make locally based peer support carer groups a priority within existing community grants programs available across portfolios.

Recommendation 9

That the Minister for the Department of Families, Housing, Community Services and Indigenous Affairs fund the expansion of the MyTime Peer Support Program to:

- include parents of school aged children with disability; and
- increase geographical coverage.

Recommendation 10

That the Minister for Families, Housing, Community Services and Indigenous Affairs and the Minister for Health and Ageing request that the Health, Community and Disability Services Ministerial Council develop a national strategy to address the training and skills development needs of carers.

Recommendation 11

That the Minister for Families, Housing, Community Services and Indigenous Affairs and Minister for Department of Health and Ageing direct their Departments to review the adequacy of case management or care coordination for carers and care receivers using community care, aged care, disability and community mental health services.

Recommendation 12

That the Minister for Families, Housing, Community Services and Indigenous Affairs extend the National Disability Advocacy Program to:

- provide family advocacy services which better recognise the role of carers providing individual advocacy on behalf of, and with, care receivers; and
- provide formal advocacy for carers in their own right when this is required.

Recommendation 13

That the Minister for Health and Ageing review arrangements for systemic carer advocacy provided through Carers Australia and the network of state and territory Carer Associations.

The review should examine the extent to which arrangements for systemic advocacy represent the diversity of carer groups and consider whether these arrangements might need to be extended or reformed.

Recommendation 14

That the Attorney-General, in conjunction with the Minister for Families, Housing, Community Services and Indigenous Affairs and the Minister for Health and Ageing, investigate whether the National Privacy Principles and the Information Privacy Principles, and equivalent provisions in state and territory privacy and mental health legislation, adequately allow carers to be involved in the treatment of the individuals for whom they care.

The Minister for Families, Housing, Community Services and Indigenous Affairs and the Minister for Health and Ageing promote to health and community care providers the importance of involving carers in the treatment and services for those receiving health and community care services.

Recommendation 15

That the Attorney-General promote national consistency and mutual recognition governing enduring powers of attorney and advanced care directives to the Standing Committee of Attorneys-General.

Recommendation 16

That the Minister for Families, Housing, Community Services and Indigenous Affairs and the Minister for Health and Ageing and the Attorney-General fund a national information campaign to raise awareness about the need for, and benefits of, enduring powers of attorney and advanced care directives in the general community and among health and community care professionals.

Recommendation 17

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.

Recommendation 18

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

Recommendation 19

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.

Recommendation 20

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.

Recommendation 21

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.

Recommendation 22

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.

Recommendation 23

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.

Recommendation 24

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.

Recommendation 25

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.

Recommendation 26

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.

Recommendation 27

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.

Recommendation 28

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.

Recommendation 29

That the Minister for Families, Housing, Community Services and Indigenous Affairs and the Minister for Health and Ageing seek agreement through the Health, Community and Disability Services Ministerial Council to expand the nationally consistent assessment process based on the Carer Eligibility and Needs Assessment-Revised questionnaire.

This will need to ensure the inclusion of carers accessing services offered through the Department of Families, Housing, Community Services and Indigenous Affairs and the state and territory governments.

Recommendation 30

That the Minister for Families, Housing, Community Services and Indigenous Affairs and the Minister for Health and Ageing address the shortages of health and community care services for people living in regional and remote locations.

Recommendation 31

That the Minister for Families, Housing, Community Services and Indigenous Affairs fund research into the profiles and specific needs of Indigenous carers.

Recommendation 32

That the Minister for Families, Housing, Community Services and Indigenous Affairs and the Minister for Health and Ageing examine the adequacy of culturally appropriate community care services funded by the Australian Government for Indigenous carers, particularly for those living in remote areas, with the intention of increasing the accessibility and availability of those services.

Recommendation 33

Recognising the ageing demographic of the carer population and the increased longevity of many care receivers, that the Minister for Families, Housing, Community Services and Indigenous Affairs and the Minister for Health and Ageing increase capital and recurrent funding for respite care services funded by the Australian Government as a matter of urgency to more closely match demand across the country.

Particular attention should be paid to improving the:

- availability and accessibility;
- affordability;
- responsiveness to the needs of both carer and care receiver of respite services; and
- responsiveness to the needs of carers and care receivers in living regional, rural and remote areas.

Recommendation 34

That the Minister for Health and Ageing and the Minister for Families, Housing, Community Services and Indigenous Affairs increase funding for in-home assistance for carers in order to more closely meet demand.

Recommendation 35

That the Minister for Families, Housing, Community Services and Indigenous Affairs and the Minister for Health and Ageing undertake pilot studies to test the potential for the Australian Government's funding for carer respite and in-home assistance to be re-allocated directly to carers through 'individualised funding programs' (also known as 'consumer directed care' and 'self managed funding').

Recommendation 36

That the Minister for Families, Housing, Community Services and Indigenous Affairs and the Minister for Health and Ageing seek agreement through the Health, Community and Disability Services Ministerial Council to collect nationally consistent data to more accurately determine the number of carers, their profile and the level of unmet need for community based carer support services.

Recommendation 37

That the Minister for Education, Employment and Workplace Relations examine options to build capacity in the community care workforce, particularly initiatives to encourage retention of trained workers in the sector.

Recommendation 38

That the Minister for Families, Housing, Community Services and Indigenous Affairs through the Health, Community and Disability Services Ministerial Council, encourage states and territories to provide additional funding for disability support workers in long day care, out of hours care and school holiday care to improve access for employed carers.

Recommendation 39

That the Minister for Health and Ageing and the Minister for Families, Housing, Community Services and Indigenous Affairs expand any continuation of the Employed Carers Respite Initiative to provide extended respite and support for all working carers, including those who provide care to people with disabilities or mental illness who are under the age of 65 years.

Recommendation 40

That section 65(1) of the *Fair Work Act 2009* be amended to extend the right to request flexible working arrangements to all employees who have recognised care responsibilities, including to those who are caring for adults with disabilities, mental illness, chronic illness or who are frail aged.

Recommendation 41

That the Minister for Education, Employment and Workplace Relations ensure that employment service providers:

- consider the specific needs of carers seeking suitable employment; and
- encourage and support employers to provide employment opportunities for carers.

Recommendation 42

That the Minister for Education, Employment and Workplace Relations ensure that employment service providers consider the skills development and training needs of carers, particularly long-term carers, when developing plans to assist those wishing to enter or re-enter the workforce after a period of absence.

Recommendation 43

That the Minister for Families, Housing, Community Services and Indigenous Affairs direct the Department of Families, Housing, Community Services and Indigenous Affairs to increase the number of hours of work, volunteering or study that those receiving Carer Payment can undertake.

Recommendation 44

That the Minister for Education, Employment and Workplace Relations direct the Department of Education, Employment and Workplace Relations, in association with state and territory education departments, to develop flexible policies to make it easier for students to combine education with caring.

Recommendation 45

That the Minister for Families, Housing, Community Services and Indigenous Affairs direct the Department of Families, Housing, Community Services and Indigenous Affairs to extend the eligibility criteria for its Respite for Young Carers at Risk Program to include assistance for more than one young carer in a family unit where the care responsibilities are shared.

Recommendation 46

That the Minister for Health and Ageing direct the Department of Health and Ageing to provide a preventative health care program targeted at carers. This could be achieved by extending the Enhanced Primary Care Program to include carers who receive Carers Payment and/or Carer Allowance as an at risk population group requiring intervention under this program.

Recommendation 47

That the Minister for Families, Housing, Community Services and Indigenous Affairs direct the Department of Families, Housing, Community Services and Indigenous Affairs to review the temporary cessation of care requirements for Carer Payment and Carer Allowance recipients, particularly in relation to:

- the adequacy of the 63 days of respite per year particularly in comparison to minimum conditions of paid employment; and

- the requirement of carers to use all or part of the allowable period of time to cover periods of time, when as a result of illness, they are unable to provide care.

Recommendation 48

That the Minister for Health and Ageing expand the National Carers Counselling Program to better meet the demand for counselling services by carers.

Recommendation 49

That the Minister for Health and Ageing direct the Department of Health and Ageing to raise awareness among General Practitioners of the high incidence of mental health problems among carers and their families and of the options available for support.

Recommendation 50

That the Minister for Social Inclusion nominate carers as an early priority for social inclusion on the social inclusion agenda and with the Australian Social Inclusion Board.

Conduct and Context of the Inquiry

- 1.1 Australia's 2.5 million carers make a significant contribution to society, often at considerable personal cost to themselves. Despite the positive aspects of providing care for a loved one in need, carers also frequently sacrifice their finances, careers, social networks and even their own health. Increasingly however, in the absence of adequate supports and assistance, carers are questioning the lack of life choices available to them and their capacity to sustain the caring role. Many carers have made it known that they are already in crisis. It is recognition of the current plight of carers, and predictions that in the near future the number of people requiring care will exceed the number of people able and willing to provide care, that have provided the impetus for the current inquiry.
- 1.2 The Inquiry into Better Support for Carers was referred to the House of Representatives Standing Committee on Family, Community, Housing and Youth on 14 May 2008. An advertisement calling for written submissions was placed in *The Australian* on 28 May 2008. Information on the Inquiry, including its terms of reference and on how to make a submission was available on the Parliament of Australia website. The Inquiry was also advertised through an extensive mail out to interested parties, including peak bodies and organisations, and state and territory governments.
- 1.3 At the outset of the Inquiry, the Committee Chair, Ms Annette Ellis MP (Member for Canberra), indicated that the Committee was particularly keen to hear first hand from carers themselves. Of the over 1300 written submissions to the Inquiry, some 1200 were from individuals, the vast majority of whom identified themselves as current or former carers. A list of submissions is provided at Appendix A. In addition, 24 documents were received as exhibits. These are listed at Appendix B.

- 1.4 The Committee held fourteen public hearings between July and December 2008, taking evidence from around 250 witnesses. More than half of the witnesses appearing at the public hearings were carers. Other witnesses were representatives of government departments and agencies, peak organisations, service providers and academics. A feature of many of the public hearings was the carers' roundtable sessions. These sessions provided the opportunity for individual carers to describe their own experiences to the Committee and to present their views on ways in which the needs of carers could be better met. Details of the public hearings for the Inquiry are listed at Appendix C. Information on income support payments and supplementary payments as at 1 July 2008, including information on eligibility criteria, income and assets test thresholds is at Appendices D to F.

Context of the Inquiry

- 1.5 The Inquiry into Better Support for Carers has garnered its own sizeable and credible body of evidence. It is important to emphasise that it is the Inquiry's own evidence which has informed the Committee's deliberations during the Inquiry process and which has assisted the Committee to reach its conclusions.
- 1.6 However, it is also important to acknowledge that the Inquiry was conducted in a highly dynamic policy environment. Since the November 2007 election, the Australian Government¹ has implemented several new initiatives and programs that have impacted either directly or indirectly on carers.² The Australian Government has also initiated a number of major reviews of government policy, some of which may have important implications for carers.³
- 1.7 In this dynamic environment, it is imperative that the implications of these parallel processes on the outcomes of the current Inquiry are acknowledged. In addition, a number of the issues that have emerged in evidence to this Inquiry have also been considered previously as part of other recent parliamentary inquiries or policy review processes. Where

1 In this report the term Australian Government is used whenever possible in preference to Commonwealth Government or Federal Government.

2 See for example: From March 2008, access to Utilities Allowance, a payment to assist with regular household bills, was extended to recipients of the Carer Payment.

3 See for example: The 2008-09 inquiry into Australia Future Tax System (the Henry Review), which encompasses the Pension Review (the Harmer Review).

this is the case, this report may make reference to the outcomes of these other inquiries and reviews.

- 1.8 Other background material for the report, including statistics and data on carers has been drawn from a range of sources, including government department/agency reports and research from government and non-government sources. These sources of information are identified in the text or referenced in footnotes.
- 1.9 While not intended to be an exhaustive or comprehensive list of all relevant initiatives, the following section of this chapter provides a brief overview of some of the current and significant policy reviews that have implications for carers.

Current Australian Government Policy Reviews

- 1.10 In providing an overview of Australian Government policy reviews that are relevant to the current Inquiry, consideration has been given to the interrelationship between the needs of carers and care receivers. In many cases, carers have commented that measures intended to meet the support needs of the care receiver, often also improve the capacity of the carers themselves to provide care.⁴ Therefore, while carers are the focus of the Inquiry, the overview below includes information on some policy initiatives which are principally intended to address the needs of care receivers, but are also likely to have significant consequences for carers.

Inquiry into Australia's Future Tax System

- 1.11 On 13 May 2008, a major review of Australia's future tax system was announced by the Treasurer, the Hon Wayne Swan MP. According to the review's terms of reference:

The comprehensive review of Australia's tax system will examine and make recommendations to create a tax structure that will position Australia to deal with the demographic, social, economic and environmental challenges of the 21st century and enhance Australia's economic and social outcomes.⁵

4 See for example: Name withheld, Submission No 19, p 2; Ms J Bissett, Submission No 54, p 2; Ms A Hewat, Submission No 866, p 4; Ms L Thomas, Transcript of Evidence, 12 August 2008, p 48; Ms B Epstein-Fisch, Transcript of Evidence, 12 August 2008, p 88.

5 Australian Government, The Treasury website, viewed 20 March 2009 at www.treasury.gov.au/contentitem.asp?NavId=037&ContentID=1376.

- 1.12 The review is being conducted under the auspice of a review panel chaired by the Secretary to the Treasury, Dr Ken Henry AC. The review, which involves community consultation, is being conducted in several stages over 2008 and 2009. The review panel will provide a final report to the Treasurer by the end of 2009.⁶

Pension Review

- 1.13 On 15 May 2008, and as part of the broader review of Australia's taxation system, the Minister for Families, Housing, Community Services and Indigenous Affairs, the Hon Jenny Macklin MP, also announced a review of the pension system.⁷

- 1.14 The Pension Review, chaired by Dr Jeff Harmer, Secretary for the Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) will:

... investigate measures to strengthen the financial security of seniors, carers, and people with disability.⁸

- 1.15 In August 2008, a Pension Review Background Paper was released to support the public consultation process.⁹ The paper provides information on the income support system and considers issues associated with the Pension Review's three key terms of reference:

- the appropriate levels of income support and allowances;
- the frequency of payments; and
- the structure and payment of concessions or other entitlements.

- 1.16 The review which involves significant community consultation is being overseen by a reference group. The Secretary for FaHCSIA reported to the Treasurer and the Minister for Families, Housing, Community Services and Indigenous Affairs, through the Chair of the Australia's Future Tax System Review Panel in late February 2009. At the time of writing, the

6 Australian Government, The Treasury website, viewed 20 March 2009 at www.taxreview.treasury.gov.au/content/Content.aspx?doc=html/timeline.htm.

7 Australian Government, Department of Families, Housing, Community Services and Indigenous Affairs website, viewed 20 March 2009 at www.fahcsia.gov.au/internet/facsinternet.nsf/seniors/pension_review.htm.

8 Australian Government, Department of Families, Housing, Community Services and Indigenous Affairs website, viewed 20 March 2009 at www.fahcsia.gov.au/internet/facsinternet.nsf/seniors/pension_review.htm#3.

9 Australian Government, Department of Families, Housing, Community Services and Indigenous Affairs website, viewed 20 March 2009 at www.facs.gov.au/internet/facsinternet.nsf/seniors/pension_review.htm.

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, Disability Support Pension (DSP) and other allowances and concessions accessed by carers and care receivers. These reforms will be announced as part of the May 2009-10 Budget.

Council of Australian Governments (COAG) Reform Agenda

- 1.17 The Council of Australian Governments (COAG) is the peak intergovernmental forum in Australia. The role of COAG is to initiate, develop and monitor the implementation of policy reforms that are of national significance and which require cooperative action by Australian governments. In the 2008-09 Budget, the Australian Government through COAG, committed to implementing a more effective and efficient model of 'modern federalism' through a reform agenda.¹⁰
- 1.18 One of the items to be progressed under the agenda, is reform to the roles and responsibilities between the Australian Government and states and territory governments for:
- community and residential care services for aged people;
 - community and residential care for people with disabilities; and
 - community care and support services for people with mental illness.¹¹
- 1.19 The stated objective of this reform is to:
- ... help build seamless service systems to meet better the needs of the aged, people with disability, people with mental illness and their carers on a national basis.¹²
- 1.20 According to the COAG Communiqué of 2 October 2008:
- The development of a reform package will be underpinned by the following principles:
- **continuity of care for clients, which is responsive to changing needs:** delivered by seamless and responsive services tailored to changing care needs;

10 The Hon Wayne Swan MP & The Hon Lindsay Tanner MP, Budget: Australia's Federal Relations *Budget Paper No. 3 2008-09*, pp 11-27.

11 Council of Australian Governments website, COAG Communiqué 2 October 2008, p 3, viewed 8 December 2008 at www.coag.gov.au/coag_meeting_outcomes/2008-10-02/index.cfm#aged.

12 Council of Australian Governments website, COAG Communiqué 2 October 2008, p 3, viewed 8 December 2008 at www.coag.gov.au/coag_meeting_outcomes/2008-10-02/index.cfm#aged.

- **simple access to services:** delivered by streamlined assessment and eligibility criteria;
- **seamless transition of care for clients:** delivered by an assurance of client choice to receive ongoing 'care in place', and smooth interfaces between care systems;
- **simplified accountability of governments to the community:** delivered by clearer responsibility of levels of government for policy and service provision to a particular client group;
- **reform of roles and responsibilities should be budget-neutral for both levels of government:** delivered by the transfer of current funding to mirror the transfer of responsibilities for service provision; and
- **creation of a national aged care system and national disability service system for community and residential care:** delivered by strengthened policy responsibility for delivery of the spectrum of community and residential care services for a particular client group.¹³

1.21 A Roles and Responsibilities Working Group has been established to progress the program of reforms and COAG has requested that specific proposals in relation to reforms to community mental health, disability services and aged care are brought to it for consideration in the first half of 2009.

National Disability Agreement

- 1.22 The COAG reform agenda has also included fundamental reform to Commonwealth-state funding arrangements. Reform has included rationalisation of Specific Purpose Payments (SPP) from over 90 to five or six SPPs, including one to cover the disability area supported by the National Disability Agreement (NDA).
- 1.23 The NDA, which on 1 January 2009 replaced the third Commonwealth State Territory Disability Agreement (CSTDA), provides an agreed framework between the Australian Government and state and territory governments for funding and administration of specialist disability support services.
- 1.24 In brief, under the NDA funding contributions for disability services are provided by the Australian Government and by state and territory governments. The states and territories have primary responsibility for the
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13 Council of Australian Governments website, COAG Communiqué 2 October 2008, pp 3-4, viewed 8 December 2008 at www.coag.gov.au/coag_meeting_outcomes/2008-10-02/index.cfm#aged.

administration of specialist disability support services, with the exception of employment services for people with a disability, which is the responsibility of the Australian Government.¹⁴

1.25 Under the NDA, over the next five years, the Australian Government will provide \$5.3 billion to the states and territories, including funding to assist state and territory government's delivery of specialist disability services. Of this, \$408 million will go to assist with the National Disability Reform Agenda. Some of the key reforms under consideration include:

- improved access to disability care including consideration of systems that provide a single point of access;
- nationally-consistent assessment processes and a quality assurance system;
- a renewed focus on early intervention and planning to ensure that clients receive the most appropriate and timely support;
- service providers will be better able to develop train and employ care workers;
- more consistent access to disability aids and equipment;
- a commitment by all levels of government to work together to better measure the level of unmet demand for disability services; and
- continued work on reform of roles and responsibilities in relation to community mental health, disability services and aged care.¹⁵

National Disability Strategy

1.26 The development of a National Disability Strategy (NDS) was a 2007 election commitment by the Australian Government. The NDS is intended to provide a framework to address the complex needs of people with disabilities, their carers and families. The NDS will be developed by FaHCSIA in consultation with state and territory governments, and with disability and carer stakeholders.

1.27 In October 2008, FaHCSIA released a NDS discussion paper to support the consultation process. According to the discussion paper the NDS:

... aims to provide an enduring framework of targeted actions that addresses barriers and promotes a more inclusive and universally accessible society for the benefit of the entire community.

14 Council of Australian Governments, National Disability Agreement, pp 3-9.

15 Council of Australian Governments website, viewed 29 January 2009 at www.coag.gov.au/coag_meeting_outcomes/2008-11-29/docs/20081129_national_disability_agreement_factsheet.pdf.

The Strategy will set out a high level vision that will be underpinned by clear outcomes with actions, target dates and performance measures. The Strategy will align relevant policies and initiatives to help improve integration across governments and in related policy areas.

The National Disability Strategy will be an important mechanism to ensure that the principles underpinning the United Nations Convention on the Rights of Persons with Disabilities are incorporated into policies and programs affecting people with disability, their families and carers.¹⁶

- 1.28 During October and November 2008, FaHCSIA undertook a series of public consultations to give interested parties the opportunity to give input and feedback on the direction of the NDS. Input and comments could also be submitted in writing with a closing date of 7 January 2009.¹⁷ The outcomes of the consultations and key points from submissions will be summarised in a report in early 2009 and the NDS released in mid 2009. The NDS will also be informed by the National People with Disabilities and Carer Council, chaired by Dr Rhonda Galbally AO.

National Mental Health and Disability Employment Strategy

- 1.29 The development of a National Mental Health and Disability Employment Strategy has been initiated as part of the Australian Government's broader Social Inclusion Agenda. The Strategy aims to address the barriers faced by people with disability and/or mental illness that make it harder for them to gain and keep work.

- 1.30 In the first quarter of 2008, the Department of Education, Employment and Workplace Relations (DEEWR) released a discussion paper for comment. During April and May of 2008, DEEWR held 13 face to face consultations that were open to the community and interested parties. As a result of the consultations, the following six priority areas to increase employment opportunities for people with a disability and/or mental illness were identified:

- improving disability employment services;

16 Australian Government, Department of Families, Housing, Community Services and Indigenous Affairs website, viewed 29 January 2009 at www.fahcsia.gov.au/disability/nds_discussion_paper/nds_paper.rtf.

17 Australian Government, Department of Families, Housing, Community Services and Indigenous Affairs website, viewed 29 January 2009 at www.fahcsia.gov.au/internet/facsinternet.nsf/disabilities/nds.htm.

- providing greater encouragement, assistance and support for people with disability wishing to re-enter the workforce;
- innovation;
- tackling employer misconceptions;
- increasing Australian Public Service employment of people with disability; and
- improving access to education and training.¹⁸

1.31 The National Mental Health and Disability Employment Strategy will be released later in 2009.¹⁹

Disability Investment Group

1.32 On 23 April 2008 the Parliamentary Secretary for Disabilities and Children's Services, the Hon Bill Shorten MP, announced the establishment of a Disability Investment Group (DIG). The DIG is chaired by Mr Ian Silk, Chief Executive of Australian Super, and has members with experience and knowledge of philanthropic investment.

1.33 The terms of reference for the DIG are to:

- Identify international best practice in leveraging greater investment in disability support.
- Identify opportunities to increase private sector involvement and investment in the funding of disability services and related infrastructure, including new innovations to develop alternative funding sources and arrangements for people with disability and their families; identify barriers to this and how they might be overcome.
- Identify current and potential avenues for philanthropic investment in disability support.
- Explore government assistance to encourage family and private investment in the provision of housing, education, employment, equipment and other support for people with disability.
- Consider, with the community and financial institutions, avenues for new products and services to assist families plan for the future of their child with a disability.
- Develop options for investment in housing for people with disability through private and shared equity.

18 Australian Government, Department of Education, Employment and Workplace Relations website, viewed 30 January 2009 at www.workplace.gov.au/NR/rdonlyres/37D9990A-A765-4580-BF02-5850A37AA77E/0/StrategypaperFinalRTF.rtf.

19 Australian Government, Department of Education, Employment and Workplace Relations website, viewed 20 March 2009 at www.workplace.gov.au/workplace/Publications/PolicyReviews/EmploymentStrategy/.

- Develop ways to assist people with disability, their families and not-for-profit organisations to engage with the private sector to enable development of accommodation and support options.
 - Identifying research reforms to encourage private sector engagement in research.²⁰
- 1.34 The DIG has sought advice and ideas that are relevant to its terms of reference from people with disability, their families and carers, and from organisations involved in any aspect of disability. The DIG will report to the Australian Government later in 2009.

Recent or Current Australian Parliamentary Inquiries

- 1.35 In addition to the policy initiatives described above, there has been a number of parliamentary committee inquiries conducted either by the House of Representatives or by the Senate where issues that are pertinent to the current Inquiry have been raised and considered. A brief overview of these inquiries is provided in chronological order according to the date of tabling.
- 1.36 In February 2005, the House of Representatives Standing Committee on Family and Community Services²¹ announced an inquiry into balancing work and family. The inquiry's terms of reference included consideration of:
- the impact of taxation and other matters on families in the choices they make in balancing work and family life.
- 1.37 The inquiry report, tabled in December 2006, included consideration of the added pressures of balancing work and family responsibilities for people who care for a child with a disability or an aged family member.²²
- 1.38 During 2006, the Senate Standing Committee on Community Affairs conducted an inquiry into the funding and operation of the CSTDA. The inquiry's terms of reference included consideration of:

20 Australian Government, Department of Families, Housing, Community Services and Indigenous Affairs website, viewed 20 March 2009 at www.facs.gov.au/internet/facsinternet.nsf/disabilities/policy-dig.htm.

21 The House of Representatives Standing Committee on Family and Human Services was the predecessor in the 41st Parliament to the current Parliament's House of Representatives Standing Committee on Family, Community, Housing and Youth.

22 The Parliament of Australia website, Department of the House of Representatives, *Balancing work and family*, viewed 20 March 2009 at www.aph.gov.au/house/committee/fhs/workandfamily/tor.htm.

- the appropriateness or otherwise of current Commonwealth/State/Territory joint funding arrangements, including an analysis of levels of unmet needs and, in particular, the unmet need for accommodation services and support; and
 - an examination of the ageing/disability interface with respect to health, aged care and other services, including the problems of jurisdictional overlap and inefficiency.
- 1.39 In February 2007 the Senate Committee tabled its report *Funding and operation of the Commonwealth State/Territory Disability Agreement*. The inquiry made 29 recommendations to underpin considerations for reform of the next CSTDA and to improve the delivery of specialist disability services.²³ The primary recommendation was:
- That Commonwealth, State and Territory governments jointly commit as part of the fourth CSTDA to substantial additional funding to address identified unmet need for specialist disability services, particularly for accommodation services and support.²⁴
- 1.40 Also in 2007, the House of Representatives Standing Committee on Legal and Constitutional Affairs conducted an inquiry into the adequacy of current legislative regimes and the legal needs of older Australians. Notably in relation to the current inquiry, the *Older People and the Law* report considered issues associated with substitute decision making. The report makes 13 recommendations in relation to improving legislative regimes and systems associated with substitute decision making.²⁵
- 1.41 In October 2008, the Senate Standing Committee on Community Affairs released its report on Special Disability Trusts (SDTs). SDTs were introduced in 2006 to assist parents and carers concerned about what would happen to a person with a disability when they were no longer able to provide care. The lower than anticipated take-up of SDTs, and concerns about their operation expressed by carers and families provided the impetus for the inquiry.

23 The Parliament of Australia website, Department of the Senate, *Inquiry into the funding and operation of the Commonwealth State/Territory Disability Agreement*, viewed 20 March 2009 at www.apf.gov.au/Senate/committee/clac_ctte/completed_inquiries/2004-07/cstda/tor.htm.

24 The Parliament of Australia website, Department of the Senate, *Inquiry into the funding and operation of the Commonwealth State/Territory Disability Agreement*, viewed 20 March 2009 at www.apf.gov.au/Senate/committee/clac_ctte/completed_inquiries/2004-07/cstda/report/b01.htm.

25 The Parliament of Australia website, Department of the House of Representatives, *Older people and the law*, viewed 20 March 2009 at, www.apf.gov.au/house/committee/laca/olderpeople/report.htm.

- 1.42 The Committee's report, *Building trust: supporting families through Disability Trusts* makes 14 recommendations intended to increase awareness of the trusts, and improve the operation of the Trusts by reducing the complexity and costs of establishing and maintaining a SDT.²⁶
- 1.43 In December 2008, the House of Representatives Legal and Constitutional Affairs Committee also announced an inquiry to examine the *Draft Disability (Access to Premises - Buildings) Standards*.²⁷
- 1.44 The draft standards were developed by the Australian Building Codes Board and the Australian Human Rights Commission. The standards are intended to make public buildings more accessible for people with mobility, vision and hearing impairments. The terms of reference for the inquiry included a requirement for the Committee to inquire into and report on:
- The appropriateness and effectiveness of the proposed Premises Standards in achieving their objects.²⁸
- 1.45 The Committee will report on its finding later in 2009.

Key Themes Emerging from this Inquiry

- 1.46 The nature of the Inquiry has been such that many of the written submissions and verbal testimonials from carers have involved detailing what are frequently very personal, and sometimes distressing, experiences. While not able to investigate specific grievances raised by carers or intervene in individual cases, the Committee found this body of evidence to be compelling and highly illustrative of the day-to-day challenges faced by many carers. The Committee used these personal stories to identify the common themes emerging from the evidence and to focus its attention on the reforms to government policy and practical steps that it could recommend to improve the lives of carers and their families.
- 1.47 In synthesising the evidence from the Inquiry the following broad themes emerged:

26 The Parliament of Australia website, Department of the Senate, *Building trust: Supporting families through Disability Trusts*, viewed 20 March 2009 at www.aph.gov.au/Senate/committee/clac_ctte/disability_trusts/report/c01.htm.

27 The Parliament of Australia website, Department of the House of Representatives, viewed 15 December 2008 at www.aph.gov.au/house/committee/laca/disabilitystandards/tor.htm.

28 The Parliament of Australia website, Department of the House of Representatives, viewed 15 December 2008 at www.aph.gov.au/house/committee/laca/disabilitystandards/tor.htm.

- lack of recognition of the role and contribution that carers make to society and absence of a national and strategic approach to supporting carers and their families;
- difficulties in accessing necessary and relevant information on the supports and services available to carers and lack of assistance for carers to develop the range of skills needed to support them in their role;
- financial stresses facing many carers and their families as a consequence of opportunity costs²⁹, the level of government financial assistance and the additional costs of disability and caring;
- dissatisfaction with the community care systems. Specifically, evidence highlighted significant concerns in relation to the complexity of systems, the level of unmet need, the costs of accessing services, inflexible delivery of services and in some cases, the questionable quality of care;
- lack of choice for carers in relation to participation in the workforce and/or education, primarily due to shortages of respite or alternative care options for the care receiver and inflexible workplace practices; and
- the physical, emotional and social impacts of caring on the health and wellbeing of carers and families.

Structure of the Report

- 1.48 The broad themes identified above have provided the basis for the structure of the report. It should be noted that the order of presentation of the chapters is not intended to be indicative of any judgement of the comparative importance of the issues.
- 1.49 Following the context presented in this chapter, chapter 2 provides a broad overview of background information on the carer demographics and on the government carer supports and services. The remainder of the report comprises the following chapters:
- chapter 3: A National and Strategic Approach to Carer Recognition and Policy;

²⁹ The income forgone by carers providing care rather than participating in paid employment.

- chapter 4: Information, Skills and Capacity Building;
 - chapter 5: Financial Assistance;
 - chapter 6: Access to Supports and Services;
 - chapter 7: Employment and Education; and
 - chapter 8: Health and Wellbeing.
- 1.50 In addition, although the terms of reference for the Inquiry indicated that the Committee will inquire into the needs of particular groups within the caring population, as the Inquiry has progressed the multiplicity of carer groups has become increasingly evident. While not intended to be an exhaustive list of all possible carer groups, in addition to those groups identified in the terms of reference (i.e. new carers, younger carers, older carers, Indigenous carers and those with multiple care responsibilities), evidence has been received from long-term carers, former carers, carers of people with a mental illness, carers living in regional and remote locations, working carers, male carers, grandparent carers and foster parent carers.
- 1.51 Given that the majority of issues considered in the report are broadly relevant to all carers, the report does not seek to address the specific needs of particular carer or care receiver groups in separate chapters. Rather, where issues have additional relevance to specific carer or care receiver groups this will be emphasised in the text.
- 1.52 In considering the many issues raised in evidence, the compelling need for significant and fundamental reforms to the system of supports and services for carers and care receivers has emerged. To some extent the need for significant reform is reflected by the large number of reviews of government policy and by the current reform agendas described earlier in this chapter. However, the development and implementation of systemic reform is likely to require a significant period of time. In recognition of this, while the report contains some recommendations intended to promote longer term fundamental systemic reform, it also includes other recommendations which address the most pressing and frustrating aspects of the current system which will give immediate relief to carers in the shorter term.
- 1.53 Evidence to the Inquiry has provided a snapshot of the personal and lived experiences of over 1200 carers living throughout Australia. As the Committee is keen for the report to provide a platform for the voice of carers, the report makes extensive use of excerpts from submissions and transcripts, enabling carers to tell their own stories in their own words.

Carer Identification, Demographics and Supports and Services

- 2.1 This chapter provides information on the identification of carers, carer demographics, current carer policy in Australia and the main supports and services available to carers. The chapter will:
- consider issues associated with the definition and use of the term 'carer';
 - consider the challenges associated with the identification of carers;
 - describe the current demographic and socio-economic profile of carers and consideration of the potential impacts of future demographic trends and social changes on caring; and
 - provide an overview of government supports available to carers, including a brief description of the income support system and the major government support programs and services for carers.

Definition and Use of the Term 'Carer'

- 2.2 One of the early issues arising from evidence to the Inquiry was to consider what is meant by the term 'carer' – who the term applies to, who it does not apply to and whether the term itself is appropriate. In its submission, under the heading of 'Who are Carers', Carers NSW observed that:

Carers are usually family members or friends who provide support to children or adults who have a disability, mental illness/disorder, chronic condition or who are frail aged. Carers can be parents, partners, brothers, sisters, sons, daughters, friends

or children of any age. Carers may care for a few hours a week or every day. Carers are unpaid. They may receive incomes from a range of sources including government pensions and benefits.¹

2.3 In Australia, the main source of demographic and social data on carers is provided by the Australian Bureau of Statistics (ABS). There are a number of ABS data sources which provide information on carers, including general purpose surveys such as the Census of Population and Housing conducted every five years and more targeted surveys such as the Survey of Disability, Ageing and Carers (SDAC). The SDAC, which is the primary source of data on carers in Australia, uses the following definitions for carer and primary carer:

- 'a carer' - person of any age who provides informal assistance, in terms of help or supervision, to a person with disability, or long-term medical condition, or an older person aged 60 years or over. The assistance must be ongoing or likely to be ongoing for at least six months;
- 'primary carer' - a person who provides the most informal assistance, in terms of help or supervision, to a person with one or more disabilities. The assistance has to be ongoing, or likely to be ongoing, for at least six months and be provided for one or more core activities (communication; mobility; and self care).²

2.4 As caring is frequently provided in a family setting, it is not unusual for more than one person to contribute to the provision of care. Those people who share in providing care but who are not the primary carer as defined above are often referred to as secondary carers, described in the submission from Carers NSW as:

A secondary carer provides informal care in a supporting role where either another family member or formal services provide the majority of care.³

2.5 However, evidence to the Inquiry from some carers and organisations has indicated the meaning and use of the term carer can be problematic. As noted by Carers SA, some carers are uneasy with the term:

Many carers grapple with the term 'carer' and whether or not they want to be seen as a carer. They call themselves a family member, or a friend, or a neighbour, a partner or a lover, but the term 'carer'

1 Carers NSW, Submission No 661, p 6.

2 Australian Bureau of Statistics (2008), *A Profile of Carers in Australia*, 4448.0, pp 102-107.

3 Carers NSW, Submission No 661, p 6.

is often seen to be so objective that they don't want to be called this.⁴

- 2.6 Also in relation to the use of the term carer, Ms Becky Llewlyn observed that:

'Carer' as a term changes a person with a name and many other roles into someone who is defined by an external reality – the shifting medical and health status of someone with whom they are in relationship.⁵

- 2.7 Furthermore, Ms Llewlyn suggested that the term carer reinforces the concept of an unequal relationship between the carer and the care receiver, stating:

I still believe that this word [carer], used as a tool of government policy, is a source of inbuilt resentment by one person for the other. It differentiates one as the 'goodie', the other the 'baddie'. One the 'giver', the other the 'taker', one the 'active', the other the 'passive', harking back to the medical model of people with impairments as 'patient', passively suffering. 'Carer' reinforces one person's actions against the other's, the person who has been linguistically categorised in a deficit model of 'need'.⁶

- 2.8 To address these issues, Ms Llewlyn recommended the use of 'person first' language, suggesting the following alternative approach to describing carers:

What would be more useful is to retain the common word used for a relationship, 'wife', 'husband', 'daughter', 'son', 'neighbour', 'friend' and add the phrase, 'with disability responsibilities' or 'who supports that person'.⁷

- 2.9 Another issue that was raised relates to confusion around the precise meaning of the term carer due to its broad usage. The term may be applied to a number of different groups, including paid care workers and parents of younger children without disabilities or special needs.⁸ Ms Clare Masolin,

4 Carers SA, Submission No 684, p 7; See also: Carers Support Network of South Australia, Submission No 675, p 6; Ms C Murray, Submission No 1134, pp 1-2; Ms M Sweeney, Transcript of Evidence, 6 August 2008, p 89.

5 Ms B Llewlyn, Submission No 185, p 4.

6 Ms B Llewlyn, Submission No 185, p 4.

7 Ms B Llewlyn, Submission No 185, p 5.

8 National Carers Coalition, Submission No 571, p 9; Carers Network of South Australia, Submission No 675, p 6; Ms M Walsh, Submission No 752, p 2; Ms C Masolin, Submission No 1190, p 1.

who cares for her 13 year old son who has moderate cerebral palsy and associated medical complications, observed:

Historically, the term 'carer' has been used to refer to a person providing a paid service under contract with an employer. Language is powerful, and a distinction between the terms 'carer' and 'care worker' needs to be plainly established.⁹

- 2.10 Similarly, the National Carers Coalition, a group representing carers of people with a lifelong dependent disability under the age of 65 years, noted:

The term 'carer' has become generic to virtually mean anyone who provides care and support to another person, no matter if this support is minor or if this support is so great that it overrides the caregiver's entire existence and leaves little time for any kind of quality for an independent life. Parents and foster parents of able children are all now called carers. Paid disability and aged care workers and pre-school workers are called carers.¹⁰

- 2.11 To address this ambiguity, the National Carers Coalition notes that its membership had been forced to use the alternative term 'family carer' and stated:

... this generic use of the word 'carer' forces the original carers [to] call themselves unpaid family carers to differentiate themselves.¹¹

Meaning and Use of the Term Carer in the Inquiry

- 2.12 The Committee understands that individuals who provide care often do not wish the nature of their relationship with another to be primarily defined by their caring role. While the use of 'person first' language is preferred when describing individual carers, the Committee understands that there is a need for a simple term which can be used to collectively describe a diverse, but distinct group of people who through the provision of care, share common experiences and challenges. Despite limitations with the term carer and concerns expressed by some, in the view of the Committee, carer is currently the most appropriate term given its prominence in the legislation, policy, academic literature and the general acceptance of the term by the wider community.

9 Ms C Masolin, Submission No 1190, p 1.

10 National Carers Coalition, Submission No 571, p 9.

11 National Carers Coalition, Submission No 571, p 9.

2.13 However, the Committee recognises that the use of the term carer without explanation or interpretation can be ambiguous, hence the inclusion of the following definition from the Inquiry's terms of reference:

For the purpose of this inquiry carers are defined as 'individuals providing unpaid support for others with ongoing needs due to a long-term medical condition, a mental illness, a disability or frailty'.¹²

2.14 To reduce ambiguity further, in the text of this report the term carer will not be used to describe paid support workers, child care workers, parents of children without special needs or any other group that is not covered by the definition above.

'Hidden' Carers

2.15 A common concern raised throughout evidence relates to the existence of an unquantified population of 'hidden' or unidentified carers.¹³ Carers are considered to be hidden carers if they:

- do not identify themselves as a carer (self-identify) or prefer not to disclose their caring role to others; and/or
- do not appear in statistics and data relating to carers.

Carer Identification

2.16 While some reservations were expressed with regard to meaning and use of the term carer, identification as carer is an essential first step to accessing supports and services. As noted in the submission from the ACT Government:

Recent research indicates that if a person does not see themselves as a 'carer', they are unlikely to search for, or easily find, government services that meet their needs as a carer. They will remain in the parlance of the literature, 'hidden'. Government efforts to support

12 The Parliament of Australia website, Department of the House of Representatives, viewed 20 February 2009 at www.aph.gov.au/house/committee/fchy/carers/tor.htm.

13 See for example: Carers Victoria, Submission No 652, p 15; Private Mental Health Consumer Care Network, Submission No 696, p 4; Anglicare Canberra and Goulburn, Submission No 724, p 6; ACT Government, Submission No 1000, p 4; Disability Service Commission, Submission No 1039, p 3; Australian Government Departments (FaHCSIA, DoHA & DVA), Submission No 1109, p 10; NSW Government, Submission No 1278, p 4.

carers will be less effective if they are not able to improve self-recognition of carers, about their role and the associated needs.¹⁴

- 2.17 There are various reasons why an individual providing care may not self-identify as a carer, or why they may prefer not to be identified by others as a carer. Some individuals may not recognise that undertaking certain activities or providing assistance for another actually constitutes caring. Mr John Wilkinson, a carer himself for over 10 years who has also undertaken voluntary and professional work in relation to community services for people with disability and people with mental illness, noted that some carers do not self-identify as they consider their activities to be an integral part of family life, stating:

These people view their caring as a normal part of life, of being a wife, husband, sibling or even a friend, and never think of themselves as Carers and are thus isolated without support.¹⁵

- 2.18 Evidence suggests that different cultural attitudes towards family responsibility and understanding in relation to the concept of caring, exacerbated by difficulties with language results in reduced self-identification among Indigenous carers and carers from culturally and linguistically diverse (CALD) backgrounds.¹⁶ In its submission, the Queensland Government noted:

... understanding of the term 'carers' also varies among different cultural groups. People from some cultural backgrounds may be unfamiliar with the specific notions of 'care' and 'carers', believing that the role of caring is a natural duty of particular family roles, for example mother, daughter. These different understandings within some segments of the community can make appropriate recognition of carers and their contributions difficult.¹⁷

- 2.19 Specifically in relation to CALD carers, the National Ethnic Disability Alliance noted:

... the definition of a carer will vary significantly as a result of cultural and linguistic factors. Carers from CALD backgrounds

14 Carers Tasmania, Submission No 671, p 8.

15 Mr J Wilkinson, Submission No 1035, p 2.

16 See for example: Carers NSW, Submission No 661, p 31; Carers Australia, Submission No 699, p 34; St George Migrant Centre, Submission No 746 (Attached Report), p 17-18; University of Western Sydney, Submission No 758, p 2.

17 Queensland Government – Department of Premier and Cabinet, Submission No 1203, p 10.

may not readily identify as 'carers' and they may comprise a significant proportion of the hidden carer population.¹⁸

- 2.20 Carers Australia suggested that Indigenous carers often do not self-identify, seeing their caring role as a natural extension of family duty:

Indigenous carers are less likely to see themselves as 'carers' because caring 'for their own' is what they do.¹⁹

- 2.21 Young carers²⁰ were also identified as a group that was more likely to see the assistance they provide as being an integral part of normal family life and therefore not identify themselves as carers. As noted by Ms Britta Meyer of Carers WA, in relation to young carers:

Self-identification is a huge issue because children just do not identify, and even in general carers do not necessarily identify, because they see themselves as sisters, brothers, sons and daughters.²¹

- 2.22 Another group of hidden carers are those who recognise their own caring role, but are reluctant to disclose it to others.²² Evidence to the Inquiry suggests that reluctance to be identified as a carer is particularly prevalent among older carers, CALD carers, carers of people with mental illness and young carers.

- 2.23 Referring to research conducted in 2005 by Carers Australia and by Carers Victoria, the submission from the Australian Government departments (the departments of Families, Housing, Community Services and Indigenous Affairs; Health and Ageing; and Veterans' Affairs) noted that over 25% of older carers were 'hidden' in the sense that they do not seek assistance and are therefore unknown to service providers.²³ This point was also emphasised in the submission from ANGLICARE Sydney which notes:

18 National Ethnic Disability Alliance, Submission No 1110, p 9.

19 Carers Australia, Submission No 699, p 34.

20 Definitions of young carer vary. See for example: the Australian Bureau of Statistics Survey of Disability, Ageing and Carers consider young carers to be carers aged 15-24 years. Carers NSW provides the following definition 'A young carer is a child or young person 25 years or under who provides support for a family member who has a long term disability, mental illness, other illness, drug or alcohol problem.'

21 Ms B Meyer, Transcript of Evidence, 23 July 2008, p 6. See also: Prof B Cass, Transcript of Evidence, 6 August 2008, p 73 & p 79.

22 See for example: Ms P Berrutti, Submission No 429, p 2; University of Western Sydney, Submission No 758, p 2; National Network of Adults and Adolescent Children who have Mentally Ill Parents, Submission No 1243, p 1.

23 Australian Government Departments (FaHCSIA, DoHA & DVA), Submission No 1109, p 10.

Research indicates that many ageing carers are hidden and have never engaged with formal services. For ageing carers in particular, their role has been a long term one, they have confidence in what needs to be done and there is sometimes reluctance to hand over the care of their adult child to others. Many ageing carers have found services not suitable for their offspring or have had negative experiences which has made them reluctant to pursue further service access. For ageing carers there may also be issues with social isolation and a sense of self reliance which has inhibited their access to services.²⁴

- 2.24 Concerns around negative attitudes towards disability, illness and caring including stigma and discrimination were also identified as reasons that some carers prefer not to disclose their role.²⁵ Ms Jenny Au Yeong, Chief Executive of the Ethnic Disability Advocacy Centre, explained that negative attitudes toward disability in some cultures might cause CALD carers to remain hidden, stating:

Disability is often seen as a hidden, negative thing within the family. People do not always talk about disability openly and they sometimes hide their kids with disability in the home. Consequently, they may not be accessing sufficient services and support for the individual with a disability due to that mentality and attitude towards disability.²⁶

- 2.25 A generally poor understanding of mental illness in the community and the stigma associated with mental illness were also reported as factors contributing to the reluctance of carers for people with a mental illness to be identified.²⁷ The Royal Australian and New Zealand College of Psychiatrists outlined a number of reasons why carers of people with mental illness may not identify as carers:

The number of mental health carers in Australia is hard to quantify as many carers do not identify themselves as carers due to the significant stigma associated with mental illness. The nature of the care giving role is also not often understood by many professionals or by society. The practice of blaming families for

24 ANGLICARE Sydney, Submission No 769, p 32.

25 See for example: Queensland Government, Submission No 1203, p 10.

26 Ms J Au Yeong, Transcript of Evidence, 28 July 2008, p 65.

27 See for example: ARAFMI (Queensland), Submission No 574, p 3; Mental Health Council of Australia, Submission No 682, p 5; National Network of Adults and Adolescent Children who have Mentally Ill Parents, Submission No 1243, p 1; Ms P Mason, Submission No 808, p 1; Dr J Freiden, Transcript of Evidence, 12 August 2008, p 3.

contributing to, if not causing mental illness has not completely disappeared, though community awareness of mental illness is rising. The periodic nature of episodes of mental illness means that often carers do not meet the assessment criteria to be recognised as a carer.²⁸

- 2.26 Evidence also indicates that in some cases young carers were reluctant to disclose their caring role for fear of family break-up and removal from the family home.²⁹ In addition, identification as a carer was reported to have resulted in harassment and bullying for some young carers.³⁰ As reported in the submission from Siblings Australia in relation to young sibling carers:

Siblings [of children with special needs] can be particularly vulnerable to bullying or teasing. One little girl found that others would not play with her as she had 'disability germs'.³¹

- 2.27 Alarming, bullying in the education system was reported by at least one young carer to have extended beyond her peers to include teachers as she explained at a public hearing in Canberra:

I found it extremely difficult to concentrate at school because I was teased by students and, believe it or not, at one stage at one particular school I was bullied by the teachers – not all of them but there were definitely two who did.³²

The Need for Increased Carer Self-Identification

- 2.28 The Committee recognises the importance of carer identification. Firstly, self-identification by carers themselves is critical as the first step in seeking assistance to support them in their role. Secondly, identification of hidden carers, including those carers who are reluctant to disclose their caring role, is also crucial to providing a sound evidence base for effective policy and for planning delivery of adequate and appropriate carer supports and services.
- 2.29 The Committee has heard of some initiatives that have been implemented to assist various populations of carers to self-identify or to address the concerns of those carers who, for whatever reasons, are reluctant to be

28 Royal Australian and New Zealand College of Psychiatrists, Submission No 672, p 2.

29 AICAFMHA-COPMI National Initiative, Submission No 683, p 3.

30 See for example: Ms T Haines, Submission No 1128, p 1; Ms R Foldesi, Transcript of Evidence, 26 July 2008, p 47.

31 Siblings Australia, Submission No 701, p 3.

32 Ms T Haines, Transcript of Evidence, 26 September 2008, p 17.

identified by others. For example, in relation to young carers, the Committee notes initiatives such as the Young Carer Scholarship Program run by Rotary Club of Mount Eliza³³ and the Connecting Young Carers to Life Opportunities and Personalised Supports (CYCLOPS) program run by Anglicare Canberra and Goulburn.³⁴

- 2.30 While supporting local initiatives which assist or encourage hidden carers to self-identify, the Committee believes that much more needs to be done on a national level. Increased self-identification among carers, and addressing the concerns of those carers who are reluctant to disclose their role to others could well be components of a national carer awareness and community education campaign. The need for such a campaign is considered in more detail in chapter 3.

Carer Identification through Surveys

- 2.31 Another category of hidden carers not yet considered in the chapter are those that are not identified through various carer surveys, and are therefore not quantified or are under-represented in carer statistics.
- 2.32 The ABS's SDAC mentioned earlier is probably the most comprehensive source of detailed information about carers in Australia, as the survey takes an objective and structured approach to identifying carers using responses to interviewer based questions. In contrast, many other ABS population based surveys such as the Census of Population and Housing rely on carers to self-identify and are therefore more prone to an underestimation of carer numbers.³⁵
- 2.33 Nevertheless, while acknowledging that SDAC is currently the best source of demographic and socio-economic information on carers, the Australian Institute of Health and Welfare (AIHW) noted that SDAC also has certain limitations. Specifically, AIHW noted that the SDAC focus on primary carers and the definition of carer used in the survey excludes certain carer population groups, stating:

... the SDAC definition of primary carer may not produce a picture of the full extent of high-end caring activity. In addition to being the main provider of assistance, the SDAC requires that the person has been or expects to be providing assistance with the core activities of daily living (self care, mobility, communication) for a

33 Rotary Club of Mount Eliza, Submission No 572, pp 1-4.

34 Various witnesses, Transcript of Evidence, 26 September 2008, pp 37-44.

35 Australian Bureau of Statistics (2008), *A Profile of Carers in Australia*, 4448.0, p 74.

period of at least 6 months. This definition has been shown to be too narrow for the purpose of representing the diverse circumstances and needs of primary carers ... It potentially excludes, for example, primary carers of people with mental illness, particularly episodic mental illness, and high intensity palliative care for periods of three or four months.³⁶

- 2.34 In addition, as the SDAC definition of carers is restricted to persons aged 15 years and over, the difficulties associated with obtaining reliable data on the number of young carers under 15 years of age was raised in evidence.³⁷

Amendments to the Survey of Disability, Ageing and Carers

- 2.35 The Committee understands that disability and caring is a difficult area in which to collect information. However, comprehensive and reliable data on carer numbers, demographics and socio-economic characteristics are essential to developing effective policy and to establishing systems which are capable of delivering adequate and appropriate supports and services for carers.
- 2.36 While the SDAC is currently the most reliable source of demographic and socio-economic information on carers in Australia, the Committee has some concerns. Firstly, it is concerned that certain carer population groups such as those providing care for people with episodic mental illness, carers providing palliative care and carers under the age of 15 years, are currently excluded from the SDAC on a definitional basis. Secondly, the SDAC is conducted only once every six years, and the Committee is concerned with the infrequency of the survey.³⁸
- 2.37 With regard to the definitional exclusion of particular carer population groups the Committee is aware that in anticipation of the next SDAC to be conducted later in 2009, the ABS has implemented a review process to improve the collection of carer data. The AIHW and Australian Government departments with portfolio responsibilities for carers, including FaHCSIA and DoHA, have already contributed to that process.³⁹ To support their contributions, the Committee recommends that the ABS specifically consider expanding the information it currently

36 Australian Institute of Health and Welfare, Submission No 1033, p 6.

37 See for example: Professor B Cass, Transcript of Evidence, 6 August 2008, pp 73-78; Mr K Waters, Transcript of Evidence, 26 September 2008, p 37.

38 Australian Bureau of Statistics (2008), *A Profile of Carers in Australia*, 4448.0, p 73.

39 Australian Government Departments (FaHCSIA, DoHA & DVA), Submission No 1109, p 49.

collects on carers to include more information on secondary carers, and to increase identification of hitherto hidden carer groups such as carers aged less than 15 years, and carers providing episodic care and palliative care. This may be achieved either through an expansion to the SDAC or through the establishment of an alternative carer specific survey.

- 2.38 Also, in view of the importance of comprehensive and reliable data to inform the development of policy and determine the level of need for supports and services, the ABS should consider increasing the frequency of SDAC to once every three years.

Recommendation 1

- 2.39 **That the Treasurer direct the Australian Bureau of Statistics, either through an extension to its Survey of Disability, Ageing and Carers or through the development of an alternative carer specific survey, to expand the information it collects on carers to include information on:**

- secondary carers;
- carers providing episodic care;
- carers providing palliative care; and
- carers aged 15 years and under.

The Australian Bureau of Statistics should also consider increasing the frequency of the Survey of Disability, Ageing and Carers to three yearly intervals.

The Demographic and Socio-Economic Profile of Carers

- 2.40 In October 2008 the ABS published *A Profile of Carers in Australia*.⁴⁰ The publication draws together data from four ABS collections to examine the characteristics of people who provide care for those with a disability, a long-term health condition or to older people. The primary source of data is the 2003 SDAC, but data from the 2006 General Social Survey, the 2006 Time Use Survey and the 2006 Census of Population and Housing also provided additional information on some aspects of the lives of carers.⁴¹

40 Australian Bureau of Statistics (2008), *A Profile of Carers in Australia*, 4448.0.

41 Australian Bureau of Statistics (2008), *A Profile of Carers in Australia*, 4448.0, p 73.

- 2.41 The publication presents data on:
- the demographic characteristics of carers;
 - income and housing;
 - carer participation in the workforce;
 - carer social participation and wellbeing; and
 - sources of support and use of respite.
- 2.42 The publication also presents information on a number of discrete carer groups including Indigenous carers, young carers and older carers. While it is not possible within the confines of this report to present a comprehensive summary of data from the ABS carer profile, selected key findings are presented below. Where data has been obtained from another source, this is footnoted.
- 2.43 In 2003, there were 2.5 million carers in Australia aged 15 years and over, that is 16% of the population. Of these, 475,000 or 19% of carers were primary carers.
- 2.44 Though men represent close to half the number of all carers, almost three quarters of primary carers (71%) are women. In 2003, 13% of primary carers were aged 15-34 years, 63% were aged 35-64 years and 24% were aged 65 years or over. The median age of the total carer population was 48 years and for primary carers was 52 years.
- 2.45 The carer rate among women peaked in the 55-59 year age group, with 25% of women in this age group being carers. The carer rate among men peaked in the 75-79 year age group, with 26% of men in this age group being carers.
- 2.46 Approximately 91% of primary carers were related to the people they are caring for, with approximately 42% of carers caring for partners, 26% of carers caring for a parent and 23% of carers caring for a child. With regard to the relationship between primary carers and their care receivers, the AIHW observed:
- Primary carers aged up to 45 years are predominantly parents, mostly mothers, providing assistance to a child with a disability, but offspring and partners are also well represented in this group of primary carers.
 - In the 45-64 years age group spouses and partners account for the highest proportion of primary carers, slightly ahead of sons and daughters caring for a parent/s.

- Spouses/partners are the overwhelming majority of older primary carers (65+) and at much older ages (75+), there are roughly equal numbers of men and women.⁴²
- 2.47 The most common reasons reported by primary carers for taking on the caring role were family responsibility (58%), the carer feeling that they could provide a better quality of care than others (39%) and emotional obligation (34%).
- 2.48 More detailed information on other characteristics of carers and their lives (e.g. income, workforce participation, health and wellbeing, use of supports and services etc) is presented in subsequent chapters of this report. In brief evidence relating to carer income, employment and wellbeing indicates that:
- the proportion of all carers living in low income households was higher than for non-carers across all age groups; in 2003, 32% of all carers and 44% of primary carers were living in low income households compared to 17% of non-carers;⁴³
 - the proportion of carers that participate in the workforce is lower than for non-carers; in 2003, 63% of carers aged 15-64 years were employed compared to 75% of non-carers. Only 48% of primary carers of this age were employed, and of these more were likely to work part-time rather than full time;⁴⁴ and
 - carers have the lowest wellbeing of any population group surveyed so far, with an average stress rating classified as moderate depression and being more likely than non-carers to be experiencing chronic pain.⁴⁵

Changing Models of Care and Implications of Demographic and Social Trends

- 2.49 Both internationally and in Australia changes in accepted models of care have resulted in significant deinstitutionalisation for people with disabilities, mental illness and for frail aged. To a large extent institutional care has been replaced by 'care in place' or 'ageing in place'. A consequence of the move from institutional care to care in the community,

42 Australian Institute of Health and Welfare, Submission No 1033, p 8.

43 Australian Bureau of Statistics (2008), *A Profile of Carers in Australia*, 4448.0, p 52.

44 Australian Bureau of Statistics (2008), *A Profile of Carers in Australia*, 4448.0, p 51.

45 Australian Unity Wellbeing Index (2007), Survey 17.1, *The Wellbeing of Australians – Carer Health and Wellbeing*, pp vi-vii.

as noted by the AIHW below, is that society has become increasingly reliant on the contribution of unpaid carers:

The deinstitutionalisation of health and welfare services that started in the 1980s has given added significance to the role and contribution of carers in Australia.⁴⁶

2.50 The extent of the increased reliance on unpaid carers is illustrated by data presented by the AIHW:

AIHW analyses have shown, for example, that if 1981 patterns of use of institutional care had been maintained until 1996, then an additional 80,700 people would have been living in health and welfare institutions in 1996, or 38% more than actually were according to the 1996 Census ...⁴⁷

2.51 As noted earlier, carers are most often family members – parents, spouses, daughters or sons - but may also be friends or neighbours. While the responsibilities for caring crosses all social and demographic groups, the distribution of caring responsibility falls most heavily on women.⁴⁸ In its submission Carers Victoria observed:

Until recent decades, there was an expectation that the majority of care would be provided by women, supported financially by men in full time, secure work. Our submission argues that this paradigm of caring no longer applies in modern Australia. It is not economically or socially sustainable and, importantly, the community's expectations have shifted.⁴⁹

2.52 Carers Australia has also suggested that the shift from institutional care has not been matched by adequate investment in health and community care services to support carers and care receivers:

Over the past 20 years policies and programs for people with disabilities, people with mental illness and older people have been premised on the assumption and fact that care in a normal community setting with family and other support is preferable to institutional care. However the shift from institutional models of care has not been matched by adequate development and resourcing of appropriate health and community care services.

46 Australian Institute of Health and Welfare, Submission No 1033, p 5.

47 Australian Institute of Health and Welfare, Submission No 1033, p 5.

48 Carers NSW, Submission No 661, p 6.

49 Carers Victoria, Submission No 652, p 4.

Choice about how care is provided within families or other community settings is extremely limited.⁵⁰

- 2.53 Ms Shirley Matheson, a carer for her war veteran husband also noted that in the absence of adequate support for community services the responsibility of providing care had shifted from government to families, stating:

Although the philosophy of de-institutionalization may be sound and seeks to keep those who cannot care for themselves living in and connected to their local community, they have failed to support the carer. It is clear that through this policy the government has made significant savings and has failed to pass on the funds previously associated with state and institutional caring to appropriate community supports to assist carers. Quite simply, it appears that money has disappeared back into government coffers, leaving already stretched general community services to cope with increasing demand from 'undervalued carers'.⁵¹

- 2.54 Several submissions have highlighted the likely impact of demographic and social changes on the predicted future supply and demand for informal care and have speculated on the implications for governments and the community.⁵² As noted in the submission from Carers Australia:

The projected rapid ageing of Australia's population is well known. This represents a key challenge for governments and communities in the design and shape of Australia's future health and community care systems and how to achieve the right balance between formal and informal care.⁵³

- 2.55 In addition to the ageing population, a number of other social changes which might impact on future demands for informal care were noted in the joint submission from the Australian Government departments, including:

... increasing rates of relationship breakdown; estrangement of parents from adult children; reduced family formation among

50 Carers Australia, Submission No 699, p 8.

51 Ms S Matheson, Submission No 587, p 2. See also: Ms B Tickner, Transcript of Evidence, 20 August 2008, p 89.

52 See for example: Australian Unity, Submission No 667, p 3; Carers Australia, Submission No 699, p 7; Australian Institute of Health and Welfare, Submission No 1033, p 18; Australian Government Departments (FaHCSIA, DoHA & DVA), Submission No 1109, pp 34-36.

53 Carers Australia, Submission No 699, p 7.

young adults; widespread altered role perception among women; and a large increase in lone person households.⁵⁴

- 2.56 Referring to work conducted by the National Centre for Social and Economic Modelling (NATSEM), Carers Australia noted that the future demand for carers is likely to significantly outstrip supply, stating:

[NATSEM] estimate there will be a 160 per cent increase in the number of people over 65 needing care from 539,000 people in 2001 to 1,390,000 in 2031. This compares with a 25 per cent projected increase for people less than 65 years ... Against this trend, NATSEM predicts there will be a diminishing 'caretaker ratio' - the ratio of the number of people likely to provide care to the number of people anticipated to require care. In 2000 the ratio was 2.5. NATSEM estimates that over the next 50 years the ratio will fall below one.⁵⁵

- 2.57 With numbers of people requiring care predicted to rise and a shortage of people able and willing to provide care, Carers Australia suggests that:

These trends have extremely important implications for policy and program design in the future and for the resources likely to be needed to support formal and informal care.⁵⁶

Consideration of the Implications of Demographics and Social Change

- 2.58 The Committee acknowledges that changing paradigms of care, particularly the shift from institutional care to care in the community has led to increased reliance on informal care provided by unpaid carers, most often relatives of the care receiver. Therefore, the Committee is concerned by evidence which indicates that the current levels of support are insufficient to give carers the assistance they need to care, or to enable them to make genuine choices in relation to the level of their involvement. This is even more concerning in view of the expected increase in demand for care and predicted shortfall in the supply of people to provide that care.
- 2.59 Although the Committee will defer detailed consideration of the evidence relating to the adequacy or otherwise of current government supports and

54 Australian Government Departments (FaHCSIA, DoHA & DVA), Submission No 1109, p 35. See also: Ms B Tkalcevic, Transcript of Evidence, 12 August 2008, p 15.

55 Carers Australia, Submission No 699, p 7.

56 Carers Australia, Submission No 699, p 7.

services for carers until later in the report, the next section provides an overview of the existing system, including its administration and brief descriptions of the major assistance for carers provided by the Australian Government.

Government Administration of Supports and Services

2.60 Throughout the Inquiry, evidence has emphasised that support for carers can not be considered in isolation, as the support needs of carers and care receivers are intrinsically linked. In broad terms, carers are assisted by services which:

- primarily aim to directly support carers (e.g. carer information and support services, carer counselling services and carer respite services etc); and
- primarily aim to provide support to care receivers, but which also alleviate the caring responsibilities of carers.

2.61 Given the interrelationship between supporting the needs of carers and care receivers, it is sometimes very difficult to determine whether a support or service is primarily intended to meet the needs of carers or care receivers. In fact, many supports and services have both the carer and the care receiver as dual clients. For example, personal care services that are intended to meet the personal care needs of the care receiver (e.g. assistance with showering etc), may also at the same time assist the carer.

2.62 Therefore, while the focus of the Inquiry is on the needs of carers, consideration will also be given to supports and services that have a dual client base or which, while intended primarily to meet the needs of care receivers, also enhance the carer's capacity to provide care.

Administration of Government Supports and Services for Carers and Care Receivers

2.63 A major theme emerging from evidence to this Inquiry is the complexity and fragmentation of funding, administration and delivery of supports and services for carers and for care receivers. Current systems of funding and administration involve all three tiers of government (i.e. Australian Government, state and territory governments, and local governments). They also cross a range of different government portfolios (e.g. health, aged care, disability services, community mental health services, housing, transport and employment).

- 2.64 At Australian Government level the development of policy and administration of programs that specifically target carers and care receivers is spread across three departments. These are the Department of Families, Community Services and Indigenous Affairs (FaHCSIA), the Department of Health and Ageing (DoHA), and the Department of Veterans' Affairs (DVA). In addition, Centrelink under the auspices of the Department of Human Services is responsible for administering the delivery of payments and related services.
- 2.65 FaHCSIA at the national level has responsibility for disability policy and programs for people under the age of 65 years. DoHA has responsibility for the national policy for the care of people over the age of 65 years, which includes community based and residential aged care services. DVA is responsible for policy and programs to fulfil Australia's obligations to war veterans and their dependants. A range of supports, services and programs to assist carers, including respite, carer counselling, information and advocacy are funded and administered by DoHA, FaHCSIA and DVA.
- 2.66 Adding further to the already complex milieu some programs for carers and care receivers are jointly funded and administered by the Australian Government and by state and territory governments. For example, specialist disability services under the National Disability Agreement (NDA). The range of specialist disability services varies between jurisdictions, as do the specifics of eligibility criteria and program or service design. Delivery of programs targeted at carers and care receivers also frequently involves local government and non-government sector organisations.
- 2.67 Many submissions have commented on the detrimental consequences of the systemic complexity associated with supports and services for carers and care receivers. Evidence has also highlighted the lack of coordination between government departments and across tiers of government developing services for carers and care receivers. This has resulted in fragmentation leading to gaps in some supports and services, duplication in others and poor transitions between the disability and aged care services. Brainlink Services, an organisation that provides support for people with acquired brain injury and their carers, summarised many of these issues:
- The Service System for people with disabilities, chronic illness, and frail aged is ineffective, fragmented, problematic in many ways, which in turn makes the role of carer more difficult. People fear loss of service, hard to navigate, not sure what is

available/possible, conflicting information, divisions between [Home and Community Care] HACC and Disability and Aged Care, etc. Lack of clarity regarding 'entitlements', eligibility, multiple 'buckets of money'. For instance, multiple agencies involved with one individual, multiple funding streams, so complex that most professionals can't figure it out, never mind the general public who need assistance. If you are caring 24/7, exhausted and emotionally struggling, what hope have you got!!!!⁵⁷

- 2.68 Not surprisingly, many carers have described the confusion and frustration they have experienced when attempting to determine the services available to assist them or their care receiver.⁵⁸ Other submissions have also noted the administrative difficulties and inefficiencies for governments and for service providers caused by fragmented and complex support and service systems.⁵⁹

Financial Assistance for Carers

- 2.69 The joint submission from Australian Government departments describes the purpose of Australia's income support system for carers and their families as:

... a comprehensive social safety net through an interlinked range of payments and benefits covering people who are unable to obtain employment, including those with disabilities, their carers and carers of the frail aged.⁶⁰

- 2.70 The submission explains that while FaHCSIA has policy responsibility for Australia's income support and supplements for carers, the payments are delivered through Centrelink.⁶¹ There is a range of different payments and allowances available to carers and their families. Depending on family and caring circumstances some carers will receive income support in the form of Carer Payment, while others may receive other social security income support payments such as the Age Pension, Parenting Payment or Newstart Allowance, and in some situations Disability Support Pension

57 BrainLink Services, Submission No 690, pp 6-7.

58 See for example: Ms R Sexton & Mr T Sexton, Submission No 136, p 3; Ms M Anderson, Submission No 331, p 2; Ms C Sebbens & Mr J Doyle, Submission No 615, p 2; Ms M King & Mr R King, Submission No 817, p 3; Mr B Taylor, Submission No 923, p 2.

59 See for example: Ms M-L May, Submission No 891, p 3; Carers Victoria, Submission No 652, pp 27-28; Ms G Pierce, Transcript of Evidence, 12 August 2008, pp 38-39.

60 Australian Government Departments (FaHCSIA, DoHA & DVA), Submission No 1109, p 15.

61 Australian Government Departments (FaHCSIA, DoHA & DVA), Submission No 1109, p 15.

(DSP). Brief descriptions of the income support payments and supplementary payments available specifically for carers is provided below. Additional information on income support payment rates and other payment features such as eligibility criteria, income and assets test thresholds as at 1 July 2008 is at Appendices D to F.

- 2.71 Carer Payment is an income support payment available to people who, because of the demands of their caring role, are unable to support themselves through substantial labour force participation.⁶² The Carer Payment is both income and assets tested.
- 2.72 Carer Allowance is a supplementary payment available to people who provide daily care and attention in a private home to a person who has a disability, severe medical condition or who is frail aged. Carer Allowance is not taxable and is not subject to an income or assets test. Carers Allowance can be paid in addition to Carer Payment or other social security income support payments.⁶³
- 2.73 Carer Payment (child) and Carer Allowance (child) are paid to carers of children aged less than 16 years, while Carer Payment (adult) and Carer Allowance (adult) are paid to carers of people aged 16 years and over.⁶⁴
- 2.74 Since October 2006, recipients of Carer Allowance (child) are eligible for an annual Child Disability Payment intended to assist families with the purchase of equipment, therapy or respite. The Child Disability Payment is not taxed, nor does it count as income for social security or family assistance purposes.⁶⁵
- 2.75 In each of the Budgets from 2004 to 2008 carers in receipt of Carer Payment and/or Carer Allowance have also received an annual Carer Bonus as a lump-sum non-taxable payment.
- 2.76 Since 2007, in some circumstances carers may be able to access the Carer Adjustment Payment (CAP). CAP is available as a one-off non-taxable payment to families following a catastrophic event involving a young child aged up to 6 years (e.g. following diagnosis of a serious or severe illness, childhood stroke, car accident). Under these circumstance, the CAP

62 Australian Government Departments (FaHCSIA, DoHA & DVA), Submission No 1109, pp 15-16.

63 Australian Government Departments (FaHCSIA, DoHA & DVA), Submission No 1109, p 19.

64 The (child) and (adult) categories in respect of Carer Payment and Carer Allowance relate to differences in the claim/assessment processes involved depending on the age of the care receiver.

65 Australian Government Departments (FaHCSIA, DoHA & DVA), Submission No 1109, p 19.

may be provided to assist a family going through a period of significant adjustment.⁶⁶

- 2.77 Carers may also be eligible for a range of other supplementary payments from Centrelink including Rent Assistance, Utilities Allowance, Telephone Allowance, Pharmaceutical Allowance or the Pensioner Education Supplement.
- 2.78 Although not a payment for carers, in many carer households the DSP received by a care receiver is a key source of household income. The DSP is provided for people aged 16 years or over with a physical, intellectual or psychiatric impairment that prevents them from working, or being re-skilled to work, for 15 hours per week at or above minimum wage for at least two years.⁶⁷

Concession Cards

- 2.79 In addition to income support and supplementary payments, some carers may also receive concession cards. All recipients of the Carer Payment automatically receive a Pensioner Concession Card. Recipients of Carer Allowance (child) receive a Health Care Card issued in the child's name. The Pensioner Concession and Health Care Cards give the cardholder access to low cost medicines through the Pharmaceutical Benefits Scheme, reduced out-of-hospital medical costs through an extended Medicare Safety Net, and access to bulk billed general practitioner (GP) appointments at the GP's discretion for the person named on the card.
- 2.80 Other concessions or subsidies for the person named on the card may be offered to cardholders by state and territory governments (e.g. reductions on public transport fares, reduced council rates, educational concession etc) though these vary between jurisdictions. The range of concessions available to Pensioner Concession Cards holders is more extensive than the range available to Health Care Card holders.⁶⁸

Australian Government Programs and Services

- 2.81 In addition to financial assistance through income support and other supplementary payments, the Australian Government funds a range of other programs and services that directly target carers. As noted earlier in this chapter, there are also a large number of programs and services which

66 Australian Government Departments (FaHCSIA, DoHA & DVA), Submission No 1109, p 21.

67 Recipients of the payment at 10 May 2005 are required to be unable to work 30 hours a week.

68 Australian Government Departments (FaHCSIA, DoHA & DVA), Submission No 1109, p 23.

could be considered to have a dual client base, in that they provide assistance to both the carer and the carer receiver. The main services and programs for carers provided by FaHCSIA, DoHA and DVA are discussed briefly below.⁶⁹

Department of Families, Housing, Community Services and Indigenous Affairs

2.82 FaHCSIA provides a range of carer programs and services which target particular carer groups. Targeted carer support programs administered by FaHCSIA include:

- the Mental Health Respite Program which provides a range of respite options for carers of people with a severe mental illness and for carers of people with intellectual disability;
- Older Carers Respite which is available to carers aged 60 years and over that are caring for a son or daughter with a severe or profound disability aged 25 years or over;
- Respite and Information Services for Young Carers is available to carers up to 25 years of age. This program provides young carers who are at risk of leaving education prematurely with up to five hours in-home respite per week during school term, and up to two weeks respite each year to study for exams, attend training or for recreation;
- Respite and Support for Carers of Young People with Severe or Profound Disability which provides immediate and short term respite for these carers;
- Helping Children with Autism Package which includes the establishment of an advisory service to assist carers of children up to the age of 6 years with autism spectrum disorders to find services and access early intervention;⁷⁰ and
- MyTime Peer Support provides access to facilitated peer support groups for parents and carers of young children with disabilities or a chronic medical condition; a support worker is provided to organise play activities and other assistance to the children while parents participate in activities and discussions.

69 Australian Government Departments (FaHCSIA, DoHA & DVA), Submission No 1109, pp 24-33.

70 This is a joint Australian Government initiative also involving the Department of Health and Ageing and the Department of Education, Employment and Workplace Relations.

- 2.83 Two other FaHCSIA carer initiatives that warrant mention provide assistance with planning of future care arrangements for a care receiver. These are the Special Disability Trusts (SDTs) and Family Relationships Services for Carers.
- 2.84 SDTs enable immediate family members and carers who have the financial means to do so, to make private financial contributions to the Trust for the current and future care and accommodation needs of their family member with a severe disability.
- 2.85 Family Relationships Services for Carers provide advice and mediation to assist families wishing to make arrangements for the future care of their family member with a disability or experiencing disagreement around the future needs of a family member with a disability.

Department of Health and Ageing

- 2.86 The National Respite for Carers Program (NRCP) is the main DoHA funded program providing assistance for carers. The NRCP:
- ... contributes to the support and maintenance of caring relationships between carers and their dependent family members or friends by facilitating access to information, respite care and other flexible respite support appropriate to individual carer needs and circumstances, and the needs of the people for whom they care.⁷¹
- 2.87 Funding under the NRCP is provided for:
- over 600 community based respite services across Australia, delivered in a variety of settings (e.g. in-home, day care centres, residential overnight care) to suit the needs of the carer and the care receiver;
 - 54 Commonwealth Respite and Carelink Centres nationally which provide a single point of contact to assist carers seeking information about community care, aged, disability and other support services available in a local region; and
 - the National Carer Counselling Program offered through the network of state and territory Carer Associations in Australia to provide

71 Australian Government Departments (FaHCSIA, DoHA & DVA), Submission No 1109, pp 24-33.

counselling on issues that are specific to carers needs such as depression, stress-related issues, grief, loss and coping skills.⁷²

- the Carer Information and Support Program supports the development and distribution of national products by the DOHA as well as funding Carers Australia to deliver specialist services through the network of Carer Associations.⁷³

2.88 In addition DoHA funds a number of services which may be seen as having a dual client base, addressing the needs of both the care receiver and the carer. These include community care services provided through the Home and Community Care (HACC) program, aged care services and funding packages, as well as the provision of residential aged care.

2.89 The HACC program provides services such as domestic assistance, assistance with personal care, as well as professional allied health care and nursing services to frail aged and younger people with disabilities. Access to HACC services is based on needs assessment of individuals to establish the level and type of HACC support required. HACC is jointly funded by the Australian Government and by state and territory governments. While the national HACC policy is the responsibility of DoHA, state and Territories governments manage the day to day administration of the program.

2.90 The following aged care packages, while primarily intended to provide support for the care receiver, may also assist carers undertake their caring role:

- Community Aged Care Package (CACP);
- Extended Aged Care at Home (EACH); and
- Extended Aged Care at Home Dementia (EACHD).

2.91 The range of services available under these packages varies but may include domestic assistance, assistance with personal care, clinical care, home safety and modification and transport for the care receiver to medical appointments or to shops. Eligibility for the aged care packages requires a comprehensive assessment of the support needs of the care receiver by an Aged Care Assessment Team (ACAT).

72 Australian Government Departments (FaHCSIA, DoHA & DVA), Submission No 1109, pp 25-26.

73 Australian Government Departments (FaHCSIA, DoHA & DVA), Submission No 1109, pp 25-26.

- 2.92 Only CACP specifically provides temporary in-home respite to enable the carer to have a break. Emotional support and assistance in adjusting to the caring situation is however, available for both the carer and care receiver under EACH and EACHD packages.⁷⁴
- 2.93 Planned and emergency short-term respite care is also available in Australian Government subsidised residential aged care facilities. Except in emergency situations, the care receiver must have been assessed by an ACAT.⁷⁵

Department of Veterans' Affairs

- 2.94 The Department of Veterans' Affairs (DVA) provides carer programs to veterans, war widows and widowers. The Veterans' Home Care program provides low level home care services (e.g. domestic assistance, personal care, respite care and safety-related home and garden maintenance) for eligible veterans, widows and widowers.⁷⁶
- 2.95 In addition, DVA provides a range of other programs to support veterans and war widows/widowers in their homes. While these programs are intended to meet the needs of the veteran client, they can also assist the carer to provide care and include:
- Rehabilitation Appliances Program which provides aids and appliances to eligible DVA clients (e.g. walking frames, continence products and oxygen);
 - HomeFront which provides safety inspections to make homes of eligible clients safer from falls and accident hazards; and
 - access to medical transport for eligible clients.⁷⁷

State and Territory Government Programs and Services

- 2.96 As previously noted, specialist disability services are jointly funded by the Australian Government and by state and territory governments. The roles

74 Australian Government Departments (FaHCSIA, DoHA & DVA), Submission No 1109, pp 27-28.

75 Australian Government Departments (FaHCSIA, DoHA & DVA), Submission No 1109, pp 27-28.

76 Australian Government Departments (FaHCSIA, DoHA & DVA), Submission No 1109, p 33.

77 Australian Government, Department of Veteran's Affairs website, viewed 12 February 2009 at www.dva.gov.au/health/vets_families_carers.htm.

and responsibilities for the funding and administration of specialist disability services are in accordance with the NDA which came into effect on 1 January 2009, replacing the previous CSTDA.

- 2.97 The range of specialist disability services and services provided through other state and territory government programs varies, as do the specifics of eligibility criteria and program design. It is beyond the scope of this report to provide a detailed description of state and territory programs and services. However, submissions from carers have focussed on programs and services which provide:
- alternative care and accommodation (supported accommodation) for carer receivers;
 - early intervention services for children with special needs;
 - assistance or subsidies to obtain access to, or to purchase disability aids and equipment (e.g. the Victorian Aids and Equipment Program and the Community Aids Equipment Program in WA);
 - transport for carers and/or care receivers in order to facilitate access to a range of services, including non-emergency health related appointments (e.g. Patient Assisted Transport Scheme in WA);
 - access to concessions on public transport, utilities (e.g. electricity and gas), reduced motor vehicle registration and local government rates or other subsidies, usually associated with possession of a Pensioner Concession Card; and
 - a companion card though some state and territory schemes, specifically Victoria, WA, SA and Tasmania. These cards enable people with a disability to access social opportunities, events and facilities without having to also pay for the person that must accompany them. Queensland and NSW are currently in the process of implementing companion card schemes.⁷⁸

78 Australian Government Departments (FaHCSIA, DoHA & DVA), Submission No 1109, p 33.

A National and Strategic Approach to Carer Recognition and Policy

- 3.1 This chapter examines the role and contribution of carers to society and identifies the need for greater formal recognition. The chapter will:
- provide information on the caring role and consideration of the contribution that carers make to society;
 - consider the importance of carer recognition and strategies to promote improved carer recognition through:
 - ⇒ initiatives to increase community awareness of carers and promote a better understanding of their needs;
 - ⇒ review of existing legislation and policies that impact on carers; and
 - ⇒ the introduction of national carer recognition legislative and policy frameworks.

The Role and Contribution of Carers

- 3.2 Each caring situation has unique aspects reflecting the circumstances of the carer, the care receiver and the family. The association between carers and care receivers covers the spectrum of family relationships and friendships. Carers provide care for children and adults with a wide range of health and mental health conditions, disabilities and the frail aged. For some, the caring experience may span months or years, for others it spans decades and may involve providing care for one or more care receivers at various times.
- 3.3 Through written submissions and verbal statements to the Inquiry, over 1200 carers have shared their experiences, often describing the range of

tasks that they are required to undertake on a daily or regular basis, and the challenges that they encounter in providing care.¹ While some carers have described the rewards associated with providing care², many have indicated that providing care, even for a loved one, is frequently demanding. The caring role is often a 24 hour a day, seven days a week responsibility.³ Ms Sheralyn Hughes who cares for her 20 year old son with a severe autism spectrum disorder described her role in the following stark terms:

Endless, thankless, poor, a no win situation, desperate, extremely depressing and very bleak.⁴

- 3.4 Another carer, Ms Michela Cardamone, who cares for a family member with a mental illness described her role as follows:

Terrifying, traumatic, overwhelming, confusing, stressful, isolating, lonely, undervalued, under resourced, not understood, unsupported, unheard, invisible, frustrating, depressing, emotionally draining, physically exhausting.⁵

- 3.5 While it is clear that no two caring situations are the same, the excerpts below illustrate the breadth and intensity of the caring role.

Ms Joy Roze - carer for her son with autism spectrum disorder

Carers have a diverse role to play in their caring position dependant on the type of disability involved. There can be heavy lifting or restraint management involved, sleep deprivation, endless appointments to attend, medication to collect and administer, behavioural management to implement, adjust and uphold, extra home duty chores such as more frequent changing of bed linen, cleaning, specialised food preparation and extra laundry.

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- 1 See for example: Ms S Menegatos, Submission No 63, p 1; Ms S Hand, Submission No 322, p 1; Ms M Wright, Submission No 330, p 1; Ms J Schroeter, Submission No 838, p 1; Ms J-A Beattie, Submission No 1045, p 1.
- 2 See for example: Ms A Bellchambers, Submission No 349, p 1; Ms T Hayes, Submission No 933, p 2.
- 3 See for example: Ms T Camilleri, Submission No 48.1, p1; Ms K Stanley, Submission No 51, p 1; Ms S Hughes, Submission No 158, p 1; Ms P Bastow, Submission No 161, p 1; Ms J Thorburn, Submission No 170, p 1; Ms L Brown, Submission No 325, p 1; Ms R May, Submission No 351, p 1; Ms J Gutteridge, Submission No 708, p 1; Mr T Stroud, Transcript of Evidence, 12 August 2008, p 50.
- 4 Ms S Hughes, Submission No 158, p 1.
- 5 Ms M Cardamone, Submission No 799, p 1.

The Carer's role is constant. The Carer is on call 24 hours per day, seven days per week with most of us receiving little or no relief from our caring role.⁶

Ms Kerryn McDonall – carer for her two daughters with disabilities

To care for all my daughters' personal care, medical care, equipment needs, as well as cooking, cleaning, washing, shopping etc etc. These needs are for a lifetime, my eldest daughter is 25 and I am still changing nappies, cleaning up the mess she has made, trying to work out what she wants, putting things away so she doesn't break them, as well as bathing, dressing, cutting up her food, cleaning teeth, doing her hair, putting her shoes on again and again, putting on music in the hope she may stay still for a few minutes.

My 16 year old has a physical disability so I do most of the same for her but with more lifting. Then there are appointments with doctors, specialist, dentists, physios, schools, case workers (who keep changing), to arrange and attend.

Another role is to advocate for my daughters and to find services that meet their needs this takes a lot of emotional energy and time often with very limited results.⁷

Ms Careen Dew – young person assisting with care for her 9 year old brother with multiple disabilities

I am 21 years old and, together with my mum and my 18 year old brother, I care for my younger nine-year-old brother, Alec, who suffers from multiple disabilities which have left him unable to speak, eat, walk and even smile. My caring role for him is quite endless. It also extends to caring for his twin brother who is not disabled but, because Alec has had over 150 hospital admissions and with my mum by his side, I am pretty much the second parent of the house who looks after everything else whilst also trying to work part-time and study law down here in Sydney.⁸

Mr Francis Horgan – carer for his wife with diabetes

As a Carer, I feel that my role is important in facilitating the health and happiness of my wife who is eighty years old: has Type 2 Diabetes for more than ten years: as well as heart/blood pressure problems: loss of balance occasionally and suffers from shortness of breath. I assist my wife in her daily living activities; outside shopping; driving activities and

6 Ms J Roze, Submission No 485, p 2.

7 Ms K McDonall, Submission No 518, pp 1-2.

8 Ms Careen Dew, Transcript of Evidence, 6 August 2008, p 45.

companionship; twenty four hours per day. This support allows my wife to enjoy an independent lifestyle in her own home.⁹

3.6 Despite the diversity of caring situations many carers also share common experiences. In drawing a broader picture of common experiences, Ms Deirdre Croft identified the following four dimensions of the caring role:

- **Physical dimensions of caring** (e.g. lifting, bathing, feeding, managing medication, hygiene requirements, behavioural management etc).
- **Practical dimensions of caring** (e.g. financial and administrative requirements, providing transport, assistance with shopping, domestic maintenance etc).
- **Emotional dimensions of caring** (e.g. based on a personal relationship, concern for, and commitment to, the wellbeing of the person with disability, advocating for and representing their needs etc).
- **Moral/ethical dimensions of caring** (e.g. as a way of living life compassionately with concern and practical consideration for the needs and vulnerabilities of others).¹⁰

3.7 In considering the contribution that carers make to society, many carers firstly describe the direct benefits for the care receivers. Carers emphasised the importance of being able to provide the best possible quality of life for the care receiver and helping to maintain a level of independence thereby preventing early or inappropriate entry into institutional or residential care.¹¹ Many carers also noted that by providing unpaid informal care in their own homes, they are saving governments significant amounts of money.¹² For example, as explained by Ms Saara Arnoldy, a carer of over 30 years for her son with multiple disabilities:

I have been called a hero! I never wanted to be one. I never wanted to be a divorced mother to a child with disabilities. I love my son, so there is only one thing to do, to look after him the best I can. The contribution I have made towards my son's welfare is immeasurable. The contribution I have made to society in monetary form can be calculated in very large figures.¹³

9 Mr F Horgan, Submission No 513, p 1.

10 Ms D Croft, Submission No 1219, p 4.

11 See for example: Ms M Loyer, Submission No 61, p 1; Mr K Matthias & Ms M Matthias, Submission No 710, p 1; Ms M Ross, Submission No 713, p 1; Ms L Dowd, Submission No 848, p 2; Ms J Steepe, Submission No 1023, p 6.

12 See for example: Ms B Kelly, Submission No 12, p 1; Mr N Faint, Submission No 20, p 1; Ms L Baker, Submission No 807, p 9; Mr G Bateson, Submission No 906, p 1; Ms N Jensen, Submission No 1052, p 1; Ms C Gray, Submission No 1133, p 1.

13 Ms S Arnoldy, Submission No 774, p 1.

3.8 There have been several estimates of the imputed economic value of the informal care provided by carers. In 2005, Access Economics estimated the value of the opportunity cost, that is the income forgone by carers spending time providing care rather than undertaking paid work, to be \$4.9 billion for that year.¹⁴ Using the replacement valuation method, that is the cost of buying the equivalent number of hours of care from the formal care sector, Access Economics estimated that the economic value of informal care to be \$30.5 billion for that year.¹⁵ The Australian Institute of Health and Welfare provides another estimate of the economic value of unpaid care (2005-06) for people with disabilities, including those who need assistance because of old age as \$27.4 billion.¹⁶

3.9 Although the estimates vary to some degree, the conclusion is that the current mix of informal and formal care arrangements results in significant savings for governments. However, these savings to governments have come at a cost to carers and their families. As noted by ANGLICARE (Sydney):

Informal care combined with some community-based care costs society far less than institutionalised care. It is the informal care component that reduces the cost of care, however this is the form of care that is least subsidised. Government benefits to informal carers were estimated at 35% of the opportunity cost to carers in 2005.¹⁷

3.10 Importantly, as indicated by many submissions the contribution of carers to Australian society can not be measured in purely monetary terms. More broadly carers also contribute by:

- building and maintaining family life and relationships;
- promoting social inclusion for people with disabilities, mental illness, serious medical conditions and for the frail aged; and
- supporting community cohesion.

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

15 Access Economics (2005), *The Economic Value of Informal Care*, p 15.

16 Australian Institute of Health and Welfare, Submission No 1033, p 4.

17 ANGLICARE Sydney, Submission No 769, p 15.

Carer Recognition

- 3.11 Despite their significant contribution to society, many carers have stated that they feel their role is still not fully understood or appreciated by governments or by the wider community, including professional groups that have significant and frequent interaction with carers (e.g. health professionals, community service providers). As a consequence, many consider that the contribution of carers continues to be undervalued.¹⁸ As observed by the Carers Support Network of South Australia:

Generally speaking, there is an appalling level of awareness within our society of the impact of caring. The financial, social, medical impacts are often profound and result in poverty, social isolation and poor health of the carer. Doctors, teachers, health workers, and above all - Centrelink workers, have poor understanding of what a day in the life of a carer looks like.¹⁹

- 3.12 Also describing a general lack of recognition and appreciation, the National Carers Coalition stated:

There can be little doubt that the role and contribution of family carers is undervalued, taken for granted, exploited and clearly sidelined by our governments and our society; by all those who should care.²⁰

- 3.13 As one carer observed, for her and for many other carers, caring is effectively a 'hidden' activity, with even family, friends and neighbours failing to fully appreciate the demands associated with the caring role:

It is a hidden life because most of it occurs behind closed doors. Nobody, apart from my husband and children - not my extended family or even my closest friends and definitely not my neighbours - know what I do and how hard I work.²¹

- 3.14 Time and time again carers have specified the best way to recognise carers and to demonstrate that their contribution is genuinely valued, is through adequate provision of practical supports and services both for carers and
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18 See for example: Palliative Care Australia, Submission No 688, p 1; Name withheld, Submission No 1038, pp 1-2; Ms L P Dryburgh, Submission No 1048, p 1; Ms H Johnson, Transcript of Evidence, 12 August 2008, p 60; Ms W L Cheung, Transcript of Evidence, 12 August 2008, p 41.

19 Carers Support Network of South Australia, Submission No 675, p 5.

20 National Carers Coalition, Submission No 571, p 10.

21 Name withheld, Submission No 1248, p 1. See also: Ms C Alliston, Transcript of Evidence, 13 August 2008, p 50.

care receivers.²² Specifically, carers have frequently called for increased levels of income support, greater assistance with meeting the additional costs of disability and care, greater access to community care services, particularly suitable respite, and for improved access to services for care receivers, including a range of supported accommodation options. The importance of demonstrating carer recognition through the provision of adequate supports and services is illustrated by the following statements:

Ms Deborah Edwards - carer for her severely disabled adult son

We work day in and day out, but we're not seen as workers. We save society a 'bucket load' of money, but are never thanked for that. We are the hidden army, as we have neither the time and energy nor the money to participate in society to any great extent, so we are unnoticed and easily ignored. ... a change in attitude towards Carers at a Government level is needed. Total reform of the way financial and physical support is delivered to us so that we are no longer 'welfare recipients' with all the stigma that is attached to that, but partners who carry out critical work for Government in a cost-effective way. Until then I don't believe we will truly feel that we are valued members of society at large.²³

Ms Narelle Hughes - carer for her adult daughter with profound intellectual and physical disabilities

We have all heard the wonderful words spoken by many and varied people about the great contribution carers make in society and I am pleased that there is some recognition of my seemingly never-ending role. However, words do not put food on the table, or compensate carers for the loss of earnings they may have made, or help to accumulate savings for the future, or fund a retirement which is unlikely to come anyway. We are feted during Carers Week and given a 'bonus' in the Budget if we fight for it. Carers of working age need to be paid a wage commensurate with the work they do. Carers need to be recognised as workers who are providing a vital service which would otherwise need to be provided by the Government.²⁴

22 See for example: Ms L Belsham, Submission No 96, p 1; Ms J Cheal, Submission No 116, p 2; Mr I Morris, Submission No 162, p 1; Ms C Agnew, Submission No 166, p 1; National Carers Coalition, Submission No 571, pp 15-17; Ms J Bourke, Submission No 981, p 6; Name withheld, Submission No 1038, pp 1-2; Ms A-M Newbold, Submission No 1042, p 1; Ms D Currow, Submission No 1180, pp 1-3.

23 Ms D Edwards, Submission No 159, pp 1-2.

24 Ms N Hughes, Submission No 830, p 3.

3.15 The Committee has become only too aware of the significant social and economic contribution that carers make to Australian society. Clearly, given the considerable financial and personal costs for carers themselves, the importance of adequately recognising their contribution is fundamental. Many carers have identified the critical importance of practical measures which recognise the contribution of carers by providing adequate supports and services to meet the needs of carers, care receivers and their families. Detailed consideration of the issues associated with supports and services for carers is presented later in the report. However, the remainder of this chapter considers other options for enhancing carer recognition. These are:

- initiatives to increase community awareness;
- review of existing legislation and policy;
- the introduction of national carer recognition legislation and policy; and
- a review of arrangements for systemic carer advocacy.

Increased Community Awareness

3.16 A number of submissions have referred to recent media exposure that has raised the profile of carers, highlighting their plight and the critical role that they play in society.²⁵ However, some carers and organisations have identified that there is still a need for further awareness raising through a national publicity campaign and community education.²⁶ For example, the Carers Support Network of South Australia indicated its support for:

Public awareness campaigns about:

- the financial contribution that Carers make to our society (billions of dollars per year);
- the role of Carers and what they do - legitimise their role by providing information throughout public media about their levels of skills and knowledge.²⁷

25 See for example: Ms P Bodegraven, Submission No 509, p 2; Ms L Baker, Submission No 807, p 7; Ms D Etherington, Submission No 1204, p 4.

26 See for example: Name withheld, Submission No 22.1, p 1; Taskforce on Carer Costs, Submission No 23 (Attachment 1), *The Hidden Face of Care: Combining work and caring responsibilities for the aged and people with a disability*, p 36; Ms P Bodegraven, Submission No 509, p 2; Carers Support Network of South Australia, Submission No 675, p 5; Carers SA, Submission No 684, p 11; National Seniors Australia, Submission No 686, p 4; Brotherhood of St Laurence, Submission No 694, p 2; Sir Roden Cutler Charities, Submission No 700, p 2; Ms K McCann, Submission No 751, p 7; Name withheld, Submission No 1044, pp 1-2; Ms C Masolin, Submission No 1190, p 1; Ms H Johnson, Transcript of Evidence, 12 August 2008, p 60.

27 Carers Support Network of South Australia, Submission No 675, p 5.

- 3.17 Similarly, Anglicare Canberra and Goulburn also recommended a national community awareness campaign to raise the profile of carers using electronic and print media, billboards and community events. In making this recommendation, Anglicare Canberra Goulburn suggested that increased community awareness might 'mobilise' enhanced community support for carers, saying:

The Australian community, in general has demonstrated a great generosity of spirit towards people who experience misfortune and those who are disadvantaged. Specific education campaigns to help raise awareness of the circumstances carers find themselves in, will be likely to mobilise members of the community to show their support in practical ways.²⁸

- 3.18 Carers Tasmania identified the following possible benefits of increased community education on the role of carers and their contribution to society:

Greater community education is needed to help people understand more about caring. This will have a two-fold effect: firstly, to assist people to self-identify and self-refer to services if they have support needs; and, secondly, to increase wider community awareness of caring needs and promote inclusion.²⁹

- 3.19 In addition to raising awareness in the wider community, evidence has also identified the need for initiatives that target specific professional groups. For example, the submission from the Queensland Government recommended:

Development and delivery of programs to raise awareness of and responsiveness to carer's needs and issues within services, government agencies, businesses, and educational institutions.³⁰

A National Community Education Campaign

- 3.20 The Committee agrees that a national community education campaign to raise the profile of carers is needed to enhance carer recognition and promote a greater appreciation of the valuable contribution that carers make to society. As well as validating the role of carers, a better appreciation of the challenges associated with providing care, and a better

28 Anglicare Canberra and Goulburn, Submission No 724, p 9.

29 Carers Tasmania, Submission No 671, p 8.

30 Queensland Government, Department of Premier and Cabinet, Submission No 1203, p 9.

understanding of the specific needs of carers should promote a more inclusive and supportive society.

- 3.21 In addition to raising the profile of carers in the community more broadly, the Committee agrees that there is also a need for education that specifically targets particular sectors and professional groups. For example, a campaign could specifically target employees in the health and community services, education and private sectors.
- 3.22 As noted in chapter 2, a national community education campaign should also seek to target those carers who may not readily self-identify as such, and to address the concerns of those carers who may be reluctant to disclose their role to others. Importantly the campaign should advise these carers of the government services available to them.
- 3.23 An effective national education campaign will need to be tailored to the different target groups, taking into account strategies to reach new carers, young carers, carers from culturally and linguistically diverse (CALD) and indigenous backgrounds. Similarly, publicity targeting specific sectors or professional groups will need to be delivered in different ways.
- 3.24 Although the Committee considers that a national community education campaign is warranted, it also acknowledges that there is limited value in raising community awareness in the absence of other measures which increase access to supports and services for carers and care receivers. Therefore, the Committee emphasises that its support for a national community education campaign should be viewed as part of a proposed broader suite of reforms to recognise carers through practical measures.

Recommendation 2

3.25 That the Australian Government, through the Department of Families, Housing, Community Services and Indigenous Affairs and the Department of Health and Ageing support a national community education campaign to promote a better understanding of the role and needs of carers, and an appreciation of the contribution that carers make to society.

The campaign should also include components to promote increased awareness of their role among 'hidden' carers who may not readily self-identify and to address the concerns of carers who may be reluctant to disclose their role to others.

Carer Recognition through Legislation and Policy

3.26 Evidence from individuals and from organisations have emphasised the importance of developing robust legislative and policy frameworks to raise the profile of carers and to uphold carer rights. Several submissions have referred to frameworks of carer legislation and policy in other countries, such as the United Kingdom, Ireland, New Zealand, Canada and Sweden.³¹

3.27 For example, Ms Mary Lou Carter notes that the United Kingdom has enacted three pieces of carer specific legislation.³² Between them these confer a number of rights for carers including:

- an assessment of the carer's ability to provide care;
- an assessment of the carer's own needs; and
- access to services and information.³³

3.28 To complement this legislation in June 2008 the United Kingdom Government released its carer strategy *Carers at the heart of 21st century families and communities*. The strategy sets out the short-term agenda to be

31 See for example: National Carers Coalition, Submission No 571, p 14; Carers Australia, Submission No 699, pp 31-32; Ms N Brown, Submission No 951, p 7; Ms M L Carter, Submission No 1291, pp 4-5; Ms A Ashton, Transcript of Evidence, 26 September 2008, p 5.

32 These are: *The Carers (Recognition and Services) Act, 1995*; *The Carers and Disabled Children Act 2000*; and *The Carers (Equal Opportunities) Act, 2004*.

33 Ms M L Carter, Submission No 1291, pp 4-5. See also: Ms N Brown, Submission No 951, p 7.

achieved by 2011 and a long-term vision for the future support of carers to be achieved by 2018.³⁴ The essence of the strategy is embedded in its vision statement:

Our vision is that by 2018, carers will be universally recognised and valued as being fundamental to strong families and stable communities. Support will be tailored to meet individuals' needs, enabling carers to maintain a balance between their caring responsibilities and a life outside caring, while enabling the person they support to be a full and equal citizen.³⁵

- 3.29 Arguing the case for a legislative basis to support carer rights in Australia, and to provide a legislative foundation for the implementation of carer policy, Carers ACT stated:

Legislation is a critical component of social structure. It provides a foundation of support which underpins policy development and service provision. It outlines the rights and responsibilities of all people affected, and it ensures their due protection under the law. Carers may feel more secure when their rights and responsibilities are clearly set out in such a charter.³⁶

- 3.30 In also providing its support for carer legislation and national strategic carer policy, Carers Australia observed:

Carer legislation, carer policies and/or action plans have been introduced in all states and territories and some overseas countries. This action is a vehicle for enhancing and embedding recognition of carers and in some cases conferring rights or provisions within existing legislation.³⁷

- 3.31 With regard to the preferred legislative model Carers Australia noted that carer recognition legislation may require reform to existing legislation, the introduction of new legislation or a combination of both, stating:

Whether it is one act or more and/or reform to existing legislation is a question about the best form of legislation. However to

34 United Kingdom Government, Department of Health website, *Carers at the heart of 21st century families and communities* (2008), viewed 25 February 2009 at www.dh.gov.uk/en/publicationsandstatistics/publications/publicationspolicyandguidance/DH_085345.

35 United Kingdom Government, Department of Health website, *Carers at the heart of 21st century families and communities: a caring system* (2008), p 9, viewed 25 February 2009 at www.dh.gov.uk/en/publicationsandstatistics/publications/publicationspolicyandguidance/DH_085345.

36 Carers ACT, Submission No 702, p 13.

37 Carers Australia, Submission No 699, p 9.

demonstrate true recognition for the role and contribution of carers, national carer legislation is needed.³⁸

The Framework of Existing Legislation and Policy

3.32 The scope of existing legislation and policy which directly or indirectly impacts on carers is broad. As shown in Table 3.1 some states and territories, have already introduced specific carer recognition legislation. Some states and territories, either in addition to carer specific legislation or as an alternative to carer specific legislation, have carer policies in the form of carer strategies or action plans. Through these strategies and action plans governments articulate their commitments to carers.

Table 3.1 State and Territory Specific Carer Recognition Legislation, Strategies and Action Plans

State / Territory	Specific Carer Recognition Legislation ³⁹	Carer Strategy / Action Plan
Australian Capital Territory	No	Caring for Carers Policy 2003 Carers Action Plan 2004-08
New South Wales	No	Carers Action Plan 2007-12
Northern Territory	<i>Carers Recognition Act 2006</i>	Carers Charter
Queensland	<i>Carers Recognition Act 2008</i>	Carers Recognition Policy 2003 Carers Action Plan 2006-10
South Australia	<i>Carers Recognition Act 2005</i>	SA Carers Policy Carers Charter
Tasmania	No	No
Victoria	No	Caring Together: a Carer Participation Action Plan 2003-08
Western Australia	<i>Carers Recognition Act 2004</i>	Carers Plan for Western Australia 2004-07

Source: Parliament of Australia, Parliamentary Library 2009.

38 Carers Australia, Submission No 699, p 10.

39 Table 3.1 lists specific carer recognition legislation introduced by states and territories. The table does not include reference to Acts introduced to increase carer recognition through amendments to existing legislation as introduced in NSW, ACT or Victoria.

3.33 Evidence to the Inquiry indicates that the carer recognition legislation and policies that have been introduced by the states and territories are generally viewed favourably. For example, Carers Tasmania outlined the potential benefits of carer recognition legislation as follows:

Carer charters, such as those in operation in Western Australia and in the Northern Territory have proved that legislated minimum standards are the surest way of beginning a process of consistent compliance across whole of government and related services. These standards set clear and achievable guidelines for carer access to information, consultation in care processes, and provision of information. They also provide for strategic consultation, representation and participation in all planning matters related to carers.⁴⁰

3.34 Emphasising the importance of state and territory based carer specific legislation to support carer rights and reinforce carer policy, Ms Dianne McCarthy of the Association for Children with a Disability observed:

I would like to say that a [carers] charter basically means little or nothing unless there is legislation to back it up. There are already some charters that currently exist and there are some efforts in this state [Victoria] to introduce a carers charter as well. But that is not backed by legislation. That is the essence of it. One thing complements the other.⁴¹

3.35 In addition to the state and territory based carer recognition legislation, carers are potentially affected by other legislation, including human rights, equal opportunities and anti-discrimination legislation which may be international, national, or state and territory based.⁴²

3.36 Therefore, rather than introducing carer recognition legislation, some states and territories have elected to increase carer recognition and rights through amendments to existing legislation. For example, the *NSW Anti-Discrimination Amendment (Carers Responsibilities) ACT 2000 (NSW)* amended the *Anti-Discrimination Act 1977 (NSW)* to include a provision prohibiting unlawful discrimination on the grounds of caring

40 Carers Tasmania, Submission No 671, p 14.

41 Ms D McCarthy, Transcript of Evidence, 12 August 2008, pp 94-95.

42 See for example: Carers South Australia, Submission No 684, p 10; ACT Government, Submission No 1000, p 2.

responsibilities.⁴³ More recently through the *Carer Recognition Legislation Amendment Act 2006 (ACT)* the ACT Legislative Assembly introduced amendments to the *Discrimination Act 1991 (ACT)*, *Guardianship and Management of Property Act 1991 (ACT)* and to *Human Rights Commission Act 2005 (ACT)* to strengthen a number of provisions relating to carer recognition.⁴⁴

3.37 The introduction of state and territory based carer recognition legislation and amendments to broader human rights and anti-discrimination legislation suggest that recognition of carers is increasing. However, inconsistencies between jurisdictions have prompted calls from carers and organisations for a legislative framework that is both more robust and consistent between the jurisdictions.⁴⁵

3.38 In addition to concerns regarding the lack of consistency in carer recognition legislation, an issue that has frequently been raised relates to the limitations of some legislative and policy frameworks in terms of acknowledging carers across all government portfolio area. For example, finance, housing, employment, education and transport. The importance of acknowledging carers across the full range of services was emphasised by the Disability Support Commission which noted that:

Access to other [mainstream] essential services – especially housing, transport, education and health – is a constant struggle for many carers.⁴⁶

3.39 Although WA was the first state to introduce carer recognition legislation and policy, Mr Paul Coates of Carers WA told the Committee that there is a need to broaden the existing legislation:

We are looking for joined-up thinking in government. By that I mean not just focusing on carers programs but looking at all areas of policy. For example, in the area of affordable housing we

43 Parliament of New South Wales website, viewed 26 February 2009 at www.parliament.nsw.gov.au/prod/PARLMENT/NSWBills.nsf/0/A62946D1E1E60DFECA2568D3001C3E30?Open&shownotes.

44 ACT Government, ACT Legislation Register website, viewed 26 February 2008 at www.legislation.act.gov.au/a/2006-47/default.asp.

45 See for example: Ms M Trewhella, Submission No 154, p 5; Ms J Harrison, Submission No 301, p 1; National Carers Coalition, Submission No 571, p 3; Carers NSW, Submission No 661, pp 9-10; Carers South Australia, Submission No 684, p 10; Ms T Hayes, Submission No 933, p 3; Ms E Walker, Submission No 973, p 2; Mr K Wood, Submission No 1007, p 3; Disability Services Commission, Submission No 1039, p 3; Ms J-A Beattie, Submission No 1045, p 3; Ms C Masolin, Submission No 1190, p 3; Ms M Ryan, Submission No 1155.1, p 22.

46 Disability Support Commission, Submission No 1039, p 5.

believe that carers should be taken account of in policy and service delivery. Carers could be included as one of the priority groups in the allocations of affordable housing policy, rental policy and arrears operational policies to take account of carers' needs there. In education, we believe that awareness and recognition of carers should be endemic throughout the whole education system, particularly regarding young carers. In the school and education system, for example, teachers need to be made aware of the issues of young carers and the fact that they may have young carers in their class so that there is more flexibility in the delivery of education. We believe the transport policy and system need to take account of carers in allowing access, which is particularly important in regional and remote areas.⁴⁷

The Need for Review of Existing Carer Legislation and Policy

- 3.40 The Committee agrees that a robust legislative and policy framework will enhance carer recognition and provide the basis to develop policy, programs and services that better meet the needs of carers. To date the approach to increasing carer recognition has been on a state by state basis with some states and territories introducing specific carer recognition legislation and/or policies, while others have amended broader non-carer specific legislation. As a consequence, the extent to which existing legislative and policy frameworks address the needs of carers varies between jurisdictions.
- 3.41 To reduce these inconsistencies the Committee concludes that a systematic review of existing legislation and policy, in particular in relation to health and community care, is warranted in order to ensure carers are adequately recognised. Given the need to achieve harmonisation across jurisdictions, the Committee believes that consideration by the Council of Australian Governments (COAG), through the Health Community and Disability Services Ministerial Council (HCDSMC) is required.
- 3.42 However, given the breadth of legislation and associated policy that may impact on carers, the Committee is also cognisant that some relevant items will be outside the scope for consideration by the HCDSMC. The Committee suggests that a review of broader legislation that impacts on carers may also need to be considered, possibly under the auspices of COAG.

47 Mr P Coates, Transcript of Evidence, 23 July 2008, pp 2-3.

Recommendation 3

3.43 **That the Minister for Families, Housing, Community Services and Indigenous Affairs and the Minister for Health and Ageing propose to the Health, Community and Disability Services Ministerial Council (HCDSMC) that the Australian Government and each jurisdiction review existing legislation and policy relating to health and community care to ensure that carers are adequately recognised.**

If legislation affecting carers falls beyond the jurisdiction of HCDSMC then it should be referred to the appropriate ministerial council for review.

A National and Whole of Government Approach to Carer Legislation and Policy

3.44 To address concerns regarding the inconsistency of carer recognition legislation and policy between states and territories, and to achieve greater cross portfolio consideration of carer issues, the Committee has received evidence which suggests that there is a need for a national and whole of government approach to carer recognition legislation and policy.⁴⁸

3.45 Providing her support for the introduction of national carer legislation, Ms Valerie Simpson, a carer for over 30 years for her son with high support needs, as well as for her two other adult children also with disabilities, stated:

I strongly believe there should be Uniform Carer Legislation in place throughout Australia, in this way Carers will be recognised by governments.⁴⁹

3.46 Another long term carer living in WA and providing care for her husband with a degenerative neurological condition, also argued the case for national legislation, saying:

In this state [Western Australia] we have the Carer Recognition Act 2004 which seeks to acknowledge the valuable role of carers and bring them into the decision making processes via

48 See for example: Name withheld, Submission No 559, p 4; Ms K McCann, Submission No 751, p 5; Name withheld, Submission No 853, p 3; Families Australia, Submission No 1088, p 18; Ms C McDiarmid, Transcript of Evidence, 20 August 2008, p 48; Mr D Herd, Transcript of Evidence, 6 August 2008, p 63; Ms R Warmington & Mr P Saunders, Transcript of Evidence, 13 August 2008, pp 10-11.

49 Ms V Simpson, Submission No 260, p 5.

consultation with them on both service provision and strategic direction of health and disability services.

This is a useful first stage of valuing carers and one that the Federal government could follow to ensure that across all sections of government, attention was paid to make relevant decisions considering people with disabilities, chronic illness and frailty and the needs of their carers. Federal legislation could bring parity across the states.

Federal legislation could set the stage for national leadership on a wide range of decision making levels and policies such as: planning infrastructure of public resources and venues which address access issues, this equates to adequate Australian building codes provisions.⁵⁰

- 3.47 The Ethnic Disability Advocacy Centre, while acknowledging state and territory legislative advances in carer recognition, argued for national legislation and associated policy, saying:

Each of the State governments through their Carer Recognition Acts and policies is demonstrating a desire to support carers. However there is still a need for a national carer's legislation with targeted strategies and action plans for supporting carers - especially with integration of shared responsibilities between state and commonwealth governments, families and communities.⁵¹

- 3.48 Carers NSW raised the importance of national carer recognition legislation that complements state and territory legislation, stating:

Carers NSW believes national overarching legislation is important to recognise, protect and provide equal opportunity to carers across Australia. The key to effective national carer legislation will be to ensure its compatibility to state and territory legislation so that one does not negate the other.⁵²

- 3.49 Mr Dougie Herd from the Office of the Disability Council of New South Wales called for the Australian Government to take the lead in developing national carer legislation and policy, saying:

We need the Parliament of Australia, the Government, to give a lead that brings together the different stakeholder interests of

50 Name withheld, Submission No 853, p 3.

51 Ethnic Disability Advocacy Centre, Submission No 787, p 9.

52 Carers NSW, Submission No 661, p 9.

people with disability and their family members, friends and others. It brings to some kind of resolution the problems that have existed ... between states and territories. Unless we get the balance between the states and federal system right we will continually have a problem of people not knowing where the lead should come from and therefore what they should expect from different arms of government.⁵³

- 3.50 Ms Tania Hayes, a full time carer for her husband for the past 11 years also noted the challenges for carers that arise as a consequence of the involvement of multiple government agencies representing various portfolio interests, noting:

Currently carer issues cross many government programs. No single Australian Government agency has responsibility for coordinating carer support policies. Each of these agencies has their own priorities that often take precedence over the interests of carers. There needs to be a co-ordinated approach to ensure policies work together to address the range of carer needs in a way that allows flexibility and options for individual carers and their families.⁵⁴

- 3.51 Summarising information provided by a number of Defence Force family carers in relation to the importance of national carer policy, the submission from the Defence Special Needs Support Group reported:

... carers felt that they were not valued nor recognised for the contribution that they make in society. Some expressed concern that there was no National Carers Strategy or Policy at a Federal level to recognise their caring role. They felt that this would assist with job security, support and appropriate service provision and provide recognition at a high level.⁵⁵

- 3.52 To guide the implementation of legislated carer rights and to monitor outcomes, evidence has also highlighted the importance of developing an adequately resourced national carer strategy or action plan. Commenting on the complementarity of national carer legislation and a national carer action plan, Ms Annemarie Ashton of Carers ACT said:

To have one without the other, you would miss out on some essential components. Having an action plan without the

53 Mr D Herd, Transcript of Evidence, 6 August 2008, p 58.

54 Ms T Hayes, Submission No 933, p 3.

55 Defence Special Needs Support Group, Submission No 695, p 2.

legislation would make it too easy for everything to just get shelved if there was a change of government.⁵⁶

3.53 As also explained by Ms Joan Hughes, Chief Executive Officer of Carers Australia:

Carers keep saying, 'Why don't people value and acknowledge what we do?' We believe that you can do that within legislation, but you also have to have a strategy; you have to be able to monitor whether that is having an impact on carers' lives.⁵⁷

Elements of National Carer Legislation and Policy

3.54 In considering the potential elements of national carer legislation and policy, evidence to the Inquiry has suggested the following components:

- increased recognition of carers by:
 - ⇒ the wider community to support an enhanced awareness of the challenges carers face and the needs of carers⁵⁸;
 - ⇒ governments to promote carer involvement through consultation and ongoing engagement in the development of carer legislation, policy and service planning⁵⁹; and
 - ⇒ professionals working in the health system and community care system to acknowledge the involvement of carers as partners in care.⁶⁰
- the right of carers to receive an assessment of their health and welfare needs, their information and skills development needs, and their needs for supports and services to assist them in their role;
- access to supports and services to assist carers to provide sustainable care and/or which allow the carer to access life choices beyond their caring role; and
- support for carer participation in education and/or employment, including carer rights in the workplace.⁶¹

56 Ms A Ashton, Transcript of Evidence, 26 September 2008, p 7.

57 Ms J Hughes, Transcript of Evidence, 28 November 2008, p 13.

58 See for example: Carers SA, Submission No 684, p 28;

59 Queensland Government, Department of Premier and Cabinet, Submission No 1203, p 9.

60 See for example: Carers Victoria, Submission No 652, p 32; Ms M Wells, Submission No 1034, p 3.

61 See for example: National Carers Coalition, Submission No 571, p 40; Carers Victoria, Submission No 652, p 32; Disability Council of NSW, Submission No 662, p 9; Carers

- 3.55 Advocates for national carer legislation and policy also argue that it should acknowledge the diverse needs of different carer populations, including young carers, CALD carers and Indigenous carers.⁶²
- 3.56 The importance of including processes for assessing the impact of a national care legislation and policy, for monitoring compliance and providing a mechanism for carers to raise grievances or complaints has also been emphasised.⁶³ With regard to establishing a suitable grievance process, Carers Australia suggest that the following models are worthy of consideration:
- a dedicated Commissioner within the Human Rights and Equal Opportunity Commission;
 - an independent Carer Commissioner established under specific carer legislation, along the line of Children's Commissioners at the state level; or
 - a Carer Ombudsman position within the Commonwealth Ombudsman's Office.⁶⁴
- 3.57 Several submissions have also noted the importance of providing adequate funding and resources to support the implementation and effective operation of a national carer legislative and policy framework.⁶⁵ In relation to this, Ms Annemarie Ashton of Carers ACT stated:
- It is very important that the [national carer recognition] charter also has provision to resource an education program. Having the best charter in the world is not any good if nobody in public or in government knows it is there, how to use it and what it means. We would like an obligation that all carers are informed of their rights and responsibilities under any such charter and that service providers have that information as well so they fully understand rights and responsibilities of carers and also of the health profession.
- We would like to see an element of compliance in the charter. If you do not actually put a compliance mechanism within the

Australia, Submission No 699, pp 9-11; Ms M Wells, Submission No 1034, p 3; Ms M L Carter, Submission No 1291, p 11; Ms A Ashton, Transcript of Evidence, 26 September 2008, p 5.

62 See for example: Carers NSW, Submission No 661, p 33; Carers SA, Submission No 684, p 28; Ethnic Disability Advocacy Centre, Submission No 787, p 19; Queensland Government, Department of Premier and Cabinet, Submission No 1203, p 10.

63 See for example: Carers Australia, Submission No 699, p 12; Ms A Ashton, Transcript of Evidence, 26 September 2008, pp 5-6.

64 Carers Australia, Submission No 699, p 12.

65 See for example: Australian Association of Families of Children with a Disability, Submission No 581, p 2; Carers ACT, Submission No 702, p 14.

charter, government departments and agencies will not address and achieve that systemic reform.

The establishment of an appropriate federal body is essential to review the implementation of such a charter, to receive and review reporting on compliance, to receive complaints from carers on non-compliance and to have sufficient power to take proper action to redress evident non-compliance.⁶⁶

Support for National Carer Legislation and Policy

- 3.58 The Committee acknowledges the weight of evidence urging an improvement in carer recognition and carer rights through specific carer recognition legislation and associated policy. While recognising that most states and territories already have carer recognition legislation and/or carer strategies or action plans, the Committee believes that a national approach to establish consistent and minimum acceptable standards is justified. Therefore, the Committee supports the introduction of overarching national carer legislation to complement existing state and territory legislation.
- 3.59 The Committee also believes that national carer legislation will need to be complemented by national carer policy which details precisely how and when governments will meet their commitments to carers. Although the Committee sought advice from several sources on the essential elements for inclusion in a national carer recognition framework, it is clear that further detailed consideration and consultation with key groups, including with carers themselves, is required. Importantly, national carer policy, as with national carer legislation, will need to build on and complement existing state and territory frameworks.

66 Ms A Ashton, Transcript of Evidence, 26 September 2008, pp 5-6.

Recommendation 4

3.60 **That the Minister for Families, Housing, Community Services and Indigenous Affairs seek the Health, Community and Disability Services Ministerial Council to develop a nationally consistent carer recognition framework, comprising:**

- **national carer recognition legislation, which complements state and territory carer legislation; and**
- **a national carer strategy which builds on and complements state and territory carer policies.**

3.61 Importantly, once established the effective implementation and operation of a national carer recognition framework will require adequate resourcing to support an education program to inform carers, governments, community care service providers, health professionals and others of their rights and responsibilities under the framework. The framework will also need to possess mechanisms for monitoring compliance, for assessing outcomes for carers and for addressing any grievances that may arise.

A National Coordination Mechanism or Office for Carers

3.62 In addition to calls for the introduction of a national carer recognition framework, submissions from some carers and organisations have identified the need for a mechanism or entity to oversee the development of carer legislation, policy, programs and services that are nationally coordinated, effectively linked across all tiers of government and across portfolios. To achieve coordination across the various tiers of government, Carers SA proposed:

That strategic partnerships be developed between national and state jurisdictions similar to the Commonwealth State and Territories Disability/Council of Australian Governments Agreements be explored as avenues for a national/state strategic nexus for carer support.⁶⁷

3.63 Based on her own experiences of providing care both for her elderly father and for her son with profound and severe disabilities, Ms Helen Johnson

⁶⁷ Carers SA, Submission No 684, p 7.

highlighted apparent inequities in the levels of support available to the frail aged and their carers in comparison to younger people with disabilities and their carers, noting:

... there is so much more funding available to those who are ageing and support for their Carers in comparison to parents and/or Carers who are caring for children and young adults with a disability for a greater length of time.⁶⁸

- 3.64 To address this inequity Ms Johnson proposed that responsibility for the provision of supports and services for the frail aged, for people with disabilities and for their carers could be assumed by a single Australian Government portfolio, suggesting:

Perhaps the whole portfolio needs to be called 'Health, Ageing, Disability and Carers (HADC) portfolio. This will bring responsibility at a Commonwealth level and hopefully a positive outcome for some of the most vulnerable members of the Australian community.⁶⁹

- 3.65 Ms Mary Walsh, who has also provided long term care for more than one care receiver with differing care needs, highlighted the inefficiencies for the Australian Government and for carers arising as a consequence of separated portfolio responsibilities, explaining:

... having Health and Ageing (Aged care and HACC) in one department, and Disability (FaHCSIA) in a separate department are internal barriers which create inefficiencies for Government and additional barriers for carers irrespective of the type of carer. Many carers of people with lifetime disability are now also carers for their ageing parents, so they have to deal with two separate departments - as well as Centrelink and the medical fraternity.⁷⁰

- 3.66 To effectively administer and coordinate carer legislation, policy, programs and services, some submissions have suggested that there is a need for the establishment of a single national government entity.⁷¹ For example, Palliative Care Australia (PCA) explained:

68 Ms H Johnson, Submission No 1178, p 2.

69 Ms H Johnson, Submission No 1178, p 3.

70 Ms M Walsh, Submission No 752, p 4.

71 See for example: Name withheld, Submission No 500, p 26; Carer Support and Respite Centre, Submission No 585, p 3; Carers Support Network of South Australia, Submission No 675, p 4; National Seniors Australia, Submission No 686, p 5; Australian Association of Gerontology, Submission No 915, p 1.

To date there has been little coordination of service funding and service provision across federal, state and local government areas and limited co-ordination between voluntary agencies, leading to unequal social and geographical distribution of services. PCA believes a key contribution of an 'Office for Carers' could be to support better outcomes through greater coordination.⁷²

3.67 Advocating for the establishment of a 'National Office for Carers', Carers Australia observed:

Carer issues and policies sit across many government portfolios. There is currently no framework to assist departments achieve coherence across policy and program initiatives. Also there is no vehicle for coordinating a broad national carer strategy or action plan. This is a perpetual challenge for governments.⁷³

3.68 Carers Australia proceeded to make the following suggestions in relation to a possible location for a National Office for Carers:

The optimal location of this office is with the Department of Prime Minister and Cabinet in line with its strategic influence and coordinating role across government.

The Federal Government has established an Office of Work and Family and one option is that the Office for Carers be located within this structure. However the Government is also in the process of developing its social inclusion agenda and strategy and it may be that a future Social Inclusion Unit is established. This may be an alternative structure within which an Office for Carers could be situated.⁷⁴

Support for Increased Coordination

3.69 Given the need to achieve a national framework of carer legislation and policy that is effectively linked across all levels of government and portfolio, the Committee agrees that there is a need to establish a coordinating mechanism or entity. Rather than seeking to establish a new entity, the Committee considers that there is merit in the suggestion to embed the functions of a national office for carers in an existing Australian Government department.

72 Palliative Care Australia, Submission No 688, p 8.

73 Carers Australia, Submission No 699, p 10.

74 Carers Australia, Submission No 699, p 10.

- 3.70 Given its role in coordinating the administration of legislation and policy across Australian Government departments and in supporting intergovernmental relations with state and territory governments, the Department of Prime Minister and Cabinet (PM&C) might be an appropriate location for a national office for carers.⁷⁵ It is unclear however, whether the role of an office for carers could be assumed by the Office of Work and Family that already exists within PM&C, or whether a new office will need to be established within this Department to support the role.

Recommendation 5

- 3.71 **That the Department of Prime Minister and Cabinet establish a national office for carers, either within the Office of Work and Family or as a new office within the Department.**

That the Australian Government nominate a lead Minister to be responsible for overseeing the development of nationally coordinated carer legislation, policy, programs and services so that these are effectively linked across all levels of government and portfolios.

- 3.72 Specifically with regard to the coordination and streamlining of policy, programs and services provided by the Australian Government, the joint submission from the Australian Government departments (FaHCSIA, DoHA & DVA) themselves recognise problems for carers and care receivers arising as a consequence of the involvement of different portfolios in providing programs and services, stating:

The Australian Government recognises the difficulties [the involvement of various portfolios and levels of government] poses for carers and their families and the complexities they face in navigating the service delivery system.⁷⁶

- 3.73 Although the joint submission from the Australian Government departments (FaHCSIA, DoHA & DVA) proceeds to indicate that the various Australian Government departments with portfolio responsibility for carers and for care receivers are working together on options for

⁷⁵ Australian Government, Department of Prime Minister and Cabinet, *Annual Report 2007-08*, p 8.

⁷⁶ Australian Government Departments (FaHSCIA, DoHA & DVA), Submission No 1109, p 43.

structural reform to simplify and streamline programs and services, the Committee understands that this is likely to be a challenging and time consuming process. An alternative approach to achieving greater coordination and streamlining of carer policy and programs at the level of the Australian Government would be for a single Australian Government department to assume portfolio responsibility for people with disabilities, people with mental illness, the frail aged and their carers.

Recommendation 6

- 3.74 **That the Australian Government consider consolidating portfolio responsibility for people with disabilities, people with mental illness, the frail aged and their carers into a single Australian Government department.**

Information, Skills and Capacity Building

- 4.1 This chapter looks at the increasing demands placed on carers to provide quality care in diverse caring situations, and the breadth of knowledge and diversity skills required to fulfil the caring role. The chapter will examine carers' needs for:
- information;
 - peer support networks;
 - training and skills development;
 - coordination of services or case management; and
 - advocacy support, both for themselves and on behalf of the care receiver.
- 4.2 The chapter also looks at the need to increase recognition of carers by health professionals and community service providers as partners in the care team. The final section briefly explores existing legal mechanisms relating to substitute decision making.

Diversity of Information Needs

- 4.3 Changes in health, mental health, disability and age care policies have supported shifts from institutional care to care at home. Carers are increasingly required to manage complex health and care needs of people with serious medical conditions, disability, mental illness and terminal illness. Current policies rely not only on the availability and willingness of people to provide care, but also on their ability, their competence and capacity to provide care.

4.4 However, as the Ethnic Disability Advocacy Centre explained:

... family carers generally find themselves taking on this role 24/7 with little preparation, knowledge or support for the task at hand. They are expected to do it with professionalism and frequently need to juggle the numerous other roles within their usual daily routine. Family carers take on many of the skills of 'professional' roles such as health care nursing, life coaches/counsellors and educators, social facilitators, negotiators and advocates, care managers, futures planners, etc.¹

4.5 Many carers reported feeling ill-equipped to carry out the many facets of the caring role. Throughout the evidence, carers and organisations have pointed out the need for carers to be given increased access to relevant information, education, training, family and carer advocacy, case management and care coordination services. Many are, in fact, calling on public policy makers, healthcare professionals and community care service providers to recognise carers as members of the care team providing a service to meet the needs of the care receiver.

4.6 Understandably, the information carers find useful will vary according to their situation. Ms Lee-Ann Heron, from the organisation Special Kidz Special Needs, described some of the questions she was concerned about at the commencement of her caring role:

When I first found out my daughter has special needs I had so many questions, like: What services and supports are available? Where do I find information on her condition? What are her therapy options? What are her equipment options? What are our childcare & respite options? What are her education options? What are my career options? ... It took a long time to find the answers to these questions ... time that is precious to carers like me. ²

4.7 On the other hand, for many carers, including older carers considering their own future and that of the care receiver, information on legal and financial issues, alternative accommodation and care options may be a priority.³ As Ms Dulcie Sullivan explained:

I have cared for Paul for his entire life ... In 2007 due to my increasing age I applied to VCAT [Victorian Civil and

1 Ethnic Disability Advocacy Centre, Submission No 787, pp 5-6.

2 Special Kidz Special Needs, Submission No 567, p 12.

3 See for example: Huntington's Victoria, Submission No 670.2, pp 5-6; Prof J Wilson, A-Prof C Tilse & Prof L Rosenman, Submission No 698, pp 1-3; Ms M Robbins, Submission No 1139, p 2.

Administrative Tribunal] to appoint a Public Trustee to manage his financial affairs ... I also applied to VCAT to appoint a Public Advocate for guardianship of his medical, dental and housing requirements ... The E. W. Tipping foundation have been assisting with some 'Home skills Training' for when Paul finally goes to live without me. This transitional period is not easy for me due to lack of knowledge of choices available.⁴

4.8 The information needs of carers are as diverse as their care situations. However, evidence has suggested that there are common subject areas that carers want information about. These include information on:

- the care receiver's medical condition or disability, and options for treatment, therapy, aids and equipment;
- the practical aspects of providing care, including nursing care, personal care and behavioural management;
- services and supports;
- self care; and
- legal and financial issues, including guardianship and substitute decision making, mental health legislation, social security, financial and future planning.

Barriers to Information Access

4.9 As noted previously, health and community care service systems are complex and fragmented. Currently there is no single access point for carers to seek information. Carers WA presented the following picture:

There remains a multiplicity of agencies and services that provide information which can present a confusing, off-putting and impenetrable process for carers.⁵

4.10 The impact on carers is explained by the Yarrawonga Mulwala Carers Support Group:

Many carers report difficulty accessing appropriate information throughout their caring life. There is a broad range of information available for carers however dissemination of this information is

4 Ms D Sullivan, Submission No 126, p 3.

5 Carers WA, Submission No 566, p 20.

very fragmented - often what carers find out depends on which agency they have been referred to. Many carers report 'stumbling on information' which would have been useful to them much earlier on.⁶

- 4.11 The result is confusion and frustration for many carers. The following comments from carers provide examples of how carers experience barriers to accessing information:

Mr Rolf Regal – carer for his wife who has multiple sclerosis

Assistance for people with disabilities and their carers is already available from many different sources, e.g. from each of the three levels of government, as well as from charitable organisations and other private bodies. It is delivered in a multitude of different ways, and eligibility criteria are many and varied. Initially, when carers first take on their caring role, after a fresh diagnosis or an accident, most carers know nothing about any of this. One of the most frequently expressed frustrations which carers have is, that they do not know what assistance is available and what they may be entitled to i.e. we have a communications problem.⁷

Mr Henry Thomas - carer for his wife who has dementia and who is now in residential care

It was a little complex in that I did not know where the care services were. I started ringing up the shires and eventually got talking to the Towong shire where I actually live. They provided HACC [Home and Community Care] services but they also told me that I should get an ACAT [Aged Care Assessment Team] assessment, which I did. That then put me into a package which was taken over by an agency in Wodonga. So I was never really able to get a grasp on where funding was coming from between the various agencies, and because I was then on a package which the agency in Wodonga was looking after, they were talking to the Towong shire and then to me. So I was never properly in the loop. Initially, even before I had the ACAT assessment, things were

6 YNH Services Inc and Yarrawonga Mulwala Carers Support Group, Submission No 678, p 4. See also: Ms W Smith-Squires, Submission No 263, p 2; Committed About Securing Accommodation for People with Disabilities, Submission No 577, p 5; Ms J Gutteridge, Submission No 708, p 2; Mr R King & Ms M King, Submission No 817, pp 1-2; Name withheld, Submission No 904, p 3; Ms F Tountzis, Submission No 1140, p 2; Ms M Edwards, Submission 1147, pp 4-5; Ms C Atkinson, Submission No 1158, p 1; Ms M Major, Submission No 1163, pp 2-3; Ms A Arnold, Submission No 1166, p 2; Ms J Cooper, Submission No 1194, p 1.

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

being done, services were being provided, but when I asked, 'Who is paying for this? Where is the money coming for this and that?' I was told, 'Well, there are various buckets of money,' and that is as far as it really got. So I did not understand what the system was and, over the four to six years, I only started to find out more through groups ... where I could speak to other carers, find out what they had been given in services and then compare my situation with theirs.⁸

Name Withheld - an employed carer who has been caring for her elderly mother for 20 years

Difficult and time consuming to obtain the information as service providers are not forthcoming with such information until they have secured a package ...

I have found it extremely difficult and time consuming to obtain information on care and what is available. I appreciate that there are associations like Carers Queensland who handle respite and they have been helpful but the situation became difficult when I then tried to put their information into practice. I started to hit brick walls especially as far as respite and in home care were concerned.⁹

- 4.12 The evidence suggests that carers expend energy, time and resources which they often do not have, exploring various options to find information and services that they require for themselves or for the care receiver. Carers report that they feel that the onus is on them to ask the right questions to the right agency to elicit relevant information. As one carer explained:

It is also very difficult to access information - you ring one Department and get passed to another Department or get told it is State or Federal or vice versa. In the end, you give up trying because, as a carer, you just don't have time to keep following things up or to do the amount of paperwork involved.¹⁰

- 4.13 The barriers to accessing information for carers from culturally and linguistically diverse (CALD) backgrounds are even greater. Ms Au Yeong, a carer in Perth, pointed out several of the significant barriers confronting carers from CALD backgrounds and certain strategies which,

8 Mr H Thomas, Transcript of Evidence, 1 October 2008, p 8.

9 Name withheld, Submission No 904, p 1.

10 Ms M Cochrane, Submission No 824, p 2. See also: Ms M Robbins, Submission No 1139, pp 2-3.

in her view, could help overcome certain barriers:

[Migrant carers] do not know they have rights or they think: 'As a migrant I shouldn't be saying that I want this and that, because I need it. I'll be grateful for what I receive and therefore I do not ask for help.' Secondly, they do not know what help to ask for. The system is a nightmare. It is so complex for people who have good English comprehension. A migrant or a refugee recently arrived would not know how to navigate the system or what to ask for. So that empowerment and that self-advocacy is one issue. Also, you need to look at providing sufficient interpreting and translation. The mainstream services should be aware and take note of where to disseminate that information and whether it needs to be translated into different languages ... Perhaps through the ethnic communities themselves – through ethnic radio perhaps. There are a couple of avenues that mainstream services need to look at in getting the information out.¹¹

- 4.14 Although the vast majority of carers have contact with health services, evidence indicates that many are not provided with basic information on services and supports. One such carer, Ms J Burke, commented:

I care for my husband with an ABI [Acquired Brain Injury] and I have breast cancer. I wasn't aware of 63 days respite for carers until 3 years into my husband's stroke. Why don't medical facilities, medical personnel tell you about these things from the start?¹²

- 4.15 For some carers the need for information is urgent and critical. In its submission, the National Network of Adolescent and Adult Children who have a Mentally Ill Parent (NNAAMI) quoted one of the organisation's members as saying:

'I was on the verge of attempting suicide, giving up, packing it all in, finishing it all, no more, had it all planned out, until I saw the NNAAMI [web]site by accident. I now know I'm not alone. I cried and cried! The whole time reading those stories, not much different to my own'¹³

11 Ms J Au Yeong, Transcript of Evidence, 23 July 2008, p 65.

12 Ms J Burke, Submission No 99, p 1. See also: Ms J Lehmann, Submission No 1258, pp 5-6; Mr R Sinclair, Transcript of Evidence, 13 August 2008, pp 2, 4; Ms R Warminton, Transcript of Evidence, 13 August 2008, p 17; Ms H McDougall, Transcript of Evidence, 1 October 2008, p 9.

13 National Network of Adolescent and Adult Children who have a Mentally Ill Parent, Submission No 1243, p 5.

- 4.16 A number of submissions commented on the lack of availability of information about financial assistance available to carers through Centrelink. One such submission, provided by Mr Peter Casey, observed:

... one member of our circle had absolutely no idea that there was such a thing as a carers allowance or payment available from Centrelink. This poor woman had been performing the task of carer alone and unassisted for years and my heart really went out to her. Being the sceptic that I am I can see how such a situation might come about because Centrelink is remarkably reticent in advertising allowances and other facilities available to carers and they should bear at least some of the blame for such a regrettable oversight.¹⁴

- 4.17 Another submission, from Huntington's Victoria, highlighted difficulties with Centrelink services, which some carers experience:

There are many issues with incorrect information being given from Centrelink staff to clients, in addition to extremely distressing incidents of poor service provision. The one issue that makes our clients cry is when they talk about Centrelink.¹⁵

- 4.18 The Commonwealth Ombudsman also raised concerns about the difficulties carers face accessing and understanding information about social security entitlements:

Our experience has been that complainants are not aware of the difference between carer payment and carer allowance. Nor are they aware of other supplementary payments such as mobility allowance and pensioner education supplement that might be payable to the person who was receiving the care (the care receiver).

In most cases that we investigate, particularly those where the level of care required is high, the carer has taken on responsibility for managing the financial, as well as physical needs of the care receiver. They do not have time to research what payments or services might be available for them, whether online, or by phone enquiries or visits to Centrelink.¹⁶

14 Mr P Casey, Submission No 3, p 5. See also: Ms J Dajic, Submission No 56, pp 1-2; Name withheld, Submission No 484, p 1; Ms F Tountzis, Submission No 1140, p 2.

15 Huntington's Victoria, Submission No 670.2, p 4. See also: Ms J Nicholas, Submission No 1149, pp 2-3; Mr D Nicholas, Transcript of Evidence, 13 August 2008, p 23.

16 Commonwealth Ombudsman, Submission No 511, p 3.

- 4.19 Centrelink uses a 'life events' model which aims to match customers or potential customers with all the correct payments and services applicable to their situation or combination of circumstances.¹⁷ However, the Ombudsman's investigations have shown that, in practice, the life events model used by Centrelink does not always ensure that customers are advised of the full range of services which their situation entitles them to.¹⁸
- 4.20 The evidence clearly suggests that carers want clear, accessible and relevant information on financial and non-financial services and supports which are available. As one carer summed up:
- ... it is essential that all carers, and in particular new carers, are aware of what help is available. That help, even now, is considerable but many people flounder around, unaware of what is available. This may be the fault of the medicos who make the diagnoses not being *au fait* with the system - but I believe that it is at that point that the carer should be allocated a case manager, introduced to Carers Australia and any other source of information necessary to their efficient functioning as a carer. This could save a lot of heartache.¹⁹

National Networks Providing Information

- 4.21 There are three key national networks which can provide carers with information and support:
- Commonwealth Respite and Carelink Centres;
 - Carers Australia and the state and territory network of Carer Associations; and
 - Centrelink.
- 4.22 There is a national network of 54 Commonwealth Respite and Carelink Centres across the country. The joint submission from the Australian Government departments (Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA), Department of Health and Ageing (DoHA) and Department of Veterans' Affairs (DVA)) explained that the Centres:
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17 Commonwealth Ombudsman, Submission No 511, p 2.

18 Commonwealth Ombudsman, Submission No 511, p 2.

19 Mr R Smeaton, Submission No 69, p 3. See also: Ms W Smith-Squires, Submission No 263, p 2.

- provide information for carers, the aged and other members of the community seeking free and confidential advice on community care, aged, disability and other support services available in local regions;
- provide information about costs for services, assessment processes and eligibility criteria and maintain an extensive database of services; and
- network with Aged Care Assessment Teams (ACATs), general practitioners, allied health providers and community organisations.²⁰

4.23 Nevertheless, a number of carers and organisations have been critical of the Commonwealth Respite and Carelink Centres' capacity to meet the needs of carers. For example, Carers WA suggested that the Centres cannot adequately address the information needs of carers because they have to provide services to a wide range of clients.²¹ The issue of Commonwealth Respite and Carelink Centres having insufficient local knowledge has also been raised:

Setting up services that cover such a large geographic area [that] they have no 'real' knowledge of the area is counter productive [and] causes a high level of frustration with other services and client's. In Macarthur, the Commonwealth Information service that is meant to cover our area is not based locally. A local provider reported one of their clients had said 'oh I rang them, first I had to spell the name of the town I lived in, then they just read me stuff off a database'. That same person through a local service provider was referred to another agency, informed of a local unfunded support group that had commenced recently and was invited to attend a consultation regarding their needs.²²

4.24 Others are more complimentary. One carer described the service as:

... a wonderful and crucial service to families/carers with children/adults with highly specialised care needs.²³

4.25 The information services provided by the Commonwealth Respite and Carelink Centres are bolstered by information services provided by Carers Australia and the national network of state and territory Carers Associations. The Carers Associations are funded through several

20 Australian Government Departments (FaHCSIA, DoHA & DVA), Submission No 1109, p 26. See also: Mr K Tracey-Patte, Transcript of Evidence, 28 November 2008, p 25.

21 Carers WA, Submission No 566, p 20.

22 The Macarthur Aged & Disability Forum, Submission No 749, pp 3-4. See also: Ms C Morka, Transcript of Evidence, 12 August 2008, p 66.

23 Ms J Tams, Submission No 908, p 7.

Australian Government programs²⁴ to deliver a range of information products, specialist information and advice services to carers, including young carers, and to service providers.²⁵

4.26 In the view of Carers Australia, the two national networks comprising Carer Respite and Carelink Centres and the Carers Associations, provide a sound national structure for the provision of information and support to carers.²⁶

4.27 Centrelink is also a national network which provides information and advice on social security and financial issues for, among many other client groups, carers and care receivers. For some, Centrelink is ideally placed to disseminate broader information to carers.²⁷ Ms Susan Pringle from the Cooina Family Support Group, commented:

Information provision is random and may be around at a time when it has little significance and so is overlooked when required. Centrelink is the ideal avenue of forwarding relevant information to carers on a regular basis.²⁸

4.28 The three national networks all provide advice to carers and/or care receivers, but each has a slightly different focus. In addition, there are also state and territory and local government agencies, not-for-profit and for-profit organisations delivering health and community care services and supports to carers and care receivers, including information services of different kinds. What many carers have called for is a 'one-stop-shop' or 'single access point' to bring together advice on all the services available for carers and care receivers.²⁹

24 For example through the Carer Information and Support Program, the National Carer Counselling Program, and the Respite and Information Services for Young Carers.

25 Australian Government Departments (FaHCSIA, DoHA & DVA), Submission No 1109, pp 26-32.

26 Ms J Hughes, Transcript of Evidence, 28 November 2008, p 16.

27 See for example: YNH Services & Yarrowonga Mulwala Carer Support Group, Submission No 678, p 4.

28 Ms S Pringle, Transcript of Evidence, 1 October 2008, p 39.

29 See for example: Mr F De Rosa, Submission No 63, p 2; Mr W de Goede, Submission No 366, p 1; YNH Services Inc and the Yarrowonga Mulwala Carers Support Group, Submission No 678, p 4; Mr G Jarvis, Submission No 767, p 2; Ms M-L May, Submission No 891, p 3; Name withheld, Submission No 904, p 3; Ms V Wood, Submission No 1164, p 1; Mr J Halford, Transcript of Evidence, 12 August 2008, p 43; Ms M Anderson, Transcript of Evidence, 12 August 2008, p 44; Mr R Sinclair, Transcript of Evidence, 13 August 2008, p 8.

A Single Access Point for Carers

- 4.29 A typical example of the calls for a one-stop-shop was made by Ms Colleen Atkinson who commented:

... within my home file I have information on the following agencies - Commonwealth Carers Respite Centres; Commonwealth Carelink Centres; Carers SA; Carer Support & Respite Centre Inc; Commonwealth Carer Resource Centre; HACC; local government; plus a number of NGO's offering respite. Where do I start? ... Consider a review of the above-mentioned agencies (vis-a-vis respite), and establishment of a 'one-stop shop' central agency which can provide straight forward but comprehensive information about services to carers - and which is widely advertised so it is easy for carers to access.³⁰

- 4.30 The case for a one-stop-shop to respond to carers' information needs was also argued by Carers WA in the following terms:

The need for information can be best met in the form of a one stop shop dedicated to carers in which the multiplicity of service providers, health professionals and others can be linked. In addition many carers do not respond well to call centres and phone services only and would prefer a person centred face to face model of service delivery. The location of information centres for carers has to be addressed as it is not meeting carer's needs. The information needs of carers would be best met in a variety of central settings such as information centre for family carers in every teaching hospital, local community centre and Centrelink offices.³¹

- 4.31 DoHA and state and territory governments are currently piloting Access Point Demonstration Projects in at least 11 locations across the country.³² The Access Points are designed to provide one-stop-shops to make access to community care services easier for carers and care receivers by:

30 Ms C Atkinson, Submission No 1158, p 1.

31 Carers WA, Submission No 566, p 20. See also: Brotherhood of St Lawrence, Submission No 694, p 5; Mr R Haines, Mr P Sparrow and Mr G Vogt, Transcript of Evidence, 13 August 2008, pp 69-74.

32 Australian Government, Department of Health and Ageing website, viewed 12 March 2009 at www.health.gov.au/internet/main/publishing.nsf/Content/ageing-twf-access-status.htm. See also: Australian Government Departments (FaHCSIA, DoHA & DVA), Submission No 1109.1 pp 4-6; Name withheld, Submission No 1304, p 1.

- providing information about community care services;
 - providing advice on eligibility for services;
 - conducting a broad assessment of needs, including the carer needs; and
 - facilitating referrals to community care service providers or for a more comprehensive assessment.³³
- 4.32 Each Access Point Demonstration Project will operate for about 12 months and be evaluated at three levels: project, jurisdictional and national. The evaluations will inform decisions about potential broader rollout of Access Points in the future.³⁴
- 4.33 The Committee considers that the Access Point Demonstration Projects have merit as they are an attempt to make access to community care easier by bringing together Australian Government, and state and territory services in a consistent way. However, for Access Points to fully meet the needs of carers for a one-stop-shop, they will need to have the capacity to assist all carers in diverse caring situations. This will require Access Points to provide carers with information and advice, assessment and referral to services across the fragmented community care system. This includes aged care services, disability services and community mental health services as required by the carer and care receiver.
- 4.34 It is unclear what linkages, if any, will exist between the assessment and referrals provided through Access Points with other programs delivered by state and territory governments, for example the Aged Care Assessment Program and disability programs.³⁵ Even if the single access model is deemed a success, it is also not clear whether Access Points would replace or complement the Commonwealth Respite and Carelink Centres. The risk is that yet another layer of program orientated and ultimately narrowly focussed reform will perversely lead to more complexity and confusion for carers rather than less.

33 Australian Government Departments (FaHCSIA, DoHA & DVA), Submission No 1109.1, pp 4-6.

34 Australian Government Departments (FaHCSIA, DoHA & DVA), Submission No 1109.1, pp 4-6.

35 Australian Government Departments (FaHCSIA, DoHA & DVA), Submission No 1109, p 28.

Recommendation 7

- 4.35 **That the Minister for Families, Housing, Community Services and Indigenous Affairs and the Minister for Health and Ageing, seek agreement through the Health, Community and Disability Services Ministerial Council to extend the Access Points Demonstration Projects to include disability services and community mental health services.**
- 4.36 The reality is that it may never be practical to have a genuine one-stop-shop to help carers and care recipients given the range of their needs and because they are also likely to need to use Centrelink for financial services. In that case and certainly in the short term, there appears scope to improve the links between the existing networks (as well as with state and territory information services). Without wishing to make a specific recommendation, the Committee encourages the Health, Community and Disability Services Ministerial Council to improve the coordination between agencies so that they can provide seamless and consistent advice across programs and jurisdictions to carers and care receivers.

Peer Support Groups

- 4.37 Carers and organisations consistently reported that peer support groups and networks are an extremely valuable source of information and empowerment for carers.³⁶ Peer support groups for carers function in different locations across Australia providing carers with information, advice, support and social opportunities as well as providing a means for advocating for supports and services. Many of these groups are unfunded and are not legal entities in their own right. Other support groups, such as Coinda Family Support Group based in Albury/Wodonga, have evolved into incorporated bodies funded by government to provide support services to carers and care receivers.³⁷

36 See for example: Ms J Cheal, Submission No 116, p 2; Mr J Davis, Submission No 368, p 1; Ms S Jalanski, Submission No 446, p 2; Ms A Atkins, Submission No 771, p 1; Mr G Ingram & Ms K Ingram, Submission No 865, p 1; Ms J Rafferty, Submission No 1183, p 1; Mr H Thomas, Transcript of Evidence, 1 October 2008, p 8.

37 Coinda Family Support Group, Submission No 693, p 1.

4.38 Some peer support groups are affiliated and supported by state and territory Carers Associations. For example, Carers Queensland provides support to over 100 carer groups throughout the state which provide opportunities for carers to meet and share experiences on a regular basis.³⁸ Other support groups have been established under the auspices of particular programs. For example, the Dementia Respite Options program in Albury NSW provides dementia specific services including carer support groups to people in the region.³⁹

4.39 Another support group from Albury NSW, Daughters in Demand, was formed over ten years ago by a group of nurses caring for elderly parents who wanted emotional and other support to balance the demands in their lives.⁴⁰ This and many similar groups exist through the generosity of carers and former carers who come together to support each other, share experiences and knowledge and volunteer their time, a resource which is often extremely limited.⁴¹

4.40 Some unfunded carer support groups, such as the Kiewa Valley Carer Support Group in Victoria, have concerns about their sustainability and capacity to meet the needs of local carers.⁴² Occasionally, there appears to be some limited possibilities for funding from state and territory governments. As indicated by the Myrtleford Carer Support Group:

Just recently, we applied to DHS [Victorian Department of Human Services] for some non-recurrent funding around running some activity days to better support carers. We ran a music therapy day one month, and then last week we ran a Humour in Caring day.⁴³

4.41 Many carers believe that the support offered by a peer support network is extremely beneficial. One such carer, Ms Michiko Parnell, explained how beneficial she believed peer support would have been to her and her husband at the time of their child's diagnosis:

We were told of our child's diagnosis and left the paediatrician's office to face the unknown and the grief on our own. It would have been very helpful for the paediatrician to give us a number to

38 Carers Queensland, Submission No 703, p 12.

39 Ms H McDougal, Transcript of Evidence, 1 October 2008, p 6. See also: Mr P Sparrow, Transcript of Evidence, 13 August 2008, pp 68-69.

40 Ms M Campbell, Transcript of Evidence, 1 October 2008, p 14.

41 See for example: Ms G Esson, Submission No 647, p 2; St Helens Support Group, Submission No 798, pp 1-2.

42 Mr G Lindsey, Transcript of Evidence, 1 October 2008, p 26.

43 Ms C Sanderson, Transcript of Evidence, 1 October 2008, p 32.

call, that we could get a home visit or just have another parent WHO HAS BEEN THROUGH THIS, to act as a bit of a 'peer support' role. Even a national support line (like Lifeline) so that I could talk to someone who has lived the experience, would have been enormously helpful. Looking back, five years later, what would have helped my mental health more than anything is the HOPE that we would enjoy our lives after the catastrophe of the diagnosis and in spite of the workload of the care and barriers we face in everyday life.⁴⁴

4.42 As another carer explained in her submission:

... I am on antidepressants and need to talk to others on how they cope and get advice [on] how they cope ... Getting advice and help [on] how to handle certain situations like alcohol abuse, money issues and general advice ... Providing more information on what help is available.⁴⁵

4.43 Given the importance to carers of peer support, many carers and organisations have recommended the expansion of informal peer support networks. One such recommendation was made by ANGLICARE Sydney:

Carer Peer Support programs be funded to encourage networking, social interaction and further support for advocacy. Carer Support programs also need to run in the evenings and weekends to ensure that working carers can access them.⁴⁶

4.44 The valuable contribution made by the non-government and voluntary sectors using peer support, self help and consumer or group advocacy models was also commented on by the Royal Australian and New Zealand College of Psychiatrists in respect of people with mental illness and their carers.⁴⁷ The College recommended:

... more support should be given to the development and expansion of non government organisations to assist carers access meaningful supports, and promote self help and consumer advocacy ...⁴⁸

44 Ms M Parnell, Submission No 849, p 1.

45 Ms C Cornish, Submission No 1150, pp 1-2. See also: Ms J Davis, Submission No 1167, p 2.

46 ANGLICARE Sydney, Submission No 769, p 19. See also: Ms S Durkin, Submission No 329, p 2; Submission No 855, p 2; Australian Association of Gerontology Inc, Submission No 915, p 2; Mr R Taylor, Submission No 923, pp 1-2.

47 The Royal Australian and New Zealand College of Psychiatrists, Submission No 672, p 3.

48 The Royal Australian and New Zealand College of Psychiatrists, Submission No 672, p 3.

- 4.45 There is no doubt of the value of peer support groups for providing carers with information, support, social contact and, at times, advocacy. The Committee believes that there is further potential for government to encourage the development and geographical coverage of such groups. One way this could be accomplished is through the provision of small grants to assist groups with expenses. Access to small grants programs for carer peer support groups would need to take into account that some groups will not be incorporated bodies nor be affiliated with an incorporated body such as a Carer Association.

Recommendation 8

- 4.46 **That the Australian Government make locally based peer support carer groups a priority within existing community grants programs available across portfolios.**

- 4.47 In addition to the informal peer support groups considered above, there is a national network of peer support groups for carers of young children (i.e. under school age) with a disability. This is funded by the FaHCSIA. The MyTime Peer Support Groups give carers the chance to socialise and share ideas with others who understand the rewards and challenges of the caring role. The groups also provide an opportunity for carers to access information about available community support services and parenting information. The MyTime Peer Support Program commenced in February 2007 and has established 175 peer support groups.⁴⁹

- 4.48 The submission from Uniting Care Remote Family Services in Bairnsdale, Victoria, endorsed the support offered to parents of young children through the MyTime Peer Support Groups. The submission strongly advocates for the expansion of the Program in terms of its coverage of regional and remote areas as well as the level of assistance provided to individual MyTime Peer Support Groups:

Our group commenced in February this year and we have found MyTime funding hopelessly inadequate and are desperately looking for more funding so as to more adequately support these families.⁵⁰

49 Australian Government Departments (FaHCSIA, DoHA & DVA), Submission No 1109.2, p 9.

50 Uniting Care Remote Family Services, Submission No 656, p 2.

4.49 The Committee sees the value of a national network of MyTime Peer Support Groups to provide support to parents caring for young children with disability. The Committee notes that FaHCSIA is trialling a small number of MyTime Peer Support Groups for parents of school age children with disability. Assuming this proves successful, the Committee supports an expansion of the Program to include this group of carers and their children. In addition, the Committee believes the benefits of the Program for carers warrants further expansion to increase geographical coverage, particularly in regional and remote locations.

Recommendation 9

- 4.50 **That the Minister for the Department of Families, Housing, Community Services and Indigenous Affairs fund the expansion of the MyTime Peer Support Program to:**
- include parents of school aged children with disability; and
 - increase geographical coverage.

Skills Development and Capacity Building

4.51 As previously mentioned, the health and community care service systems rely heavily on carers continuing to provide care in their own homes for care receivers and increasingly, to care for those with high support needs who have been discharged from formal health services into community settings.⁵¹ As stated simply by one carer:

Carers ... relieve the stretched resources of hospitals, aged care facilities by keeping their caree at home.⁵²

4.52 As a result, Carers WA explained:

... [carers] are significantly involved in the clinical processes including recovery and rehabilitation as well as the ongoing care of people with long term and, in some cases terminal, health issues.⁵³

51 Carers SA, Submission No 684, p 24.

52 Ms A M MacArthur, Submission No 871, p 1.

53 Carers WA, Submission No 566, p 22.

- 4.53 However, the majority of carers commence their caring role with little or no warning, as Carers Australia reported:

Carers can come into their caring responsibilities at any stage throughout their life. This could be with the birth of a child with a disability, an accident, the onset of mental illness, the diagnosis of a terminal illness or with an ageing parent becoming frail.⁵⁴

- 4.54 It is clear from the evidence that many carers over time develop a high level of skill in a wide range of areas. A carer who has cared for her husband who has a degenerative neurological condition commented:

Over the past 29 years I have become my husband's physiotherapist as necessary to keep his muscles from total atrophy, podiatrist and manicurist as due to poor balance he cannot manage such tasks, his wound nurse, as wheelchair living is an occupational hazard for tissue tearing; pressure care specialist, as the body loses muscle the pressure areas on the bottom and the feet become susceptible to pressure sores; case manager for keeping track of care workers who come to the home to carry out personal care routines and this means filling in when they don't arrive, educating ... on the new or re instituted treatments; negotiator for access to care or respite care. Overnight care includes re positioning due to pain in my husband's legs, assisting with bladder/bowel functions as necessary ...

I act therefore as a para-professional, with a wider range of skills than they, as I have to act in such a wide variety of roles whereas their skills are compartmentalised.⁵⁵

- 4.55 However, understandably, at the outset of caring most carers are unprepared for the role. As Carers WA observed:

Most carers are not trained in basic nursing care when taking the care recipient home ... and basic training is required in order to support carers adequately and therefore provide the care recipient with the best quality of life possible⁵⁶

- 4.56 The comments from the state and territory Carer Associations are supported by many individual carers who reported that at the

54 Carers Australia, Submission No 699, p 45.

55 Name withheld, Submission No 853, pp 1-2. See also: Ms A Arnold, Submission No 1166, p 1; Ms E Fudge, Transcript of Evidence, 13 August 2008, p 54.

56 Carers WA, Submission No 566, p 22. See also, Mr R Sinclair, Transcript of Evidence, 13 August 2008, p 2.

commencement of their caring role they felt ill equipped and believed they lacked the skills, knowledge or capacity to cope effectively with the practical and emotional aspects of providing care. Some typical comments from carers are presented below:

Ms Judith Small - an employed carer who cares for her husband

My role as a carer commenced in December 1993 when my husband, Bob, was diagnosed with a very large Brain Tumour and subsequently had surgery for its removal. These events left him paralysed from the waist down and unable to speak. He was hospitalised for 2 months after which he was discharged into my care, on the grounds that medical staff felt Bob was making better progress when I took him home on weekends. There was no consideration as to my capacity to cope.⁵⁷

Ms Claire Hill - carer for her 95 year old father

I struggle with my father's care - I am not a nurse and often find it hard to know how to proceed with things like, for example, wound care.⁵⁸

Ms Julie Witts - carer for her daughter

I don't have any formal training and feel there is less importance put on my role than that of paid carers who assist my daughter ... As a carer, I need help with training to deal with the specific needs of the person I care for.⁵⁹

Perth Carers Forum Group - a group of 42 carers from diverse caring situations

... carers reported that they could be providing significant care in the line of nursing care, with very little training or skills. It is just assumed that they would have to somehow learn and undertake complex care tasks. Carers felt that the burden and strain placed on them needed to be recognised and that relevant, trained support should be provided to ensure that they are skilled and prepared for their caring role from the outset.⁶⁰

57 Ms J Small, Submission No 110, p 1.

58 Ms C Hill, Submission No 1117, p 1.

59 Ms J Witts, Submission No 326, p 2.

60 Perth Carers Forum Group, Submission No 883, p 4.

4.57 Many carers are asking governments to provide formal training to equip them for the caring role.⁶¹ There are some opportunities available across the community care system to receive skills development in relation to the caring role. For example, Alzheimer's Australia described its role in providing training for carers under the Dementia Caring Project which was funded in 2006 by the DoHA:

Alzheimer's Australia partnered with 52 Commonwealth Carer Respite Centres who contacted carers and families of persons with dementia to develop a menu of skills enhancement activities that consumers desired. The project enabled over 900 individuals to take part in various learning and skills enhancement sessions.⁶²

4.58 Alzheimer's Australia reported that there was a positive uptake of the training by carers, with the following skill areas being the most sought after:

- Accessing legal information;
- Understanding dementia;
- Advocacy;
- Self care strategies;
- Managing behaviours of concern;
- Continence management;
- Health and well being;
- Communication;
- Accessing information to support decision making, for example, information on residential care, Centrelink, and support services;
- Home maintenance;
- Personal care;
- Role reversal related practical tasks such as car maintenance and cooking; and
- Use of computers and the internet including internet banking, online shopping and e-mail.⁶³

4.59 However, it appears that formal training available to carers is largely *ad hoc* and often limited in scope and duration.⁶⁴ In response, carers and

61 See for example: Ms D Stewart, Transcript of Evidence, 13 August 2008, p 27.

62 Alzheimer's Australia, Submission No 1002, p 16. See also: NSW Government, Submission No 1278, p 13.

63 Alzheimer's Australia, Submission No 1002, p 16.

64 Carers SA, Submission No 684, p 25. See also: Ms M Alford, Transcript of Evidence, 13 August 2008, p 4.

organisations have recommended the expansion of training opportunities for carers to support them in their caring roles.⁶⁵ Carers SA summed up the training and skill development needs of carers as follows:

Training is required across a range of topics such as the carer's roles and responsibilities; disabilities and illnesses; manual handling; carer personal care and health and well being; communication and relationships; negotiation and advocacy, including making complaints; the health and community services system ... and managing the relationship with paid care support workers.⁶⁶

4.60 The training requirements of carers will vary to some degree according to their stage of life and the needs of the care receiver. For some carers the dominant need may be for skills in relation to accessing and understanding information on legal and financial issues, for other carers acquiring skills to manage complex care needs may be required, while for others developing skills in relation to safety issues and managing concerning behaviour is of the utmost importance.⁶⁷ A parent of three children, two of whom have an autism spectrum disorder, explained she urgently required skills to manage:

Constant behaviour issues. Constant safety issues. Constant violence; threats; damage. I need help with teaching; safety; behaviours ... I need someone to show me how to teach my kids.⁶⁸

4.61 In her submission, Ms Michela Cardamone who is a carer for a family member with a mental health condition and employed as a carer consultant, points out that carers constantly need to advocate for themselves and the care receiver and often don't have the skills to negotiate with mental health professionals. She commented that there was a need for carers to have:

Education about the privacy act, and how this impacts on caring for a person with mental illness. How to negotiate with clinicians around issues concerning confidentiality. It is important for family members to be able to get information about what is happening to their loved ones. This is particularly the case when it is clear that

65 Carers WA, Submission No 566, p 6. See also: Ms J Coulter, Submission No 1151, p 2.

66 Carers SA, Submission No 684, p 25.

67 Huntington's Victoria, Submission No 670.2, pp 5-6. See also: Mr R Sinclair, Transcript of Evidence, 13 August 2008, p 3.

68 Ms M McIlroy, Submission No 108, p 1.

after treatment most mentally ill people will be returned to their families.⁶⁹

- 4.62 The Committee accepts that the training and skills development needs of carers are currently not being fully met. The challenge, however, is to provide appropriate and accessible training that reflects the diverse situations of carers. In these circumstances training should not be developed in an *ad hoc* manner and the Committee sees benefit in a national training and skills development strategy for carers. This may very well be built on existing educational and training programs.
- 4.63 The Committee also suggests that such a training strategy for carers examines the use of flexible approaches and delivery mechanisms, including use of e-learning and video conference media.⁷⁰
- 4.64 The Committee has targeted its recommendation below to the Ministers for Families, Housing, Community Services and Indigenous Affairs and Health and Ageing and the states and territories through the Health, Community and Disability Services Ministerial Council. However, the Committee would expect the Department of Education, Employment and Workplace Relations and its state equivalents, at least, to be involved in planning and implementing a national training and skills strategy for carers.

Recommendation 10

- 4.65 **That the Minister for Families, Housing, Community Services and Indigenous Affairs and the Minister for Health and Ageing request that the Health, Community and Disability Services Ministerial Council develop a national strategy to address the training and skills development needs of carers.**

69 Ms M Cardamone, Submission No 799, p 3.

70 See for example: Carers WA, Submission No 566, p 22; Carers SA, Submission No 684, p 25.

Coordination and Representation

Case Management/Care Coordination/Carer Support Planning

- 4.66 Carers often seek the support of a case manager or coordinator to advise them and help them access services for themselves and for the care receiver. Most carers welcome these services but argue that they are inadequate.
- 4.67 There are a number of Australian Government, state and territory funded case management, care coordination or carer support planning programs to help carers to find and arrange services for care receivers. At the Australian Government level, the National Respite for Carers Program, Australian Government Aged Care Packages⁷¹ and Home and Community Care (HACC) all provide some level of care coordination and/or case management services to carers and care receivers.⁷²
- 4.68 Under the first of these, the National Respite for Carers Program, the Carer Associations in each state and territory provide specialised advice, support and referrals including ‘guided referrals’ to carers. A guided referral is generally a one-off process, provided when a carer is assessed as lacking the skill, time and capacity to access services which are urgently required, for example a counselling service.⁷³ Also, under the National Respite for Carers Program, Commonwealth Respite and Carelink Centres offer information, service coordination, carer support planning and referral.⁷⁴ However:
- ... there is a clear distinction between ‘coordination’ and ‘case management’. For the [Commonwealth Respite and Carelink] Centres to become involved in ‘case management’ would require substantial additional funding as it is a resource intensive activity.⁷⁵

71 These are Community Aged Care Packages (CACP), Extended Aged Care at Home (EACH) Packages and Extended Aged Care at Home Dementia (EACHD) Packages.

72 Australian Government Packages offer subsidised packages of care for older, frail people with complex care needs. Home and Community Care (HACC) is a joint program of the Australian, state and territory governments.

73 Australian Government Departments (FaHCSIA, DoHA & DVA), Submission No 1109.1, pp 4-5.

74 Australian Government Departments (FaHCSIA, DoHA & DVA), Submission No 1109.1, pp 4-5.

75 Australian Government Departments (FaHCSIA, DoHA & DVA), Submission No 1109.1, p 5.

4.69 As mentioned, Australian Government Aged Care Packages offer subsidised packages of care for older, frail people with complex care needs. The packages comprise the Community Aged Care Packages (CACP), Extended Aged Care at Home (EACH) packages and Extended Aged Care at Home Dementia Packages (EACHD). Under these packages, approved providers may use a case management approach to arrange and coordinate services for the care receiver. A significant number of older frail people who receive an Australian Government Aged Care Package, are also supported by carers. In these situations the carers may participate in the case management offered through the package, as explained by the Australian Government departments below:

In administering the package (and at the care recipient's request), the approved provider is required to recognise the role of the carer and reflect the importance of both clients and carers in the planning, provision, and review of the package of service.⁷⁶

4.70 Case management services for carers and care receivers are also available through HACC for its clients. The service:

... comprises active assistance received by a HACC client from a formally identified agency worker who coordinates the planning and delivery of a suite of HACC services to the individual client.

In 2007-08, some 7 percent, or around 58,000, of HACC clients received case management services through the Program.⁷⁷

4.71 Finally, case management and coordination services are also provided through various state and territory government disability and community services programs. However, the complaints to the Committee about the lack of case management and coordination services available for care receivers and their carer, suggest that the existing services are inadequate.

Carers Want More Case Management

4.72 Both new and experienced carers report that they often require additional assistance to navigate the service system, access information and coordinate services for the person for whom they are caring.⁷⁸ A typical comment was made by Ms Megan Major:

⁷⁶ Australian Government Departments (FaHCSIA, DoHA & DVA), Submission No 1109.1, p 5.

⁷⁷ Australian Government Departments (FaHCSIA, DoHA & DVA), Submission No 1109.1, p 5.

⁷⁸ See for example: Ms M Nazzari, Submission No 100, pp 1-2; The Partners of Veterans Association of Australia Inc, Submission No 566, p 5; Ms S Matheson, Submission No 587, p 6; St George Migrant Resource Centre, Submission No 746, p 10; ANGLICARE Sydney, Submission No 769, p 6; Ms L Baker, Submission No 807, p 16; Name withheld, Submission No

When my husband had his stroke, the hospital social worker helped me apply for carers allowance, obtain an 'Advice for Carers Package', organised a 'Post Acute Care Program', and gave me information about 'Home and Community Care Services'. A month after my husband came home I was drowning in paperwork and information and going round in circles trying to find out who actually did what!

I got lost in 'the maze' as I tried to work out who to contact for various types of support. I had to deal with: District Nursing Service and Cognitive Dementia and Memory Service - West Gippsland Health Care Group, Gippsland Regional Aged Care Assessment Service - Latrobe Community Health Services, Carers Victoria, Baw Baw Home and Community Care, Commonwealth Carer Respite Centre and Commonwealth Carer Resource Centre, Centrelink, plus GPs, physician and Neurologist.

I found this very stressful. I believe if I had been able to continue with the support of the hospital social worker and if the local healthcare group co-ordinated the services I would not have 'fallen in such a big heap'.

- 4.73 The evidence provides many examples of challenging caring experiences which could have been alleviated to some extent had the carer been assisted to access and coordinate appropriate support services. Some typical comments from carers include:

Mr Martin Hengeveld - carer for his 60 year old partner who has Alzheimer's disease

My biggest challenge has been, and still is, to come to grips with who does what. There are 9 agencies who all have a finger in the pie, of which none stand out as truly supportive. When all this started I would have loved to have a 'case manager', who would have been my constant source of reference throughout my caring time, some one who might even ring up occasionally to check on how we are going.⁷⁹

Ms Giovanna Walker - an employed carer, caring for her elderly father

Getting access to services is a challenge. I work full time, and between the national helpline and local council it involved many

860, p 1; Mr R Hart & Ms M Hart, Submission No 1174, p 2; Ms M Anderson, Transcript of Evidence, 12 August 2008, pp 44-45.

79 Mr M Hengeveld, Submission No 29, p 1.

phone calls, I didn't know where to go. I felt helpless, no one would take responsibility.⁸⁰

Name withheld – carer of a young child who was born with Trisomy 13, a condition which causes severe developmental delay

After a year of struggling, my daughter had been admitted into the Sunshine Hospital and whilst she was in hospital the nurses were shocked to find out that I wasn't receiving any home help and organised the social worker to come and see me.

Consequently I received some home help and respite and my daughter was put on waiting lists for early intervention services, which is now receives.⁸¹

Name withheld – a carer for two daughters who use mental health services

As soon as a family member is thought to have a mental illness, the prospective carer should be able to discuss the situation with a social worker (free of charge) to help the carer start off on the path to accessing help - medical, counselling, financial. If a caseworker were assigned from the start, the carer would be more competent and over time require less help from government. It would prevent subsequent problems, and facilitate people re-joining society.⁸²

Mr Robert McEachern and Ms Grace McEachern – carers for their 38 year old son who has a severe life long disability, living in rural NSW

A support network/caseworker who can supply information on what is of assistance eg aids, respite, financial.

At the moment there seems to be many different organizations who have brokered for money to help...Finding these organizations seems to be by word of mouth... For us also is the looming decision of the day we can no longer look after our son Will we be able to obtain long term care when we make that decision? Will that care be available locally so he can still be a part of our lives and possibly spend day visits with us? What will

80 Ms G Walker, Submission No 266, p 1.

81 Name withheld, Submission 852, p 1.

82 Submission No 855, p 3.

happen when we can no longer drive? Being in our local country community will be important for our son's well being⁸³

- 4.74 Many carers want case management/coordination services to work with them in partnership to address whole of life planning for the care receiver. Mr Kevin Hewitt, a Victorian carer, raised these issues in the following terms:

... what I need is a good working partnership where we can plan for the future for a better life and more productive life for my daughter. In this process we would have planned timelines and available resources guaranteed ... Get out of the crisis needs controlling system ... there needs to be more face to face case management – need to develop working partnerships with families ...⁸⁴

- 4.75 Similarly, carers also seek partnerships with a range of service providers to jointly plan for and provide the best quality of life possible for the care receiver. As a carer, Mr Arthur Skimin, explained to the Committee in Canberra:

We are frustrated by the fact that the carer of the patient is not recognised by the professional care providers. This is frustrating because we feel that we are out of the loop. We are also frustrated by the case management processes. Many carers are aged and once you are in your mid to late 70s you can drop off the twig any day. What happens to that individual then? How do they keep their quality of life and self-esteem as the years roll on?⁸⁵

- 4.76 The need for more case management services is supported by organisations and governments. ANGLICARE Sydney, which operates the Commonwealth Respite and Carelink Centres in the Nepean and South West Sydney Regions, argued that these could be funded to expand their services to offer case management for care receivers and their carers.⁸⁶

- 4.77 In particular, as young carers may be especially vulnerable, service providers are calling for the need for case management support for this group. The Queensland Government emphasised the need to help these younger people:

83 Mr R McEachern & Ms G McEachern, Submission No 1171, p 4.

84 Mr K Hewitt, Submission No 328, p 2. See also: Sunnyfield Independence, Submission No 663, pp 2-4; Perth Carers Forum Group, Submission No 983, p 4.

85 Mr A Skimin, Transcript of Evidence, 26 September 2008, p 14.

86 ANGLICARE Sydney, Submission No 769, pp 8-9.

The key transition points and different developmental stages experienced through adolescence would require review and adjustment of interventions, resources and supports needed by the young carer. Consequently, engaging in a regular process of case review and management involving care recipient, care provider and support agencies would be required (Adequate resourcing would need to be available to support this kind of response to young carers).⁸⁷

Case Management Dissipating Funds?

4.78 A number of carers and organisations note however, the costs of diverting already scarce resources to case management or brokerage. For example, the Friends of EACH Action Group, is critical of the case management model used by Aged Care Packages as a 'leakage of funds' away from direct care and respite, saying:

The Case management model ... is jammed packed with Case management costs, administration costs and outsourcing costs. These costs accumulate and the end result is that between 70 and 80 percent of the package is dissipated in costs and is not utilized to purchase hours of support that is required to assist the person being cared for and as indicated earlier the provision of respite for the Carer. There is very little scope for the assessment or consideration of the quality of care provided and support provided by this model to the person being care for and for the caregiver.⁸⁸

4.79 Ms Helen Johnson, who cares for her son who is profoundly and severely disabled noted the reduction of funds available directly for care:

Currently the Victorian State Government is kind enough to provide us with a 'Linkages funding Package' where after brokerage dollars (as this package must have a case manager attached to it) we receive approximately \$6.5K.⁸⁹

4.80 Despite these concerns, the Committee believes the argument for case management is clear. The fact that carers are concerned that funding case

87 Queensland Government, Department of Premier and Cabinet, Submission No 1203, p 15. See also: Carers NSW, Submission No 661, p 29; ANGLICARE Sydney, Submission No 769, pp 8-9.

88 Friends of EACH Action Group, Submission No 1279, p 11. See also: Ms G Hawthorne, Submission No 12, p 2; Ms J Killeen, pp 1-2; Ms M-L May, Submission No 891, p 3; Mr T Stroud, Transcript of Evidence, 12 August 2008, p 49.

89 Ms H Johnson, Submission No 1178, p 3.

management reduces the amounts left over for care, reflects the overall lack of funding available – a matter that will be discussed in more detail in subsequent chapters. Innovative funding models to be discussed in chapter 6 have the flexibility to allow carers and care receivers to choose whether or not they wish to purchase case management/coordination services.

- 4.81 The Committee understands that carers require easy access to clear and up-to-date information, but at times they also require professional assistance to understand the options for their care receiver and help to liaise with service providers. Carers may also require assistance to consider longer term planning for themselves, the care receiver and other family members. Case management may be particularly relevant for new carers and for those facing transitions in their own lives or in the lives of those for whom they care.

Recommendation 11

- 4.82 **That the Minister for Families, Housing, Community Services and Indigenous Affairs and Minister for Department of Health and Ageing direct their Departments to review the adequacy of case management or care coordination for carers and care receivers using community care, aged care, disability and community mental health services.**

Advocacy for Carers

- 4.83 Advocacy is about speaking out, acting or writing, with minimal conflict of interest, on behalf of a person or a group, in order to promote their best interests. There are a range of different approaches to advocacy described in disability and carer literature. Broadly, however, advocacy can be described at two levels - 'individual' advocacy and 'systemic' advocacy.
- 4.84 Individual advocacy focuses on achieving outcomes for individual carers or care receivers. It can be useful to consider the following types of individual advocacy:
- self-advocacy – when a person raises their concerns themselves with, for example, professionals, media and politicians;
 - informal or family advocacy – when a family member, friend or neighbour advocates on behalf of a family member or friend; and

- formal advocacy (including legal advocacy) – provided by a paid staff member of a service on behalf of an individual.
- 4.85 Systemic advocacy on the other hand, is a form of advocacy provided by organisations or associations representing the rights and interests of a group rather than a particular individual. Systemic advocacy tends to focus on influencing government policy and practices.
- 4.86 A number of submissions to the Inquiry have suggested empowering carers to advocate for themselves and on behalf of those that they care for, and by enhancing carers' capacity to advocate systemically to ensure that carer interests are upheld and to remove policy barriers and discriminatory practices.

Individual Advocacy

- 4.87 Funding for disability advocacy is provided through the National Disability Agreement and delivered by 63 non-government organisations across Australia. The program is targeted at people with disability under the age of 65 years, to overcome barriers that affect their daily life and their ability to participate fully in the community. One of the models of advocacy funded under the National Disability Advocacy Program (NDAP) is informal or family advocacy which supports family members to advocate with, or on behalf of, a care receiver.⁹⁰
- 4.88 Many carers have commented on the value of formal disability advocacy services for care receivers.⁹¹ However, it is arguable that carers themselves, rather than formal advocacy services, provide most of the advocacy required by care receivers.⁹² Carers also report that disability family advocacy services, designed to support them in their informal advocacy role on behalf of a person with a disability, are often difficult to access.⁹³ In the view of the National Carers Coalition, the extent of informal family advocacy provided by carers themselves on behalf of care receivers, coupled with the apparent lack of formal family advocacy services, should be addressed by the establishment of a new family

90 Australian Government Departments (FaHCSIA, DoHA & DVA), Submission No 1109.2, p 2. The National Disability Advocacy Program does provide funding for some systemic advocacy on behalf of people with disability.

91 See for example: Ms H Johnson, Submission No 1178, p 8; Mr R Gow, Transcript of Evidence, 15 October 2008, p 5.

92 See for example: Ms S Harmer, Submission No 430, p 1; Gippsland Carers Association, Submission No 660, p 4; Mr R Gow, Transcript of Evidence, 15 October 2008, p 6.

93 See for example: Ms F Galbraith, Submission No 1089, pp 5-6. See also: National Carers Coalition, Submission No 571, pp 4-6; Gippsland Carers Association, Submission No 660, p 4; A4 Autism Aspergers Advocacy Australia, Submission No 1105, pp 2-3.

advocacy network for carers to be funded by the Australian Government.⁹⁴

- 4.89 Many carers have identified the need for additional training to enhance their own capacity to advocate on their own behalf and on behalf of care receivers. The importance of building the capacity of carers for self advocacy has been mentioned earlier in the chapter.
- 4.90 However, evidence suggests that there is also a pressing need for carers to have access to formal advocacy services for carers in their own right. Carers Queensland reported that carers currently seek advocates to work with them in a range of situations including dealings with employers, guardianship boards and tribunals, government agencies including Centrelink, service providers and health funds.⁹⁵ Carers ACT provided further examples of where carers themselves need assistance:

Carers of people with mental health issues and drug or alcohol addiction may face an additional problem when their personal possessions are damaged or stolen by the carer-recipient. These losses are not covered by insurance. It is also difficult to track down where stolen items have been sold and try to claim them back. Carers will not usually take action that leads to criminal charges against the care-recipient. However carers do need access to advocacy and support when dealing with such complex issues to assist with finding ways to resolve issues without putting the carer or care relationship at risk.⁹⁶

- 4.91 Carers themselves have described distressing situations where they were not able to achieve a positive service response or intervention through their own efforts. Ms Carmen Polidano, a carer for her 31 year old son, described her difficult caring situation:

My son has been physically violent and verbally abusive since he was 14 years old. When the violence started, my daughters were very young. As a family, we endured 15 years of domestic violence and verbal abuse. We lived in constant fear. I lost contact with friends, as my son would become violent if I even talked with

94 See for example: Mr R Gow, Transcript of Evidence, 15 October 2008, pp 4-7. See also: Ms F Anderson, Submission No 979, p 12; Ms A Geach-Bennell, Submission No 1022, p 1; Ms F Galbraith, Submission No 1089, p 5; Ms H Johnson, Submission No 1178, p 8; Ms N Brown, Transcript of Evidence, 6 August 2008, p 48.

95 Carers Queensland, Submission No 703, p 12. See also: Carer Support and Respite Centre Carer Group, Submission No 585, p 4; Carers ACT, Submission No 702, pp 26-28.

96 Carers ACT, Submission No 702, p 20. See also: Mr J Wilkinson, Submission No 1035, p 6.

them on the phone. My daughters could not socialise at home for the same reasons. We became socially isolated and extremely depressed. We lived with this problem daily and did our best to keep it from escalating to the point where we had to call the Police. We were a family unit constantly on the verge of collapse. Family and Police intervention didn't help. The only way the police could help was if I pressed charges. Our only other avenue of help, a support agency for the disabled, Care Connect, advised us to ring 000 - so we continuously went round in circles. There is nowhere a Carer can go to get help or protection from violence. Calling the Police is not the best way to resolve domestic violence involving someone with a disability. This is a medical problem not a criminal problem.⁹⁷

- 4.92 The need to increase formal individual advocacy services for carers is supported by many carers and organisations.⁹⁸ Carers Australia, which receives Australian Government funding to provide information and specialist advice to carers, reported that they cannot keep up with the demand from carers for formal advocacy services:

We have not done enough promotion of our services because we cannot meet the demand. A lot of those families want individual advocacy, and that can be very expensive, especially when you get into the legal side of caring ... So there is a need to look at individual carer advocacy.⁹⁹

- 4.93 Not all the evidence to the Inquiry, however, supported an expansion of services targeted at carers. A community based, state-wide disability advocacy agency providing advocacy services for children and adults with a developmental disability in NSW, expressed their concerns:

... at the amount of funding that is being deflected from the disability service system into programs for carers, as often the benefit is aimed at the carer alone, is short lived and creates a demand for more of the same. This is opposed to providing support which is long term, benefits the person with disability

97 Ms C Polidano, Submission No 259, p 2.

98 See for example: Ms V Simpson, Submission No 260, p 5; Carers NSW, Submission No 661, p 14; Australian Association of Gerontology Inc, Submission No 915, p 3; Ms J O'Connor, Submission No 1003, p 3; Ms F Galbraith, Submission No 1089, pp 5-6; National Ethnic Disability Alliance, Submission No 1110, pp 22-23; Mr G Schlecht, Transcript of Evidence, 20 August 2008, p 34.

99 Ms J Hughes, Transcript of Evidence, 28 November 2008, p 13.

equally, and builds on, rather than replaces, naturally occurring supports.¹⁰⁰

- 4.94 As with the arguments above for and against greater funding for case management, arguments against funding carer advocacy reflect the overall lack of resources for care receivers and carers alike.
- 4.95 The Committee notes that the Australian Government has undertaken to improve service delivery and access to advocacy for people with disability, and supports this commitment.¹⁰¹ The evidence to the Inquiry suggests further work needs to be done to recognise and support the pivotal role carers play in advocating on behalf of care receivers and when required, to provide carers with advocacy services in their right.

Recommendation 12

4.96 **That the Minister for Families, Housing, Community Services and Indigenous Affairs extend the National Disability Advocacy Program to:**

- **provide family advocacy services which better recognise the role of carers providing individual advocacy on behalf of, and with, care receivers; and**
- **provide formal advocacy for carers in their own right when this is required.**

4.97 The Committee also suggests that the proposed extension to the NDAP be accompanied by a change in program name to encompass both people with disability and their carers, and to more adequately reflect the objective of the National Disability Agreement to support:

People with disability and carers to have an enhanced quality of life and participate as valued members of the community.¹⁰²

Systemic Carer Advocacy

4.98 Systemic advocacy for carers is currently considered core business for Carers Australia as the national peak body for carers and for the network

100 Family Advocacy, Submission No 768, p 1.

101 Australian Government Departments (FaHCSIA, DoHA & DVA), Submission No 1109.2, p 2.

102 Council of Australian Governments, National Disability Agreement, p 3.

of state and territory Carer Associations.¹⁰³ Specific funding for this is provided by DoHA. Some carers have commented positively in relation to the systemic advocacy provided by the Carer Associations.¹⁰⁴ Others have questioned whether the current arrangements represent the full diversity of carer views.¹⁰⁵ For example, Ms Estelle Shields a long-term carer for her adult son with intellectual disabilities, stated:

[Carers], the workers at the coalface, must have an equal voice with service providers and peak bodies and we must have our own funded advocacy.¹⁰⁶

4.99 Elaborating on concerns with the existing structures of systemic carer advocacy, Mr Robert Gow a Queensland member of the National Carers Coalition, said:

It is a fact that disability advocates and service provider organisation peaks represent themselves and their constituents – that is, people with disabilities and service providers respectively. It is a fact that their role is not to represent the interests of carers. It is a fact that carer’s advocates and disability advocates do not necessarily share the same concerns. Certainly there are some crossovers, that is true, but it is a fact that the two are not mutually inclusive. Please do not assume that because advocates and peaks raise issues that involve carers that they represent carers.¹⁰⁷

4.100 Ms Jean Tops, Victorian Liaison for the National Carer Coalition, also proceeded to outline her concerns in relation to the dual role of the carer associations as service providers and as advocates for systemic reform for carers saying:

We want to make it very plain here that the carer associations are in fact service providers. On their own admission, they provide thousands of services to carers every year, and when they do that

103 Carers Australia website, viewed 11 March 2009 at www.carersaustralia.com.au/?/national/article/view/via:0:157. See also: Australian Government, Department of Families, Housing, Community Services and Indigenous Affairs, viewed 11 March 2009 at www.facs.gov.au/disability/national_disability_advocacy/default.htm.

104 See for example: Name withheld, Submission No 244, p 10; Mr J Halford, Transcript of Evidence, 12 August 2008, p 43.

105 See for example: National Carers Coalition, Submission No 571 (Attachment 2), pp 1-14; Ms N Brown, Transcript of Evidence, 6 August 2008, p 47.

106 Ms E Shields, Submission No 35, p 1.

107 Mr R Gow, Transcript of Evidence, 15 October 2008, p 5.

they do an excellent job. It is inappropriate for service providers to also be advocates for carers.¹⁰⁸

4.101 To address these concerns the National Carers Coalition suggests that there is a need for substantial reform to the current arrangements for systemic carer advocacy, recommending the establishment of a new advocacy model, which represents the interests of carers of people with lifelong dependent disabilities.¹⁰⁹

4.102 Ms Joan Hughes, Chief Executive Officer of Carers Australia, responded to these concerns by noting:

There is an issue with lots of families who have not been part of a system. They are families who would criticise disability advocacy groups, carer advocacy groups and ageing advocacy groups, because they feel like their voice has not been heard, and that is absolutely valid. We have a role at Carers Australia, as the national peak body, to work with these groups.¹¹⁰

4.103 Specifically in relation to the dual role of Carer Associations as service providers as well as providers of systemic carer advocacy, Ms Hughes proceeded to say:

Even though we are providing advice and services to carers, we also have the capacity through our research and evidence to talk with government about some of those strong issues.

... We also started as a grassroots organisation, and a lot of people do not know the history. Seventy-five per cent of board members of carers associations are current or former family carers. When you explain that to people, they say, 'Oh really?' We have mums and dads who are presidents of our associations, but we have not promoted that well enough. ... Carers Australia will continually fight for better support for those families, but we need to bring those other groups in. I am very committed, and so is the board of Carers Australia, to have meetings with some of those national alliances and see how we can work together.¹¹¹

4.104 Mr Andrew Stuart of DoHA, explained that it is not unusual for government to fund organisations to provide both services and systemic advocacy. Mr Stuart expressed that in his opinion:

108 Ms J Tops, Transcript of Evidence, 15 October 2008, p 10.

109 National Carers Coalition, Submission No 571 (Attachment 2), pp 1-14.

110 Ms J Hughes, Transcript of Evidence, 28 November 2008, p 13.

111 Ms J Hughes, Transcript of Evidence, 28 November 2008, p 13.

Carers Australia is a very good and strong advocate that is able to open doors in this House [the Australian Parliament]; I certainly do not have any sense of any reticence because they are also a funded program delivery organisation. I would just put on record that I particularly respect the way that they always bring and give a voice to individual carers at the functions that they manage.¹¹²

- 4.105 While the Committee acknowledges the concerns expressed by some carers with regard to systemic carer advocacy, it notes that others have commented favourably on the role of the Carer Associations in representing their views and advocating for systemic reform. In view of the conflicting evidence, the Committee does not believe that a compelling case for fundamental reform to existing arrangements for systemic carer advocacy has been demonstrated. The Committee also notes Carers Australia's commitment to represent the full diversity of carers, including groups that have not previously engaged.
- 4.106 Nevertheless, to investigate further the concerns expressed by some carers, the Committee believes that a review of existing arrangements of systemic carer advocacy may be beneficial. Specifically, the Committee recommends that existing arrangements for systemic carer advocacy be examined to determine how arrangements might be extended or reformed to further promote representation and inclusion of the diversity of carers, with particular focus on those that may feel that they are under represented.

Recommendation 13

- 4.107 **That the Minister for Health and Ageing review arrangements for systemic carer advocacy provided through Carers Australia and the network of state and territory Carer Associations.**

The review should examine the extent to which arrangements for systemic advocacy represent the diversity of carer groups and consider whether these arrangements might need to be extended or reformed.

Carers as Partners in Care

- 4.108 As discussed in chapter 3, carers and organisations are calling on the Australian Government to formalise the recognition of carers through the

112 Mr A Stuart, Transcript of Evidence, 28 November 2008, p 38.

adoption of national legislation and a strategic policy framework. One element for consideration is for formal recognition of the essential contribution of carers in the care, treatment and management of people affected by serious medical and mental health conditions. With changes in health, mental health, disability and age care policies supporting shifts from institutional care to care at home, carers are asking for recognition as partners in care by health, mental health, disability and aged care professionals and by service providers.¹¹³

- 4.109 Carers in many different types of caring situations have commented on the lack of recognition they are given by health professionals.¹¹⁴ Ms Michela Cardamone, an employed carer who works as a carer consultant in the Psychiatric Disability Rehabilitation Support Sector in Victoria observed:

My own experience has shown me that when strong and trusting relationships developed between my family member, the mental health professionals involved in her care, and myself, a far better outcome was achieved than any of us could have hoped for in caring for or treating her independently. Sadly though, this has not been the experience of the majority of carers I have come in contact with. Many, particularly those involved with the adult mental health sector, describe being shut out, ignored, disempowered and disrespected by the mental health system within which their loved one is treated.¹¹⁵

- 4.110 The complexity of the issue, particularly for carers of people with a mental illness, was raised by another Victorian carer, in the following comment:

The Confidentiality Act needs to be reviewed and understood. Too frequently a seriously ill, often deluded family member will be placed in hospital, and will be asked, in that state, if he, she wishes to have carers informed of treatment plans etc. If the consumer does not want the carer involved, the carer is out of the picture.¹¹⁶

113 See for example: Mr W de Goede, Submission No 366, p 1; Ms S Matheson, Submission No 587, p 5; Carers NSW, Submission No 661, pp 10-12; Carers Australia, Submission No 699, p 10; Ms H Johnson, Submission No 1178, p 9; Dr M Leggatt, Transcript of Evidence, 12 August 2008, pp 9-10; Mr P Saunders, Transcript of Evidence, 13 August 2008, p 11; Ms J McMahon, Transcript of Evidence, 13 August 2008, pp 91-92; Ms A Ashton, Transcript of Evidence, 26 September 2008, p 5.

114 See for example: Name withheld, Submission No 503, p 1; Ms J Nicholas, Submission No 1149, 3-4; Ms L Harper, Submission No 1162, p 4.

115 Ms M Cardamone, Submission No 799, p 1.

116 Ms A Burgess, Submission No 127, p 2. See also: Ms C Alliston and Ms C Fudge, Transcript of Evidence, 13 August 2008, pp 56-57.

4.111 The recognition of carers as partners in care would involve carers in assessment, treatment, discharge and care planning and implementation, services delivery, and monitoring.¹¹⁷ The recognition and involvement of carers as partners in care has a great deal to offer not only the carers but the formal care team and the care receiver, for instance:

- carers can provide valuable information and feedback to health care professionals;
- providing carers with information, education and training and involving them in discharge and care planning can increase compliance with discharge plans, prevent readmissions and improve the quality of care; and
- during hospitalisations, carers can support care receivers and act as quality monitors, alerting staff to potential costly problems before they happen.¹¹⁸

4.112 The recognition of carers as partners in care has been included in some state and territory government carer recognition legislation, mental health legislation and health policies.¹¹⁹ WA was the first jurisdiction to enact carer recognition legislation. As Carers WA explained:

Within Western Australia state legislation, the health and disability departments are expected to include carers as partners of health professionals in care planning and to support carers own needs as a community and family member.¹²⁰

4.113 Carers SA raised the importance of educating service providers in relation to such legislative and policy obligations:

... when it comes to building the participation of carers in service delivery, and a genuine sense of partnership with them, many service providers need guidance ... A comprehensive education and training program for service providers on carers and the caring role is required if services are to have the capacity to respond to developments arising from the State Government's Carers Recognition Act 2005 and SA Carers Policy.¹²¹

117 Carers Victoria, Submission No 652, p 32.

118 Carers NSW, Submission No 661, p 11.

119 See for example: Ms R Warmington, Transcript of Evidence, 13 August 2008, p 13.

120 Carers WA, Submission No 566, p 20. See also: Carers NSW Submission No 661, p 9; Carers SA, Submission No 684, p 11.

121 Carers SA, Submission No 684, p 11. See also: Ms R Warmington, Transcript of Evidence, 13 August 2008, pp 13-14.

- 4.114 The issue of recognising carers as partners in care with health and community care service providers raises complex issues about balancing the needs and interests of carers, care receivers and service providers. The submission from the Royal Australian and New Zealand College of Psychiatrists commented on the complexity in the mental health sector:

The involvement of family carers in the care of their family members with severe disability from mental illness is complicated by legal, ethical, bureaucratic processes that are often complex and difficult to navigate and 'cultural' issues. For instance, there may be confusing agendas between traditional ethical notions of confidentiality, privacy principles and legal obligations under the various State mental health acts. It is, however, noted that a duty to inform family is contained within Australian model mental health legislation and further enacted in some Mental Health Acts such as current NT legislation. While privacy is a valued right and needs to be protected it is imperative that other rights and responsibilities that protect the safety and quality of people's lives are also balanced in considerations. This is a complex area, but one that warrants review.¹²²

- 4.115 In its submission the Mental Health Council of Australia also called on governments to review policies in relation to confidentiality:

Mental health carers are often excluded from involvement in care due to privacy and confidentiality provisions. There is an urgent need for such policies to be reviewed and for a nationally consistent policy to be developed to clarify, for both service providers and carers, what can and cannot be shared in the absence of patient consent ...¹²³

- 4.116 The evidence strongly indicates that the involvement of carers as partners in care with health, mental health and community care service providers, can have positive results for all involved. This benefit needs to be balanced with the right of care receivers if they wish for privacy. The Committee understands that this is a vexed issue, particularly in relation to people who suffer episodic mental illness. However, there is considerable support from mental health professionals for the inclusion of family members who play key roles in the care and support of people with mental illness.

122 Royal Australian and New Zealand College of Psychiatrists, Submission No 672, p 4. See also: Dr J Freiden & Dr M Leggatt, Transcript of Evidence, 12 August 2008, pp 4-5.

123 Mental Health Council of Australia, Submission No 682, pp 9-10. See also: Ms J Hardy, Transcript of Evidence, 13 August 2008, p 93.

Health information privacy in particular, is a complex issue bound by Australian Government, state and territory legislation and regulation and professional codes of conduct.

Recommendation 14

4.117 That the Attorney-General, in conjunction with the Minister for Families, Housing, Community Services and Indigenous Affairs and the Minister for Health and Ageing, investigate whether the National Privacy Principles and the Information Privacy Principles, and equivalent provisions in state and territory privacy and mental health legislation, adequately allow carers to be involved in the treatment of the individuals for whom they care.

The Minister for Families, Housing, Community Services and Indigenous Affairs and the Minister for Health and Ageing promote to health and community care providers the importance of involving carers in the treatment and services for those receiving health and community care services.

Substitute Decision Making

4.118 Under various state and territory legislative regimes, carers, in certain situations, can act as substitute decision makers for care receivers. In instances where a care receiver has a disability which impacts on their decision making ability, carers may seek formal guardianship through state and territory Guardianship Boards and Tribunals. Such powers can provide carers with the authority to make decisions on behalf of the care receiver.

4.119 There are also various provisions under state and territory legislation for a competent adult to appoint an enduring guardian or an enduring power of attorney to make personal decisions and manage financial matters on their behalf if the time comes when they are unable to do so for themselves.¹²⁴ However, these arrangements are not straightforward:

... current legal provisions relating to enduring powers of attorney and advance care directives are complex and vary across the jurisdictions; terminologies are confusing and inconsistent and all

¹²⁴ See for example: NSW Guardianship Tribunal, Submission No 659, p 1; Mr T Tregale & Ms H Tregale, Submission No 766.1, pp 1-2.

too often the wishes of the person with dementia are not appropriately followed. Currently the opportunity of advance decision making is underutilised.¹²⁵

- 4.120 There is a lack of awareness in the general community of issues in relation to substitute decision making, including guardianship, enduring powers of attorney and advanced care directives. Alzheimer's Australia points out that:

Research has demonstrated that not all health professionals, including general practitioners are well informed about the enduring powers and advance directives and may lack the time or skills to assist people with this process. Lawyers also vary in their knowledge of the issues confronting people with a recent diagnosis of dementia.¹²⁶

- 4.121 The NSW Guardianship Tribunal's submission suggested:

... it would be beneficial to provide accessible and extensive community education to increase awareness of the legal options available for the appointment of substitute decision makers. Increased community education about enduring guardianship and enduring power of attorneys would be beneficial. It is important that such education also clarifies the duties and obligations of appointed substitute decision makers to always act in the best interests of the person with a disability.¹²⁷

- 4.122 A number of jurisdictions also have legislative processes to govern the use of 'advanced care directives' which enable an individual to make a statement about how they wish to be treated and who they wish to be involved in their treatment at a time in the future should the individual not have the capacity to make health care decisions for themselves. The evidence contained a degree of support for the use and promotion of advanced care directives. The Mental Health Council of Australia stated:

A practical way to overcome the problems associated with protecting the privacy and confidentiality of the person with the mental illness is to develop Advance Directives. Advance Directives allow consumers, when they are well, to plan what they would like to happen to them if they become unwell, and provides

125 Alzheimer's Australia, Submission No 1002, p 19.

126 Alzheimer's Australia, Submission No 1002, p 19. See also: Ms R Beale, Submission No 741, p 3; Ms M Robbins, Submission No 1139, p 2.

127 NSW Guardianship Tribunal, Submission No 659, p 2.

carers with a clear outline as to what extent they should be involved in treatment and recovery planning. Although Advance Directives may explicitly exclude carers from involvement in a person's care, they are a powerful and practical tool that can easily circumvent current privacy and confidentiality legislation with the prior permission of the person with a mental illness ... An Advance Directive pro-forma, that is legally valid in all states, should be developed so that consumers are able to decide what care they receive and who should be involved. Not only will this clarify the role of mental health carers, it will also lead to improved outcomes for the person with a mental illness as it can be used to guide treatment based on what has worked in the past for a particular person.¹²⁸

- 4.123 For people with dementia and their carers, there can be significant problems when advanced care directives or enduring powers of attorney are not in place. As explained by Alzheimer's Australia:

While informal arrangements can often work well in families, many individuals with dementia and their family carers encounter significant problems when wishes for future care and decision-making are unknown. End-of-life care can also become more difficult in the absence of advance directives. If powers are not in place the guardianship law may have to be utilised.

An increasing number of people with dementia who have not put enduring powers in place are referred to Guardianship Tribunals across Australia. Approximately 50% of all referrals relate to people with dementia.¹²⁹

- 4.124 The Committee is aware of the complexity of issues which confront carers in relation to the area of substitute decision making, including guardianship, enduring powers of attorney and advanced care directives. The evidence provided to the Committee suggests that the use of enduring powers of attorney and advanced care directives can be further utilised and that a uniform national approach is desirable.

128 Mental Health Council of Australia, Submission No 682, pp 9-10.

129 Alzheimer's Australia, Submission No 1002, p 19.

Recommendation 15

- 4.125 That the Attorney-General promote national consistency and mutual recognition governing enduring powers of attorney and advanced care directives to the Standing Committee of Attorneys-General.

Recommendation 16

- 4.126 That the Minister for Families, Housing, Community Services and Indigenous Affairs and the Minister for Health and Ageing and the Attorney-General fund a national information campaign to raise awareness about the need for, and benefits of, enduring powers of attorney and advanced care directives in the general community and among health and community care professionals.

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 Guilfole, 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.

Access to Supports and Services

- 6.1 This chapter considers issues relating to the access and effectiveness or otherwise of current community care services for carers. The chapter will:
- examine issues associated with the availability and accessibility of community care services for carers, including carers living in regional and remote locations and Indigenous carers;
 - examine issues associated with the availability, accessibility, affordability and quality of respite services for carers; and
 - examine issues associated with the availability, accessibility, affordability and quality in-home assistance for carers.
- 6.2 This chapter will also consider the need and options for structural and/or fundamental reform to community care systems.
- 6.3 Finally the chapter will consider the importance for carers of access to adequate community care services for care receivers.

Community Care Services

- 6.4 The broad community care system for carers and care receivers is made up of a number of different service systems, namely:
- community care services;
 - aged care services;
 - specialist disability services;
 - community mental health services; and
 - veterans' care services.

- 6.5 In addition, carers and care receivers using these services may be accessing other services in the health, mental health and palliative care sectors, as well as other services provided through education, employment, housing, transport and income support. The adequacy of all these services, individually and collectively, directly affect the quality of life for carers and care receivers alike.
- 6.6 Community care services have evolved to help improve the capacity of people with a disability, chronic illness, mental illness or frailty to live independently or, in circumstances where informal care is provided by family members or friends, to support the carers to provide adequate and sustainable care. In these circumstances, community care services are either targeted to support:
- care receivers directly, while possibly also indirectly alleviating the caring responsibilities of carers; or
 - carers directly, while also aiming to meet the needs of care receivers.
- 6.7 Based on their experiences, carers have raised a diverse range of issues and concerns relating to community care systems and services for carers and for care receivers. Carers and organisations report that not only is it difficult to discover and access appropriate community care services, but where they are available – and often they are not – they may not be of adequate quality.

The Accessibility and Availability of Community Care Services

Navigating the Service Maze

- 6.8 A common theme from carers is that the current array of community care services is too complex and confusing for those trying to identify and access services.¹ The complexity of community service systems derives from a number of factors, including:
- the linked but different needs of care receivers and carers;

1 See for example: Ms M Anderson, Submission No 331, p 2; Carer ACT, Submission No 702, pp 24, 34; Submission No 855, p 3; Mr R Taylor, Submission No 923, p 2; Ms J Steepe, Submission No 1023, p 6; Ms M Major, Submission No 1163, pp 1-2; Ms C Masolin, Submission No 1090, p 3.

- the multiple portfolio and program areas across all levels of government that are involved in the funding and administration of community care services;
- the separate service systems which provide assistance to carers and care receivers, namely, the community care, aged care, disability, community mental health and veterans' care services; and
- the involvement of government and not-for-profit and for-profit non government organisations in the delivery of services to carers and care receivers.

6.9 The result is that carers may have to identify community care services for themselves or their care receiver from different government departments and agencies, across different levels of government and delivered through a range of community or private sector organisations. These fragmented and complex service systems have resulted in a 'service maze', which is a source of frustration to carers. Furthermore, once services are identified, carers and care receivers are then confronted by varying eligibility requirements and assessment processes to access them.²

6.10 The experiences recounted below are typical of the frustration experienced by many carers trying to navigate community care systems to determine what services are available to support them or their care receiver:

Ms Kerry Ferguson - sole carer for a 22 year old with Cantu Syndrome

I am continually frustrated by the process to procure funding, services, packages, shared supported accommodation, case management and respite. Applications are not always clearly developed or transparent. It is a repetitive process that is impersonal, time consuming, highly frustrating and costly. Upon completion, even if the criteria are met, there is no guarantee of a successful outcome. This is directly due to funding shortfalls. Therefore, families are denied choice and there is no availability or flexibility. You may make several applications, attend requested meetings or make numerous telephone calls, all to no avail. There are few services that will accept applications for support and have established waiting lists.³

2 See for example: Ms K Batram, Submission No 33, p 1.

3 Ms K Ferguson, Transcript of Evidence, 1 October 2008, pp 39-40.

Ms Carey Sebbens and Mr John Doyle - carer for their fourteen year old son with complex care needs

There is an incredible maze of carers services, recreational, respite, post school options, advocacy, specialists, specialist medical experts etc that are very difficult to navigate. Basically the only way you find out about services your family member maybe eligible for is through word of mouth which is extremely frustrating and distressing especially when you learn of a service that may have benefited the person you care for years too late to make any difference.⁴

Ms Anne-Marie MacArthur - carer for her elderly mother

Although services are available to carers trying to access those services is akin to being in an ever increasing maze with illegible signposts so that the carer never really knows where to go or in which direction to take. To add to this mix the carer, in this case myself, is physically exhausted and emotionally spent. Not a happy combination when trying to understand bureaucratic-speak.⁵

Ms Megan Major - provides care for her husband with Parkinson's Disease and Lewy Body Dementia following a stroke

When my husband had his stroke, the hospital social worker helped me apply for carers allowance, obtain an 'Advice for Carers Package', organised a 'Post Acute Care Program', and gave me information about 'Home and Community Care Services'. A month after my husband came home I was drowning in paperwork and information and going round in circles trying to find out who actually did what!

I got lost in 'the maze' as I tried to work out who to contact for various types of support. I had to deal with: District Nursing Service and Cognitive Dementia and Memory Service - West Gippsland Health Care Group, Gippsland Regional Aged Care Assessment Service - Latrobe Community Health Services, Carers Victoria, Saw Saw Home and Community Care, Commonwealth Carer Respite Centre and Commonwealth Carer Resource Centre, Centrelink, plus GPs, physician and Neurologist.

4 See for example: Ms C Sebbens & Mr J Doyle, Submission No 615, p 2.

5 Ms A-M MacArthur, Submission No 871, p 1.

I found this very stressful. I believe if I had been able to continue with the support of the hospital social worker and if the local healthcare group co-ordinated the services I would not have 'fallen in such a big heap'.⁶

- 6.11 Even for carers seeking to access a single type of service, such as respite, the challenges of navigating the maze are still immense as explained in the submission from the Macarthur Aged and Disability Forum:

There are so many services that have been set up for respite but all of them are run by different agencies and have different guidelines. In Macarthur no one service provides the range of respite options carers require. Funding has been made available however the competitive process has resulted in a confusing mish mash of services. Add to this the confusion caused with different guidelines for every State, Federal and State/Federal funded programs and people who work in the sector have difficulty making sense of it all, imagine a carer who is already stressed, tired and at their wits end finally deciding to get some respite and they are faced with the above - giving up is a very practical option.⁷

- 6.12 The problem of finding suitable services is particularly challenging for carers from culturally and linguistically diverse (CALD) backgrounds. The submission from the Centre for Cultural Research, University of Western Sydney, identified the need for 'cultural competence' to successfully navigate and negotiate the community care system:

The capacity of carers to find information, make contact and negotiate services was influenced by what we describe as 'cultural competence'... This encapsulates knowledge of how the system of community and social care works, including the culture of service delivery, language of care provision, and the power structures within and across both government and non-government organizations. The fact that many carers, particularly CALD carers, knocked at the wrong doors, did not know or use the 'right' language, and/or disclosed needs to the wrong person resulted in frustration and led to many participants taking on an excessive burden of care.⁸

6 Ms M Major, Submission No 1163, pp 1-2.

7 The Macarthur Aged and Disability Forum, Submission No 749, p 3. See also: Ms I Stockfeld, Transcript of Evidence, 12 August 2008, p 45.

8 Cardona B, Chalmers S, Neilson B, *Diverse Strategies for Diverse Carers, The Cultural context of Family Carers in NSW* (2006), p 52 (quoted in Submission No 758, p 1).

- 6.13 With such a splintered array of services, carers and care receivers may find that their individual circumstances do not allow them to be pigeonholed neatly into a single support category. This can create difficulties for carers navigating service options in determining, for example, whether the disability or mental health service system is responsible for supporting a care recipient with an intellectual disability and a mental illness.⁹
- 6.14 It is not only carers of people with multiple medical conditions who are faced with the challenges of accessing services across service systems. MND [Motor Neurone Disease] Australia, made the point that care provision for people with neurological conditions also often cross over a number of service systems over time:
- Care provision for people with MND crosses traditional departmental boundaries including; health, disability, aged, chronic disease and palliative care and involves a combination of local, non-government, state and federal funding bodies: it does not fit into a single established funding stream. People with rapidly progressive neurological disease and their carers struggle to navigate this complex system. ... Carers consistently report to MND Associations that they become lost in the service provision maze.¹⁰
- 6.15 To some extent the difficulty facing carers in navigating the complex community care services could be alleviated by the provision of a single access point for information and increased access to case management services. The Committee has acknowledged this, at least partial solution, in recommendations made earlier in the report. Another partial solution is to streamline community care services through improved coordination and structural reform and this is addressed later in this chapter.

Eligibility and Assessments for Accessing Services

- 6.16 A by-product of having many, fragmented and narrowly focussed services is that carers and care receivers are forced to undergo multiple eligibility assessments before they can access services. Carers WA described carers and care receivers experiencing 'assessment fatigue' from the onerous assessment requirements:

The amount of assessments for essentially the same illness/disability and [care] situation is a barrier in itself. Many

9 Ms S Crowe, Transcript of Evidence, 6 August 2008, p 80.

10 MND Australia, Submission No 568, p 9.

carers and care receivers have 'assessment fatigue' from the amount of hoops that they have to jump through - many just do not bother asking for help, knowing that they would have to go through the assessment process again. For some, it may be easier to stay home themselves and provide all of the care, rather than being assessed for a service that may not be available, or at a convenient time, or that is not meaningful for the care recipient.¹¹

- 6.17 While the needs of carers may be considered when the needs of care receivers are being assessed for services, some evidence to the Inquiry has argued that it is important for carers to also have the option of a full assessment of their needs in their own right. For example, Carers SA suggested:

... carers not only have the right to be assessed independently of the care recipient but also should have the results of that assessment taken into account for the provision of services. This would offer a protection to carers to have their needs taken into account at that time.¹²

- 6.18 The reality is that there is no nationally consistent approach to assessing the needs of carers, or even a common language for defining need. In recognition of this, the Department of Health and Ageing (DoHA) in conjunction with the state and territory governments and the community care sector is developing national assessment tools for assessing carer needs including the Australian Community Care Needs Assessment-Revised (ACCNA-R) and the called the Carer Eligibility and Needs Assessment-Revised (CENA-R). The CENA-R is intended to be used for DoHA's carer related programs and services.¹³ Each carer assessment will consider:

- the extent of care hours required to assist the care recipient;
- an estimate of carer health;

11 Carers WA, Submission No 566, p 17.

12 Carers SA, Submission No 684, p 20. See also: Ms S Ruggiero, Transcript of Evidence, 12 August 2008, p 12.

13 ACCNA-R is used to collect and record relevant information about the needs of both the care recipient and carer at a 'broad and shallow' level. It will be used within some of the Access Point Demonstration Projects. CENA-R is a carer-specific assessment which adds to the information about a carer to form a 'deep and narrow' view of the caring relationship and an assessment of a carer's support needs. See also: Australian Government, Department of Health and Ageing website, viewed 20 February 2009 at www.health.gov.au/internet/main/publishing.nsf/Content/ageing-twf-assessment-ncaf.htm.

- the development of a coping profile which notes challenges and supports for the carer, an evaluation of carer burden, and an assessment of carer mental health and well-being; and
 - a screen of the physical capabilities of the carer to assess whether they themselves require supports and services.¹⁴
- 6.19 The Committee supports any initiative to minimise the bureaucratic burden placed on carers and welcomes the CENA-R initiative. The Committee believes that further development and application of the CENA-R should aim to fully utilise the CENA-R as a national assessment tool for carers across all Commonwealth, and state and territory government services and programs. The Committee, however, also recognises that it may be difficult to integrate CENA-R as an assessment tool with the eligibility requirements for payments delivered by Centrelink.
- 6.20 However, the possibilities of linking the CENA-R to the current development of a single assessment process for Carer Payment and Carer Allowance¹⁵ should be considered in terms of the Committee's previous recommendation in relation to the acceptance of recent supporting documents to verify claims for Care Payment and Carer Allowance.

Recommendation 29

- 6.21 **That the Minister for Families, Housing, Community Services and Indigenous Affairs and the Minister for Health and Ageing seek agreement through the Health, Community and Disability Services Ministerial Council to expand the nationally consistent assessment process based on the Carer Eligibility and Needs Assessment-Revised questionnaire.**

This will need to ensure the inclusion of carers accessing services offered through the Department of Families, Housing, Community Services and Indigenous Affairs and the state and territory governments.

14 Australian Government Departments (FaHCSIA, DoHA & DVA), Submission No 1109, p 50. See also: Australian Government, Department of Health and Ageing website, viewed 20 February 2009 at www.health.gov.au/communitycare_thewayforward.

15 Australian Government Departments, (FaHCSIA, DoHA & DVA), Submission No 1109, p 45.

- 6.22 The ultimate goal should be to reduce the requirement for carers and care receivers to undergo multiple assessments in order to access services within and across sectors.
- 6.23 Some evidence emphasised that carer assessments should take a 'whole of family' situational approach to take into account the needs of primary carers and secondary carers who may also support a care recipient.¹⁶ Whatever else, the eligibility criteria for services, funding and other supports needs to be flexible enough to accommodate the diversity of caring roles.¹⁷ The Committee was also reminded by the Disability Council of NSW that any carer assessment needs to be done on the basis that the care recipient also has their support needs assessed.¹⁸ In fact the needs of carers cannot be assessed without taking into account the needs of care receivers.

Community Care Services in Regional and Remote Locations

- 6.24 Evidence to the Inquiry indicates that carers living in regional and remote areas often face particular challenges accessing community care services. Services may simply not be available locally, forcing carers and care receivers to travel sometimes long distances.¹⁹ As Carers Australia explained:

Carers in these areas will often not have access to the internet, will need to travel long distances to access health professionals, information and support programs, will need to rely on other relatives or friends to care for other family members and their place of residence while they are travelling and will have additional costs associated with travelling. This has become particularly difficult with the increases in petrol prices.²⁰

- 6.25 In a specific example, the Horsham Family Advisory Committee, an advisory body to the Ballarat Health Services Psychiatric Service, pointed

16 Carers ACT, Submission No 702, p 22. See also: Carers SA, Submission No 684, p 20; Carers Australia Transcript of Evidence, 28 November 2008, pp 10-11, 15.

17 The Perth Carer Forum Group, Submission No 983, p 3.

18 Disability Council of NSW, Submission No 662, p 9.

19 See for example: Ms J Mort, Submission No 44, p 1; Mr M McDonald & Ms J McDonald, Submission No 589, pp 1-2; Mr C Kellett, Submission No 707, pp 1-3; Mr T Stroud, Transcript of Evidence, 12 August 2008, p 59; Ms R Warmington, Transcript of Evidence, 13 August 2009, pp 14-15; A Prof R Parker, Transcript of Evidence, 26 November 2008, p 4.

20 Carers Australia, Submission No 699, p 37.

out the challenges facing regional and remote area carers of those with a mental illness:

Mental health family and carers need to travel large distances to access specialised services in regional centres or cities and therefore face increased financial costs for travel. As well there is a lack of accessible public transport options in rural areas which adds to the family burden when an individual with [mental illness] becomes so unwell that they cease driving.²¹

- 6.26 Carers Australia suggested delivery of supports and services for carers living in regional and remote areas using a variety of means to suit individual requirements:

Carers in rural and remote areas of Australia need access to support programs, education and training, information and resources to be delivered by a medium that suits their individual needs and requirements. This could be through the internet, DVDs or in-home support by visiting service providers. It is absolutely critical that when addressing the needs of Australia's carers, the Committee has a particular focus on how best to meet the needs of those carers living outside metropolitan and large regional centres.²²

- 6.27 The Committee understands that providing any services in regional and remote areas can be difficult. Later in the chapter the Committee makes recommendations to address the shortages of health and community care services for carers generally. While recognising that these shortages are a national problem, the Committee encourages the Minister for Families, Housing, Community Housing and Indigenous Affairs and the Minister for Health and Ageing to consider the particular difficulties carers and care receivers face accessing services in regional and remote Australia. Later in the chapter, the Committee also examines the potential of individualised funding models to give carers and care receivers greater control over the services they receive. Potentially these models will allow carers in regional and remote areas to make maximum use of existing local resources and infrastructure.

21 The Horsham Family Advisory Committee (Victoria), Submission No 1108, p 5.

22 Carers Australia, Submission No 699, p 37.

Recommendation 30

- 6.28 **That the Minister for Families, Housing, Community Services and Indigenous Affairs and the Minister for Health and Ageing address the shortages of health and community care services for people living in regional and remote locations.**

Community Care Services for Indigenous Carers

- 6.29 The Committee received limited evidence from or about Indigenous carers. The fact that Indigenous carers often do not self-identify as such because many see caring as a natural extension of family duty also reduces the likelihood of their seeking any assistance from community care services.²³ This issue of carers not identifying themselves as such is considered earlier in the report.
- 6.30 However, even when assistance is sought it appears that Indigenous carers face particular challenges in accessing appropriate community care services.²⁴ Evidence has emphasised that a mix of Indigenous specific services and culturally sensitive mainstream services for Indigenous carers and care receivers is important.²⁵ One Indigenous carer who did contribute to the Inquiry suggested that Indigenous carers and care receivers would make greater use of mainstream disability and aged care services if the services employed more Indigenous health workers.²⁶
- 6.31 Although it appears that even in urban areas, Indigenous people can face difficulties accessing services, these difficulties are likely to be magnified for Indigenous carers living in rural or remote areas. The evidence that has been put to the Committee paints a stark picture of the challenges:

Remote communities are difficult to service. They are reached usually by four-wheel drive or by air. The road option takes time, the air option is expensive. Most contact to the Carers NT by carers is through health centres and by telephone. The telephone system

23 Carers Australia, Submission No 699, p 34.

24 Queensland Government, Department of Premier and Cabinet, Submission No 1203, p 15; Ms I Sullivan, Transcript of Evidence, 6 August 2008, pp 41-42; A-Prof R Parker, Transcript of Evidence, 26 November 2008, p 4.

25 Ms J Tongs, Transcript of Evidence, 3 December 2008, p 5.

26 Name withheld, Submission No 1304, p 5. See also: Ms S Freeburn, Transcript of Evidence, 6 August 2008, p 5.

can be very problematic. Many carers have only limited access to a phone to make outgoing calls, and often, no access to incoming calls. There is usually only one solar powered public phone on a community often not in working condition.²⁷

- 6.32 However, the lack of definitive information on the specific needs of Indigenous carers poses a significant problem for those seeking to provide community care services that are adequate and culturally appropriate.²⁸ As explained by Carers Australia:

In the light of what is known, it is possible to conclude that Indigenous carers and the people they support are significantly worse off than the majority of caring families. However it is difficult to bring before the Committee precise evidence about the circumstances and needs of Indigenous carers. Caring has not been a specific focus of the considerable research and consultation on needs or the development of national strategies to improve health outcomes and address other aspects of disadvantage and discrimination. There is little documentation of the way in which caring is occurring within communities, who is caring, the resources and supports that people are drawing on, the needs of family members providing care or the extent to which carers and families have access to services.²⁹

- 6.33 The Committee is concerned about the lack of evidence to the Inquiry from Indigenous carers, but more so about the more general the lack of information about the profile and needs of Indigenous carers. The Committee believes that further research on the specific needs of Indigenous carers, particularly as these pertain to community care services is required.

Recommendation 31

- 6.34 **That the Minister for Families, Housing, Community Services and Indigenous Affairs fund research into the profiles and specific needs of Indigenous carers.**

27 Carers NT, Submission No 685, p 17. See also: Dr Z de Ishtar, Submission No 1279, pp 9-10.

28 See for example: Ms S Freeburn, Transcript of Evidence, 6 August 2008, p 5.

29 Carers Australia, Submission No 699, p 34.

Recommendation 32

- 6.35 **That the Minister for Families, Housing, Community Services and Indigenous Affairs and the Minister for Health and Ageing examine the adequacy of culturally appropriate community care services funded by the Australian Government for Indigenous carers, particularly for those living in remote areas, with the intention of increasing the accessibility and availability of those services.**
- 6.36 This latter recommendation is a special case of the more general recommendations made later in this chapter. However, the Committee believes that the dearth of information on Indigenous carers, their needs and the services (or lack thereof) available for them warrants special attention.
- 6.37 The Committee would also like to see improved outcomes for Indigenous carers reflected in the Council of Australian Governments (COAG) National Indigenous Reform Agreement in the future.³⁰

Respite Care Services and In-Home Assistance

- 6.38 In evidence to the Inquiry, carers identified a range of services for carers as being either unavailable, not available to the extent required, too expensive or failing to meet the needs of the carer and/or the care receiver. The shortages of case management and advocacy services have already been discussed in earlier chapter 4. However, the two services that were repeatedly mentioned as being of critical importance for carers, and also in short supply, are respite care and in-home assistance.

Availability of Respite Care Services

- 6.39 Respite services are defined by the Australian Bureau of Statistics as formal respite care which allows carers time for other activities which may be tasks related to their caring role or engagement in other activities

30 Council of Australian Governments website, viewed 12 February 2009 at www.coag.gov.au/coag_meeting_outcomes/2008-11-29/index.cfm#indigenous.

related to the carer's own needs.³¹ There are various forms of respite, which includes in-home respite either in the carer's presence or absence, or residential respite where the care receiver is cared for away from the family home, either overnight or for a longer period.

6.40 Many carers have indicated that access to appropriate, affordable, timely and regularly planned respite, as well as emergency respite when required, is crucially important in providing carers with a degree of choice in relation to the caring role and the ability to balance caring with other aspects of their lives. Furthermore, access to adequate levels of respite care is critically important in order for many carers to continue in their caring role.³² Not surprisingly, the need for respite is greatest for carers with multiple care responsibilities or in circumstance where the intensity of the caring role is high.

6.41 The following accounts are typical of the experience shared by many carers, emphasising both the importance of respite to them and the difficulties that many face in accessing these services:

Ms Sharon Guest and Mr Stuart Neal – carers for their daughter mild to moderate hearing loss, autism, moderate to severe global developmental delay, and the rare and fatal illness Sanfilippo Syndrome

We had to phone up respite organisation after respite organisation, repeating *ad nauseam* our devastating situation, only to be channelled elsewhere or told there was nothing on offer.

It took hundreds of phone calls to be either told that no services are available or that we could be put on a waiting list but that this would probably take years to bear fruit. Commonly our calls weren't returned. We endured this for six months - and got nowhere. ... It also became abundantly clear that respite is very

31 Australian Bureau of Statistics, *A Profile of Carers in Australia* (2008), p 59.

32 See for example: Ms E Shields, Submission No 35, p 1; Mr R Morrison, Submission No 40, pp 1-2; Ms A Seales, Submission No 52, p 2; Ms B Fischer, Submission No 140, pp 1-2; Mr R Elliot, Submission No 253, p 2; Ms J Bellamy, Submission No 337, p 3; Mr F Hambridge, Submission No 355, p 1; Mr R Anderson, Submission No 360, p 2; Name withheld, Submission No 512, pp 3-4; Ms L Baker, Submission No 807, p 5; Name withheld, Submission No 904, pp 1-3; Ms J Parrott, Submission No 916, p 2; Ms E Walker, Submission No 973, pp 2-3; Mr D Gill, Submission No 1136, p 2; Ms M Major, Submission No 1163, pp 1-3; Ms M Mockler, Submission No 1253, p 1; Ms S Crowe, Transcript of Evidence, 6 August 2008, p 81; Ms S Mina, Transcript of Evidence, 12 August 2008, pp 48-49; Ms A Stacey, Transcript of Evidence, 13 August 2008, p 21; Ms J Hope, Transcript of Evidence, 9 October 2008, pp 2-5; Ms K Pritchard, Transcript of Evidence, 28 November 2008, pp 1-2.

limited. Any respite - should you get it - is short term. Our situation was not short term. It was going to get progressively worse. We were horrified to discover that there is nothing available of any consequence for families such as us who are simply left to cope on their own.³³

Ms Glenis Hawthorne - long term carer with her husband for their daughter with intellectual and physical disabilities

Insufficient respite services are made available. In our caring role with our child, we have provided care for all but three nights in twenty seven years. There appears to be endless 'packages' to support the aged but very little available to support families who are caring for children with disabilities. What happens when you wear out the Carers and they are no longer able to fulfil their caring duties? Give us all a break before that happens!

Ms Oi yun Leongue - mother of four children, two of whom have autism

... there is a shortage of respite houses in my local area. The respite house my daughter currently attends is always unavailable for weekend bookings and we are always on the accommodation waiting list. As the Mother of two autistic children, my husband and I need a break. We are only given seven hours of respite per week and the years and years of stress and anxiety have taken a toll on our health. If this level of stress and worry continues, I fear we will soon reach our breaking point. We urgently need help now, in the form of more respite.³⁴

- 6.42 Many service providers also frequently reported that the supply of respite services is not keeping pace with the demand. As the Australian Red Cross explained:

Carers manage until they cannot manage. We cannot afford to then say, 'Oh, but we haven't got the services today or tomorrow; how does next week or next month suit you?' because carers are at breaking point and they are not very good at putting their hands up and asking for help. We take six of those calls a day, and it used to take us one or two calls to put respite in place for them. It can now take us 10 calls to put respite in place for them. It is getting harder to find appropriate services that can cope with the

33 Ms S Guest & Mr S Neal, Submission No 872, pp 4-5.

34 Ms Oi Yun Leongue, Submission No 1029, p 1.

numbers that are coming through and the complexity that is coming through.³⁵

- 6.43 The shortfall in respite services appears to be national and across the various respite service options. Ms Margaret Fisk, the National Coordinator of the Defence Special Needs Support Group, which provides supports to Defence Force families caring for a family member with a disability or special needs, provided a national perspective:

Respite waiting lists in many areas are closed or are extremely long with agencies reporting that they not taking any more referrals. For example in Townsville, the majority of respite is geared towards those caring for the elderly so if you relocate to Townsville and you care for a severely disabled member of your family, it is highly unlikely that you will receive any respite support for quite some time (other than short term or emergency offered by the CCRC) [Commonwealth Carer Respite Centre]. Similar situations occur in Canberra, areas of Melbourne, Sydney and Brisbane.³⁶

- 6.44 The situation in Western Australia seems similar:

Carers Advisory Council members have had opportunities to consult with carers in both metropolitan Perth and regional Western Australia. ... Without exception the lack of respite services and the lack of respite options is raised in these forums. In particular, carers comment that emergency, overnight, short and long stay options are often not available unless booked well in advance.³⁷

35 Ms L Crumlin, Transcript of Evidence, 23 July 2008, p 50. See also: Disability Assistance for Shoalhaven, Submission No 256, p 2; Neuro Muscular Alliance Tasmania, Submission No 569, p 2; Carer Support Network of SA, Submission No 675, p 2; YNH Services Inc and Yarrowonga Mulwala Carers Support Group, Submission No 678, p 3; National Seniors Australia, Submission No 686, p 6; Child and Adolescent Mental Health Services Eastern Health (VIC), Submission No 762, pp 1-3; ANGLICARE Sydney, Submission No 769, pp 25-30; Queensland Government, Department of Premier and Cabinet, Submission No 1203, pp 17-18.

36 Defence Special Needs Support Group, Submission No 695, p 3. See also: Carers Australia, Submission No 699, p 27.

37 The Hon Sue Ellery MLC, Minister for Child Protection; Communities; Women's Interests; Seniors and Volunteering, Submission No 761, p 4.

Affordability of Respite

6.45 Services like respite need not only to be available, but also to be affordable.³⁸ The cost of respite care services, particularly overnight respite, can be beyond some carers. Many carers on low incomes find the costs associated with accessing respite and other support services unfair and unrealistic. The priority for one carer was:

Realistic and affordable respite that Carers can afford to pay. They get paid a pittance for doing the same job, so can hardly be expected to afford the ridiculous rates charged.³⁹

6.46 A typical situation was described by Ms Beverley Schulz who cares for her 22 year old daughter:

Carers need more respite hours/nights per year to be made available, at less dollars per night. At present we pay \$25.00 p/night so have had to cut back on how often we access respite ... We simply can't afford to pay \$25 for night stays.⁴⁰

6.47 Another carer, Ms Helen White who provides care for her 17 year old son with significant intellectual disability and autism also called for more affordable respite options, recounting:

I had one respite provider price out from 3 pm Friday until 9 am Monday at over \$3000! Clearly my son will not be going there!⁴¹

6.48 The impact of the cost residential aged care respite on a household income was also raised by Mr Peter Aris, a Tasmanian carer, who cares for his wife:

We are allowed at present nine weeks a year for respite. How can we possibly afford respite when the full pension is taken off the patient when they go into respite care? Most carers cannot afford to take respite. No wonder their health deteriorates. I believe carers should have a higher financial status than that of pensioners due to their greatly increased costs.⁴²

38 See for example: Ms D Lamond, Submission No 46, p 4; Ms S Jakanski, Submission No 446, p 3; Carers SA, Submission No 684, p 22; National Seniors Australia, Submission No 686, p 6; MS Society of Tasmania, Submission No 747, p 3; St George Migrant Resource Centre, Submission No 746, p 37; Ms N Brown, Submission No 951, p 12; Ms R M Painter, Submission No 1143, p 2; Ms S Gambin, Transcript of Evidence, 12 August 2008, p 72.

39 Ms D Edwards, Submission No 159, p 5.

40 Ms B Schulz, Submission No 286, p 1.

41 Ms H White, Submission No 72, p 1.

42 Mr P Aris, Transcript of Evidence, 9 October 2008, p 23.

Respite Needs to be Flexible

6.49 For carers to have a degree of choice in their own lives, respite care services should be flexible enough to meet the needs of both carer and carer receiver. However, there appears to be limited opportunity to tailor respite services to the needs of the carer, the care receiver or both.⁴³ Some carers have observed that the respite services offered appear to suit the funding priorities and organisational structures of the respite providers rather than the needs of their clients.⁴⁴ As acknowledged by the Western Australian Government, providing respite should require flexibility and consideration of diverse client needs:

The very great challenge for respite is to be sufficiently flexible and responsive to meet the individual physical, emotional, financial and cultural needs of carers and the persons they care for within a wide range of changing economic, social and environmental situations and circumstances.⁴⁵

6.50 A number of submissions identified the need for the timing and duration of respite to be more responsive to the needs of carers, for example, to be provided overnight, on weekends or during school holidays.⁴⁶ While some carers emphasised the importance to them of overnight or residential respite to allow them time away from their caring role⁴⁷, others expressed the preference for respite to be provided in the home setting.⁴⁸

6.51 Yet others have suggested that more respite be provided in such a way that it allows the carer, the care receiver and their families to spend quality time together in a supportive setting. For example, Mr Frank Poole, who provides care for his wife with severe physical disabilities suggested:

43 See for example: Ms M Bartlett, Submission No 58, p 1; Ms H White, Submission No 72, pp 1-2; Name withheld, Submission No 559, p 3.

44 See for example: Ms J Mann, Submission No 192, p 2; Ms C Franklin, Transcript of Evidence, 23 July 2008, p 45; Ms M Sweeney, Transcript of Evidence, 6 August 2008, p 89; Ms L Light, Transcript of Evidence, 6 August 2008, p 92; Mr T Stroud, Transcript of Evidence, 12 August 2008, p 49.

45 WA Government, Department for Communities, Submission No 761, p 4.

46 See for example: Ms H White, Submission No 72, p 1; Ms S Bailey, Submission No 370, p 2; Ms S Gibb, Submission No 1135, p 3; Ms J Waymouth, Transcript of Evidence, 23 July 2008, p 55; Mr W Haynes, Transcript of Evidence, 6 August 2008, p 65.

47 See for example: Ms E Shields, Submission No 35, p 1; Mr R Morrison, Submission No 40, p 2; Ms S Menegatos, Submission No 63, p 3; Ms J Whitehill, Submission No 65, p 2.

48 See for example: Ms H Davies, Submission No 28, p 1; Ms M Huddleston, Submission No 37, p 1; Ms P Haldane, Submission No 41, p 2; Ms D Osborne, Submission No 43, p 2; Ms J D'Angelo, Submission No 60, p 2; Ms A Bellchambers, Submission No 349, p 2.

It would be nice if facilities existed for the carer and the cared for to be able to have a weeks respite together where there was someone to do the housework and cooking and give the carer a break at least from these chores but still not feel guilty about leaving a loved one in someone else's care.⁴⁹

- 6.52 Evidence suggests that accessing respite is particularly challenging for carers of people with dual diagnosis or high level and/or complex care needs.⁵⁰ For example, Ms Careen Dew, a young carer who assists in providing care for a younger brother with multiple disabilities, explained that her family did not meet eligibility criteria for many respite services as his case was classified as a 'medical' problem rather than as a 'disability'. As a result, Ms Dew noted:

Over the past nine years we have only had respite during the night twice, so it is something that we definitely need. For some reason we have to apply every six months with these respite agencies and we are still being refused and rejected just for little amounts of time, four hours here and there.⁵¹

- 6.53 In the case of younger care receivers (i.e. under 65 years) with high care needs, another criticism repeatedly made is that often the only respite option available is in an aged care facility – an option resisted by many. As explained by Ms Glynis Thyer, who provided care for her husband (now deceased) with multiple sclerosis:

To place a person in their 20's, 30's 40's or 50's in an Aged Care Facility for respite is incredibly difficult for their Carer. The person in need often fights/opposes the idea of going in to respite, especially in to a place that is not suitable to their needs. This puts added emotional pressure on the Carer.⁵²

- 6.54 Carers reported not using respite services because the only option available to them was a placement in an aged care facility:

I would love there to be more respite care accommodation for my husband that is not an aged care facility. It is not fair to think that

49 Mr F Poole, Submission No 67, p 1. See also: Ms C Polak & Mr W Polak, Submission No 902, p 4; Ms B Cardona, Transcript of Evidence, 6 August 2008, p 17; Ms S King, Transcript of Evidence, 6 August 2008, p 34.

50 See for example: Ms A Bellchambers, Submission No 349, p 2; Ms S Scrivener & Mr D Scrivener, Submission No 1113, p 4; Ms S Crowe, Transcript of Evidence, 6 August 2008, pp 80, 84.

51 Ms C Dew, Transcript of Evidence, 6 August 2008, pp 45, 50.

52 Ms G Thyer, Submission No 679, p 2. See also: Ms E Ingram, Submission No 242, p 1.

when I need a rest I have to put him in an old person's home so rather than do that I try to carry on the way things are now and not have a rest.⁵³

- 6.55 The need for respite to take into consideration cultural issues was also raised in evidence.⁵⁴ At a hearing in Sydney, Ms Beatriz Cardona provided the Committee with a number of situations where community care services had failed to accommodate specific cultural or religious requirements. The following example relates to an elderly carer from Macedonia who refused the offer of respite on the basis that she could not accompany her daughter who has a disability:

This example highlights how concepts such as carer and respite resonate differently among different communities and individuals. The label 'carer' is often difficult to translate because it is partly embedded in a diversity of family rules and caring relationships. Moreover, the notion of respite for this family meant that both daughter and carer needed the respite, which did not equate with separation and nor did it equate with the notion of her daughter being a burden. The service was unable to meet the reality of this family's specific needs. We also have the issue of quality of service available. Part of the reason the mother wanted to go with her daughter was because of her concern that her daughter may not be adequately cared for.⁵⁵

- 6.56 As mentioned earlier, respite options in regional or remote areas are often more limited than in urban areas, meaning that facilities are some distance away, and then are sometimes still unsuitable. Carers NT explained the situation for people living in remote communities in the Northern Territory:

... until recently the only respite that could be provided was to fly the care recipient into Darwin and place her/him into a nursing home. Carers, the wider community and the care recipient resisted this option ...⁵⁶

53 Ms C Bazeley, Submission No 333, p 1.

54 See for example: Australian-Polish Community Services, Submission No 654, pp 1-2; Ethnic Disability Advocacy Centre, Submission No 787, p 17; Ms B Cardona, Transcript of Evidence, 6 August 2008, pp 17-18.

55 Ms B Cardona, Transcript of Evidence, 6 August 2008, p 17.

56 Carers NT, Submission No 685, p 17. Carers NT notes that local and culturally appropriate programs are beginning to be offered on some NT Indigenous communities e.g. the 'Troopy Program' described on p 22 of the submission.

- 6.57 The unsuitability of this respite option for Indigenous care receivers and carers living in remote locations was further explained by Carers NT:

Indigenous culture is absolutely associated with the land that is owned by the various groups. This connection inculcates the very essence of the people who believe that they belong to the land, rather than the land belonging to them. This connection is such that care recipients do not want to be taken from their land to attend hospital or access respite outside of their country. Older people are terrified that if they are placed in a nursing home in one of the urban settings, to provide their carer with respite, they will die away from their land. For example, out of 57 carers registered on one community only 5 care recipients agreed to access respite by coming into Darwin.⁵⁷

The Urgent Need for More Respite

- 6.58 The overwhelming evidence received by the Committee indicates that respite services are an essential support for sustaining carers in their caring role. The unmet need for respite services results in increased levels of stress for carers, their families and those being cared for, reduced economic and social participation and reduced levels of health and wellbeing.
- 6.59 The evidence suggests that current respite services are unable to meet the need from carers for both emergency and short term respite, as well as for planned, regular respite services. Access to those services that are available is often prioritised on the basis of the degree of urgency or severity of the caring and family situation. What alarmed the Committee however, is that this approach places carers and their families in the invidious situation of needing to present the worst possible picture of their circumstances. One carer explained an assessment process to access respite services used by the NSW Government in the following terms:

It would also be less stressful if families did not have to 'beg' each year for these services, currently families are assessed each year and given points ... more points are scored if your marriage is breaking down, more points if you are depressed, more points if a family member is dying!⁵⁸

57 Carers NT, Submission No 685, p 21.

58 Ms F Galbraith, Submission No 1089, p 3. See also: Family Advocacy, Submission No 768, p 3; Mr C Rook, Transcript of Evidence, 23 July 2008, p 42.

- 6.60 The Committee sees the shortage of local, timely, and appropriate respite services as one of the key issues facing carers. At the same time, services also need to be flexible, culturally appropriate, easily accessible and affordable. Many of the criticisms of respite services are manifestations of the fundamental problem that there are simply not enough respite services to meet demand. Ultimately, there needs to be more respite services which, in turn, requires a financial commitment from the Australian Government.

Recommendation 33

- 6.61 **Recognising the ageing demographic of the carer population and the increased longevity of many care receivers, that the Minister for Families, Housing, Community Services and Indigenous Affairs and the Minister for Health and Ageing increase capital and recurrent funding for respite care services funded by the Australian Government as a matter of urgency to more closely match demand across the country.**

Particular attention should be paid to improving the:

- **availability and accessibility;**
- **affordability;**
- **responsiveness to the needs of both carer and care receiver of respite services; and**
- **responsiveness to the needs of carers and care receivers in living regional, rural and remote areas.**

- 6.62 The Committee is conscious that state, territory and local governments also fund and administer respite services and that any increase in services by the Australian Government should not be offset by a diminution in services by other jurisdictions. Indeed the review process being undertaken by the Council of Australian Governments (COAG) discussed in chapter 1 and below will be an ideal mechanism to ensure that the provision of respite is increased without cost shifting or another round of the 'blame game' between governments.

In-Home Assistance for Carers

- 6.63 Many carers have identified in-home assistance or support as being highly valued.⁵⁹ The main forms of in-home assistance include:
- domestic assistance (e.g. assistance with household jobs such as laundry and ironing etc);
 - assistance with personal care for the care receiver (e.g. assistance with bathing, showering and toileting etc); and
 - assistance with general care and maintenance of the home and yard (e.g. changing light bulbs, lawn mowing and gardening)
- 6.64 Currently these types of in-home assistance are provided for people with a disability, for the frail aged and for their carers through the Home and Community Care (HACC) program. As noted earlier in the report, HACC is jointly funded by the Australian, state and territory governments, although the states and territories manage the day to day administration of the program. For the frail aged and their carers, in-home assistance is also available through the Australian Government's Aged Care Packages⁶⁰, and for veterans and their carers, though the Veterans' Home Care program.
- 6.65 As with respite services, evidence suggests that the demand for in-home assistance for carers exceeds supply, and that the levels of assistance when available are not adequate.⁶¹ An older carer, Mr Noel Sweeney, saw his priority need as a carer as:

Access to reliable home help. Some charities can help, but how clean could your house be with a half - hour's cleaning a fortnight?

It would be a total change to my life if there were more realistic help forthcoming. I eagerly look forward to stepping outside my

59 See for example: Ms P Haldane, Submission No 41, p 2; Ms L Bristow, Submission No 64, p 2; Mr T Vanderputt, Submission No 106, p 1; Ms S Vote, Submission No 134, p 1; Mr W Woolhouse, Submission No 201, p 1; Mr A Corbett, Submission No 251, p 1; Ms S Durkin, Submission No 329, p 2; Ms P Birch, Submission No 345, p 1; Ms E Forrester, Submission No 361, p 1; Ms A Esendag, Submission No 362, pp 1-2; Ms B McMahon, Submission No 705, p 1; Ms F Tountzis, Submission No 1140, p 2.

60 Community Aged Care Package (CACP); Extended Aged Care at Home (EACH); and Extended Aged Care at Home Dementia (EACHD).

61 See for example: Name withheld, Submission No 31, p 1; Ms B Borg, Submission No 76, p 2; Ms H Stone, Submission No 94, p 2; Ms S Vote, Submission No 134, p 1; Mr N Kaye, Submission No 143, p 2; Ms C Hunt, Submission No 271, p 2; Ms A Micallef, Submission No 272, p 2; Mr P Zachariadis, Submission No 279, p 2.

front gate one day, knowing that I don't have to do everything on my own.⁶²

- 6.66 Similarly, Mr Frank Poole, another older carer, suggested that elderly carers would benefit from:

More assistance to carers in the house cleaning, ironing, vacuuming side would be appreciated, as many carers are themselves elderly and in my case with having to support my wife and do these chores my own back is beginning to feel the strain and I am concerned that a time will be reached when my back will not allow me to care for my wife. Anything that can stall that off will be an advantage to all.⁶³

- 6.67 A carer with multiple caring responsibilities, Ms Diana Lamond, stressed the importance of adequate levels of domestic assistance and requested:

More domestic assistance. Queensland Health send a person to clean on a fortnightly basis - 2 hours. Running a home with two disabled men is exhausting. There is always housework, ironing, washing, shopping.⁶⁴

- 6.68 Carers of young children have also commented on the value of in-home help. For example, Ms Trish Welstead, the mother of two daughters one of whom has Cystic Fibrosis, explained that practical domestic assistance would be extremely helpful to her and her family, especially during periods when her daughter was hospitalised:

When Zoe goes into hospital, she stays for two weeks at a time minimum. I stay with her for most of that time and my husband stays for some days. By the time I get back home, I have a whole house to re-organise and try and catch up with washing, cleaning the toilet, bathroom, etc. My husband works long hours and only just manages to get our other daughter organised and off to school every day ... If it weren't for my parents who are in their late 60s and late 70s, I literally would not survive these times.⁶⁵

- 6.69 However, not all applications for domestic assistance are responded to positively. Ms Carmel Flavell, a sole parent carer, who has four children, described her attempt to access domestic assistance:
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62 Mr N Sweeney, Submission No 133, p 1.

63 Mr F Poole, Submission No 67, p 1.

64 Ms D Lamond, Submission No 46, p 4.

65 Ms T Welstead, Submission No 616, p 1. See also: Ms L Leggo, Submission No 773, p 3; Ms C Paisley-Dew, Submission No 826, p 5.

In order to lessen some of the demands made upon me I referred myself to Home Care of NSW hoping to get some domestic help. I was hoping Home Care could assist me even though I am working ... As for the domestic help, I have been waiting for 12 months now and have heard nothing.⁶⁶

- 6.70 Assistance with personal care, while principally a service for the care receiver, also reduces the care load for the carer. A large number of carers commented on the value to them of this type of support. As with domestic assistance however, evidence suggests that demand for this type of assistance exceeds supply and that where available, the level of assistance is inadequate.⁶⁷
- 6.71 Carers also frequently commented on the need for greater assistance with home maintenance, including yard maintenance. Some carers indicated that they were unable to undertake routine home maintenance tasks due to the physical demands or the need for skills and technical 'know how'. Often with limited financial resources, carers indicated that they could not afford to cover the sometimes significant costs associated with engaging tradesmen.⁶⁸
- 6.72 From the evidence it appears that in-home assistance and supports are highly valued by the carer, and particularly by older carers, carers of young children and adults with high care needs and by those with multiple caring responsibilities. However, like many of the other services for carers, the levels of help appear generally inadequate across the nation. To provide carers with the assistance they need to provide sustainable care the Committee concludes that the availability and levels of in-home assistance and supports also need to be increased to more closely meet demand. While the bulk of in-home assistance funded by the Australian Government is provided by DoHA through the HACC program, FaHCSIA, as the other major funder of carer services, should also consider increasing funding for in-home assistance.

66 Ms C Flavell, Submission No 186, p 3.

67 See for example: Name withheld, Submission No 22.1, p 1; Name withheld, Submission No 31, p 1.

68 See for example: Ms B Elliot, Submission No 36, p 1; Mr R Spring, Submission No 49, p 1; Ms M Weller, Submission No 53, p 2; Ms M Bartlett, Submission No 58, p 2; Ms M Trehwella, Submission No 154, p 2; Ms S Smith, Submission No 901, p 1; Name withheld, Submission No 1295, pp 12-13.

Recommendation 34

- 6.73 **That the Minister for Health and Ageing and the Minister for Families, Housing, Community Services and Indigenous Affairs increase funding for in-home assistance for carers in order to more closely meet demand.**

Waiting Lists as a Response to the Lack of Community Care Services

- 6.74 As noted earlier the evidence to the Inquiry indicates a national shortage of community based services for carers (and care receivers) generally, frequently resulting lengthy waiting to access services.⁶⁹ Moreover, some carers suspect that the widespread use of waiting lists to access services is a *de facto* mechanism to manage demand where it exceeds supply.⁷⁰ Tellingly, one carer even reported on the use of a waiting list to get onto a waiting list!⁷¹ Another carer explained how after three years on a waiting list for residential age care for her elderly mother, she had been advised that a place was available, one year after her mother had died!⁷²
- 6.75 Ms Maria Antonas, a carer in Western Australia, summed up the delay she experienced in getting assistance from an Extended Aged Care at Home (EACH) Package by saying:

I get nothing from any care-organisation other than 'You're on the list!!!' I need help with every aspect of caring. To be put on the 'EACH' Waiting List for over nine-months is unjust.⁷³

- 6.76 In practice, waiting lists mean that services are effectively not available for many in need as noted by Ms Sue Harmer, a carer living in Victoria:

I am submitting to the inquiry because of the complete lack of services available on the ground. There are services on paper, but if you attempt to get services for either yourself, as carer, or for

69 See for example: Ms D McIntyre, Submission No 187, p 1; Name withheld, Submission No 512, p 3; Ms C Phillips, Submission No 755, p 2; Ms K Boyd, Submission No 783, p 2; Ms L Coyte, Submission No 868, p 1; Ms S Gibb, Submission No 1135, p 3; Name withheld, Submission No 1248, p 2.

70 Mr M Beardmore & Ms J Beardmore, Submission No 59, p 2.

71 Ms S Harmer, Submission No 430, p 2.

72 Ms N O'Boyle, Submission No 327, p 2.

73 Ms M Antonas, Submission No 299, p 1. See also: Ms M Alford, Transcript of Evidence, 13 August 2008, p 4.

person/s with a disability, you will find that you will get the run around, and or placed on the waiting list, to which there is a list for everything ...⁷⁴

- 6.77 Another carer, who wrote about the use of waiting lists and the difficulties facing carers who attempt to access residential respite services in Victoria, even on an occasional basis, expressed the dilemma confronting many carers, in the following terms:

The wait lists in Victoria are a joke. It has taken over two years on a waiting list for us to access occasional residential respite with Yooralla for Nicholas. Let me put this clearly: the need is huge and the services paltry. Many people will struggle for years without help.⁷⁵

- 6.78 As explained by Ms Linda Glover at a hearing in Hobart, service providers struggling to meet demand are forced to resort to waiting lists:

We do have waiting lists. We have waiting lists in our aged-care programs. We have waiting lists of people wanting Community Aged Care Packages of care and a HACC program for school holiday respite for young people with disabilities.⁷⁶

- 6.79 The use of waiting lists by over stretched service providers may also discourage carers from seeking access to services. In its submission, Carers ACT observed:

Waiting lists are also a disincentive for many Carers. Anecdotal evidence received by Carers ACT often indicates that carers may be told there is a waiting list and give up without gaining a place on the list. Some carers are not told that the waiting list may be prioritized and that they will never reach a high-enough priority to actually receive services.⁷⁷

- 6.80 Carers are not only faced with waiting lists to access services, they are also faced at times with waiting lists to access assessments to determine eligibility for services. One carer explained the situation she and her sister were experiencing as they waited to access an aged care assessment to determine eligibility for residential respite :

Our second difficulty is with the ACAT [Aged Care Assessment Team] assessment system. Understandably, the assessment must

74 Ms S Harmer, Submission No 430, p 1.

75 Ms C Pereira, Submission No 880, p 3.

76 Ms L Glover, Transcript of Evidence, 9 October 2008, p 46.

77 Carers ACT, Submission No 702, p 24.

be carried out each year in order to determine that receivers are receiving their entitlements, or conversely are not receiving things they are not entitled to. However, it would appear that the department providing this service is seriously understaffed/overworked. We had our last assessment in March 2007. I telephoned to arrange this year's assessment in March or April of this year [2008], and we still have not been given an appointment ... Without a current ACAT assessment, we are unable to access respite care ...⁷⁸

- 6.81 To some extent the use of waiting lists is a legitimate mechanism for prudently managing and controlling supply of a service. However, excessively long waiting lists are an indicator of unmet demand. The consistent complaints from carers about ubiquitous and long waiting lists for services is yet more evidence that support for carers is inadequate.

Options for Reform

- 6.82 The Committee appreciates that it is neither desirable nor economically feasible for all care to be provided by the taxpayer. Indeed many carers have indicated that they do not want to give up their caring role, rather they want to continue to provide care with adequate support. This chapter has attempted to demonstrate the shortfall in services for carers from their perspective and in their own words. On this evidence, carers deserve better support from governments than they are currently receiving. Moreover, the shortfall in services is likely to grow as the population in need of assistance grows, and as government policies and the community continue to expect community living for care receivers.
- 6.83 This will challenge all governments to reduce the unmet demand for carer support services. It will involve more efficient use of existing resources and, as the Committee has already recommended, increased expenditure on a number of fronts. There will also be pressures to examine new ways of funding services.

Better Coordination

- 6.84 Carers have long drawn attention to the lack of coordination between

78 Ms S Scrivener & Mr D Scrivener, Submission No 1113, p 3.

government services, as Ms Cynthia Perieira, a Victorian carer, expressed colloquially:

At the moment the system that exists in Victoria is a dog's breakfast, complex beyond belief and what you access depends on luck, not need in many instances. ... Stop the buck passing between state and federal governments. Work together to achieve the above. Carers do not care who does what. We just want it to happen.⁷⁹

6.85 Australian governments are now collectively acknowledging the need to improve delivery of community based aged, disability and mental health services. As mentioned earlier in this report, COAG agreed in October 2008 on the need to reform the roles and responsibilities between the Commonwealth, States and Territories for:

- community and residential care services for aged people;
- community and residential care for people with disabilities; and
- community care and support services for people with mental illness.

6.86 COAG has advised that the anticipated reforms promise seamless service systems to better meet the needs of care receivers and carers on a national basis.⁸⁰ The Committee looks forward to the outcomes of COAG's deliberations with interest, particularly if they do actually lead to greater coordination between the governments.

Innovative Funding Models

6.87 However, many carers and organisations are arguing that better coordination within the existing system is not enough. One alternative model for allocating services to carers is via 'individualised funding'. Supporters of individualised funding (also known as self-managed funding, consumer directed care, self governed support or self directed support) packages argue that this funding model provides far greater control to carers and care receivers over the services they receive.⁸¹

79 Ms C Perieira, Submission No 880, p 2. See also: Ms K Tucker, Submission No 321, p 2; Ms M Bohan, Transcript of Evidence, 12 August 2008, p 34; Ms N Sheldon, Transcript of Evidence, 12 August 2008, p 86.

80 Council of Australian Governments website, COAG Communiqué 2 October 2008, pp 3-4, viewed 18 February 2009 at www.coag.gov.au/coag_meeting_outcomes/2008-10-02/index.cfm#aged.

81 See for example: Carer Support and Respite Centre Carer Group, Submission No 585, p 7; Julia Farr Association, Submission No 689, p 3; Mr C Dalton, Submission No 972, pp 2-3; Exhibit No

- 6.88 There are variations of the individualised funding model in operation in a number of jurisdictions, both at the state and territory level in Australia and internationally – most notably in Europe, North America and the United Kingdom.⁸²
- 6.89 In essence, a care receiver is allocated a personal budget after their needs have been assessed. The care receiver can then use that budget to purchase the support services they want – which could include paying a full time carer. The principle is to put people at the centre of assessing their own needs and tailoring support to meet their needs.⁸³
- 6.90 In the United Kingdom, once allocated a budget, a care receiver then devises a plan indicating how they will spend that money on their support (a ‘support plan’). A care manager has to approve the support plan, but within broad parameters, a care receiver can determine who, how and what services they want. Care receivers can take varying degrees of personal responsibility for devising their support plan and then purchasing the services. Receivers can use a family member or pay a service broker for assistance or, alternatively, trusts, legal guardians or carer organisations can act on a funding recipient’s behalf.⁸⁴ Importantly, regardless of the delegation of decision making, a recipient’s budget can only be spent on services to support that person.⁸⁵
- 6.91 A similar funding model based on a voucher rather than cash system is proposed by Carers WA for carers:
- A nationally funded program should be introduced to promote respite as a health promotion initiative and develop a highly flexible system via a voucher system which can provide carers with options to choose and design their own forms of respite.⁸⁶
- 6.92 The Julia Farr Association sees many potential benefits arising from individualised funding as it offers:

18, *Consumer-Directed care: A way to empower consumers*, Alzheimer’s Australia Paper No 11, May 2007; Ms B Epstein-Frisch, Transcript of Evidence, 12 August 2008, pp 90-91.

82 The individual funding model can be used more widely for delivering government programs. For example, the Australian Government uses case based funding for employment services.

83 United Kingdom, Northwest Commissioning Roadmap website, viewed 17 February 2009 at www.northwestroadmap.org.uk/index.php.

84 In Canada ‘microboards’ - small groups of committed family and friends that join together with a person with disability to create a small non-profit society – commonly perform equivalent roles.

85 United Kingdom, In Control website, viewed 17 February 2009 at www.in-control.org.uk.

86 Carers WA, Submission No 566, p 6.

... no greater cost to government and in some instances it produces savings; much greater satisfaction among people accessing it, so people and their families tend to report greater satisfaction with the arrangements because of that sense of control and the sense of being able to orchestrate something that feels more relevant; and also the evidence suggests that people are getting more from the arrangement in terms of actual things that go on in their lives – you know, in terms of material support and also social inclusion in the life of the wider community.⁸⁷

- 6.93 However, there are risks with individualised funding. It may place more responsibility on care receivers and carers than they wish to take on. Thus any system should allow care receivers to choose the level of self sufficiency they are comfortable with or allow carers or guardians to choose on their behalf. There is also the risk that governments may abrogate their responsibilities to people who have received a support payment. For service providers and agencies it would also mean a move away from contestable and tender driven funding of service delivery to an income model driven directly by consumer demand.
- 6.94 There are degrees of individualised funding built in to some of the existing aged care and disability programs. For example, funding allocated through Australian Government Aged Care Packages (CACP, EACH, EACHD) can be used to purchase services to assist older, frail people with complex care needs. Furthermore, brokerage funds are available through the Commonwealth Respite and Carelink Centres to support individual carers.⁸⁸ Also, a number of state and territory governments in Australia use individualised funding in one form or another and to varying degrees in order to improve the flexibility of disability services. For example, Disability ACT and Disability Services Victoria offer forms of ‘Individual Support Packages’ to those with disability⁸⁹.
- 6.95 The various forms and hybrids of individualised funding models are all attempts to provide care receivers (and indirectly carers) with greater

87 Julia Farr Association, Transcript of Evidence, 13 August 2008, p 91. See also: Julia Farr Association, Submission No 689, p 3; Ms F Anderson, Submission No 979, p 6; Ms L Kelly, Submission No 1173, p 2; Mr T Stroud, Transcript of Evidence, 12 August 2008, p 49; Brotherhood of St Laurence, Transcript of Evidence, 12 August 2008, pp 68-69.

88 Exhibit No 18, *Consumer-Directed care: A way to empower consumers*, Alzheimer’s Australia Paper No 11, May 2007, pp 8-9.

89 For the ACT www.dhcs.act.gov.au/disability_act/policies and for Victoria www.dhs.vic.gov.au/disability/supports_for_people/individualised_support_packages2, viewed 18 February 2009.

control over the services they receive. The Committee sees merit in the Australian Government exploring whether carers should receive cash or vouchers to manage the services they receive – for example respite and in-home assistance. In addition to empowering carers and increasing transparency in relation to expenditure, another possible advantage of the individualised funding model is that by determining the type and mix of services, demand from carers themselves can influence service availability, sustainability and mix at the local level.

- 6.96 One introductory step for individualised funding could be to transfer into the hands of carers the brokerage funds available through the National Respite for Carers Program currently provided to carers through the Commonwealth Respite and Carelink Centres in order that carers could determine how the money is spent.⁹⁰ Through pilot studies, different models of individualised funding for carers could be tested and any difficulties identified and ironed out. There may need to be quality assurance and accountability mechanisms put in place and certainly provisions would be needed for carers who do not want the added responsibility of managing their own support budget.

Recommendation 35

- 6.97 **That the Minister for Families, Housing, Community Services and Indigenous Affairs and the Minister for Health and Ageing undertake pilot studies to test the potential for the Australian Government's funding for carer respite and in-home assistance to be re-allocated directly to carers through 'individualised funding programs' (also known as 'consumer directed care' and 'self managed funding').**
- 6.98 Ultimately individualised funding programs, with appropriate safeguards, could be used to pool funding across governments for care receivers and carers.

The Need for Improved Data and Forward Planning

- 6.99 This chapter has used anecdotal, albeit consistent, comments of carers and carer organisations to illustrate the extent of unmet need for carer support services. The Committee has sought empirical data from a range of

⁹⁰ Exhibit No 18, *Consumer-Directed care: A way to empower consumers*, Alzheimer's Australia Paper No 11, May 2007, p 9.

sources, including from the key Australian Government departments responsible for supporting carers and care receivers, on the capacity of the community services sector to meet the demand for services.⁹¹ While there is data on program clients, the data cannot be used to determine the total number of carers seeking access to services or identify those carers that do not use formal services.

- 6.100 There are significant gaps in the data available on carer numbers, profile, patterns of service use and needs. For example, the most reliable data on carers comes from the Australian Bureau of Statistics Survey of Disability, Ageing and Carers. That survey distinguishes between 'carers' and 'primary carers' but only collects detailed data on primary carers. The same survey does not classify carers under the age of 15 as primary carers and excludes data on intermittent or short term carers such as those caring for people with a mental illness.⁹²
- 6.101 The Committee is pleased to note, however, that the Australian Institute of Health and Welfare is examining the feasibility and utility of a National Carers Data Repository.⁹³ The Committee is aware of the challenges of calculating reliably the number of carers, their profile and the totality of support services they use. However, without comprehensive, consistent and integrated data it remains difficult to plan future services and, more importantly, accurately determine the levels of unmet need.

Recommendation 36

- 6.102 **That the Minister for Families, Housing, Community Services and Indigenous Affairs and the Minister for Health and Ageing seek agreement through the Health, Community and Disability Services Ministerial Council to collect nationally consistent data to more accurately determine the number of carers, their profile and the level of unmet need for community based carer support services.**

91 Australian Government Departments (FaHCSIA, DoHA & DVA) Submission No 1109.1, pp 1-3; Australian Government Departments (FaHCSIA, DoHA & DVA) Submission No 1109.2, pp 1-2; Australian Government Departments (FaHCSIA, DoHA and DVA), Transcript of Evidence, 28 November 2008, pp 20-21.

92 Australian Institute of Health and Welfare, Submission No 1033, p 19. See also: Ms E Fudge, Transcript of Evidence, 13 August 2008, pp 51-52.

93 Australian Institute of Health and Welfare, Submission No 1033, p 19.

The Community Care Workforce

- 6.103 As noted in the submission from Carers Victoria, the development of a robust and skilled workforce is fundamental to addressing shortfalls in community care services:

The ability to sustain and expand community care services remains dependent on the recruitment and retention of an adequate, skilled and robust workforce. Recruitment and retention issues are apparent in the current community care service system. This may be attributed, in part, to low pay, lack of career path, and the isolated nature of the work. The ageing of the current community care workforce is a further concern. Shortages in the availability of community care workers will become an increasing problem as the workforce shrinks and competition for workers increases. It is likely to become increasingly difficult, and more expensive, for community care providers to recruit the workforce they need to meet growing demand.⁹⁴

- 6.104 However, evidence from carers and organisations alike indicates that there is a chronic shortage of adequately trained and skilled paid support workers and other community care workers and very high levels of staff turnover.⁹⁵ The Carer Support Network of South Australia stated:

Carers report that the current system of paid in-home care workers is unreliable and of low quality. We hear incidents on a regular basis of the care worker being late or not turning up, not having the skill set required to provide good care, or not having an appropriate attitude towards the Care Recipient. Under these circumstances it becomes impossible for the Carer to be able to depend on reliable care and plan for their future participation in the workforce.⁹⁶

- 6.105 Many carers have also indicated that current services relying on paid support workers are unreliable and the quality of some services is questionable, as these excerpts from the evidence illustrate.

94 Carers Victoria, Submission No 652, p 33.

95 See for example: Ms A Rea, Submission No 14, p 1; Mr K Hewitt, Submission No 328, p 1; Name withheld, Submission No 1038, p 4; Ms N Sheldon, Transcript of Evidence, 12 August 2008, p 86.

96 Carers Support Network of SA, Submission No 675, p 8.

Mr C Howe and Mrs C Howe - parents of three daughters, including one with a physical disability

We have trained these workers in the needs of our daughter and organised a nursing visit to complete a catheterisation and tube feed while we are out. Whilst this respite service is so very necessary we are often extremely frustrated at the lack of reliability of these workers due to illness, studies, or moving on to permanent, better paid jobs. This frustration is amplified (for us and our children) when we have to meet and train new support workers on a regular basis. Support workers are paid a relatively low wage and often use this work as a 'second job' or a way of earning money while they are at Uni. Support workers are not seen as 'valuable' in our society today and yet for Carers their support worker can be their one lifeline to a regular break from Caring.⁹⁷

Ms Pamela Bianchi - provides care for her son with Duchenne Muscular Dystrophy

We have experienced first hand the incompetent, inexperienced, the uncaring and at times apathetic manner of some direct [paid] care workers. Each agency must be more accountable for the persons in its employ. One comment we received indirectly when we did make a complaint about a [paid] carer that was sent to us was that basically 'do we want a service or not?' Many carers, especially older people do not make complaints as they fear that they will be abandoned by the service provider or victimised.⁹⁸

Ms Jayne Lehmann - mother of three daughters, including one with intellectual and physical disabilities

We have had care workers who have seen Sarah have a seizure and then will not come back again as they are too scared. Funny, I thought that was what they were being employed to do - care for our daughter and her associated problems.

The turnover of [paid] carers is enormous, which makes it stressful in itself. You already feel like you are living in a gold fish bowl let alone having to have a steady stream of new people corning through your home. Most of the carers are not skilled enough to

97 Mr C Howe & Mr C Howe, Submission No 1193, p 2.

98 Ms P Bianchi, Submission No 809, p 3.

deliver the care we require and I have to do extra training and emotional support of them! Some agencies employ a lot of students or people looking to provide care for a short period of time, before moving onto something else. This increases the turnover issues.⁹⁹

- 6.106 To address these issues, carers and organisations have suggested better training, remuneration, employment conditions, and career progression for paid support workers and workers in the community care sector.¹⁰⁰
- 6.107 It is anticipated that an increase in community care workforce training places supported through the Australian Government's Productivity Places National Partnership with state and territory governments will alleviate shortages of trained workers to some degree.¹⁰¹ However, the Committee considers that an increase in training opportunities will also need to be complemented by initiatives to encourage greater workforce retention. This is likely to require greater recognition of the workers in the community care sector through improved remuneration and employment conditions, and options for career advancement.

Recommendation 37

- 6.108 **That the Minister for Education, Employment and Workplace Relations examine options to build capacity in the community care workforce, particularly initiatives to encourage retention of trained workers in the sector.**

Availability of Services for Care Receivers

- 6.109 An analysis of the services available for care receivers, as distinct from carers, is outside the scope of this report. However, the Committee's

⁹⁹ Ms J Lehmann, Submission No 1258, p 1.

¹⁰⁰ See for example: Ms L Walmsley, Submission No 353, p 3; Ms M Van de Vusse, Submission No 443, p 2; Ms P Bodegraven, Submission No 509, p 2; Huntingdon's Victoria, Submission No 670.2, pp 3-4; Young People in Nursing Homes National Alliance, Submission No 764, p 4; Ms E Scott, Submission No 839, p 7; Mr C Dalton, Submission No 972, p 2; Ms T Clough, Transcript of Evidence, 23 July 2008, p 44.

¹⁰¹ Australian Government, Department of Education, Employment and Workplace Relations website, viewed 16 March 2009 at www.deewr.gov.au/Skills/ProductivityPlaces/Pages/default.aspx.

evidence suggests that services for care receivers are also extremely important for carers. As one carer commented in the closing remarks of her submission:

... the best way to support carers is to address all needs of the young and aged with a disability ...¹⁰²

- 6.110 The Australian Institute on Health and Welfare explains this in the following terms:

Services for care receivers also assist carers. In other words, supporting carers involves providing services to address a carer's own needs but also ensuring that the wider service 'system' works for carers in relation to the people they assist.¹⁰³

- 6.111 In addition to targeted services for care receivers, care receivers and consequently carers are also affected by the availability and access to the 'wider service system' including areas such as transport, housing, employment and education. For example, many carers have commented on the lack of suitable public or community transport options to enable care receivers to attend school, day care, employment, medical or other appointments.¹⁰⁴ Carers themselves are often required to provide transport to address this shortfall.

- 6.112 The lack of affordable and suitable housing has also frequently been raised in evidence. While housing affordability is a national problem, particularly for people on low incomes, evidence indicates that people with a disability or mental illness carry a comparatively high risk of becoming homeless. In particular carers have emphasised that shortages of suitable public housing have resulted in carers and their families being placed on lengthy waiting lists for accommodation.¹⁰⁵ The Committee understands that the Australian Government has implemented a number

102 Ms D Beccari, Submission No 102, p 2.

103 Australian Institute of Health and Welfare, Submission No 1033, p 2. See also: Mental Health Council of Australia, Submission No 682, p 8.

104 See for example: Ms A Bannigan, Submission No 706, pp 1-2; 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; Ms R Houston, Submission No 1148, p 2; Ms L Light, Transcript of Evidence, 6 August 2008, p 92.

105 See for example: Name withheld, Submission No 22, p 1; Ms K Tucker, Submission No 321, p 2; Ms N Green, Submission No 831, p 2; Ms J Walsh, Transcript of Evidence, 13 August 2008, p 26; Ms B Tickner, Transcript of Evidence, 20 August 2008, p 89.

of major initiatives that are intended to alleviate shortages of affordable housing and address issues associated with homelessness.¹⁰⁶

- 6.113 In part, the demand for respite services discussed earlier in the chapter is linked to the shortfall in services for care receivers. For example, some carers gain a degree of respite if those they care for can obtain employment or can participate in community access services (predominantly day activity programs).¹⁰⁷ However, in June 2007, the Australian Institute of Health and Welfare reported significant levels of unmet demand for community access services for people with disabilities, particularly day activity services.¹⁰⁸
- 6.114 Under the National Disability Agreement, the Australian Government has responsibility for employment services for people with a disability. To ensure public accountability in this regard, data on the labour force participation rate for people with a disability aged 15-64 years will be published annually by the COAG Reform Council. In addition, strategies to address the barriers faced by people with disability and/or mental illness that make it harder for them to gain and keep work are being developed through the National Mental Health and Disability Employment Strategy described earlier in the report.¹⁰⁹ The Committee looks forward to viewing the Strategy when it is released later in 2009.
- 6.115 The plight of many older carers is particularly distressing as they struggle to find adequate support for those for whom they are caring. Many, who have often spent decades caring for sons and daughters with disabilities, are worried about the lack of alternative long-term care for their adult children.¹¹⁰ A submission from a carer, drawing on her own experience,

106 Australian Government, Department of Families, Housing, Community Services and Indigenous Affairs website; viewed 16 March 2009 at www.facs.gov.au/internet/facsinternet.nsf/housing/nav.htm.

107 See for example: Ms M Edwards, Submission No 30, p 1; Ms B Hunt, Submission No 348, p 1; Ms F Anderson, Submission No 979, p 6.

108 Australian Institute of Health and Welfare, *Current and future demand for specialist disability services* (2007), Disability services, Cat no DIS50, pp 77-78. See also: Australian Government Departments (FaHCSIA, DoHA & DVA), Submission No 1109.2, p 4.

109 Australian Government, Department of Education, Employment and Workplace Relations, viewed 30 January 2009 at www.workplace.gov.au/NR/rdonlyres/37D9990A-A765-4580-BF02-5850A37AA77E/0/StrategypaperFinalRTF.rtf.

110 See for example: Ms J Johnson, Submission No 16, p 1; Ms J Poat & Mr W McGhie, Submission No 24, pp 1-4; Ms E Shields, Submission No 35, p 2; Mr R Morrison, Submission No 40, p 2; Ms A Ferguson, Submission No 45, p 1; Ms E Smalley, Submission No 105, p 1; Ms D Sullivan, Submission No 126, p 5; Ms E Shutt & Mr S Shutt, Submission No 310, p 2; Ms K Tucker, Submission No 321, p 2; Ms J Bellamy, Submission No 337, pp 1; Ms R May, Submission 351, p 1; Ms M-J Galiazzo, Submission No 359, pp 1-2; Ms L Wetherill, Submission No 1025, p 2; Ms S

questioned the preparedness of governments to deal with the ageing profile of carers:

The government has no idea what is going to hit it in the next decade. There is an epidemic of children like Nicholas who survived a traumatic birth and multiple disabilities and will be becoming adults without a future. Who will look after him when we cannot? In the past such children would not have survived. Why did the doctors save him when the services that he will desperately need in the future are not there? ... I would like an answer to this question in particular.¹¹¹

- 6.116 The lack of appropriate, alternative accommodation and care options for care receivers is one of the most pressing concerns for carers.¹¹² It leaves carers with little or no choice but to continue caring, often well past retirement age as explained below:

The one measure that must be put in place with urgency is the measure that will eventually see us relieved of our caring role. The best support that a carer can have is to know that theirs is a finite tour of duty and that one day in the future they will no longer be required to care. This is because a strategy has been mapped and is being implemented to ensure that adults with a dependent disability, who are citizens with equal rights in this great and wealthy nation of ours, will be taken care of by the community. They will be taken care of, not when their parents have died or are about to do so, but when their parents have reached retirement age. It seems to me to be totally inequitable that those parents who have had the most difficult experience of parenthood are the same ones who may never have a retirement. Lifelong carers such as myself are desperate to see progress in the provision of supported accommodation, but we see only rhetoric, debate and promises.¹¹³

Schreiber, Transcript of Evidence, 13 August 2008, pp 22-23; Mr H Thomas, Transcript of Evidence, 13 August, pp 30-31.

111 Ms C Pereira, Submission No 880, p 3.

112 See for example: Nardy House, Submission No 17, p 3; Mr R Morrison, Submission No 40, p 2; Mr T Sexton & Ms R Sexton, Submission No 136, p 4; Ms P Bristow, Submission No 546, p 1; Ms J Barnes, Submission No 623, p 2; Ms M Turner, Submission No 715, p 1; Ms B Liskus, Submission No 720, p 1; Mr P Rankin, Submission No 759, p 5; Ms M Rouse, Submission No 1142, p 3; Ms R A Houston, Submission No 1148, p 2; Ms L Downing, Ms S La Fontaine and Ms C Straw, Transcript of Evidence, 26 November 2008, pp 10-15.

113 Ms E Shields, Submission No 35, p 2. See also: ARAFMI QLD, Submission No 574, p 5; Mr K Matthias & Ms M Matthias Submission No 710, p 1; Ms M Ross, Submission No 713, p 1;

- 6.117 It is clearly undesirable to have carers forced to continue in their role because there is no other option. In desperation, carers may resort to refusing to collect care receivers from short term residential respite care, which is distressing and undignified for all:

The truth is that most families with adult sons and daughters who want to transition out of the care role have just one option. That is to force governments hand by relinquishing the cared for person into respite care services so that government will make a place available within the supported accommodation program.¹¹⁴

- 6.118 At the other end of the age scale, carers are also burdened and worried by the lack of early intervention services for young children with disability as Ms Faye Galbraith, a mother of two sons, both with 'a severe, complex disability', raised:

I have often said that the most difficult aspect of having children with a disability is not so much having a child with a disability as such but having to fight to the point of exhaustion and despair for services and supports which should be freely offered by Government to parents and carers in our situation. I have heard many people say this. By no means is life easy but it is made a whole lot harder by bureaucratic red tape and the simple absence of funding in the area of disability.¹¹⁵

- 6.119 In Hobart, Ms Sue Hodgson told the Committee that the current expectation that carers will care until they die or until they become incapacitated themselves, should be replaced with an expectation, supported by policies and services and that people with a disability will be able to live separately from their families once they reach adulthood.¹¹⁶ The Committee can only concur.

- 6.120 Members were reminded again and again during the Inquiry that the needs of carers and those they care for are inextricably bound. In a more practical sense, the levels of support for carers are directly affected by the levels of support for care receivers and vice versa. While the Committee makes recommendations in this report to improve the lives of carers, the need to improve support for care receivers is just as pressing.

114 National Carers Coalition, Submission No 571, p 34.

115 Ms F Galbraith, Submission No 1089, p 1. See also: Ms K Tucker, Submission No 321, p 1; Ms M Anderson, Submission No 331, p 1; Ms A-M Newbold, Transcript of Evidence, 12 August 2008, p 98.

116 Ms S Hodgson, Transcript of Evidence, 9 October 2008, p 24. See also: Ms S Crowe, Transcript of Evidence, 6 August 2008, p 81.

Employment and Education

7.1 This chapter considers the challenges that carers face in combining their caring role with employment or formal education. While the focus of this chapter is primarily on issues affecting carer participation in employment, many of the issues considered will also apply to carer participation in formal education. The chapter will:

- provide information on carer participation in paid employment;
- consider the influence of the income support system on carer participation in employment;
- examine the barriers to participation in paid employment including:
 - ⇒ the shortage of alternative, suitable and affordable care options;
 - ⇒ the lack of flexible employment opportunities;
 - ⇒ the lack or loss of skills following absence from the workforce; and
- consider the impact of caring on participation in education, particularly the impact on young carers.

Carer Participation in Paid Employment

7.2 Caring has a significant impact on the capacity of carers to participate in paid employment or to partake in training or educational opportunities. Data from the 2003 Australian Bureau of Statistics (ABS) Survey of Disability, Aging and Carers (SDAC) found that carers of working age (i.e. 15-64 years) were less likely to be participating in paid work than non-carers, with approximately 63% of carers in paid employment compared with 73% of non-carers. The proportion of primary carers who are in paid

employment is only 48%, with the majority working part-time rather than full-time.¹

- 7.3 Not surprisingly therefore, a considerable volume of evidence to the Inquiry emphasised the very real challenges experienced by carers attempting to balance their caring role with employment. As described by one group of working aged carers:

Our group agrees that the juggling act of work and caring is extremely difficult. Consequently some of us have decided not to work, while others work only part-time. This has meant a significant drop in income and not following the career paths we might have.²

- 7.4 Some carers have indicated that the demands and intensity of their caring responsibilities prevent them from participating in employment at any level.³ As explained by Ms Nuriani Magnusson, who cares for her two adult daughters:

My time is fully occupied with either one or both of my children needing help – this restricts my getting a job.⁴

- 7.5 A number of carers also indicated that they had left employment specifically to commence caring⁵, while others noted that they needed to alter or reduce their hours of employment or take time off work as a consequence of their caring responsibilities.⁶

- 7.6 Ms Margaret Bartlett, who cares for her husband with multiple chronic medical conditions, described the effects commencing care had on her workforce participation as follows:

As an experienced qualified operating theatre sister, with double certificates, I expected to progress with my career when I returned to work, in 1969, after our 2 children started school. After my

1 Australian Bureau of Statistics (2008), *A Profile of Carers in Australia*, 4448.0, p 51.

2 Ms R Kyne et al, Submission No 873, p 3.

3 See for example: Mr N Faint, Submission No 20, p 2; Ms J Roze, Submission No 485, p 4; Mr T Stroud, Transcript of Evidence, 12 August 2008, p 54.

4 Ms N Magnusson, Submission No 269, p 1.

5 See for example: Ms M Huddleston, Submission No 37, p 1; Ms L Belsham, Submission No 96, p 1; Ms L McIver, Submission No 191, p 1; Ms E Interlici, Submission No 209, p 1; Ms C Wood, Submission No 350, p 1; Ms C Hill, Submission No 1117, p 1.

6 See for example: Ms L Kschenka, Submission No 33, p 3; Mr C Coleman, Transcript of Evidence, 12 August 2008, p 27; Ms J English, Transcript of Evidence, 12 August 2008, p 62; Mr G Moore, Transcript of Evidence, 12 August 2008, p 63.

husband's heart attack in 1976, I had to periodically resign from work to care full-time for my husband.

There was no Government support for anyone in my position at that time. When he was well enough I had no problem finding employment again, because of my reputation and references, but I naturally had not progressed in my career. I studied and worked full time in 1982 to gain my Midwifery qualifications, but was forced to retire permanently (aged 53years) in 1993 to care for my husband full-time.⁷

- 7.7 In addition to limiting the capacity for carers to participate in employment, research conducted by the Taskforce on Care Costs (TOCC) also found negative impacts on the careers of those carers who are in paid employment, noting:

... 34% of carers [in paid employment] are of the view that their career has suffered because of the competing demands of their caring responsibilities. ... Critically in terms of using the full skill base of working carers, two-thirds (67%) of carers indicated that they would refuse a job or promotion if it meant they could not fulfil their caring responsibilities. Further nearly half (44%) have already selected a role at work which is below their skill level because it gives them the flexibility they need to balance their work and caring responsibilities.⁸

- 7.8 Similarly, in its submission Carers ACT noted:

A significant number of carers are under-utilised and working at skill levels way below their capacity because their care needs force them into lower level jobs where their absenteeism is more easily covered by an employer. Stress is a big factor for many carers, and they choose lower pay or lower skilled jobs because they understand that they no longer have the capacity to maintain demanding career positions. Yet the wastage of their skills is of concern.⁹

- 7.9 Despite these challenges, carers emphasised the importance of having the choice to combine caring with participation in employment. In particular, evidence emphasised the potential benefits of participation in paid

7 Ms M Bartlett, Submission No 58, p 1.

8 Taskforce on Care Costs (2007), *Report: the hidden face of care: combining work and caring responsibilities for the aged and people with a disability*, pp 22-23. See also: Mr C Coleman, Transcript of Evidence, 12 August 2008, p 27.

9 Carers ACT, Submission No 702, p 16.

employment for carers, both in terms of improving financial security and to carer health and wellbeing.¹⁰ Ms Deborah Edwards, who cares for her severely disabled son, described the benefits she gained by working, stating:

I have been working for the past 10 months, just 2 days a week. I have grown in self confidence and enjoy my life as someone other than a Carer. ... I desperately wanted to work full time, as I had been forced into my Caring role over 20 years ago, and had missed the financial benefits and mental stimulation that working had provided. I also wanted to be free of the continual and insulting personal probing that Carers are subjected to if they receive a payment from Centrelink.¹¹

- 7.10 At the public hearing in Hobart, Ms Annette Wilson-Strum, who provides care for her husband with an acquired brain injury, explained the personal importance of being able to balance her caring role with work as follows:

Certainly there are lots of benefits personally for me to work. I am maintaining my own skills. I have got no outside interests. I do not do anything but work or look after Peter. Those are the two things that I do. Going to work is terribly important. It is my respite, if you like. I hope my employer does not misinterpret that.¹²

- 7.11 Additional information on the impact of caring on workforce participation is available from the Families Caring for a Person with a Disability Study (FCPDS) which was conducted in 2006 by the Australian Institute of Family Studies (AIFS).¹³ In addition to key findings which indicate significant reduction in the capacity of carers to participate in paid employment, the survey also found that more than half of the carers who were not in paid employment want to work.¹⁴ On the basis of this finding the AIFS concluded that:

The fact that a large number of not-employed carers of working age expressed a desire to be in paid employment suggests that

10 See for example: Ms B Fischer, Submission No 140, p 1; Ms J Lummas, Submission No 236, p 2; Carers Victoria, Submission No 652, p 15; Ms C Thomson, Transcript of Evidence, 6 August 2008, p 75; Ms A Wilson Sturm, Transcript of Evidence, 9 October 2008, p 39.

11 Ms D Edwards, Submission No 159, p 3.

12 Ms A Wilson Sturm, Transcript of Evidence, 9 October 2008, p 39.

13 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 105-106. [Note: Due to relatively small numbers of male carers included in the survey, analysis of data was restricted to female carers only].

14 Australian Institute of Family Studies, Submission No 744, p 11.

supporting such carers may be worthwhile and result in higher levels of social inclusion.¹⁵

The Importance of Choice

7.12 The Committee recognises that in some cases the preferences of the carer and care receiver, coupled with the intensity and demands of caring, means that employment may neither be feasible nor sought. Therefore, in examining the issues associated with carer participation, the Committee is keen to emphasise there should be choice which will equally support those who need to provide care on a full time basis and those that wish to combine caring with employment.

Barriers to Participation in Paid Employment for Carers

7.13 Data from the ABS SDAC indicates that 38% of primary carers who had left employment to care indicated that they had done so because alternative care was not available or was too expensive, or because they had been unable to change their working arrangements. The remaining 62% of primary carers who ceased paid employment to commence care reported leaving for reasons such as emotional obligation or the preference to care full-time.¹⁶

7.14 Similarly, AIFS analysis of FCPDS data on labour force participation reported the following barriers identified by carers who were not currently in the workforce, but would like to work:

- no alternative disability care arrangements available;
- too disruptive for the person with a disability;
- difficult to arrange working hours;
- loss of skills from being out of the workforce;
- age; and
- cost of paying for disability care while at work.¹⁷

15 Australian Institute of Family Studies, Submission No 744, p 11.

16 Australian Bureau of Statistics (2008), *A Profile of Carers in Australia*, 4448.0, p 51.

17 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 105-106.

7.15 Ms Valerie Simpson, a long term carer who has been providing care for over 35 years for three (now adult) children with differing care needs describes her difficulties in finding work as follows:

In 1998 I felt that I should try to return to the workforce. In so doing I further decided after being turned down for several positions, purportedly due to the fact I didn't have a degree, ... to go to University to obtain a Degree. This I did and graduated in 2004. In obtaining my degree I have also accrued a HELP debt greater than the national debt. Since that time I have applied for many positions and although it has not been said, body language is very clear and speaks volumes. I believe prospective employers find that I am too old and that my caring role would be a disincentive to anyone who would even think of employing me. I have applied to Advocacy Agencies as well as employment in a managerial and coordination positions as well as other positions within the Disability Sector. Thus far I have not been successful. My conclusion is that employers see me as being:-

- a) a Carer first - that is my role and position in life.
- b) too old - given that I have years of experience is of little value it would seem; and
- c) the perception, from the people I have seen thus far, I believe, see my caring role as one of inconvenience in relation to any work I may obtain.¹⁸

7.16 For many carers wishing to combine care with employment, the absence of alternative care arrangements and lack of flexible employment options both emerged as major barriers.¹⁹ As summarised by Ms Jill Poat and Mr Will McGhie, who have been carers for over 20 years:

Caring for a person 24/7, unless there is family or external caring, results in no opportunity for work or social participation. In order for there to be any external participation from the home by the carer, there must be more than one carer. Just going out shopping is difficult or impossible without support. In short, employment is impossible and day to day living is near impossible without support.

18 Ms V Simpson, Submission No 260, p 4.

19 See for example: Mr J Halford, Submission No 250, pp 7-8; National Seniors Australia, Submission No 686, p 6; Australian Congress of Trade Unions, Submission No 725, p 1; Ms J Beattie, Submission No 1045, p 3; Mr R Sinclair, Transcript of Evidence, 13 August 2008, p 3.

Employment for carers would in most (all) cases require flexibility in the work hours. Employers would have to be encouraged to recognise the role of a carer and their limiting situation.

Employment, if undertaken by a carer for purely financial reasons, would have to be weighed against the cost of external care for the disabled person while the carer is working. Little point in working for little or no money.²⁰

7.17 Also detailing her struggle to balance caring for her daughter with profound intellectual and physical disabilities with employment, Ms Narelle Hughes explained:

... until my daughter turned thirteen she was eligible to access after school care and school holiday care and I tried to maintain paid employment. Once after school care was not available I had to find a position on a part-time basis, and that was not necessarily easy. If you consider the details of my caring role as outlined earlier, you may be able to understand that, try as I might, and even with the most understanding employers, I would not be considered the most reliable employee. My daughter's needs had to be my priority. During my years as an employee it was necessary for me to drop everything and go to my daughter on a regular basis. Seizures at school meant hours for me in hospital emergency departments, sicknesses meant that I used all sick leave, parental leave and compassionate leave and school holidays meant annual leave plus more were taken.²¹

7.18 In view of the barriers identified above, the AIFS suggested:

Given that carers cited workplace flexibility as one of the barriers to paid employment, encouraging increased workplace flexibility may provide opportunities for carers to be involved in the workforce. The lack of suitable alternative care arrangements, the other major barrier to employment cited by carers in our study, implies that appropriate and routinely available care arrangements would also help facilitate increased employment rates among carers.²²

20 Ms J Poat & Mr W McGhie, Submission No 24, p 2.

21 Ms N Hughes, Submission No 830, p 3.

22 Australian Institute of Family Studies, Submission No 744, p 11.

Access to Alternative and Suitable Care

- 7.19 Access to alternative, suitable and affordable care for care receivers was identified as essential to enable those carers who wish to participate in employment to do so. As noted in chapter 6 of the report, a large volume of evidence to the Inquiry has highlighted the inadequacy of existing respite and alternative care services. In particular, evidence suggests that the demand for alternative care for care receivers, whether it be care provided in-home or in centre-based facilities far exceeds the supply.
- 7.20 The lack of disability supported long day care, out of hours care and school holiday care have emerged as a significant issues for carers in employment or for those wishing to enter employment.²³ In relation to the shortage of long day care, the National Carers Coalition suggested that:

The Federal Government ensure that service agreement negotiation with the states and territories foster the provision of long day care for older children and adults with dependent disability aged less than 65 years to facilitate paid work opportunity for carers and to relieve the burden of caring on stressed families.²⁴

- 7.21 Describing her own experiences and the limitations associated with current care provisions for her adult daughter who is deaf, blind and severely disabled, Ms Jean Tops explained:

In fact, my 39-year-old daughter does attend an adult day program but that adult day program operates from 9 am to 3 pm. There is absolutely no way that a family member who has a young adult attending a day program could possibly access paid work with those hours of alternative care available to them. So those services definitely need to have the ability to extend their level of care to adults with dependent disabilities so that there is long day care available for families to actually have access to paid work.²⁵

23 See for example: Ms A Rea, Submission No 14, p 1; Ms J Beardmore & Mr M Beardmore, Submission No 59, pp 1-2; Ms T A T Nguyen, Submission, No 79, pp 1-2; Mr I Morris, Submission No 162, pp 1-2; Ms S Mortimer, Submission No 332, pp 1-2; Mr M Aldred & Ms H Aldred, Submission No 336, p 1; Ms S Holmes, Submission No 357, p 1; ANGLICARE Sydney, Submission No 769, p 8; Ms J Parrott, Submission 916, p 1; Ms N Brown, Submission No 951, p 9; Ms F Anderson, Submission No 979, p 8; Alzheimer's Australia, Submission No 1002, p 13; Ms G Wilson-Burns, Submission No 1080, p 9; Ms T McLure, Submission No 1200, p 2; Ms M-L Carter, Submission No 1291, pp 10, 13; Ms G Pierce, Transcript of Evidence, 12 August 2008, p 39.

24 National Carers Coalition, Submission No 571, p 5.

25 Ms J Tops, Transcript of Evidence, 15 October 2008, p 9.

7.22 Another carer, Ms Patricia Chan explained the limitations of care available stating:

For a working carer there is nowhere that opens from 7.30am and going through to 6pm What is available opens around 10 am and finishes at 2pm a few days p[er] w[EEK].²⁶

7.23 A number of carers also highlighted the need for alternative care options to be made available during school holidays.²⁷ Ms Cynthia Pereira, who cares for her 8 year old son with intellectual disability, severe autism, cerebral palsy, profound deafness and hydrocephalus, noted that she was unable to participate in paid employment:

... due [to] no after school care for my son at his special school (most special schools have no after school care or holiday care, which is a complete disgrace, as carers of children with disabilities even more than others need work as respite from their caring role and also the extra money a job would bring).²⁸

7.24 Ms Sophie Menegatos also noted the difficulty in combining caring and paid employment in the absence of school holiday care for her son with Down's Syndrome, stating:

Finding employment that will fit in with my carer's role has been difficult, even with the most considerate of employers, the biggest issue being that there is no care available during the school holidays, there are no school holiday programs available and the respite facilities offer very little as they are placed under a huge demand. (there are 12 weeks of school holidays and most employers will not give that much time off).²⁹

7.25 As Ms Maria Hart, who with her husband provides care for their 17 year old wheelchair bound son noted:

I currently work part time but am constantly faced with the hardship of finding 'care' for my disabled child in the school holidays. I sometimes wonder if the system is set up for me to be at home full time and not in the workplace where I can better contribute to society.³⁰

26 Ms P Chan, Submission No 261, p 1.

27 See for example: Mr J Kelly, Submission No 1041, p 1; Ms S Gibb, Submission No 1135, p 3.

28 Ms C Pereira, Submission No 880, p 2.

29 Ms S Menegatos, Submission No 63, p 2.

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

- 7.26 Ms Alison Bennett-Roberts, a parent of two children one of whom has a rare neurogenetic disorder and is severely disabled, describes her own experience of attempting to obtain out of work hours care for her son, and the impact of the shortage of paid support workers:

In order to maintain our work commitments, like most parents we need to utilise after school care. However, the school does not have an after school or vacation care facility. ... Due to his level of disability, we qualify for support for in home care however this is where the problems arise. To access a carer so that we can qualify for the childcare rebate, we must source a carer from a registered provider which is typically the home day care scheme organisations. Like all industries, they are experiencing a skills shortage and despite being on several organisation's waiting lists for over six months, the prospect of a carer becoming available is unlikely. ... Therefore we face the very real likelihood that one of us will need to either worked reduced hours or give up work completely if this isn't possible with our employers.³¹

- 7.27 While the shortage of alternative care options affects carers in diverse caring situations, these shortages may be particularly acute where the care needs of the care receiver are high or complex. Ms Louise Coyte, who cares for her teenage son who was born with multiple disabilities, describes her struggle to find appropriate child care. She notes that after 11 ½ years of seeking appropriate care:

... I was finally able to access regular respite with him and access some employment.³²

Recommendation 38

- 7.28 **That the Minister for Families, Housing, Community Services and Indigenous Affairs through the Health, Community and Disability Services Ministerial Council, encourage states and territories to provide additional funding for disability support workers in long day care, out of hours care and school holiday care to improve access for employed carers.**

31 Ms A Bennett Roberts, Submission No 1138, pp 1-2.

32 Ms L Coyte, Submission No 868, pp 1-2.

Employed Carers Respite Initiative

- 7.29 The evidence clearly indicates that access to alternative, suitable and affordable care is essential to provide carers with a genuine choice in relation to combining caring with participation in paid employment and/or education. In chapter 6 of the report, the Committee recommended the need to assess community care services, including respite, and to increase the supply and flexibility of services to better meet the needs of carers, including employed carers, and their families.
- 7.30 In addition, the Committee notes evidence relating to the Employed Carers Respite Initiative funded by the Department of Health and Ageing (DoHA) under its National Respite for Carers Program. The Employed Carers Respite Initiative provided \$95.5 million over four years to increase respite services for carers of older Australians who wish to combine their caring role with work. The initiative has supported 96 Employed Carers Respite Projects which offer extended hours respite and 17 Employed Carer Innovative Pilots which have examined models of support for working carers such as brokerage and case management, working with employers, and pre-employment and training for carers. DoHA has commissioned a full evaluation of the Employed Carers Respite Initiative, which is due to be completed by 30 June 2009.³³
- 7.31 The Committee looks forward to the outcomes of the evaluation and understands that its outcomes will be valuable in guiding the development and implementation of more innovative approaches to supporting working carers. Of concern to the Committee however, is the limitation of the program to providing support only for those employed carers that provide care for people aged 65 years or over. As noted by Ms Helen McDougall, a service provider based in Albury, while her experience of the program was positive the limitation 'obviously excludes many carers'.³⁴
- 7.32 To address this limitation, the Committee recommends that any continuation of the initiative include expansion of the eligibility criteria to also provide extended respite and other support for working carers who are providing care for people with disabilities or mental illness that are under the age of 65 years.

33 Australian Government Departments (FaHCSIA, DoHA & DVA), Submission No 1109.1, p 7.

34 Ms H McDougall, Transcript of Evidence, 1 October 2008, p 3.

Recommendation 39

- 7.33 **That the Minister for Health and Ageing and the Minister for Families, Housing, Community Services and Indigenous Affairs expand any continuation of the Employed Carers Respite Initiative to provide extended respite and support for all working carers, including those who provide care to people with disabilities or mental illness who are under the age of 65 years.**

Tax Relief for Alternative Care

- 7.34 In addition to increasing the supply of alternative and suitable respite care, evidence also highlights the need for alternative care for the care receiver to be made more affordable for working carers. To address this issue, carers and organisations alike have suggested that the costs of alternative care that are incurred by working carers should be tax deductible or that tax rebates should be introduced.³⁵
- 7.35 In its 2006 report, the TOCC suggested that the costs of alternative care for employed carers should be shared between more equitably between families and government as is the case with the current Child Care Tax Rebate which covers 50% of families' out-of-pocket expenses for approved childcare. TOCC recommended that:
- The Government introduce a 50% Care Cost Reimbursement for employees with caring responsibilities (for children, the elderly and people with a disability) to be capped at a net amount of \$10,000 of the out of pocket expense per household per annum.³⁶
- 7.36 The Committee is keen for the Australian Government to consider options, including the TOCC recommendation, to assist working carers with the costs associated with alternative care for the care receiver.

Flexible Work Arrangements

- 7.37 The business case for providing flexible carer friendly working arrangements is now well established and includes improved productivity and employee morale, reduced levels of absenteeism, greater employee

35 See for example: Mr L Wheaton & Ms J Wheaton, Submission No 190, p 1; Special Kidz Special Needs, Submission No 567, p 10; Carers Victoria, Submission No 652, p 25; Carers SA, Submission No 684, p 19; MS Australia, Submission No 692, p 22; Carers Australia, Submission No 699, pp 16-17; Ms J Tams, Submission No 908, p 8; Ms H Johnson, Submission No 1178, p 5.

36 Taskforce on Care Costs (2006), *Where to Now?* (Final Report), p 6.

attraction and retention, decreased turnover costs and improved corporate image.³⁷ In addition, while noting the challenges carers face in balancing care and paid employment, some carers have argued that carers make ‘good employees’ having acquired a whole range of skills as a result of caring (e.g. organisation, negotiation, dedication, research, interpretation, communication).³⁸ As Ms Evelyn Scott who cares for her adult daughter with Down’s Syndrome observed:

Carers by their very nature are responsible, motivated and conscientious; I contend that these attributes make them very worthwhile and valuable employees.³⁹

- 7.38 Although submissions from some carers in employment indicated that their employers had been willing to provide flexible working arrangements⁴⁰, many others related experiences that suggest there is a generally poor understanding among employers and work colleagues of the demands associated with caring.⁴¹ Ms Rosalind Papavasiliou, who provides care for her husband explained that many employers were reluctant to employ carers because of concerns regarding their caring responsibilities, noting:

Carers are not able to work every time the employer requests because of doctors appointments and caring duties. Carers are discriminated against in the workforce, I know it, I have personally experienced it and also was laid off one position because of it.⁴²

- 7.39 Ms Caterina Bortolot, a working carer who also provides part-time care for her elderly father, explained that in her experience:

People are more sympathetic if you care for young child as opposed to elderly parents. Men or society find the single mother

37 See for example: Carers Victoria, Submission No 652, p 20; Human Rights and Equal Opportunities Commission, Submission No 999, p 14.

38 See for example: Ms E Scott, Submission No 839, p 5; Ms C Masolin, Submission No 1190, p 2; Ms W L Cheung, Transcript of Evidence, 12 August 2008, p 41.

39 Ms E Scott, Submission No 839, p 5.

40 See for example: Name withheld, Submission No 500, p 16; Ms K O’Dea, Submission No 556, p 5; Ms M Cochrane, Submission No 824, pp 1-2; Mr C Coleman, Transcript of Evidence, 12 August 2008, pp 26-27; Ms H Johnson, Transcript of Evidence, 12 August 2008, p 46.

41 See for example: Ms D Galt, Submission No 861, p 1; Name withheld, Submission No 883, p 3; Mr K Wood, Submission No 1007, p 2.

42 Ms R Papavasiliou, Submission No 1009, p 1.

far more attractive and engaging than a woman or man who is caring for their elderly parents.⁴³

7.40 Mr Kevin Wood, a long-term carer for his son with disabilities explained:

I feel that my role was not considered by my employer. I have been treated the same as any other employee without responsibilities. It became too hard to compete in the workplace to keep up. It ended up I was forced to resign under the threat of termination.⁴⁴

7.41 As a consequence, it was reported that some carers are reluctant to disclose their caring role as they fear that they would be seen as a liability by the employer.⁴⁵ Describing her own experience in seeking employment, a primary carer providing care for her mother with multiple sclerosis explained:

At every job interview I went to, I advised them that I was a primary carer for my mother and explained what that entailed. I believe that this was to my disadvantage to tell them as I am sure that I was rejected for many roles due to this commitment.⁴⁶

7.42 Having eventually obtained paid employment, the same carer described her experiences in trying to balance her caring commitments with work and the lack of understanding displayed by her employer as follows:

When I finally did get a job, several months down the track a comment was made by my boss that 'when they took me on, they had to consider what impact my mother's health would have on my ability to perform'. I was made to feel that I should be so grateful for this position (this is a government funded position I would like to add).

My boss, although in the interview advised that they prescribe to a work life balance and flexibility, has not shown this to be the case. I have had to beg for everything and am often rejected when I require flexible working hours.⁴⁷

43 Ms C Bortolot, Submission No 1124, p 2.

44 Mr K Wood, Submission No 1007, p 1.

45 See for example: Carers ACT, Submission No 702, p 16; Dr M Summers, Transcript of Evidence, 12 August 2008, p 87.

46 Name withheld, Submission No 367, p 3.

47 Name withheld, Submission No 367, p 4.

- 7.43 Many submissions suggested that employers ought to be encouraged to consider a range of innovative options that support workplace flexibility.⁴⁸ As Ms Snjezana Jalinski, a mother of two children with moderate disabilities, explained carers need access to:

More flexible work place practices which are 'carer and family friendly'. Workplace discrimination does exist in particular for female primary carers who are perceived as a risk or less reliable or productive because they may be called away from work more often because of their carer responsibilities. So there are less jobs available to those women particularly part time, job shares and working from home. Workplaces across the board need to think outside the square and provide more supportive, creative and flexible employment opportunities.⁴⁹

- 7.44 In its submission, the Human Rights and Equal Opportunities Commission (HREOC) provided the following examples of carer-friendly initiatives that might be considered by employers:

Examples of carer-friendly initiatives include reduced working hours, flex time or working from home, specific policies that are useful for elder care include capacity to monitor throughout the day through support phone calls, extended lunch breaks to allow for meal preparation and access to carer's leave to accompany to appointments. In most cases these policies will pose negligible costs for employers.⁵⁰

- 7.45 Another example of an innovative scheme which could assist carers to participate in paid employment is the sick leave bank which is available to employees of the Victorian Transport Accident Commission. The sick leave bank allows Commission employees to voluntarily donate excess unused sick leave to a 'pool'. The sick leave bank can then be drawn upon by employees who have exhausted all their available leave, but require additional leave either because they are ill themselves or because they are caring for a family member who is ill.⁵¹ With regard to the sick leave bank

48 See for example: Ms B Kelly, Submission No 12, p 1; Mr I Morris, Submission No 162, p 2; Name withheld, Submission No 244, p 12; Ms S Jalanski, Submission No 446, p 3; Carers ACT, Submission No 702, p 15; Anglicare Canberra and Goulburn, Submission No 724, p 10; Australian Congress of Trade Unions, Submission No 725, p 6; Ms A-M Newbold, Submission No 1042, p 2; Families Australia, Submission No 1088, pp 15-16, 21.

49 Ms S Jalanski, Submission No 446, p 3.

50 Human Rights and Equal Opportunities Commission, Submission No 999, p 14.

51 Ms R Stuckey, Transcript of Evidence, 12 August 2008, pp 79-84.

concept, MS Australia explained the advantages to the employer and employee as follows:

[The sick leave bank] is a simple idea that is based on the fact that for the employer, sick leave is a liability on the balance sheet for the entire organisation, and it does not cost the organisation to draw down that liability in order to support those valued employees who would normally run out of leave and have to consider leaving work. Traditionally sick leave for employees is an individual entitlement, and when it is exhausted, it presents a major problem. Having a pool of leave it means that people with a genuine need for flexibility can be supported through periods of illness or crisis without suffering an unaffordable loss of income or losing their job altogether. As many employees never even go close to exhausting sick leave entitlements it comes at no additional cost to the employer, assuming they value the employee.⁵²

Flexible Work Arrangements and Legislation

7.46 To advance greater workplace flexibility a number of submissions to the Inquiry have suggested that there is a need to provide a legislative framework which extends carer rights in the workplace and reduces the potential for direct or indirect discrimination.⁵³

7.47 In its submission, HREOC outlined the current protection against discrimination in the workplace afforded to carers under the current *Disability Discrimination Act 1992*, but also noted that the employer is provided with a defence to a claim of unlawful discrimination in circumstances where:

- a person is unable to carry out the inherent requirements of the particular employment; and
- unjustifiable hardship would be imposed upon an employer in order for them to avoid discriminating against the aggrieved person.⁵⁴

7.48 A number of submissions have also raised issues with the National Employment Standards (NES) which were developed in 2008 to provide

52 MS Australia, Submission No 692, pp 20-21.

53 See for example: Australian Congress of Trade Unions, Submission No 725, p 3; Human Rights and Equal Opportunities Commission, Submission No 999, pp 11-13; Ms J Bourke, Transcript of Evidence, 6 August 2008, p 70.

54 Human Rights and Equal Opportunities Commission, Submission No 999, pp 10-11.

employees with a safety net of fair minimum legislated conditions. The ten NES are an integral part of the Fair Work Bill 2008 before Parliament as this report is being written, which if assented to will replace the *Workplace Relations Act 1996* in 2009.⁵⁵ The NES are:

- maximum weekly hours of work;
- request for flexible working arrangements;
- parental leave and related entitlements;
- annual leave;
- personal/Carer's leave and compassionate leave;
- community service leave;
- long service leave;
- public holidays;
- notice of termination and redundancy pay; and
- Fair Work Information Statement.⁵⁶

7.49 The main limitations identified in evidence with the NES pertain to provisions for the right to request flexible working arrangements and for personal/carer's leave. Several submissions noted that main focus of these provisions relates to parents and carers of younger, under school-aged children to the exclusion of people with other caring responsibilities.⁵⁷

7.50 Specifically, under the NES the right to request flexible work arrangements is only available to:

An employee who is a parent, or has the responsibility for the care, of a child under school age may request the employer for a change in working arrangements for the purpose of assisting the employee to care for the child.⁵⁸

55 Amendments to the Fair Work Bill 2008 made during drafting of this report are of relevance to the Inquiry. Amendments to sections 65 'request for flexible work arrangements' are considered later in the chapter.

56 The Parliament of Australia, House of Representatives, *Fair Work Bill (2008)*, Section 61, p 72. See also: Australian Government National Employment Standards, viewed 2 March 2009 at www.workplace.gov.au/NR/rdonlyres/1955FD28-3178-44CD-9654-56A3D5391989/0/NationalDiscussionPaper_web.pdf.

57 See for example: Carers NSW, Submission No 661, p 10; Human Rights and Equal Opportunities Commission, Submission No 999, pp 14.

58 The Parliament of Australia, House of Representatives, *Fair Work Bill (2008)*, Section 65, pp 76-77. See also: Australian Government National Employment Standards, p 12, viewed 2

7.51 To address this limitation, the Australian Council of Trade Unions (ACTU) and others have recommended that:

Requests for flexible working arrangements should be extended to all carers, including those who care for school-aged children, disabled or elderly or chronically ill people.⁵⁹

7.52 Through amending this provision, Carers NSW contends that:

This will increase the options for people who provide care to either continue to participate in paid work or to avoid a premature withdrawal from employment.⁶⁰

7.53 Another limitation with the NES raised in evidence relates to the provision for personal/carer's leave'. As it currently stands the NES provides ten days paid leave for if the leave is taken:

(a) because the employee is unfit for work because of a personal illness, or personal injury, affecting the employee; or

(b) to provide care or support to a member of the employee's immediate family, or a member of the employee's household, who requires care or support because of:

(i) a personal illness, or personal injury, affecting the member; or

(ii) an unexpected emergency affecting the member.⁶¹

7.54 An additional entitlement of periods of two days unpaid personal/carer's leave is also available once paid leave has been exhausted but is subject to the same criteria in relation to the purposes that the leave is taken. In its submission, the ACTU contends that the scope of the provision is too restrictive and that personal/carer's leave should apply to a wider range of carer responsibilities, stating that the provision:

... narrowly construes the range of situations for which employees with caring responsibilities need approved leave of absence. For example, routine medical appointments, general assistance such as

March 2009 at www.workplace.gov.au/NR/rdonlyres/1955FD28-3178-44CD-9654-56A3D5391989/0/NationalDiscussionPaper_web.pdf.

59 Australian Congress of Trade Unions, Submission No 725, p 4. See also: Carers Victoria, Submission No 652, p 21; Carers Australia, Submission No 699, p 16; Human Rights and Equal Opportunities Commission, Submission No 999, p 11.

60 Carers Victoria, Submission No 652, p 21.

61 The Parliament of Australia, House of Representatives, *Fair Work Bill (2008)*, Section 97, p 103. See also Australian Government, National Employment Standards, p 30, viewed 22 February 2009 at www.workplace.gov.au/NR/rdonlyres/1955FD28-3178-44CD-9654-56A3D5391989/0/NationalDiscussionPaper_web.pdf.

shopping or travel, assistance with financial or legal arrangements and so on should be able to be counted as legitimate aspects of providing care and support to a family or household member.⁶²

7.55 HREOC also argued for an increase in the amount of paid and unpaid personal/carer's leave available under the NES. In the case of paid personal/carer's leave, HREOC recommends an increase under the NES from an entitlement of 10 days per annum to 20 days per annum.⁶³ For unpaid personal/carer's leave, HREOC recommends the introduction of a new 12 month unpaid Carer's Leave Standard to be made available to employees who need to attend to the care of a seriously or terminally ill dependent.⁶⁴

7.56 Another concern relating to the NES was raised by Carers Victoria which noted:

The [NES] provisions, however, are weak in relation to the duty of the employer. Requests [for flexible work arrangements] can only be refused on 'reasonable business grounds' and this has no clarity of definition. Importantly also there is no grievance procedure or process to provide redress if requests are unreasonably refused. The employer only has to provide reasons for refusal in writing.

7.57 To address these limitations, Carers Victoria recommended:

Incorporating policy guidelines concerning what constitutes 'reasonable grounds for refusal' of the 'right to request' in the National Employment Standards. ... Ensuring the development and inclusion in the National Employment Standards of a compliance regime and a grievance mechanism concerning the 'right to request' provisions. This will extend the grievance mechanisms that are in place for the other nine National Employment Standards to the 'right to request' standard. This would provide protection against unreasonable refusal of flexible work or leave and would safeguard employees against any unintended consequences of requesting flexible work, such as

62 Australian Congress of Trade Unions, Submission No 725, p 5.

63 Human Rights and Equal Opportunities Commission, Submission No 999, p 12. See also: Carers Australia, Submission No 699, p 16; Australian Council of Trade Unions, Submission No 725, pp 5-6.

64 Human Rights and Equal Opportunities Commission, Submission No 999, pp 12-13. See also: Carers Australia, Submission No 699, p 16; Australian Council of Trade Unions, Submission No 725, p 6.

poorer quality employment, pay reductions or intensified workloads.⁶⁵

Strengthening the National Employment Standards

- 7.58 The Committee notes the considerable volume of evidence describing the difficulties that many carers experience in finding flexible employment opportunities which enable them to balance their caring responsibilities with participation in the workforce. To address these challenges the Committee believes that the introduction of initiatives to advance workplace flexibility need to be complemented by others which assist carers to find suitable employment opportunities.
- 7.59 A robust legislative foundation which extends carers rights in the workplace is important. The NES provide a basis on which to do this, particularly as they relate to personal/carer's leave and compassionate leave. These are minimum standards and they have a degree of negotiability built into them to ensure that employers and employees can make flexible arrangements. Of course, the Committee encourages all employers to provide flexible working standards for their staff beyond the minimum standards.
- 7.60 The Committee notes amendments made to the Fair Work Bill 2008 during drafting of this report are of relevance to the Inquiry. Specifically, the right to request flexible working arrangements has been extended beyond carers of children under school age to also include carers of people with a disability up to the age of 18 years. Section 65 of the *Fair Work Act 2009* now reads:
- An employee who is a parent, or has responsibility for the care, of a child may request the employer for a change in working arrangements to assist the employee to care for the child if the child:
- (a) is under school age; or
- (b) is under 18 and has a disability.⁶⁶
- 7.61 However, the Committee believes that this provision can be strengthened further in order to make it easier for carers to remain in the workforce.

65 Carers Victoria, Submission No 652, p 21.

66 Parliament of Australia website, viewed 20 March 2009 at: [www:parlinfo.aph.gov.au/parlInfo/download/legislation](http://www.parlinfo.aph.gov.au/parlInfo/download/legislation).

Particularly, the Committee believes that the right of employees to request flexible working arrangements should be extended to a wider range of carers beyond just parents of children under school age or carers for people with a disability aged up to 18 years.

Recommendation 40

7.62 **That section 65(1) of the *Fair Work Act 2009* be amended to extend the right to request flexible working arrangements to all employees who have recognised care responsibilities, including to those who are caring for adults with disabilities, mental illness, chronic illness or who are frail aged.**

7.63 The Committee has also considered the various other proposals mentioned above to strengthen the NES and make it easier for carers to remain in employment. While the Committee supports the suggestions in principle, it is wary of supporting them by recommendation without a full analysis of their economic impact or practicality. Accordingly, the Committee urges the Minister for Education, Employment and Workplace Relations to evaluate the practicality of extending the NES covering employees' entitlements to personal/carer's leave and compassionate leave contained in the *Fair Work Act 2009* to:

- increase the minimum number of days of paid personal/carer leave to which an employee is entitled;
- provide an entitlement to a specified maximum amount of unpaid carer's leave to allow a carer to care for a seriously or terminally ill dependent; and
- broaden the eligibility circumstances for a carer's entitlement to paid and unpaid personal/carer's leave to include a wider range of circumstances that those with caring responsibilities may encounter, such as to accompany care recipients to routine medical appointments.

Employment and Workplace Advisory Services

7.64 The potential benefits of a targeted information and awareness campaign to educate employers and others about the positive role that carers play in our community, and the advantages associated with employing carers and

providing a carer friendly workplace have been raised.⁶⁷ This issue of raising awareness of contribution of carers and promoting a better understanding of the needs of carers among employers has been addressed in chapter 3.

- 7.65 To further facilitate access to employment for carers, several submissions have called for the establishment of specialist employment services to provide ongoing assistance to carers seeking employment.⁶⁸ For example, ANGLICARE Sydney recommended that the Australian Government:

Establish an employment service specifically for carers, or provide for positions within employment centres for employment consultants who work specifically with carers. The service would provide upskilling programs and liaise with and educate employers, advocating for the needs of carers, especially the need for flexibility.⁶⁹

- 7.66 In addition, others have suggested the establishment of a flexible workplace advisory service to assist businesses that ‘... want to support Carers within their employ but do not know how to go about it’.⁷⁰ For example, in its submission MS Australia suggested:

An advisory service for employers is required and would target job retention and support through mutually agreed flexible arrangements entered into by the employer and employee.

Employers need technical and legal advice about how to accommodate a worker needing additional flexibility; a worker needs that as well as links to specialist support and advice about managing their illness in relation to workplace issues. Currently no single agency holds all the necessary information for all parties concerned.⁷¹

- 7.67 The introduction of the Australian Government’s new employment services will address, at least in part, the arguments for having specialist employment services for carers and for having workplace advisory

67 See for example: Name withheld, Submission No 367, pp 4, 6; Carers Victoria, Submission No 652, p 22; Ms E Scott, Submission No 839, p 6; Ms R Quaipe, Submission No 1125, p 2; Ms P Webster, Transcript of Evidence, 28 November 2008, p 10.

68 See for example: Ms D Robins, Submission No 742, p 2; Families in Partnership Cooperative, Submission No 847, p 3; Mr K Wood, Submission No 1007, p 2; Ms C Masolin, Submission No 1190, p 2.

69 ANGLICARE Sydney, Submission No 769, pp 21-22.

70 Name withheld, Submission No 500, p 28. See also: Ms E Scott, Submission No 839, p 6.

71 MS Australia, Submission No 692, p 21.

services. The new employment services, administered by the Department of Education, Employment and Workplace Relations, are designed to increase employment participation, to address skills shortages and to assist individual job seekers, particularly disadvantaged job seekers, to obtain sustainable employment.⁷²

- 7.68 Specifically, the Committee notes that the Australian Government has provided \$41 million to support Innovation Fund projects. Innovation Fund projects are intended to assist the most disadvantaged job seekers by funding projects to overcome the barriers to employment which they face. To provide Innovation Fund services, organisations must be on the Innovation Fund Panel. Following a competitive tender process, 198 Innovation Fund Panel Members were announced on 3 March 2009. Innovation Fund services are scheduled to commence on 1 July 2009.⁷³
- 7.69 The Committee also notes that the Australian Government has provided \$6 million to fund Employer Broker activities. These help employers, including small businesses, to meet local labour market needs. They will also provide an element of skilling and training to job seekers in identified areas of skill shortage. To provide Employer Broker services, organisations must be a member of the Employer Broker Panel. Following a competitive tender processes, 56 Employment Broker Panel members were announced on 11 March 2009. Employment Brokers activities are scheduled to commence on 1 July 2009.⁷⁴
- 7.70 The Committee supports these new employment services initiatives and anticipates that they will assist carers, as a disadvantaged group of job seekers, by providing specialist guidance and by encouraging and supporting employers to offer flexible work arrangements.

72 Australian Government, Department of Education, Employment and Workplace Relations website, viewed 23 March 2009 at <http://www.deewr.gov.au/Employment/NewEmployment/Pages/default.aspx>.

73 Australian Government Workplace Website, viewed 15 February 2009 at <http://www.workplace.gov.au/workplace/Publications/PolicyReviews/NewEmploymentServices/InnovationFund.htm>.

74 Australian Government, Department of Education, Employment and Workplace Relations website, viewed 23 March 2009 at www.deewr.gov.au/Employment/NewEmployment/Pages/EmployerBrokers.aspx#members.

Recommendation 41

7.71 That the Minister for Education, Employment and Workplace Relations ensure that employment service providers:

- consider the specific needs of carers seeking suitable employment; and
- encourage and support employers to provide employment opportunities for carers.

7.72 Of course, carers seeking employment are eligible to access various other programs to assist them enter or return to the workforce. These services include those available through Job Services Australia⁷⁵ and others such as the Personal Support Program, which provides individual assistance to people to tackle the barriers that are preventing them from looking for work, getting a job or participating in the community.⁷⁶

Returning to the Paid Employment after a Period of Absence

7.73 The challenges facing carers trying to return to paid employment after a period of absence was a common theme raised in evidence.⁷⁷ As illustrated by the following excerpts from submissions, once carers have been out of the workforce for any length of time, they experience loss of skills and confidence, often making it difficult to return to the workforce.

Ms Deborah Edwards – carer for over 20 years for her son with severe disability

A Carer is often out of the workforce for decades, and may find it impossible to return to work if their caring role comes to an end. A

75 From 1 July 2009 the current Job Network and Disability Employment Network will be replaced by Job Services Australia. As with the Employment Broker and Innovation Fund, services providers will be selected following a competitive tender process. At the time of drafting the successful tender applicants have not been announced.

76 Australian Government website, viewed 3 March 2009 at www.workplace.gov.au/workplace/Programmes/.

77 See for example: Ms K Stephen, Submission No 115, p 2; Ms D Vella, Submission No 273, p 1; Ms S Harris, Submission No 811, p 1; Ms M King & Mr R King, Submission No 817, p 2; Ms J Piesse O’Sullivan, Submission No 945, pp 1-2; Ms R Huisman, Submission No 1144, p 4.

person with no skills, and who also has not had the chance to accumulate savings because they have been forced to live in poverty on 'welfare' will certainly not be in a position to transition gently out of their caring role.⁷⁸

Ms Clare Masolin - carer for her 13 year old son who has moderate cerebral palsy and associated medical complications

When I became a carer 12 years ago, I was working as a professional, yet, in my caring day the ability to keep abreast of developments in that field has been lacking, hence my practical skills have lapsed - as has my confidence should I one day choose to return to work.⁷⁹

Ms Val Evans - left full-time employment three years ago to provide care for her husband with Parkinson's Disease

While I would love to return to my previous career, I am fully aware that I have become somewhat deskilled, despite efforts to remain abreast of current research and technologies. I am also somewhat older (now 54) and am only too well aware that Government Departments (my past employer) consider this age past the use-by date with their constant restructures and downsizing.⁸⁰

- 7.74 Many submissions have highlighted the need to provide practical assistance with job seeking and with retraining for carers wishing to re-enter the workforce after a period of absence.⁸¹ In his submission to the Inquiry, Mr John Kelly recommended:

Retraining: Because carers usually have to withdraw from the permanent workforce and unless there is an opportunity to work from home, deskilling rapidly occurs. Financial help could be given to enable carers to set themselves up for work at home. Opportunities should be given for retraining and help in gaining employment when the need for care no longer exists.⁸²

- 7.75 Similarly, Ms Fay Young, who has provided care for over eight years to her elderly mother suggested:

78 Ms D Edwards, Submission No 159, p 7.

79 Ms C Masolin, Submission No 1190, p 2.

80 Ms V Evans, Submission No 1201, p 1.

81 See for example: Committed about Securing Accommodation for People with Disabilities, Submission No 577, pp 4-6; Carers Support Network of South Australia, Submission No 675, p 3.

82 Mr J Kelly, Submission No 1041, p 1.

We also need help to find work when our caring role is over. We need to continue to be given an income while we retrain for work, and to be given training without having to pay for courses. And I don't mean those meaningless courses on how to write a resume, for example. Believe it or not but many of us are actually intelligent people! We need useful courses on updating computer skills, for example, or learning new ones, or depending on the carer's qualifications, given training for proper careers, perhaps within the government itself.⁸³

- 7.76 For a significant number of carers, retraining and seeking to re-enter paid employment will also coincide with changes in their caring circumstances. For example, carers may seek to re-enter the workforce as a result of the care receiver moving into permanent residential care or following the death of the care receiver. Among suggestions to assist carers during these periods of transitions, was the gradual reduction of the Carers Allowance over time or the provision of other financial assistance to carers while they retrain or upgrade skills to re-enter the workforce.⁸⁴ Mr Terry Stroud, a long-term carer for his elderly mother explained:

I have not worked in the mainstream sense for so long, no allowance is made for Carers who have to re-enter the work force & many find this adjustment extremely difficult.

Centrelink need to have a Carer adjustment policy, to help people like myself to work mainstream, once they are ready to cope with normal working conditions!⁸⁵

- 7.77 In its submission, the ACTU suggested the introduction of:

Models aimed at assisting long-term carers to re-train and re-enter the workforce such as those applied to mothers returning to work should be considered for other forms of care including for the chronically ill, disabled or elderly.⁸⁶

- 7.78 The Parents Returning to Earning Program, a Victorian Government program to support parents wishing to retrain and re-enter the workforce after a period of absence, was presented by the ACTU to illustrate the features of a successful model.⁸⁷ The program provides a grant for:

83 Ms F Young, Submission No 181, p 4.

84 Mr J Wilkinson, Submission No 1035, p 8.

85 Mr T Stroud, Submission No 549, p 2.

86 Australian Council of Trade Unions, Submission No 725, p 7.

87 Australian Council of Trade Unions, Submission No 725, p 8.

- course fees;
- Payment of Higher Education Contribution Scheme fees for the first year of a university course;
- first year Higher Education student contribution;
- child care to cover the parent's attendance at training;
- broadband access where the participant is studying by remote access (distance learning);
- transport costs incurred to attend training where there is demonstrated need;
- course materials such as prescribed books and software required for the course or other prescribed tools and equipment required for the course; and
- uniforms required for specific training (e.g. hospitality uniform).⁸⁸

7.79 The Committee acknowledges the difficulties that many carers face when seeking to re-enter the workforce after a period of absence. As noted earlier, supporting skills development and providing assistance to overcome barriers to employment for disadvantaged job seekers are integral components of the Australian Government's new employment services. The Committee is keen to ensure the skills development and training available through new employment services includes options to support carers, particularly those that have been absent from the workplace for a period of time, to update existing skills or to retrain.

Recommendation 42

7.80 **That the Minister for Education, Employment and Workplace Relations ensure that employment service providers consider the skills development and training needs of carers, particularly long-term carers, when developing plans to assist those wishing to enter or re-enter the workforce after a period of absence.**

88 Parents Returning to Earning website, viewed 11 March 2009 at www.parentsreturntowork.net.au/parents/about.asp.

Carer Income Support and Participation in the Workforce and Education

7.81 Some evidence to the Inquiry indicated that the current system of income support for carers acts as a disincentive for carers to engage in employment or education.⁸⁹ With regard to the current system of carer income supports and benefits generally, Carers WA noted:

The loss of 'benefits' and associated supports through working can be a significant barrier to carers returning to work or accepting more hours as they become available. With the increases in rent, interest rates and petrol, financial issues are of great concern to those on low and limited incomes. Returning to work can actually be a backward step financially for some families.⁹⁰

7.82 Carers Victoria noted that the Carer Payment policy reinforces the separation between caring and paid employment, stating:

Carer Payment reinforces the way in which the compatibility of paid work and caring is limited. This separation makes transitions between the two roles cumbersome and risky. Carer Payment cannot be divided between two or more people, meaning that the paid work and caring roles are commonly segregated. There is a disincentive for a single recipient of the Carer Payment to work more hours because it might mean loss of benefits.⁹¹

7.83 Evidence from many individual carers has highlighted two elements of Carer Payment policy which act as significant disincentives for carers who wish to combine work and/or education with their caring role. These are the:

- the income test which means that any income received over a certain threshold there is a reduction or loss of Carer Payment; and
- the '25 hour rule' which prevents Carer Payment recipients from working (including voluntary work) or studying for more than 25 hours per week (including travelling time).

89 See for example: Mr A Leach, Submission No 34, p 1; Ms M-J Galiazzi, Submission No 359, p 2; Ms L Krupjak, Submission No 365, p 1; Carers Victoria, Submission No 652, pp 14-15; Mr P Laughton, Submission No 770, pp 1-2.

90 Carers WA, Submission No 566, p 18.

91 Carers Victoria, Submission No 652, pp 14-15.

- 7.84 Mr Girts Ozols described his frustration in attempting to combine caring for his elderly mother with participation in part-time paid employment under existing Carer Payment policy, concluding:

In assessing the economic benefits of working on even a casual basis for the Commonwealth, juggling my working hours to suit both my mothers needs and COMCAR hours, under the limiting rules of the Carer Payment system, it became clear there was no economic benefit or incentive to keep working (even on a casual basis).⁹²

- 7.85 Another Carer, Ms Julie Mann, a mother of two children one of whom has cerebral palsy stated:

As the sole income earner I find it difficult to accept the fact that on my paltry \$12 000 - 15 000 part time wage that I receive; I am not only forced to pay tax but the Wife Pension that I receive is slowly decreased in relation to my earnings. Essentially I lose part of the pension to go to work; add in fuel costs and costs to my health and the equation means that there is very little monetary incentive for me to work. Yet I know that work provides us as a family with much more than money and frankly I enjoy working. It sets a good role model for our family and it increases mental stimulation for all of us.⁹³

- 7.86 Ms Linda Aspinall, a carer for her 16 year old son with cerebral palsy notes:

On the Carers' Pension [Payment] if I choose to work I am means tested and my working hours are restricted to 25hrs/week including travelling time and even any study hours! How can I possibly continue to meet all of Alex's needs on the pension under these restrictions or to advance in my career and/or work opportunities?⁹⁴

The Carer Payment Income Test

- 7.87 Many carers have commented on the effect of the income test applied to Carer Payment, noting that the reduction or loss of Carer Payment as a

92 Mr G Ozols, Submission No 18, p 1.

93 Ms J Mann, Submission No 192, p 1.

94 Ms L Aspinall, Submission No 1189, p 2.

consequence of earning income is a significant disincentive when it comes to combining caring with paid employment.⁹⁵

- 7.88 In considering the complex interactions between the income test applied to Carer Payment, the income earned from paid employment, the taxation system and the costs of providing alternative care for the care receiver, Carers Victoria explains:

A further barrier to workforce participation created by the Carer Payment is the way in which it interacts with the taxation system. When a Carer Payment recipient accepts paid work, their payments begin reducing as soon as they earn \$132.00 a fortnight. The value of the payment reduces even further when income tax is deducted, and the additional costs associated with participating in paid work reduce this still further. It is clear that the financial benefits of commencing or increasing paid work can quickly be compromised.⁹⁶

The Twenty Five Hour Rule

- 7.89 Many carers have also commented on the restrictive '25 hour rule' and its impact on the capacity for carers to participate in paid employment or education.⁹⁷ As noted by the TOCC in its 2007 report, *The Hidden Face of Care*:

While the Carer Payment allows carers to work up to 25 hours per week (including work study, training or volunteer work) its structure works against maximising workforce participation. By establishing a maximum hours limit a carer can work before the Carer Payment reduces and without recognising potential increased cost for quality appropriate alternative care arrangements, the structure encourages carers to minimise labour force participation.⁹⁸

95 See for example: Mr A Leach, Submission No 34, p 1; Ms M-J Galiazzi, Submission No 359, p 2; Ms L Krupjak, Submission No 365, p 1; Mr P Laughton, Submission No 770, pp 1-2.

96 Carers Victoria, Submission No 652, p 15.

97 See for example: Mr I Radford & Ms J Radford, Submission No 4, p 1; Gippsland Carers Association, Submission No 660, p 8; Ms A Geach-Bennell, Submission No 1022, p 2; Ms K Evans, Submission No 1305, p 1; Ms S Maxwell, Transcript of Evidence, 26 September 2008, p 28; Ms R Rycen, Transcript of Evidence, 9 October 2008, p 27.

98 Taskforce on Care Costs, Submission No 23 (Attachment 1), p 15.

7.90 At the public hearing in Sydney, Ms Nell Brown stated:

... the 25-hour rule is a preposterous rule. It is the most ridiculous rule. If a carer is actually working part time the travel time to and from the job is included in that 25-hour rule. If they are studying it is included in the 25-hour rule, so then they cannot work part time, even if the person that you are caring for is away at a day program or at school. It is a very silly rule and it causes a great deal of poverty.⁹⁹

7.91 The inclusion of travel time in the 25 hours is particularly restrictive for people who might have to commute to work and to those living in rural locations. For example, Ms Rosalind Papavasiliou, a carer living in country Victoria noted:

Centrelink allow 25 hours a week that you can work. The problem is, is that this includes travelling time. This is very hard for me as I live in a rural area and had to travel a long way to work. I lost 3 hours a day in travel time thus lowering my allowed hours of work.¹⁰⁰

7.92 The impact of the 25 hour rule on carer participation in education was also raised in evidence, including the likely impact of this rule on young carers whose capacity to participate in secondary and/or tertiary education may be compromised.¹⁰¹ As noted by the NSW Youth Advisory Council:

The current Centrelink restrictions imposed on the maximum time (25 hours including travel time) that fulltime carers can be away from their caring responsibilities, in order to qualify for the full carer payment, greatly disadvantages and restricts the access young carers have to attend and stay fully engaged with school. Normal school attendance, not including travel time is estimated at approximately 30 hours, this is some 5 hours above the current restrictions imposed on young carers to access the full carer payment, before even taking into consideration the travel time associated with attending school.¹⁰²

99 Ms N Brown, Transcript of Evidence, 6 August 2008, p 47.

100 Ms R Papavasiliou, Submission No 1009, p 1.

101 Ms K Szukalska, Transcript of Evidence, 26 September 2008, p 39.

102 NSW Youth Advisory Council, Submission No 789, p 2.

Increasing the Compatibility of Carer Payment Policy with Participation in Work and Education

- 7.93 The Committee is concerned by evidence which suggests that certain aspects of the carer income support system, and in particular Carer Payment policy, are acting as disincentives for those carers who wish to combine caring with paid employment and/or education. With regard to raising the thresholds for means testing and reviewing taper rates for Carer Payment, the Committee has made its recommendation in chapter 5.
- 7.94 In addition, the Committee believes that the 25 hour rule appears to be arbitrary and unnecessarily restrictive. The Committee believes that the 25 hour rule is significantly counterproductive in terms of encouraging carers to combine caring with employment and/or education. Therefore, the Committee recommends restrictions on the number of hours that those on Carer Payment can work, volunteer or study should be eased.

Recommendation 43

- 7.95 **That the Minister for Families, Housing, Community Services and Indigenous Affairs direct the Department of Families, Housing, Community Services and Indigenous Affairs to increase the number of hours of work, volunteering or study that those receiving Carer Payment can undertake.**

Carers and Education

- 7.96 As with participation in paid employment, evidence to the Inquiry suggests that the intensity of the caring role and the absence of alternative care arrangements for care receivers restrict the opportunity for carers to partake in education. Although access to education is important for carers of all ages, for young carers¹⁰³ in particular, poor school retention rates will also impact in the longer term on employment opportunities.

103 Definitions of young carer vary. For example, the Australian Bureau of Statistics Survey of Disability, Ageing and Carers consider young carers to be carers aged 15-24 years. Carers NSW, Submission No 661, p 24 provides the following definition 'A young carer is a child or young person 25 years or under who provides support for a family member who has a long term disability, mental illness, other illness, drug or alcohol problem.'

7.97 While data from the 2003 ABS SDAC found that the percentage of carers aged between 15 and 18 years attending school was similar to non-carers (67% compared to 69%), it also reported that carers aged between 18 and 24 years were less likely to have completed year 12 than their non carer peers (66% compared to 73%).¹⁰⁴ However, a 2002 study conducted by Carers Australia reported that in 1999 only four per cent of primary young carers aged between 15 and 24 years were still in education, compared with 23% of other young people.¹⁰⁵

7.98 Evidence to the Inquiry indicated that young carers often experience difficulty in attending school and completing homework due to the demands of their caring role.¹⁰⁶ As one 14 year old sibling carer explained:

When I'm at school, I am always exhausted and find it difficult to concentrate on my work. I never get any homework done because when I do have the time I am completely drained, mentally and physically. My assignments are often late or not to a standard I hope for. I often feel bitter about not being able to excel to my full potential because of my young caring duties that take up so much of my time, thought and energy. Then I feel guilty for thinking so.¹⁰⁷

7.99 Mr William Wilton, who since he was 11 years old has been assisting with the care of his brother with Duchenne Muscular Dystrophy also described the challenges he has faced with school:

I have been struggling with school, because I look after my brother most of the time, because sometimes my mum collapses. I have missed out about half a term of year 12 through the whole year. I am a bit behind on my work because of it but the teachers understand, so I get extra time.¹⁰⁸

104 Australian Bureau of Statistics (2008), *A Profile of Carers in Australia*, 4448.0, p 51.

105 Australian Government, Department of Families, Housing, Community Services and Indigenous Affairs website, *Young Carers Research Project: Final Report*, viewed 23 February 2009 at http://www.facsia.gov.au/internet/facsinternet.nsf/disabilities/carers-young_carers_report.htm#exec.

106 See for example: Rotary Club of Mount Eliza, Submission No 572, pp 1-4; Ms M Walsh, Submission No 752, p 3; Mr C Larkman, Submission No 1066, p 2; Mr W Wilton, Transcript of Evidence, 26 July 2008, pp 36-48; Ms R Foldesi, Transcript of Evidence, 26 July 2008, pp 36-48; Prof B Cass, Transcript of Evidence, 6 August 2008, p 73.

107 Name withheld, Submission No 875, p 2.

108 Mr W Wilton, Transcript of Evidence, 26 July 2008, p 37.

7.100 However, evidence from a number of young carers also indicated that their difficulties combining caring and education was not well understood by teachers. As with employers, a number of carers have commented on the need for educational institutions to demonstrate a greater understanding of the needs of carers and to be more flexible in their approach.¹⁰⁹ For example, in relation to young carers, Ms Jan Wallent observed:

We have many young carers that need to be [recognised] by the Education Department, and given better support; many children have done a days work at home before or after school, and sometimes are just plain worn out.¹¹⁰

7.101 Ms Patricia Berrutti, an adult carer with multiple caring responsibilities, emphasised the importance of flexible education policies noting:

When studying for my tertiary qualifications, I had to ask for one extension for an assignment, but I had to make sure I attended 90% of my classes. This is very difficult at times with a caring role, and I know other carers who have had to give up due to TAFE and other educational facilities not understanding the responsibilities.¹¹¹

7.102 Similarly, in its submission the ACT Government noted:

The need for flexibility is also important in relation to education and training. Carers, including young carers who study, may benefit from the flexibility to complete education at home, have their caring skills recognised as part of their education, take periodic leave from study commitments, and have extended timeframes for completing courses.¹¹²

7.103 Ms Maggie Malak, a young carer who since the age of five has assisted in caring for her wheelchair bound mother, also described the financial difficulties facing some young carers explaining:

With school and studying I find it really hard. At one stage I found that I had to take time off school to be eligible for the carer's

109 See for example: Carers WA, Submission No 566, p 5; National Disability Services, Submission No 579, p 8; Prof B Cass, Transcript of Evidence, 6 August 2008, p 74; Ms R Warmington, Transcript of Evidence, 13 August 2008, p 16; Ms C Alliston, Transcript of Evidence, 13 August 2008, p 52.

110 Ms J Wallent, Submission No 834, p 2.

111 Ms P Berrutti, Submission No 429, p 1.

112 ACT Government, Submission No 1000, p 6.

payment, because you are not allowed to be away from the person you care for more than 30 hours a week.¹¹³

- 7.104 Drawing on his own experiences, Mr Jonathon Woodgate, a young carer who had been providing care for his mother and for his brother since the age of 16 years also explained:

For younger carers, tertiary education is an important desire, but an unattainable luxury. We want to go to TAFE/University with our friends. We want the same access to freedoms that our friends get. We cannot afford to pay for the courses we want to do, and we are very hard-pressed to find a tertiary education institution that will allow us the flexibility we need to accommodate our loved ones' care needs. One strategy would be to put pressure on secondary and tertiary institutions to work with students who identify as being carers, allow us the financial, social and educational flexibility we need to learn effectively and work with relevant state/territory and federal government departments to co-ordinate an effective plan for the student/carer to achieve his/her goals.¹¹⁴

- 7.105 Suggestions for increasing carer participation in education include the expansion of services to support young carers to finish secondary and tertiary education. As noted in chapter 2 of the report, the Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) funds the Respite and Information Services for Young Carers. The Program has two components – the Supporting Young Carers Program and the Respite for Young Carers at Risk Program.
- 7.106 The Supporting Young Carers Program provides funding to the network of state and territory Carer Associations to provide direct support to young carers such as counselling and to Carers Australia for the establishment and operation of a national young carers website. The Respite for Young Carers at Risk Program targets young carers who are at risk of leaving education prematurely, and not completing secondary school or equivalent. The program allows access to up to five hours in home respite per week during the school term to attend education or training. It also provides one fortnight of respite each year to undertake activities such as study for exams, training or recreation.

113 Ms M Malak, Transcript of Evidence, 6 August 2008, pp 46-47.

114 Mr J Woodgate, Submission No 1126, p 2.

Assisting Carers to Combine Caring with Education

- 7.107 The Committee recognises the difficulties experienced by many carers who wish to combine their caring responsibilities with education. Many of the same barriers that reduce opportunities for carers to participate in employment similarly impact on the opportunities for carers to undertake education. Therefore, the Committee believes that its earlier recommendations in this chapter, seek to address the shortages of affordable, alternative care for care receivers and to extend the number of hours that carers in receipt of the Carers Payment can work, volunteer or study will also support those carers wishing to combine their caring role with education.
- 7.108 Also in chapter 3 of the report, the Committee has recommended a campaign to raise awareness of the needs of carers participating in education, including the needs of young carers still at school. To complement increased recognition of carers in the education system, the Committee recommends that education policies should accommodate the needs of carers by incorporating flexibility in terms of attendance requirements, assignment deadlines and provision of out of school learning options.

Recommendation 44

- 7.109 **That the Minister for Education, Employment and Workplace Relations direct the Department of Education, Employment and Workplace Relations, in association with state and territory education departments, to develop flexible policies to make it easier for students to combine education with caring.**
- 7.110 Specifically with regard to FaHCSIA's Respite for Young Carers at Risk Program, the Committee notes evidence which suggests uptake of the program has been disappointingly low, probably due to eligibility criteria which limits access to one young carer per family who identifies as the 'primary carer'.¹¹⁵ Given that caring responsibilities are frequently shared by more than one young carer in a family unit, the Committee supports the suggestion made by Carers Australia for:

115 Australian Government Departments (FaHCSIA, DoHA & DVA), Submission No 1109, p 32.

... broadening of the eligibility criteria and greater flexibility in the use of respite which allows the program to focus more on the whole family situation and other young people sharing care.¹¹⁶

Recommendation 45

- 7.111 **That the Minister for Families, Housing, Community Services and Indigenous Affairs direct the Department of Families, Housing, Community Services and Indigenous Affairs to extend the eligibility criteria for its Respite for Young Carers at Risk Program to include assistance for more than one young carer in a family unit where the care responsibilities are shared.**

116 Carers Australia, Submission No 699, p 42.

Health and Wellbeing

- 8.1 This chapter considers the impact of caring on the health and wellbeing of carers and their families. The chapter will consider issues associated with:
- the physical health of carers and options for assisting carers to maintain and improve their physical health;
 - the psychological and emotional wellbeing of carers and their families, and the importance of options for carers to have sufficient time out of the caring role and access to counselling support for carers and their families; and
 - social isolation experienced by many carers and consider options for increasing social inclusion.

The Impact of Caring on the Health and Wellbeing of Carers

- 8.2 A large number of submissions to the Inquiry have emphasised that the caring role potentially impacts significantly on all aspects of carers' lives, affecting carers' physical and psychological health, emotional wellbeing and social relationships. These assertions are well supported by the outcomes of recent research.
- 8.3 The 2003 Australian Bureau of Statistics Survey of Disability, Aging and Carers found that 29% of all primary carers reported a change to their overall physical and emotional wellbeing as a result of providing care. In addition, of the 64% of primary carers that reported no overall change in their health and wellbeing, approximately half reported experiencing at

least one specific negative effect such as frequently feeling worried or depressed.¹

8.4 The health and wellbeing of carers in Australia has also been the primary focus of two recent research projects; the 2007 Australian Unity Wellbeing Index Survey titled *The Wellbeing of Australians – Carer Health and Wellbeing* and the 2008 Australian Institute of Family Studies (AIFS) report titled *The Nature and Impact of Caring for Family Members with a Disability in Australia*.²

8.5 Key findings from the Australian Unity Wellbeing Index Survey include:

- carers have the lowest collective wellbeing of any population group yet discovered, with the wellbeing of carers who live with the person requiring care being the lowest ever recorded for a large group of people;
- carers have an average stress rating that is classified as moderate depression;
- carers are more likely to experience chronic pain than is normal and the wellbeing of carers is more vulnerable to pain;
- carers are highly likely to be carrying an injury; and
- wellbeing decreases linearly as the number of hours spent caring increases.³

8.6 The AIFS research, *The Nature and Impact of Caring for Family Members with a Disability in Australia* indicates that carers, in particular those under the age of 65 years, have significantly worse mental health and vitality and higher rates of depression than the general population. Key findings include:

- the risk of carers and family members experiencing a depressive episode of six months or more was greatest in the first year of caring;
- almost twice as many carers (29%) were in poor physical health than the general population (17%);

1 Australian Bureau of Statistics (2008), *A Profile of Carers in Australia*, 4448.0, p 38.

2 Australian Unity Wellbeing Index (2007), Survey 17.1, *The Wellbeing of Australians – Carer Health and Wellbeing*; Australian Institute of Family Studies (2008), *The Nature and Impact of Caring for Family Members with a Disability in Australia*, Research Report No 16.

3 Australian Unity Wellbeing Index (2007), Survey 17.1, *The Wellbeing of Australians – Carer Health and Wellbeing*, pp vi-vii.

- almost one in three female carers aged 50 years or less had separated or divorced since they started caring, while one in seven over the age of 50 years had separated or divorced since they started caring; and
- carers who had multiple care responsibilities or who were caring for children had worse mental health outcomes.⁴

8.7 A significant proportion of carers have reported suffering physical and psychological effects as a consequence of providing care. This was due to the relentless physical and emotional intensity of the caring role, exacerbated by financial hardship, a lack of respite and other supports, and the social isolation that they experience.⁵ Based on the feedback provided by carers on the negative physical and psychological impacts of caring, Carers ACT reported:

Of the total number of 259 surveys returned in the Carers ACT Territory Pre-Election Survey, 116 respondents (44%) provided additional written information to illustrate how they had been affected. Of this 116, 35 carers provided detail of how caring had negatively affected their physical health. Conditions discussed included: back or neck injuries, chronic conditions such as fibromyalgia, heart conditions, ulcers, arthritis, high blood pressure and cancer. In regard to psychological impact, 25 carers stated that they now suffered from depression, anxiety attacks or other stress related illness at a level requiring medication or other medical care. Another 56 participants provided information on how caring has impacted their general wellbeing, citing issues such as negative self-esteem, fatigue, anxiety, emotional and physical exhaustion, stress and severe social isolation.⁶

8.8 To a large extent the underlying causes of these types of adverse effects have been addressed through recommendations made by the Committee earlier in the report. These include recommendations to assist carers to access information and acquire necessary skills, to alleviate the financial disadvantages facing carers and their families, to improve access to

4 Australian Institute of Family Studies (2008), *The Nature and Impact of Caring for Family Members with a Disability in Australia*, Research Report No 16, p 98. See also: Australian Institute of Family Studies, Submission No 744, pp 2-8.

5 See for example: Ms D Osborne, Submission No 43, pp 1-2; Mr D Williams, Submission No 344, pp 1-2; Ms P Birch, Submission No 345, p 1; Mr R Sinclair, Transcript of Evidence, 13 August 2008, p 2.

6 Carers ACT, Submission No 702, p 28.

appropriate respite and other support services and to provide greater choice in relation to participation in employment and education. The importance of addressing these issues in order to improve the health and wellbeing of carers is illustrated by the Dodds family for whom one of the major frustrations of providing care for their son with a disability is:

Agencies telling you that you need counselling, when all we need is appropriate support, which in turn will reduce stress levels, depression and anxiety.⁷

8.9 In relation to the shortage of affordable respite options that allows carers to have time out of the caring role, Ms Laura Formosa asked:

How do you expect carers to maintain proper health and especially a healthy state of mind – a mind that does not fall into a depressed state? Chronic depression is often brought about by people not resting or having no time at all to themselves.⁸

8.10 As also explained by Ms Diane Vella, who provides care for her brother:

If there is no assistance given to the carer or help when they are trying to find supports for the person who they are looking after this puts extreme pressure on the carer. It is wise to remember that one can only take so [much] of this pressure before they break.⁹

8.11 Even with access to adequate supports and services, becoming a carer is inherently stressful as the role usually arises in conjunction with a traumatic and painful event that results in significant changes in the lives of carers and their families.¹⁰ As noted by Ms Thelma Camilleri, who provides care for her husband with a disability:

There are many different changes and losses carers experience; our lives may never be normal again.¹¹

8.12 Similarly, as explained by Ms Michela Cardomone, who has provided care for a member of her family with a mental illness:

Apart from the isolation and loneliness I was experiencing, like many carers I experienced anxiety and depression, trauma and grief as a direct result of the caring role. Whilst these conditions

7 Mr S Dodd & Ms H Dodd, Submission No 1196, p 1.

8 Ms L Formosa, Submission No 1296, p 2.

9 Ms D Vella, Submission No 273, p 2.

10 See for example: ARAFMI QLD, Submission No 574, pp 3-4; BrainLink Services, Submission No 690, pp 3-4; Ms J Steepe, Submission No 1023, p 10.

11 Ms T Camilleri, Submission No 48, p 1.

are considered mental illnesses in their own right, they are a fundamental part of the lived experience for carers.¹²

- 8.13 As a new carer whose child was diagnosed with a terminal medical condition also explained:

I am not ashamed to say that I am scared - about my ability to manage this, to stay strong for those around me, to come out the other end - and somehow to manage to smile on the way through. I can and do function as best as I can - and really try to stay positive and energetic for the kids, but the grief is always there. There's not an hour that goes by that I don't think about it. And this is emotionally and physically exhausting.¹³

- 8.14 As noted above, carers have been recorded as having the lowest collective wellbeing of any population group measured to date.¹⁴ The Committee's evidence corroborates the research and indicates that a combination of factors relating to the nature and demands of caring has ramifications for the wellbeing of carers. This chapter will explore in more detail the impact of caring on carers' physical health and psychological and emotional wellbeing and recommends specific measures to address their health needs.

Physical Health of Carers

- 8.15 Many carers have indicated that they suffer physically as a consequence of providing care. The physical demands of moving and lifting of care receivers who have limited mobility is an issue, with some carers reporting that they had sustained physical injury as a result.¹⁵ As noted in the submission from Special Kidz Special Needs:

Carers are often faced with lifting, twisting, and physical demands of enabling those they care for to sit, walk, bathe, toilet etc. This

12 Ms M Cardomone, Submission No 799, p 2.

13 Name withheld, Submission No 244, p 3.

14 Australian Unity Wellbeing Index (2007), Survey 17.1, *The Wellbeing of Australians – Carer Health and Wellbeing*, pp vi-vii.

15 See for example: Mr J Halford, Submission No 250, p 6; Mr R Regal, Submission No 335, p 4; Ms J Edwards, Submission No 564, p 1; Ms N Hughes, Submission No 830, p 1; Ms M Parnell, Submission No 849, pp 7-9; Mr L Hawksworth, Submission No 1018, p 1; Mr C Coleman, Transcript of Evidence, 12 August 2008, pp 29-30.

often leads to back pain and in the long term spinal subluxations (deformation) and arthritis.¹⁶

- 8.16 However, the physical impacts of providing care are broad ranging and are likely to increase as the carer ages, as the care receiver grows to adulthood or as a consequence of providing care over a prolonged period of time or at a high intensity. The following excerpts from carers' submissions illustrate the toll of caring:

Ms Leveina Belsham – carer for her 102 year old mother and for her husband (now deceased) following heart surgery and with cancer

... unfortunately the role of carer is very damaging to my health and body. Lifting both my husband and mother has caused damage to my back, knees and arms.¹⁷

Ms Janet Johnson – provides care with her husband for their two adult daughters in their late 40s and for a 15 year old grandson, each with varying degrees of intellectual impairment

We have spent most of our married life caring for them - lovingly, I hope with very little help from anyone. Consequently we are both suffering from elevated stress levels. We both have high blood pressure, digestion problems, back pain and a number of other stress related conditions including depression and anxiety.¹⁸

Name Withheld – carer for her son with cerebral palsy and mild autism

The problems I face day to day are physical health issues cast upon me due to caring. I have developed a stomach ulcer due to stress, fibromyalgia; muscle inflammation that prevents me from doing anything outside my caring role, a degenerative spine condition and depression which are all exacerbated because of caring.¹⁹

Ms Rosalie Quaife – carer for her two children, one with type 1 diabetes and the other with a mental illness

As a Carer I feel exhausted and that my quality of life has been greatly affected by my need to Care. This ultimately will result in

16 Special Kidz Special Needs, Submission No 567, p 18.

17 Ms L Belsham, Submission No 96, p 1.

18 Ms J Johnson, Submission No 16, p 1.

19 Name withheld, Submission No 650, p 1.

my state of health, physical and mental, negating my ability to care adequately. There is never a peaceful night of sleep.²⁰

Mr Noel Faint – primary carer for six people with various disabilities

I am overweight - suffer from sleep apnoea, blood pressure, stomach ulcer, bad kidneys, enlarged liver, depression, arthritis in the knees, ankles, elbow and wrists [and have] been waiting years for dental work. ... Unfortunately everybody needs come before mine but in all fairness that is my choice.²¹

Ms Jane Churchill – carer of her 16 year old son with a disability

Every day I have to wash due to my son's incontinence ... my health is deteriorating, I have arthritis, have had 2 hip operations in the last 10 years and I'm only 49. I have diabetes, chronic fatigue syndrome, scoliosis, lordosis and depression.²²

- 8.17 Despite experiencing poorer physical health, carers often reported that they had delayed attending to their own health needs. In some cases, carers indicated that the health needs of the care receiver were considered first and foremost, and with limited resources to the exclusion of considering their own health.²³ Other factors that restrict carers from addressing their own health needs include a lack of money and/or time.²⁴ For example, Ms Carolyn Paisley Dew, now a bereaved carer, stated:

I never had time (or money) to look after my own health. Since Matthew passed away, I have had a lot of really overdue work done on my teeth. I have also had two operations that each required a six-week period without lifting; each of these essential needs would have been impossible while he was alive.²⁵

Improving the Physical Health of Carers

- 8.18 Improving the physical health of carers will require a greater recognition of the importance of the carer's own health. To achieve this, the

20 Ms R Quaife, Submission No 1125, p 1.

21 Mr N Faint, Submission No 20, p 1.

22 Ms J Churchill, Submission No 66, p 1.

23 See for example: Ms M Nazzari, Submission No 100, p 1; Ms A Hewat, Submission No 866, p 8.

24 See for example: Ms L McIver, Submission No 191, p 3; Ms Y Wathen, Submission No 723, pp 1-2; Name withheld, Submission No 850, p 1; Ms D Le Cornu, Submission No 887, p 1.

25 Ms C Paisley-Dew, Submission No 826, p 4.

Committee believes that a preventive health approach based on support for measures which actively promote good health and reduce the incidence of injury and illness is crucial. Discussion earlier in the report has emphasised the need to provide carers with the skills, training and education to support them in their role. While the skills and training needs of individual carers will vary depending on the specifics of the caring situation, where appropriate this training should include safe manual handling practices and all carers should receive advice on looking after their own health.

- 8.19 Other preventative health measures that have been recommended to the Committee include the implementation of targeted health programs for carers, including the provision of free annual check-ups for carers.²⁶ For example, Carers ACT recommended:

That the government commit to providing a Primary Health Care Program for carers, including a free annual health check with a reminder system, a free annual Flu-vax, hepatitis vaccinations if needed, and a health care card.²⁷

- 8.20 In providing its support for the introduction of free annual check-ups for carers, the New South Wales Government observed:

Carers need to be encouraged not to ignore their own physical and mental health needs. General Practitioners could play a significant role in this area. The recently released UK carers strategy *Carers at the heart of 21st-century families and communities* is piloting annual health checks for carers.²⁸

- 8.21 Carers Australia pointed out that there are already a number of preventative health initiatives that target high risk groups:

There are precedents where the Federal Government has introduced health initiatives for specific population groups at risk of poor health, including Better Health Outcomes for Mental Health, the annual health checks for people aged 45-49 years with a health risk and, more recently, the Healthy Kids Check.²⁹

26 See for example: Ms J Harrison, Submission No 301, p 2; Ms S Durkin, Submission No 329, p 2; National Seniors Australia, Submission No 686, p 3; Palliative Care Australia, Submission No 688, p 10; Ms T Hayes, Submission No 933, p 4; Ms J Lehmann, Submission No 1258, p 5; Ms D Stewart, Transcript of Evidence, 13 August 2008, p 27.

27 Carers ACT, Submission No 702, p 4.

28 NSW Government, Submission No 1278, p 13.

29 Carers Australia, Submission No 699, p 21.

- 8.22 As carers experience very poor health and comparatively low levels of wellbeing, the Committee supports the introduction of a targeted preventative health program for carers. One approach to achieving this would be for the Enhanced Primary Care Program, a Department of Health and Ageing (DoHA) program which includes free health checks for at risk population groups (for example, people between the ages of 40 and 49, older Australians, Indigenous Australians and permanent residents of aged care homes) to be extended to include carers as an at risk group.³⁰ Eligibility for the program could be based on receipt of Carer Payment and/or Carer Allowance.

Recommendation 46

- 8.23 **That the Minister for Health and Ageing direct the Department of Health and Ageing to provide a preventative health care program targeted at carers. This could be achieved by extending the Enhanced Primary Care Program to include carers who receive Carers Payment and/or Carer Allowance as an at risk population group requiring intervention under this program.**
- 8.24 One issue that has been repeatedly raised by carers, relates to bulk billing by General Practitioners (GPs) and other health professionals. The Committee understands that the Australian Government already provides incentives under the Medicare Benefits Schedule (MBS) for GPs to bulk bill Pensioner Concession Card and Health Care Card holders, though the ultimate decision to bulk bill is at the doctor's discretion.³¹ However, submissions from carers indicate that finding GPs and other health professionals that are willing to bulk bill concession card holders is problematic.³²
- 8.25 To respond to these issues raised by carers, the Australian Government may wish to review the effectiveness of the MBS incentives offered to GPs to bulk bill concession card holders.

30 Australian Government, Department of Health and Ageing website, viewed 1 March 2009 at www.health.gov.au/epc.

31 Australian Government Departments (FaHSCIA, DoHA & DVA), Submission No 1109, p 23.

32 See for example: Ms C Phillips, Submission No 755, p 2; Mr A Skimin & Ms K Skimin, Submission No 810, p 2; Ms L Symons, Submission No 1043, p 2; Ms J Beattie, Submission No 1045, pp 3-4; Ms N Jensen, Submission No 1052, p 1.

The Psychological and Emotional Wellbeing of Carers

- 8.26 The evidence provided by hundreds of carers and organisations, emphasised that sustaining carers in a caring role and supporting their psychological and emotional wellbeing, means they must receive an adequate amount of 'time out' from the caring role and increased access to counselling and psychological services.
- 8.27 One carer described the interrelationship of stresses arising from the caring role, the lack of responsiveness of support services and the very real obstacles preventing carers attending to their own needs, in the following way:

In order to keep some sort of balance in life, we all need a little 'me' time on a regular basis. We Carers are people too, we need a break too. Just like everyone else, we like to feel the sunshine on our faces and wind in our hair, but do we get to do this as often as we should? No we don't. Why? Because we don't have anyone to take over the Care of our special people for us. So we seek out organisations to help us get some respite and help. What we get told is that there is nothing available due to lack of funding or you will be put on a waiting list or someone will call you back and our call just isn't returned. And if we are lucky enough to get put on a waiting list, do any of these people bother to check up on us to see if there is anything else they can do to help? No. Do any of these people refer us on to someone else who can help us? No. Do any of these people make some enquiries on our behalf because we are clearly in need of help and completely stressed out? No! A build-up of stress usually evolves and develops into depression, this might mean treatment such as counselling or intense therapy and or medication. This all costs time and money. This extra financial burden coupled with having to find the time to do the therapy all adds up to ... yep you guessed it ... more stress!!! And here we go stuck on that revolving door again!!!!³³

The Need for 'Time Out' in the Caring Role

- 8.28 A significant number of carers have reported experiencing extreme stress, anxiety and depression. The relentless intensity of the caring role and insufficient time for carers to attend to their own needs was identified as a

33 Ms D Etherington, Submission No 1204, p 1.

significant stress factor.³⁴ Many carers indicated that in the absence of sufficient 'time out' they were struggling to sustain their caring role. As explained in the submission from the National Carers Coalition:

If carers are not given timely breaks they risk burn-out. This is partly why carers have such high events of depression, physical conditions and illnesses.³⁵

8.29 The comments below are typical of those made by carers in relation to the impact of providing continuous care on their wellbeing and the importance of 'time out' or 'me time':

Ms Kerry Beamish – carer for her husband with kidney failure

The things that stress me about being a carer the most are that you have to be there all the time. There is no time for yourself, if you manage to fit in 'me' time it is for a very limited time.³⁶

Ms Judith Small – carer for her paraplegic husband since 1993 following removal of a brain tumour

I find it difficult to have the time and space for myself as we have had to move to a unit (as I could no longer maintain a home with a garden) and the TV is my husband's main interest at home with the consequence on me it is difficult for me to have time away by myself as he does not cope if I go away.³⁷

Ms Donna Etherington – carer for her son with a disability

I am susceptible to falling in and out of severe depression because of the mammoth stresses that a Caring role does bring. I am sure you would agree, dealing with depression is difficult for any individual, but it is amplified for those in a Caring role. As a Carer, you can't afford to get sick or unable to cope. If you can't be the 'Carer', then who is there to take over for you?³⁸

Name withheld – a new carer of a young child with a serious medical condition

At present, we rely on grandparents and paid babysitters for 'time

34 See for example: Ms M-J Galiazzo, Submission No 359, p 1; Ms C Franze, Submission No 622, p 3; Ms J Johnson, Submission No 1178, p 6; Ms M Anderson, Transcript of Evidence, 12 August 2008, p 44.

35 National Carers Coalition, Submission No 571, p 30.

36 Ms K Beamish, Submission No 55, p 1.

37 Ms J Small, Submission No 110, p 2.

38 Ms D Etherington, Submission No 1204, p 1.

out'. For busy working parents with the stress that this sort of diagnosis brings, this is essential. I can't imagine having to go through this without my husband's support - and it's so important that we do take time to be with each other. Without, we cannot support our family emotionally. However, respite care appears to be limited. Jamie's condition, chronic and terminal as it is, does not yet qualify us for any respite care service. I was told that he has to deteriorate further - not easy news to take.³⁹

8.30 While each individual's need for time away from the caring role will vary depending on the specifics of the caring situation, the consensus in evidence from carers is that the current respite provisions, both in-home and out-of home, are insufficient to meet demand.⁴⁰ The Committee has considered issues associated with respite earlier in the report and believes that its recommendations relating to improving access to quality respite services will assist carers gain their own time out.

8.31 In addition to the shortage of respite generally, a specific issue that has been raised by a number of carers relates to the maximum allowable allocation of 63 days per calendar year for the temporary cessation of care⁴¹ for recipients of Carer Payment or Carer Allowance. Some carers have questioned the rationale for the 63 day per year limit, arguing that it is insufficient and inequitable when compared to minimum conditions of employment. As explained by Ms Ellen Walker, a carer with over 14 years caring experience:

... currently carers can take off 63 days a year from their caring role - this does not even reflect usual working arrangements of a 37.5 hour week - indeed, carers do not even get the equivalent of weekends off in a year (104 days), let alone sick leave, holiday leave, personal leave.⁴²

39 Name withheld, Submission No 244, p 6.

40 See for example: Ms L Buckingham, Submission No 109, pp 1-2; Ms S Berardi, Submission No 550, p 1; Ms B Allen, Submission No 612, p 1; Ms G Esson, Submission No 647, p 3; Name withheld, Submission No 860, p 2; Ms D Galt, Submission No 861, p 1; Ms M Quinn, Submission No 867, p 1; Ms E Tielmann, Submission No 907, p 2; Ms G Hunter, Submission No 1090, pp 1-2; Ms D Etherington, Submission No 1204, p 2; Name withheld, Submission No 1304, p 1.

41 Temporary cessation of care provisions apply where the cessation of care is a 24 hour period. Part days do not count as temporary cessation of care.

42 Ms E Walker, Submission No 973, p 3. See also: Community Options (Dementia Respite Albury and District), Submission No 790, p 2; Ms N Hughes, Submission No 830, p 4; Mr M Tonissen & Ms R Tonissen, Submission No 1111, p 2.

- 8.32 Ms Anita Geach-Bennell, who provides care for her two daughters with high support needs, also questioned the 63 day temporary cessation of care limit, suggesting:

Remove the 63 day rule from CentreLink. My caring role of my daughters goes on during the night and day. WE SHOULD BE ABLE TO HAVE RESPITE WHEN WE NEED IT AND HOW WE NEED IT, AND NOT BE TOLD WHEN WE CAN HAVE IT.⁴³

- 8.33 An older carer, Ms Dorelle Purcell, also pointed out that the allowable 63 days of respite is often insufficient for older carers:

Whilst carers are permitted 63 days respite per year, if the carer becomes ill ... part of the 63 days must be used to avoid loss of benefits (to the carer). This is disgraceful, especially in the aged carer, as we need every one of those 63 days of respite in order to maintain our caring role.⁴⁴

- 8.34 Importantly, submissions from carers have brought the Committee's attention to the fact that, while an additional 63 day temporary cessation of care is available for periods where the care receiver is hospitalised, this is not the case where the carer temporarily ceases to provide care as a result of the carer's own hospitalisation or illness. As explained by one carer, Ms Lynn Walker:

Under Centrelink rules when a carer requires hospitalisation that time must be taken from the allowed respite days. I feel this is unfair as an ill carer would require both sick leave and respite days to regain health.⁴⁵

- 8.35 Ms Barbara Bale, who has provided care for her son for almost 37 years, explained how she had been required to use time from her 63 day 'respite' allowance to undergo treatment for cancer:

I was told to use my respite days when I was having a mastectomy, chemotherapy and Radiotherapy. This is wrong; respite is used to have a break, not to have treatment for cancer. This needs to be changed so that carers who do fall ill are supported and not told to use respite days.⁴⁶

43 Ms A Geach-Bennell, Submission No 1022, p 2.

44 Ms D Purcell, Submission No 2, p 1.

45 Ms L Walker, Submission No 470, p 1.

46 Ms B Bale, Submission No 930, p 1.

- 8.36 The Committee has already acknowledged the essential importance to carers of access to supports, particularly regular and adequate respite services, to allow them to have time out of their caring role to reduce the risk of carer burn out. The Committee also considers that the current social security provisions covering temporary cessation of care in respect of carers receiving Carer Payment and/or Carer Allowance, should be re-examined. It is the Committee's view that the allowable period of time for respite from the caring role be brought more in to line with community expectations for employment conditions, including time allowed for weekend breaks, recreational leave and sick leave entitlements.

Recommendation 47

- 8.37 **That the Minister for Families, Housing, Community Services and Indigenous Affairs direct the Department of Families, Housing, Community Services and Indigenous Affairs to review the temporary cessation of care requirements for Carer Payment and Carer Allowance recipients, particularly in relation to:**
- **the adequacy of the 63 days of respite per year particularly in comparison to minimum conditions of paid employment; and**
 - **the requirement of carers to use all or part of the allowable period of time to cover periods of time, when as a result of illness, they are unable to provide care.**

The Need for Psychological Support and Counselling

- 8.38 In addition to needing time away from the caring role to maintain a positive level of emotional wellbeing, many carers also identified the need for greater access to psychological support and counselling, both for themselves and for their families. This is particularly important during periods of transition and change, for example on commencement of caring, when the care receiver leaves school or employment, if there are significant changes in the level of care required, changes in accommodation or changes in family relationships and structures due to

separation or death.⁴⁷ As the Australian Institute of Health and Welfare explained:

Access to counselling, support and information is important for carers when they reach critical transition points: commencing or increasing caregiving (possibly involving decisions about paid employment) or ending care through death or institutionalisation.

Some carers may need help to re-engage with their community after a long period of caregiving.⁴⁸

8.39 The following comments from carers exemplify the views of many carers who raised the importance of psychological and emotional support at times of transition:

Ms Dulcie Sullivan - an older carer who cares for her 54 year old son

I particularly need help now I am 81 years old. I need to have transitional aid when relinquishing my role as a carer. This transitional period is confrontational.⁴⁹

Ms Annette McArthur - carer for her step-daughter for over 20 years and for her husband

One thing that would really help, is ready access to free counselling over the phone or in person at my own home. This would be great after a diagnosis, death or other crisis.⁵⁰

Mr Les Wheaton and Ms Judy Wheaton - cared for elderly parents in a rural community

Counselling available for carers to help them cope with all aspects of the caring role, especially transitions from one level of care to another when the carer may be dealing with feelings of guilt, anger, inadequacy etc.⁵¹

47 See for example: Ms W Bennett-Hall, Submission No 103, p 2; Ms A Dix, Submission No 431, p 2; Ms L McCulloch, Submission No 471, p 1; Ms A McArthur, Submission No 491, p 1; MND Australia, Submission No 568, p 25; Daughters in Demand, Submission No 611, p 2; Huntington's Australia, Submission No 670.2, p 1.

48 Australian Institute of Health and Welfare, Submission No 1033, p 5.

49 Ms D Sullivan, Submission No 126, p 6.

50 Ms A McArthur, Submission No 491, p 1.

51 Mr L Wheaton & Ms J Wheaton, Submission No 190, p 3. See also: Ms A Dix, Submission No 431, p 3.

- 8.40 From the evidence, it would appear that many carers are not accessing adequate counselling services to meet their needs. A number of carers have suggested that there is a need to increase the levels and affordability of emotional and psychological counselling available to carers.⁵²

The Impact on Other Members of the Family

- 8.41 The stress experienced by carers often also extends beyond the primary carer, affecting the whole family including spouses, siblings and other family members.⁵³ Relationship difficulties between siblings, is a particular area of concern identified by recent research.⁵⁴ The need for counselling services to ameliorate the impact of caring on the whole family was raised by many carers including:

Ms Beverley Tickner – carer for her adult son with mental illness

Most carers spend about 80% of their time catering to the needs of the child with the disability and 20% of time to children who are not disadvantaged. Therefore my caring role means that I have to devote a disproportionate amount of time to supervising the sick child/adult.⁵⁵

Ms Beverley Schulz – carer for her 22 year old daughter

My life revolves around my daughter instead of revolving around my husband and my family. My daughter's ill health has taken its toll on my health and I am suffering chronic pain. For the past 18 months she has suffered ill health and has had 3 stays in hospital, and had one major operation...I am approaching 50 and I need more time for me. I want to enjoy my life more but carers don't receive enough money or help to enable this to happen. My husband and I love our daughter; she is part of our family but the way things are going she will have to go into permanent care and that will cost the government more.⁵⁶

52 See for example: Ms A Silvey, Submission No 267, p 2; Ms J Wallent, Submission No 834, p 2; Ms T Hayes, Submission No 933, p 4; Ms M Hart & Mr R Hart, Submission No 1174, p 2;

53 See for example: Ms J Guilfoile, Submission No 160, p 2; Ms K Small, Submission No 165, p 1; Ms L Ruggiero, Transcript of Evidence, 12 August 2008, p 12; Ms S Gambin, Transcript of Evidence, 12 August 2008, pp 74-75; Ms V Cagliuso, Transcript of Evidence, 13 August 2008, p 21; Ms J Milburn, Transcript of Evidence, 13 August 2008, p 25; Ms K Strohm, Transcript of Evidence, 13 August 2008, pp 58-65.

54 Australian Institute of Family Studies, Submission No 744, p 5.

55 Ms B Tickner, Submission No 98, p 1.

56 Ms B Schulz, Submission No 286, p 1.

Ms Margaret Ingham – carer for her 15 year old son with Asperger's Syndrome, Oppositional Defiance Disorder, Tourettes, Depression and Attention Deficit Disorder

Our social life is virtually non-existent. My son's [Autism Spectrum Disorder] has alienated him from most of his family so we cannot visit them as a family, and some members are quite hostile towards us/him because of his bluntness and language. I can usually speak to my sisters on the telephone so to avoid confrontations. Because I side with him, (although I do not agree with him) this has caused much tension in family life.⁵⁷

Ms Alison Dix - carer for her daughter with Asperger's Syndrome and twin sons with Autism Spectrum Disorder

My husband and I also need to have marriage counselling because we are growing apart due to the responsibility and pressure of the situation. Separation has been a consideration when times get really tough and the children obviously suffer!⁵⁸

8.42 Carers frequently reported that the impact of stress on family relationships has contributed to marriage breakdown and family break up as a consequence of caring.⁵⁹ One such carer, Ms Lynne McCulloch, a long-term carer for her two sons described the impact of caring on her family in the following terms:

I feel that my role as carer for my disabled sons has cost me a lot in terms of health, friendships and marriage breakdown. ... My concern is that physically I won't be able to care for my son for too much longer as he is quite a lot taller and bigger than I am. My marriage broke down in 2003 because of a lot of the strain, both physically and emotionally.⁶⁰

8.43 Siblings Australia, an organisation which supports siblings of people with disability explained that the impact on siblings can be significant, not only as a secondary carer or through the need to take on childcare responsibilities, but also:

57 Ms M Ingham, Submission No 505, p 2.

58 Ms A Dix, Submission No 431, p 1. See also: Ms J Small, Submission No 110, p 2.

59 See for example: Name withheld, Submission No 22, p 1; Ms L Kschenka, Submission No 32, p 1; Ms C Polidano, Submission No 259, pp 2-3; Perth Carer Forum Group, Submission No 983, pp 5-6.

60 Ms L McCulloch, Submission No 471, p 1.

... because parents may be stressed and depressed and so not as available to them for support.⁶¹

- 8.44 The responsibilities taken on by siblings is eloquently explained at a hearing held in Perth by Ms Raynar Foldesi who described how she and her parents shared the responsibility for caring for her 'mentally and physically disabled' 19 year old brother and the impact on herself:

In our family, I guess like every family, we work as a team. Unlike some people, my brother, at the end of our mum's life and our dad's life, will have me as his carer. I will be his sole carer and he will be my dependant. On top of that, not only will he be part of my life but my life still has to continue also. I was lucky in that I did not have to completely stop schooling but I did miss a lot of school. I did not want to go to school; I had a lot of bullying. People, especially young kids, do not understand the difference. At the moment uni is quite tough. Even though my brother does go out and he does have carers coming in, there is always a chance that something might go wrong. Only yesterday our carer could not come in because she had a medical thing and was not able to look after my brother. Therefore I had to miss out on my training.⁶²

- 8.45 The overall evidence to the Inquiry supports the need for emotional and psychological support for primary carers as well as for other family members, including relationship counselling for spouses, siblings etc. As one carer commented:

Support for carers must include ongoing counselling & emotional support. The grief is raw with no closure, it is ongoing it effects & divides the whole family & social network.⁶³

Ending the Caring Role

- 8.46 Evidence also raises the importance of support to assist carers to transition out of the caring role and to reengage after long periods of social isolation. As one carer stated, she needed help with:

Rediscovering my own identity and support to regain mental and physical wellness again. I could well do with some life-coaching,

61 Siblings Australia, Submission No 701, p 1.

62 Ms R Foldesi, Transcript of Evidence, 23 July 2008, p 47.

63 Ms J Sykes, Submission No 237, p 1. See also: Ms J Small, Submission No 110, p 2; Ms A Dix, Submission No 431, p 1; Name withheld, Submission No 500, p 26.

personal training, help to join and play in a sports team: a mentor looking out for me.⁶⁴

- 8.47 Carers also stressed the importance of emotional and other forms of support for carers when a care receiver transitions to alternative accommodation and care. In this situation, the role of the carer may change but elements of the caring role may very well continue, as explained by the Carer Support Network of SA:

Carers whose loved one goes into residential care are in a unique position. Many still provide a high level of Caring yet they are excluded as a target group by the funding bodies – both State and Federal. This is a serious current anomaly and needs to be addressed. Carers who provide Care in this situation are providing meals, taking the Care Recipient on outings, doing washing, providing social support, helping to ensure the Care Recipient doesn't lose skills learnt at home, and so on.⁶⁵

- 8.48 The needs of bereaved carers are also an important consideration in relation to counselling and psychological support services for carers. Again, the Carer Support Network of SA commented:

... most Carers need a considerable time for re-adjustment once the Care Recipient has passed away. They have experienced social isolation, have usually left work, many have lost contact with previous friends and family. Their entire frame of reference to society has been through the needs of the person they have cared for. Carers in this situation need time and support to transition to another phase of their lives without Caring responsibilities. They need time to grieve, time to adjust, time to think about their futures, time to re-establish priorities.⁶⁶

- 8.49 An Indigenous carer also emphasised the importance of emotional support at times of transition or at the end of the caring role suggesting:

Assigning a Case Manager to an Indigenous Carer in a similar fashion to those assigned to the long-term unemployed which would greatly assist an Indigenous Carer in transitioning back to the work force because personal support may be required to

64 Ms J Guilfoile, Submission No 160, p 3.

65 Carer Support Network of SA, Submission No 675, p 12. See also: Ms N Tingey, Submission No 38, p 1; Ms H Parker, Submission No 1076, p 1; Ms S Gambin, Transcript of Evidence, 12 August 2008, p 72.

66 Carer Support Network of South Australia, Submission No 675, p 12.

address issues such as Grief and Loss, how to job search and retraining. Preferably the Case Manager position would be an identified position and filled by Indigenous staff.⁶⁷

Counselling for Carers

8.50 Telephone counselling can be a very successful intervention for carers in certain situations.⁶⁸ For example, the Life Goes On model of telephone counselling provides effective support for carers and family members facing a terminal or serious medical illness.⁶⁹ However, for others face-to-face counselling and support is more important. One such carer observed:

Carers need a support person to talk to about the stresses and demands of their role, preferable in person, not just via a telephone link-up, and opportunity to meet together away from the caring environment.⁷⁰

8.51 At the national level, counselling, emotional and psychological support for carers is provided through the network of Carers Associations which delivers the National Carer Counselling Program (NCCP) for DoHA. The program provides a range of services including, information, specialist advice and counselling services to carers in order to reduce carer stress, improve care coping skills and facilitate wherever possible, the continuation of the caring role.⁷¹

8.52 In addition to the NCCP, the Department of Families, Housing, Community Services and Indigenous Affairs administers the Family Relationships Service for Carers in each state and territory. The Family Relationship Service assists carers and families considering financial planning for the future care needs of a family member with a severe disability and provides mediation for families disagreeing over the future needs of a family member with a disability.⁷²

8.53 The national network of state and territory Carers Associations have recommended an expansion of the NCCP to meet a growing demand for

67 Name withheld, Submission No 1304, p 1.

68 Ms C Cornish, Submission No 1150, p 2.

69 Life Goes On, Submission No 257, pp 1-2.

70 Mr L Wheaton & Ms J Wheaton, Submission No 190, p 3.

71 Australian Government Departments (FaHCSIA, DoHA & DVA), Submission No 1109, p 26. See also: www.health.gov.au/internet/main/Publishing.nsf/Content/ageing-carers-nrcp.htm.

72 Australian Government Departments (FaHCSIA, DoHA & DVA), Submission No 1109, p 33. See also: [www.facsia.gov.au/internet/facsinternet.nsf/via/frsp/\\$file/FRSC_Brochure.pdf](http://www.facsia.gov.au/internet/facsinternet.nsf/via/frsp/$file/FRSC_Brochure.pdf).

this service.⁷³ Carers WA also recommends that an extended NCCP should encompass specific funding to support mobile services for families in rural and remote communities.⁷⁴

- 8.54 The Committee recommends an adequate provision of counselling and psychological support services targeted at carers as well as increasing the awareness of GPs about the vulnerability of carers and their families to mental health problems.
- 8.55 The Australian Government has recently established the Access to Allied Psychological Services (ATAPS) program which enables GPs to refer patients to allied health professionals, including psychologists, social workers, mental health nurses and other allied professionals.⁷⁵
- 8.56 The Committee understands that through ATAPS, patients are eligible for a maximum of 12 sessions per calendar year - six initial sessions with an option for a further six sessions following a mental health review by the referring GP. Sessions can be individual and/or group therapy sessions. In addition, the referring practitioner may consider that in exceptional circumstances the patient may require an additional six individual focussed psychological strategies above those already provided (up to a maximum total of 18 individual services per patient per calendar year).⁷⁶

Recommendation 48

- 8.57 That the Minister for Health and Ageing expand the National Carers Counselling Program to better meet the demand for counselling services by carers.**

73 Carers WA, Submission No 566, pp 2, 22; Carers Victoria, Submission No 652, p 26.

74 Carers WA, Submission No 566, pp 6, 22.

75 Including occupational therapists and Aboriginal and Torres Strait Islander health workers with specific mental health qualifications. See Australian Government, Department of Health and Ageing website, viewed 16 March at www.health.gov.au/internet/main/publishing.nsf/Content/mental-boimhc-ataps.

76 Australian Government, Department of Health and Ageing website, viewed 16 March at www.health.gov.au/internet/main/publishing.nsf/Content/mental-boimhc-ataps.

Recommendation 49

- 8.58 **That the Minister for Health and Ageing direct the Department of Health and Ageing to raise awareness among General Practitioners of the high incidence of mental health problems among carers and their families and of the options available for support.**

Social Isolation

- 8.59 Many carers report social isolation resulting from their caring role and the evidence describes various reasons for this. Carers often describe self imposed isolation and circumstantial isolation resulting from a lack of available respite care as well as a lack of time, money or energy to socialise. Ms Judith Sykes, a carer with caring responsibilities for an adult daughter with mental illness and that daughter's 16 year old son, explained:

Caring creates barriers in social interaction in the following ways.

- I become too tired to socialise.
- I am worried & lack concentration.
- I am involved with the problems of caring
- I have to cancel social engagements.
- I suffer social anxiety & stress.⁷⁷

- 8.60 Explanations from carers about their limited or non existent social networks include the following examples:

Ms Deborah Edwards - carer of 20 years for her son with severe disability

Sadly, the total isolation we tend to live in prevents us from making and keeping acquaintances. We just don't get the chance to socialize and make friends, and our lives are so misunderstood and feared by people outside the disability sector that they tend to keep a distance, and not visit.⁷⁸

77 Ms J Sykes, Submission No 237, p 1.

78 Ms D Edwards, Submission No 159, p 3. See also: Ms S Hewett, Submission No 298, p 1.

Ms Julie Guilfoile - carer for her son with severe disability

Extended family and friendship networks often drop just as suddenly, as extended family and friends can't cope with the reality that this family now faces.⁷⁹

Mr Richard Morrison - carer for his 29 year old son

We find we are excluded from invitations to family and friends celebrations because of: 'we knew you could not come because you have to stay home to look after Christopher' when we really know they do not want our son there.⁸⁰

Ms Narelle Hughes - carer for her daughter with high care needs

Social Isolation is a part of most carer's lives. No matter how caring and understanding friends may be, the restrictions on carers of people with high support needs make it difficult to maintain close ties. Most of our friends are now in a position of relative freedom. Their children are grown, they are able to socialise without having to find a 'babysitter'. At fifty I still cannot go out for dinner without major planning for the care of my daughter, let alone holiday for a week or two. Even if I could organise care, how would I afford it? And I am one of the lucky one's who has a partner who works.⁸¹

Name Withheld - carer for her mother

The longing for friendship, someone to talk to, since one is not able to get out, is often overwhelming. Often one has to resort to impersonal telephone counselling.⁸²

- 8.61 In some situations the care receiver's circumstances, for example, limited mobility or challenging behaviours, may contribute to the isolation experienced by carers. For example:

Ms J Burke - a carer for her husband who has an acquired brain injury

My husband never wants to go anywhere with me. Most days are based around misunderstood conversations which turn into nasty fighting. Doesn't like me going out on my own, the feeling of

79 Ms J Guilfoile, Submission No 160, p 4.

80 Ms R Morrison, Submission No 40, p 1.

81 Ms N Hughes, Submission No 830, p 3.

82 Name withheld, Submission No 1087, p 5.

isolation, he never wants to socialise and spends most of his days when at home in his pyjamas.⁸³

Ms W Bennett – a carer with two children who have an autism spectrum disorder

Social opportunities are reduced as unpredictable behaviour makes it highly stressful for me and stressful for the children. My situation makes being able to consistently and reliably attend a paid job very tenuous.⁸⁴

Ms Joy Roze – sole parent/carer for twenty years for two sons with autism spectrum disorder

At one stage I was so socially isolated due to my son's behaviour that I could not risk leaving the house with him. I remained indoors only venturing out if it was completely unavoidable. I even resorted to doing my weekly grocery shopping online as a strategy to avoid public criticism as Jayden would tantrum severely in public every time I attempted to access the community with him. My only access to a social life at that stage was the internet and although accessing it caused a lot more financial strain it was my main connection with the outside world at that time.⁸⁵

Ms Alishya Purss – a young carer for her father who has depression and frontal lobe brain damage

My friends would not understand what I do as not every 19 year old does what I do. Socially, it is hard to go out on weekends and as I used to be an active volunteer in my region in regards to red shield appeals, salvation army door knock appeals and blood donations, I can no longer contribute to society as I could before.⁸⁶

- 8.62 As discussed in more detail earlier in the report, some carers report that the support and social connections made through self help or peer support groups is extremely valuable, in fact almost a lifeline, in an otherwise isolated and demanding situation. As one carer explained:

We managed the illness as much as we could and managed to earn our living though with Bi-Polar the moods are very high and low which is difficult to live with. I am a member of ARAFMI and

83 Ms J Burke, Submission No 99, p 1.

84 Ms W Bennett-Hall, Submission No 103, p 2.

85 Ms J Roze, Submission No 485, p 5.

86 Community Options, Dementia Respite Options, Albury & District, Submission No 790, p 6.

Queensland Carers Australia which gives me company and a will to keep going.⁸⁷

8.63 A number of recommendations made in the earlier chapters of the report, address some of the key underlying causes of isolation experienced by many carers. For example:

- increasing the recognition and understanding of the caring role by the Australian community;
- increasing services and supports to assist carers in their caring role;
- increasing respite or 'time out' from the caring role;
- increasing the choice for carers to participate in employment; and
- increasing financial assistance for carers.

8.64 The evidence before the Committee paints an overwhelming picture of social exclusion. Initiatives to promote greater social inclusion for carers have also been recommended as being fundamental to raising community awareness, knowledge and understanding of carers' roles.⁸⁸

8.65 The Committee notes that the Australian Government has announced a social inclusion agenda to:

... create a fair and inclusive society where all Australians have the opportunity to find meaningful employment, access services, connect with others, have their voice heard and deal effectively with the contingencies of life.⁸⁹

8.66 At the current time, the Australian Government has identified the following priorities for the agenda:

- homelessness;
- Indigenous disadvantage;
- employment for people with mental health and disability concerns;
- children at risk; and
- jobless families.⁹⁰

87 Ms V Thomson, Submission No 300, p 2.

88 Queensland Government, Department of the Premier and Cabinet, Submission No 1203, p 2. See also: Carers Australia, Submission No 699, p 18; Carers South Australia, Submission No 684, p 6; Aged and Community Services Australia, Submission No 1085, p 3.

89 Australian Government Departments (FaHCSIA, DoHA & DVA), Submission No 1109, p 44.

90 Australian Government Departments (FaHCSIA, DoHA & DVA), Submission No 1109, p 44.

- 8.67 To implement the social inclusion agenda, the Australian Government created a social inclusion committee of cabinet in February 2008; created the positions of Minister for Social Inclusion and Parliamentary Secretary for Social Inclusion and the Voluntary Sector; and established a Social Inclusion Unit in the Department of the Prime Minister and Cabinet. In May 2008, an Australian Social Inclusion Board was established to provide advice to the Australian Government on ways to achieve better outcomes for the most disadvantaged in the Australian community.⁹¹
- 8.68 The Committee believes that the degree of social alienation suffered by carers generally, warrants them being considered as a disadvantaged group for specific attention as an early priority on the Australian Government's social inclusion agenda.

Recommendation 50

- 8.69 **That the Minister for Social Inclusion nominate carers as an early priority for social inclusion on the social inclusion agenda and with the Australian Social Inclusion Board.**

Ms Annette Ellis MP
Chair

91 Australian Government Department of Prime Minister and Cabinet, Social Inclusion website, viewed 10 March 2009 at www.socialinclusion.gov.au/pmc_social_inclusion_unit.htm and <http://www.socialinclusion.gov.au/default>.



Additional Comments — The Hon Judi Moylan MP

1. At paragraph 1.47 the Report states 'In synthesising the evidence from the Inquiry the following broad themes emerged:'

The third dot point refers to 'financial stresses' and some of the clear themes which emerged from the inquiry related to difficulties some carers experience with housing accessibility and affordability and the inability to accumulate adequate superannuation savings for retirement. Although these issues are discussed within the body of the Report they are common themes and sufficiently serious to warrant inclusion in this section.

2. This Report contains sufficient statistical evidence that the number of people requiring care is increasing. Refer to paragraphs 2.49 to 2.57 of the Report 'Changing Models of Care and Implications of Demographic and Social Trends.' To ensure adequate funding for care services, a national insurance scheme is needed as outlined in paragraphs 5.89 to 5.93 'National Disability Insurance'. As MS Australia has identified, such a scheme needs to be 'carefully designed'. Whilst it is acknowledged that the '**possibility**' of a National Disability Insurance Scheme is being considered by The Disability Investment Group, (refer to paragraph 5.93 of the Report), it is my view that a strong recommendation is needed to proceed with the development of a scheme, informed by the findings of The Disability Investment Group.
3. Further to Recommendation 32 (paragraph 6.35), I would go further and recommend that the Minister for Families, Housing, Community Services and Indigenous Affairs, the Minister for Health and Ageing and the Minister for Education, Employment and Workplace Relations, and Social Inclusion set out a specific programme and timetable to train Indigenous people in rural and remote areas to deliver care services to the community.

4. Given that at paragraph 6.120 it is acknowledged that 'Members were reminded again and again during the Inquiry that the needs of carers and those they care for are inextricably bound...' I would strongly recommend that appropriate Ministers urgently consider using some of the recent budget allocated to public housing to develop accommodation options for people with a disability. There are already excellent models of accommodation developed in Western Australia, for example, for small group living with 24 hour care available. While this does not suit every situation, it would offer a great deal of comfort to ageing carers who develop high levels of anxiety about what will happen to their family member when they become too frail themselves to continue in the caring role, or when they pass away. There are limited options, in the event of the death of a carer for appropriately accommodating the person receiving care. Many benefits could flow from such an investment for ageing and frail carers, families who may need to resume full or part-time work and for those with disability who in some circumstances may have greater independence and derive social benefits from peer support. Such housing models in Western Australia encourage and facilitate active family/carer involvement.
5. Recommendation 39 (paragraph 7.33) should be extended to include day care facilities. Funding of services should ensure that both respite and day care options are available for after school hours care and school vacation periods. In recognition of the close link between accessible, affordable care and workforce participation, I would strongly recommend that respite and day care services are also adequately funded to remain open during working hours. Refer to 7.22 of the Report.

The Hon Judi Moylan MP
Deputy Chair



Appendix A – List of Submissions

0001	Mr Robert Duley	0014	Ms Angela Rea
0002	Mrs Dorelle Purcell	0015	Mr Raymond Wells
0003	Mr Peter Casey	0016	Ms Janet Johnson
0003.1	Mr Peter Casey (Supplementary)	0017	Nardy House Inc.
0004	Mr I & Mrs J Radford	0018	Mr Girts Ozols
0004.1	Mr I & Mrs J Radford (Supplementary)	0019	Name withheld
0005	Ms Carolin Gray	0020	Mr Noel Faint
0006	Ms Pam Jerrick	0021	Mr Franjo Till
0007	Mr Terence Hunter	0022	Name withheld
0008	Ms Ruth Bray	0022.1	Name withheld (Supplementary)
0009	Mr Peter Hutten	0023	Taskforce on Care Costs
0009.1	Mr Peter Hutten (Supplementary)	0024	Ms J Poat & Mr W McGhie
0009.2	Mr Peter Hutten (Supplementary)	0025	Mrs Marie Keep
0010	National Association for Rural Student Accommodation Inc	0026	Mr Jack Thompson
0011	Ms Julie Neaves	0027	Mr C & Mrs P Dyer
0012	Ms Bronwyn Kelly	0028	Ms Hayley Davies
0013	Ms Lee Heffernan	0029	Mr Martin Hengeveld
		0029.1	Mr Martin Hengeveld (Supplementary)
		0030	Ms Melanie Edwards

0031	Name withheld	0057	Mr Stuart Robinson
0032	Mrs Lynette Kschenka	0058	Mrs Margaret Bartlett
0033	Ms Karen Bartram	0059	Mr M & Mrs J Beardmore
0034	Mr Allan Leach	0060	Mrs Jessy D'Angelo
0035	Ms Estelle Shields	0061	Mrs Mary Loyer
0036	Name withheld	0062	Mr Frank de Rosa
0037	Ms Meg Huddleston	0063	Ms Sophie Menegatos
0038	Ms Nancy Tingey	0064	Mrs Lorna Bristow
0039	Mr Alex Fabiani	0065	Mrs Joy Whitehill
0040	Mr Richard Morrison	0066	Ms Jane Churchill
0041	Mrs Pauline Haldane	0067	Mr Frank Poole
0042	Mr Alan North	0068	Mr Frank Ruzzene
0043	Ms Deirdre Osborne	0069	Mr Roy Smeaton
0044	Ms Joyce Mort	0070	Ms Helen Johnston
0045	Name withheld	0071	Miss Donne
0046	Mrs Diana Lamond	0072	Mrs Helen White
0047	Name withheld	0073	Mrs Sue Waters
0047.1	Name withheld	0074	Mrs Idalia Osborne
0048	Mrs Thelma Marie Camilleri	0075	Name withheld
0048.1	Mrs Thelma Marie Camilleri (Supplementary)	0076	Ms Bolinda Borg
0049	Mr R G Spring	0077	Ms Ann Bossio
0050	Ms Lina Sobol	0078	Mrs Gillian Devine
0051	Ms Kathleen Stanley	0079	Ms Thi Ann Thi Nguyen
0052	Ms Amanda Seales	0080	Ms Robyn Hyatt
0053	Mrs Marilyn Weller	0081	Ms Christine Osborne
0054	Ms Julie Bissett	0082	Ms Karen Beckinsale
0055	Ms Kerry Beamish	0083	Mr Joe Micallef
0056	Mrs Johanne Dajic	0084	Ms Deborah Goodman

0085	Mr Peter Sturt	0113	Ms Dominique Cullen
0086	Mrs Dianne Winbanks	0114	Ms Patricia J Glenane
0087	Mrs Violet O'Keefe	0115	Ms Kaye Stephen
0088	Mrs P Thomadakis	0116	Mrs Jill Cheal
0089	Ms Heather Birch	0117	Mrs Dagmar London
0090	Dr A H Atkinson	0118	Mrs Marianne Dalton
0091	Ms Veli Ulas Donmez	0119	Name withheld
0092	Ms Raylene Mitchell	0120	Mr Barry Leeds
0093	Mrs Maureen Gentle	0121	Mr James Kundatt
0094	Mrs Helen Stone	0122	Mr Graham Tassicker
0095	Mrs Eileen Carolus	0123	Mrs Ludmilla Horsley
0096	Mrs Leveina Belsham	0124	Ms Margaret Beckett
0097	Mrs Mary Anderson	0125	Ms Laura Pizzatti
0098	Mrs Beverley Tickner	0126	Ms Dulcie Sullivan
0099	Mrs J Burke	0127	Ms Aline Burgess
0100	Ms Monique Nazzari	0128	Mr E McReynolds
0101	Mrs Mary Bowman	0129	Ms Glenis Hawthorne
0102	Mrs Denise Beccari	0130	Ms Kathy Chamberlain
0103	Mrs Wendy Bennett-Hall	0131	Ms Orini Barnett
0104	Ms Lorraine Cogger	0132	Mr Slavko Miljevic
0105	Mrs Elizabeth Smalley	0133	Mr Noel Sweeney
0106	Mr Trevor A Vanderputt	0134	Ms Stella Vote
0107	Mr Stanley R Creffield	0135	Name withheld
0108	Ms Melissa McIlroy	0136	Mr T & Mrs R Sexton
0109	Mrs Lorraine Buckingham	0137	C French
0110	Mrs Judith Small	0138	Ms Antonette Harris
0111	Mrs Domenica Greenfield	0139	Mrs Elizabeth Ferguson
0112	Ms Anita Kemp	0140	Mrs Barbara Fischer

0141	Mrs Ethel Quadrio	0166	Ms Christine Askew
0142	Ms Amanda Kaye	0167	Mr Nicolas Vanden Dool
0143	Mr Norman Kaye	0168	Mrs Nina McLean
0144	Mr Alan Spencer	0169	Mrs Iris Swain
0145	Mrs Carolyn Cook	0170	Ms J M Thorburn
0146	Mr Allan Lancaster	0171	Ms Angie Scilluna
0147	Ms Letitia Gordon	0172	Ms Janice Rudelbach
0148	Mrs Mary Whelan	0173	Ms Christina Mauseth
0149	Mr William Fermaner	0174	Name withheld
0150	Ms Janice Pittam	0175	Mrs Kyrialli James
0151	Ms Colleen Bowden	0176	Mr D W Coole
0152	Mrs Margaret Dobell	0177	Ms Moria Cleland
0153	Name withheld	0178	Mr John Clements
0154	Mrs M D Trehwella	0179	Mr John Walsh
0155	Mrs Daphne Ambrose	0180	Ms Margaret Maloney
0156	Ms Louisa Morris	0181	Ms Faye Young
0157	Mrs Beryl Veart	0182	Ms Betsy Hilton
0158	Mrs Sheralyn Hughes	0183	Mr Noel Kennedy
0159	Mrs Deborah Edwards	0184	Mr Neville Threlfo
0159.1	Mrs Deborah Edwards (Supplementary)	0185	Ms Becky Llewellyn
0160	Ms Julie Guilfoile	0186	Ms Carmel Flavell
0161	Ms Pat Bastow	0187	Ms Dawn McIntyre
0161.1	Ms Pat Bastow (Supplementary)	0188	Mrs Maria Connell
0162	Mr Ian Morris	0189	Ms Helen Murphy
0163	Mr Brian Algeo	0190	Mr L & Mrs J Wheaton
0164	Mr Nick Maine JP	0191	Mrs Lyn Maciver
0165	Ms Kerry Small	0191.1	Mrs Lyn Maciver (Supplementary)
		0192	Mrs Julie Mann

0193	Mrs M D Iyer	0219	Name withheld
0194	Mrs Aida Vinciutto	0220	Mrs Heather Lewis
0195	Mr M J Weir	0221	Mrs Leonie Clements
0196	Mrs A Drysdale	0222	Mrs Gloria Stockbridge
0197	Ms Pamela Baroni	0223	Dr Ho Lee Ng
0198	Mr A & Mrs R Mead	0224	Ms Shirlee Fomiatti
0198.1	Mr A & Mrs R Mead (Supplementary)	0225	Ms Amanda Parker
0199	Mr B & Mrs M Graham	0226	Ms Muneera Simeone
0200	Mr Ronald Jackson	0227	Mrs Souad Reicha
0201	Mr W L Woolhouse	0228	Mr Peter Iatrov
0202	Ms Rosanna Tracy	0229	Mrs Elizabeth Ebbott
0203	Ms M Martinez	0230	Ms Leanne Cull
0204	Ms Patricia Rankin	0231	Ms Elizabeth Blyth
0205	Ms Cemal Onur Donmez	0232	Ms Anthia Hinson
0206	Mrs Doreen Polinelli	0233	Ms Sue Scrivener
0207	Ms Geraldine Potae	0234	Ms Alice Hadden
0208	Mrs Glenice McQueen	0235	Mr Alistair Whyte
0209	Ms Elena Interlici	0236	Mrs Joan Lammas
0210	Mrs Maree Connell	0237	Ms Judith Sykes
0211	Ms Rita Powell	0238	Mr Richard Hatfield
0212	Mrs Yolla Eicheikh	0239	Mr J H Dazelaar
0213	Mrs Margaret Phillips	0240	Mr Doug Doonan
0214	Mrs Kathleen Dunn	0241	Ms Bev Davis
0215	Mr Andrew Kemp	0242	Mrs Elvira Ingram
0216	Ms Lesley Hunt	0243	Ms Julie Lomas
0217	Mr Narayanasamy Govindarajoo	0244	Name withheld
0218	Mr Wayne Smyth	0244.1	Confidential
		0245	Mrs Peggy Bogar

0246	Ms Helen Rose	0274	Ms Sandi Hallewell
0247	Mr Chris Edgley	0275	Mr Kevin Hasson
0248	Mrs Beatrice Kenyon	0276	Mr Kevin James Sheedy
0249	Mrs Glenys Fayers	0277	Mrs Lillian Bromley
0250	Mr John Halford	0278	Mr Rodney Maxwell Bryant
0251	Mr Alan Corbbett	0279	Mr Procopios Zachariadis
0252	Name withheld	0280	Mr Vincent Richardson
0253	Mr Robert F Elliot	0281	Mrs Kristine Bicker
0254	Mrs Lorraine Dunton	0282	Mrs Rajanesam Gunaraja
0255	Mrs Moira Thompson	0283	J M Hulands
0256	Disability Assistance for Shoalhaven Inc	0284	Mr Robert Saliba
0257	Life Goes On	0285	Ms Betty Cusak
0258	InPsight	0286	Mrs Beverley Schulz
0259	Ms Carmen Polidano	0287	Ms Lynne Tabram
0260	Ms Val Simpson	0288	Ms Janet K St Jack
0261	Ms Patricia Chan	0289	Ms Phyllis Lock
0262	Mrs Ninfa Reid	0290	Mr Peter Gerard Gee
0263	Ms Wendy Smith-Squires	0291	Mr Laurence Brown
0264	Mrs Aileyne Mitchell	0292	Ms Michelle Burrell
0265	Ms Margaret Parnis	0293	Name withheld
0266	Ms Giovanna Walker	0294	Mrs Margaret May
0267	Ms Ann Lorraine Silvey	0295	Ms Vicki de Haas
0268	Mrs Valerie Butler	0296	Mrs Janet McNee
0269	Ms Nuraini Magnusson	0297	Mrs Joyce Williams
0270	Ms Kerry Davidson	0298	Ms Sue Hewett
0271	Mrs Christine Hunt	0299	Ms Maria Antonas
0272	Mrs Anna Micallef	0300	Mrs Violet Thomson
0273	Ms Diane Vella	0301	Ms Jane Harrison

0302	Mrs Jeanette Malone	0330	Mrs M Wright
0303	Ms Therese Clarry	0331	Mr G & Mrs M Anderson
0304	Miss Margaret Mills	0332	Ms Stephanie Mortimer
0305	Ms Jean Borwick	0333	Mrs Claudia Bazeley
0306	Mrs Graziana Bella	0334	Mrs Verna Lynch
0307	Mr Brian Cutcliffe	0335	Mr Rolf Regel
0308	Mrs Dorothy Stanford	0336	Mr M & Mrs H Aldred
0309	Ms Maureen Robinson	0337	Ms Jillian Bellamy
0310	Mr S & Mrs E Shutt	0338	Ms Mouna Elsoukmani
0311	Ms Judith Beddoe	0339	Ms Kate Hawes
0312	Name withheld	0340	Ms Susan Tomlinson
0313	Ms Lorraine Mason	0341	Ms Retta Palmer
0314	Mrs Nadia Louis	0342	Ms Sonia Turkington
0315	Ms Joanna Drew	0343	Ms R Armstrong
0316	Mrs Jenny Papadimitriou	0344	Mr Donald Williams
0317	Ms Susan Lowe	0345	Ms Patricia Birch
0318	Ms Anna Attard	0346	Ms Joanne Burns
0319	Ms Carol Cramer	0347	Ms Margaret Clinch
0320	Ms Giovanna Sortino	0348	Ms Beryly Hunt
0321	Mrs Katrina Tucker	0349	Ms Alvira Bellchambers
0322	Ms Susan Hand	0350	Ms Carol Wood
0323	Mrs Margaret Whitehouse	0351	Mrs Rhonda May
0324	Ms Sarah West	0352	Ms Beverley Ault
0325	Ms Lois Brown	0353	Name withheld
0326	Ms Julie Witts	0354	Mrs Val Vaughan
0327	Mrs Noelene O'Boyle	0355	Mr Frank Hambridge
0328	Mr Kevin Hewitt	0356	Ms Camille Brinin
0329	Ms Shannon Durkin	0357	Mrs Sharon Holmes

0358	Name withheld	0384	Mr Ronald Oats
0359	Ms Mary-Jane Galiazzo	0385	Ms Jennifer Carey
0360	Mr Robert Anderson	0386	Ms Karen Josling
0361	Mrs Ellen Forrester	0387	Ms Teresa Haris
0362	Ms Akten Esendag	0388	Mrs Vivien Miller
0363	Name withheld	0389	Ms Alyce Mourad
0364	Mr Jeff Le	0390	Ms Michelle Wilkins
0365	Mrs Lisa Krupjak	0391	Mr Neville Brown
0366	Mr Wouter de Goede	0392	Mr Giorgio Calvezzi
0367	Name withheld	0393	Ms Shirley Hamblin
0368	Mr Joe Davis	0394	Mr Clifford Hamblin
0368.1	Mr Joe Davis (Supplementary)	0395	M Allegretta-Lovey
0369	Ms Leoni Leonard-Nock	0396	Ms Debbie Worrall
0370	Ms Sally Bailey	0397	Mrs Elaine Parker
0371	Mrs Shanty Wilson	0398	Mrs Maureen Burke
0371.1	Mrs Shanty Wilson (Supplementary)	0399	Ms Nicole Viasveid
0372	Ms Lynette Pearce	0400	Mrs Vivien Siddons
0373	Mrs Eva Bowler	0401	Mrs Julie Chek
0374	Ms Rosemary Hume	0402	Mrs Mary Aldred
0375	Mrs Margaret Jones	0403	Mrs Margaret Graham
0376	Name withheld	0404	Ms Gaylene Gare
0377	Mr David Gladwell	0405	Mrs Pamela Phillips
0378	Mrs Barbara Saad	0406	Ms Rosemary Blesmy
0379	Mrs Margaret Dray	0407	Ms Toni Mitchell
0380	Mr Maxwell Thompson	0408	Mrs Helen Fuller
0381	Mr Allan Boss	0409	Mrs Mary Sime
0382	Mrs Marcia Lovi	0410	Ms Loretta Smith
0383	Ms Pat Isaacs	0411	Ms Veronica McGuire

0412	Ms Emily Pink	0440	Ms Una Harrington
0413	Ms Beth Marchbank	0441	Mrs Jessie Gamble
0414	Ms Lynette Young	0442	Ms Milly Keeling
0415	Mrs Robin Hancock	0443	Mrs Mathilda Van de Vusse
0416	Ms Sheila Stocks	0444	Mrs Helen Charlesworth
0417	Mrs Verna Dunn	0445	Mrs Jenny Heffernan
0418	Ms Michelle LeMercier	0446	Mrs Snjezana Jalanski
0419	Ms Pamela Tickner	0447	Mrs NA Stewart
0420	Mrs Lyla O'Hara	0448	Mrs Kathleen Papali'i
0421	Mrs V M Jones	0449	Mrs Joy Thomas
0422	Mrs Elaine Williams	0450	Mr K & Mrs E Perry
0423	Mrs Meaghan Holmes	0451	Name withheld
0424	Mrs E I Lunn	0452	Ms Sonia Butler Miles
0425	Ms Claudine Duval	0453	Mr P & Mrs E Smale
0426	Mr Robin Squire	0454	Mrs Kathleen Grewar
0427	Ms Elizabeth Grieb	0455	Ms Nancy Diffido
0428	Mrs Michelle Boles	0456	Ms Lee-Anne McLean
0429	Mrs Patricia Berrutti	0457	Ms Sally Bunston
0430	Ms Sue Harmer	0458	Ms Leigh Layton
0431	Mrs Allison Dix	0459	Ms Ann Madhaven
0432	Mrs Penny Holmes	0460	Mrs Judith Challen
0433	Mrs Julie Johnson	0461	Ms Catherine Swift
0434	Mrs Peter Gulen	0462	Mrs Susan Scott
0435	Mrs Filomena Alibrio	0463	Ms Donna Sweetnam
0436	Mrs Margaret Phyland	0464	Name withheld
0437	Mrs Susan Stulpinas	0465	Name withheld
0438	Mrs L Clayden	0466	Ms Jewels Smith
0439	Ms Virginia Matthews	0467	Ms Jill Coleman

0468	Mrs Melina Vella	0496	Ms Ronda Hazelton
0469	Mrs Norma Andrew	0497	Ms Glenys Vella
0470	Mrs Lynette Walker	0498	Mr Brian Stagg
0471	Ms Lynn McCulloch	0499	Mrs P A Parker
0472	Mr Philip Bray	0500	Name withheld
0473	Ms Doreen Osborne	0501	Name withheld
0474	A Atkins	0502	Confidential
0475	Lesley Westlake	0503	Name withheld
0476	Mrs Pamela Allen	0504	Name withheld
0477	Miss Tatiana Borisow	0505	Ms Margaret Ingham
0478	E J L Zupan	0506	Mrs Carina Gormley
0479	Ms Stephanie Williamson	0507	Mr Colin Walker
0480	Mrs Majorie Jones	0508	Mrs Cheryl Cosgrove
0481	Ms Diana Brassington	0509	Mrs Patricia Bodegraven
0482	Mr Ian Atkins	0510	Ms Wilma Cox
0483	Mrs Erlinda Kitching	0511	Office of Commonwealth Ombudsman
0484	Name withheld	0512	Name withheld
0485	Ms Joy Roze	0513	Mr Francis Horgan
0486	Ms Karen Hampf	0514	Ms Susan Bray
0487	Ms Doreen Abbott	0515	Mrs Lorraine Francis
0488	Mr John Iles	0516	Ms Margaret D'Elia
0489	D Miller	0517	Ms Penelope Sara
0490	Mr Peter Edgar	0518	Ms Kerry McDonald
0491	Mrs Annette McArthur	0519	Mrs Glenis Watson
0492	Ms Wai Ling Cheung	0520	Mrs Margaret Wadsworth
0493	R Bolton	0521	Ms Louise Moore
0494	Ms Carmel Jackson	0522	Ms Elizabeth Hussain
0495	Name withheld	0523	Mrs L M Jones

0524	Mrs Lydia Zaffaroni	0547	Mrs P Egan
0525	Mrs Betty May	0548	Mr G & Mrs D Walker
0526	Ms Lucinda Quick	0549	Mr Terry Stroud
0527	Ms Patricia Chalmers	0550	Mrs Sharon Berardi
0528	Mrs Jacqueline Cave	0551	Mrs Lesley Watkin
0529	Mrs June Somerville	0552	Mr John Lewis
0530	Ms Iris Russell	0553	Mrs Anna Bowlay
0531	Ms Deepika Valob	0554	Mrs Iris Stockfeld
0532	Mrs Faye Rowe	0555	Mr R L Tuxford
0533	Mrs Rosina Pellizzoni	0556	Mrs Karna O'Dea
0534	Mr R & Mrs P Bish	0557	Ms Lisa Humphries
0534.1	Mr R & Mrs P Bish (Supplementary)	0558	Ms Suzanne Wagland
0535	Ms Hazel Stephens	0559	Name withheld
0536	Ms Sandra Reardon	0560	Ms Jeanette Puckeridge
0537	Mr P M Haas	0561	Mr P & Mrs A McKerlie
0538	Ms Rebecca Paton	0562	Armidale Support Group
0539	Mr John Millard	0563	Ms Lynne Ruggiero
0540	Ms Brenda Pitcher	0564	Mrs Jan Edwards
0540.1	Ms Brenda Pitcher (Supplementary)	0565	Mrs Norma Daley
0541	Mrs Bev Wilkinson	0566	Carers WA
0541.1	Mrs Bev Wilkinson (Supplementary)	0567	Special Kidz Special Needz
0542	Mrs Mavis Cake	0568	MND Australia
0543	Mrs Theresia Borg	0569	Neuro Muscular Alliance Tasmania
0544	Mr Ronald Hewson	0570	Vision Australia
0545	Ms Dawn Springett	0571	National Carers Coalition
0546	Ms Penny Bristow	0572	Rotary Club of Mount Eliza Inc
		0573	Mill Park Schizophrenia Support Group

0574	ARAFMI (Qld)	0595	Ms June Mitchell
0575	Ms Katrina Clark	0596	Ms Maria Secatore
0575.1	Ms Katrina Clark (Supplementary)	0597	Ms Maryjane Gatt
0576	Marymead Child and Family Centre	0598	Ms Wendy Jupp
0577	Committed About Securing Accommodation for People with Disabilities	0599	Mrs Bronwyn Parkin
0578	ARAFMI (WA)	0600	Mrs Sally Richards
0579	National Disability Services	0601	Ms Lourdes Latiza
0580	Eastern Palliative Care	0602	Mrs Margaret Kiley
0581	Australian Association for Families of Children with a Disability	0603	Ms Antonia Campbell
0582	Carers Victoria & Victorian Disability Advisory Council	0604	Mrs Patricia O'Connor
0583	Hunters Hill Ryde Community Services Inc	0605	Mr Gordon Roche
0584	UnitingCare Supported Living Carers Group	0606	Ms Irene Lewis-Hansom
0585	Ms Bette Bradtke	0607	Mr S & Mrs D Murphy
0586	Ms Denise Wood	0608	Mr B & Mrs D Robertson
0587	Ms Shirley Matheson	0609	Confidential
0588	Dr Jane Tracy	0610	Sane Australia
0589	Mr M & Mrs J McDonald	0611	Daughters in Demand Support Group
0590	Mr Ken Secretan	0612	Ms Barbara Allen
0591	Mrs Gayle Robertson	0613	Confidential
0592	Mr Ange Kenos	0614	Ms Helen James
0593	Mr Robert Charlesworth	0615	Ms Carey Sebbens
0594	Mrs Margaret Spinks	0616	Mrs Trish Welstead
		0617	Mrs Helen Thomas
		0618	Ms Janice Heil
		0619	Mr A Freihaut
		0620	Ms Lorraine Murphy
		0621	Mrs Pamela Point
		0622	Ms Connie Franze

0623	J M Barnes	0651	Mr Barrie Edwards
0624	Mrs Mavis Wollin	0652	Carers Victoria
0625	Mrs Julie Blennerhassett	0652.1	Carers Victoria (Supplementary)
0626	Ms Soffia Shanawaz	0653	National Council on Intellectual Disability
0627	Mr Ron Powell	0654	Australian-Polish Community Services Inc
0628	Mr Thomas Perry	0655	Partners of Veterans Association of Australia Inc
0629	Ms Peta Colton	0656	UnitingCare Remote Family Services
0630	Mrs Barbara Howey	0657	University of NSW, Social Policy Research Centre
0631	Ms Hunt	0658	Australian Foundation for Disability
0632	Mrs Judith Hasnat	0659	Guardianship Tribunal
0633	Mr John Mackrell	0660	Gippsland Carers Association Inc
0634	Mr A J Howard	0661	Carers NSW
0635	Mrs Judith Davy	0661.1	Carers NSW (Supplementary)
0636	Ms Liga Dover	0661.2	Carers NSW (Supplementary)
0637	Ms Merrilyn Fahey	0662	Disability Council of New South Wales
0638	Mrs Margaret Lewis	0663	Sunnyfield Independence
0639	Mr John Jessup	0664	Sydney Legacy
0640	Ms Nicole McPhee	0665	Uniting Care Community Options
0641	Mrs Fay Brown	0666	Association of Childrens Welfare Agencies
0642	Mrs Roslyn Hart	0667	Australian Unity
0643	Ms Anna-Maria Sacilotto	0668	annecto, the people network
0644	Mr L & Mrs M Manno		
0645	Ms Elizabeth Cochrane		
0646	Ms Heather Ruddell		
0647	Ms Gail Esson		
0648	Mr H & Mrs B Rogerson		
0649	Mr Robert Fletcher		
0650	Name withheld		

0669	Victorian Mental Health Carers Network Inc	0686.1	National Seniors Australia (Supplementary)
0670	Huntington's Victoria	0687	Multicultural Mental Health Australia
0670.1	Huntington's Victoria (Supplementary)	0688	Palliative Care Australia
0670.2	Huntington's Victoria (Supplementary)	0689	Julia Farr Association
0671	Carers Tasmania	0690	BrainLink Services Limited
0672	Royal Australian and New Zealand College of Psychiatrists	0691	beyondblue
0673	Parkside Foundation	0692	Multiple Sclerosis Australia
0674	Frankston/Peninsula Carers' Inc	0693	Cooinda Family Support Group Inc
0675	Carer Support Network of SA	0694	Brotherhood of St Laurence
0676	Parent Project Australia Inc	0695	Defence Special Needs Support Group
0677	Mission Australia	0696	Private Mental Health Consumer Carer Network (Australia)
0678	YNH Services Inc & Yarrawonga Mulwala Carers Support Group	0697	Office of the Public Advocate
0679	Mrs Glynis Thyer	0698	Professor Jill Wilson, Associate Professor Cheryl Tilse & Professor Linda Rosenman
0680	Physical Disability Council of Australia Ltd	0699	Carers Australia
0681	Muscular Dystrophy Association Inc	0700	Sir Roden Cutler Charities Inc
0682	Mental Health Council of Australia	0701	Siblings Australia Inc
0683	AICAFMHA-COPMI National Initiative	0702	Carers ACT
0684	Carers SA	0703	Carers QLD
0685	Carers NT	0704	Ms Jessica Farrands
0686	National Seniors Australia	0705	Mrs Bronwynne McMahon
		0706	Mrs Annette Bannigan
		0707	Mr Chris Kellett
		0708	Mrs Judith Gutteridge

0709	Mrs Patricia Carbis	0736	Mrs Iris Hankin
0710	Mr K & Mrs M Matthias	0737	Mr D & Mrs J Mitchell
0711	Mrs Mary Newman	0738	Mrs Hannah Baker
0712	Ms Glenis Newman	0739	Ms Liz Banon
0713	Ms Marjorie Ross	0740	Confidential
0714	Mr K & Mrs M Hell	0741	Ms Raelene Beale
0715	Mrs Margaret Turner	0742	Ms Deborah Robins
0716	Ms Yvonne Graham	0743	Vietnamese Carer Group
0717	Mr A & Mrs R Squires	0744	Australian Institute of Family Studies
0718	Mrs Kitty Crawley	0745	Ms Liz Rix
0719	Mrs Antonella Zandegu	0746	St George Migrant Resource Centre Inc
0720	Ms Barbara Liskus	0747	MS Society of Tasmania
0721	Name withheld	0748	Lockyer Valley Community Disability Association Inc
0722	Mrs S J Malin	0749	Macarthur Aged and Disability Forum
0723	Ms Yvonne Wathen	0750	Association for Children with a Disability NSW
0724	Anglicare Canberra and Goulburn	0751	Ms Karen McCann
0725	Australian Council of Trade Unions	0752	Mrs Mary Walsh
0726	Mr Robert Sharman	0752.1	Confidential
0727	Mr L R Binns	0753	Mr Wayne Stevens
0728	Mrs Colleen Beale	0754	Mrs Jenny Craven
0729	Mr Everard Linke	0755	Mrs Christine Phillips
0730	Name withheld	0756	Ms Dianne Pooley
0731	Ms Kerry Parker	0757	Ms Karen Campbell
0732	Ms Jocelyn Pinkerton	0758	Centre for Cultural Research, University of Western Sydney
0733	Mrs Heather Olm		
0734	Mr W M Revell		
0735	Mr Peter Hillard		

0759	Mr Peter Rankin	0779	Mr M & Mrs E Jack
0760	Mr Charlie Rook	0780	Ms Sue Sullivan
0760.1	Mr Charlie Rook (Supplementary)	0781	Mrs Pamela Mills
0761	Department for Communities - Government of WA	0782	Ms Maureen Carlyle
0762	Child and Adolescent Mental Health Services	0783	Ms Kim Boyd
0763	Geelong Parent Network	0784	Mr Anthony Somerville
0764	Young People in Nursing Homes National Alliance	0785	Shoalhaven Parkinson's Support Group
0765	Ms Julie Trigg	0786	Developmental Disability Council of WA
0766	Ryde Area Supported Accommodation for Intellectually Disabled Inc	0787	Ethnic Disability Advocacy Centre
0767	Mr Graeme Jarvis	0787.1	Ethnic Disability Advocacy Centre (Supplementary)
0768	Family Advocacy	0788	Aboriginal Child, Family and Community Care State Secretariat
0769	Anglicare Sydney	0789	NSW Youth Advisory Council
0770	Mr Philip Laughton	0790	Dementia Respite Options Albury & District
0771	Mrs Alexandra Atkins	0791	Mrs Naida Guttrey
0772	Mr D & Mrs M Hughes	0792	Ameneh Mozafari
0773	Mrs Leane Leggo	0793	Mrs Pamela Hermansen
0774	Ms Saara Arnoldy	0794	Ms Carole Smith
0775	Ms Jann Harrison	0795	Mr Ronald Simmons
0776	Lifestyle in Supported Accommodation Inc	0796	Ms Min Liu
0776.1	Lifestyle in Supported Accommodation Inc (Supplementary)	0797	Mrs Betty Jackson
0777	Mrs Janice Killeen	0798	St Helens Support Group
0778	Ms Cheryl Sanderson	0799	Ms Michela Cardamone
		0800	Name withheld
		0800.1	Name withheld

0801	Name withheld	0825	Ms Shirley Marron
0802	Ms Vanessa Browne	0826	Mrs Carolyn Paisley-Dew
0803	Mr James Finster	0827	Name withheld
0804	Mr Ron Neilsen	0827.1	Name withheld
0805	Ms Jan Lyttle	0828	Schizophrenia Fellowship, Sunshine Coast Branch
0806	Mr D & Mrs R Barkhazen	0829	Mrs Willie Rylaarsdam
0806.1	Mr D & Mrs R Barkhazen (Supplementary)	0830	Mrs Narelle Hughes
0807	Ms Lesley Baker	0830.1	Mrs Narelle Hughes (Supplementary)
0808	Ms Paola Mason	0831	Ms Narelle Green
0809	Mrs Pamela Bianchi	0832	Mrs N Carter
0810	Mr A & Mrs K Skimin	0833	Ms Gwendoline Vines
0810.1	Mr A & Mrs K Skimin (Supplementary)	0834	Mrs Jan Wallent
0811	Ms Susan Harris	0835	Ms Kay Woodcock
0812	Ms Sue Sullivan	0836	Ms Barbara Williams
0813	Ms Dianne Stewart	0837	Dr Rozanna Lilley
0814	Carers' Support Group, Benalla Victoria	0838	Mrs Joyce Schroeter
0815	Mrs Cathy Cleland	0839	Ms Evelyn Scott OAM
0816	Ms Margaret Thorpe	0840	Mr Keith Dingeldei
0817	Mr R & Mrs M King	0841	Mrs Robyn Osta
0818	Ms Lily Morgan	0842	Ms Carolyn Cooper
0819	Ms Eris Dwyer	0843	Mrs Komaladevi Kaneshwaran
0820	Ms Margaret Iddles	0844	The Hon David Hawker MP
0821	Ms Marjorie Hamilton	0845	Australian Federation of Disability Organisations
0822	Mrs Gloria Wright	0846	Sutherland Shire Disability Accommodation Action Group Inc
0823	Mrs Betty Craze		
0824	Mrs Michele Cochrane		

0847	Families in Partnership Co-operative Ltd	0874	Name withheld
0848	Ms Lyn Dowd	0875	Name withheld
0849	Mrs Michiko Parnell BHsc MPH	0876	Ms Caroline Morton
0850	Name withheld	0876.1	Ms Caroline Morton (Supplementary)
0851	Ms Karelle Logan	0877	Ms Helen Barry
0852	Name withheld	0878	Mr Arthur Crimp
0853	Name withheld	0879	Mrs Sally Goodman
0854	Mr/Ms Sam Blythe	0880	Ms Cynthia Pereira
0855		0881	Name withheld
0856	Mrs Sabine Schreiber	0882	Ms Louise Monument
0857	Ms Patricia Devlin	0883	Name withheld
0858	Mr Michael Tuohy	0884	Mr K & Mrs K McCann
0859	Mrs Jennifer Tuohy	0885	Ms Sue McCarthy
0860	Name withheld	0886	Associate Professor Kenneth Pakenham
0861	Mrs Debbie Galt	0887	Mrs Debbie Le Cornu
0862	Mr Barry Bennett	0888	Name withheld
0863	Name withheld	0889	Mrs Anne Manning
0864	Mrs Jill McNamara	0890	Ms Deborah Solomon
0865	Mr G & Mrs K Ingram	0891	Ms Mo-Lee May
0866	Ms Aileen Hewat	0892	Mrs Annette Wilson Sturm
0867	Mrs Margaret Quinn	0893	Ms Bronwyn Thompson
0868	Ms Louise Coyte	0894	Ms Sylvia Fessl
0869	Mrs Cheryl Evans	0895	Mr E & Mrs C Franks
0870	Mrs Anna Robinson	0896	Mr B & Mrs J Langoulant
0871	Ms Anne Marie MacArthur	0897	Older Veterans Psychiatry Program & Aged Care Support
0872	Mr S Neal & Ms S Guest	0898	Ms Suzanne Freund
0873	Ms Ruth Kyne et al		

0899	Mr Philip James Good	0926	Mr Anthony Hamilton
0900	Ms Susanne Walden	0927	Ms Margaret Hallas
0901	Mrs Susan Smith	0928	Ms Silvra Lay
0902	Mr W & Mrs C Polak	0929	Ms Irene Lam
0903	Mrs Bevely Miller	0930	Confidential
0904	Name withheld	0931	Ms A Trovato
0905	Ms Marilyn Allum	0932	Ms Franceska Dezelak
0906	Mr Geoffrey Francis Bateson	0933	Mrs Tania Hayes
0907	Ms Evangelina Tielmann	0934	Mrs Jeannette Rodighiero
0908	Mrs Johanna Tams	0935	Ms Heather Howe
0909	Name withheld	0936	Mr George Ellison
0909.1	Name withheld	0937	Ms Beverley Hitchcock
0910	Mrs Sandra Pilkington	0938	Mr R & Mrs G Gamble
0911	Ms Cindy Turkovic	0939	Mrs Janine Maydom
0912	B Sinclair	0940	Mrs Janet Kafarela
0913	Mrs Marion Lowe	0941	Mrs June Mallinson
0914	Mrs Mavis Russell	0942	Mrs Catherine Moran
0915	Australian Association of Gerontology Inc	0943	Ms Heather Peterson
0916	Mrs Jennifer Parrott	0944	Ms Lorraine Carroll
0917	Ms Maria Ruhland	0945	Mrs Jenny Piesse O'Sullivan
0918	Mrs Mary Said	0946	Name withheld
0919	Connections	0947	Mrs Christine McDonald
0920	Mrs Gwenith Reeves	0948	Mrs Elizabeth Rickard
0921	Ms Joyce Tizzard	0949	Mrs Gaylene O'Reilly
0922	Mr Ronald Reed	0950	Mr D & Mrs L Ringland
0923	Mr Robert Taylor	0951	Ms Nell Brown
0924	Mr Daniel De Martin	0952	Ms Deborah Hayes
0925	Mrs Lena Burton	0953	Ms Sonia Hill

0954	Mrs Jill Rietmeyer	0982	Mr Tom Phillips
0955	J Rabbas	0983	Perth Carer Forum Group
0956	Ms Patricia J Moran	0984	Name withheld
0957	Mr David Galbraith	0985	Name withheld
0958	Ms Norma Gardner	0986	Mr Kenneth L Claussen
0959	Mrs Raylene Stephans	0987	Bright Carer Support Group; Kiewa Valley Carer Support Group; Myrtleford Carer Support Group
0960	Ms Tracey Keith		
0961	Ms Margaret Waters		
0962	Mr Lakshmi Chakraborty	0988	Ms Pam Henrys
0963	Ms Madeleine Witham	0989	Ms Sonja Hopper
0964	Mr P N Finlay	0990	Name withheld
0965	Ms Elizabeth Bracken	0991	Ms Karen Pisani
0966	Mrs Susanne Hillier	0992	Ms Kathy Sarra
0967	Ms Mary Taylor	0993	Ms Judith Richter
0968	Mrs Hazel Cook	0994	Mrs Rita LoPilato
0969	Mr J & Mrs S Halliday	0995	Ms Nicola J Wills
0970	Mr Chris Markiewicz	0996	Ms Mary Blackman
0971	Ms Patricia Backmann	0997	Office of the Protective Commissioner, Attorney General's Department of NSW
0972	Mr Cale Dalton		
0973	Ms Ellen Walker	0998	Cancer Council NSW
0974	Name withheld	0999	Human Rights & Equal Opportunity Commission
0975	Mr Tony Ramshaw		
0976	Mrs Aileen Pfaller	1000	ACT Government
0977	Mrs Karoline Crilley	1001	Mr Richard Morgan BA, DipEd, LLB, Bed, Med, MA
0978	Mrs Annette White		
0979	Mrs Fiona Anderson	1002	Alzheimer's Australia
0980	Ms Marilyn Hilan	1002.1	Alzheimer's Australia (Supplementary)
0981	Mrs Janet Bourke	1003	Ms Jeanette O'Connor

1004	Ms Gabee Werner	1032	Name withheld
1005	Mr P & Mrs C Hickey	1033	Australian Institute of Health and Welfare
1006	Ms Val Jones	1034	Ms Marisa Wells
1007	Mr Kevin Wood	1035	Mr John Wilkinson
1008	Ms Lisa Newton	1036	Mr Lawrence Waller
1009	Mrs Rosalind Papavasiliou	1037	Carers Action Network, Newcastle/Lake Macquarie
1010	Ms Delphine K Stagg	1038	Name withheld
1011	Mrs Shirlene J Stranieri	1039	Disability Services Commission - WA
1012	Ms Johanna Schlosmacher	1040	Ms Lynn Jones
1013	Mrs Daisy McAree	1041	Mr John Kelly
1014	Ms Susan Glasgow	1042	Ms Anne-Maree Newbold
1015	Ms Melva Morrison	1043	Ms Linda Symons
1016	Ms Sarah Gallagher	1044	Name withheld
1017	Mrs Robin Knox	1045	Ms Jo-Anne Beattie
1018	Mr Leslie Hawksworth	1046	Ms Barbara Viney
1019	Mr P & Mrs C Boyd	1047	Ms Janet Warner
1020	Mr Bill Henty	1048	Ms Lillian Dryburgh
1021	Ms Leesa Lawrence	1049	Ms Dawn Holder
1022	Mrs Anita Geach-Bennell	1050	Ms Danijela Hlis
1023	Ms Julie Steepe	1051	Mr Peter Day
1024	Name withheld	1052	Ms Noeleen Jensen
1025	Mrs Linda Wetherill	1053	Ms Dragana Bozinovski
1026	Mrs Merren Carter	1054	Ms Sharon Parker
1027	Mrs Joan M Madden	1055	Ms Anne E Cassey
1028	Mrs Gillian Quinn	1056	Mr Roger Bruhn
1029	Mrs Oi Yun Leongue	1057	Mrs Rosemary Woods
1030	Mrs Helen Barker		
1031	Ms Kerrie McLeod		

1058	Ms Wendy Cant	1086	Australian Foster Care Association Inc
1059	Mr David Colya	1087	Ms Beulah Packham
1060	Ms Kathleen Wood	1088	Families Australia
1061	D A Valentine	1089	Mrs Faye Galbraith
1062	Mrs Nancy Jacobs	1090	Ms Gwenda Hunter
1063	Mrs Glenda Blom	1091	Bathurst District Carers Voice
1064	Ms Fiona Clarke	1091.1	Bathurst District Carers Voice (Supplementary)
1065	Mrs Tracie Worner	1092	Mrs F King
1066	Mr Callum Larkman	1093	Mr Geoff Dwyer
1067	Mrs Vicki Larkman	1094	Mrs M Piazza
1068	Ms Patricia Stevens	1095	Mrs Margaret Parfett
1069	Chris Marsh	1096	Ms Yvonne Swaysland
1070	Ms Clare Langdon	1097	L J Bremner
1071	Ms Jeanette Liesfield	1098	L Lumsden
1072	Mrs Carolyne McClenaghan	1099	Mr/Ms M Kable
1073	Mr Jack Wilson	1100	Mr Mark Trickett
1074	Ms Annie Tauber	1101	Mrs Nola McHeehan
1075	Ms Melinda Karaja	1102	Mr John Lindsey
1076	Mrs Heather Parker	1103	Peninsula Carer Council
1077	Mrs Joyce Clarke	1104	Mental Illness Fellowship Victoria
1078	Mrs Vicki Langley	1105	A4 Autism Aspergers Advocacy Australia
1079	Mr Craig Coleman	1106	Centre for Cerebral Palsy WA
1080	Mrs Gina Wilson-Burns	1107	Tandem
1081	Mr Ashley Norman	1108	The Horsham Family Advisory Committee (Vic)
1082	Ms Debra Jeffrey		
1083	Mrs Patricia Pearce		
1084	Ms Raylee Edwards		
1085	Aged & Community Services Australia		

1109	Department of Families, Housing, Community Services and Indigenous Affairs; Department of Health and Ageing; and Department of Veteran's Affairs	1127	Mrs Carmel Jackson
		1128	Ms Tammara Haines
		1129	Mrs Robin McElhinney
		1130	Mr John Edwards
1109.1	Department of Health & Ageing (Supplementary)	1131	Mrs Dianne Evans
		1132	Mrs Roma Pead
1109.2	Department of Housing, Community Services and Indigenous Affairs (Supplementary)	1133	Ms Clare Gray
		1134	Mrs Catherine Murray
		1135	Ms Sue Gibb
1110	National Ethnic Disability Alliance & Multicultural Disability Advocacy Association of NSW	1136	Mr Dennis Gill
		1137	Ms Cathryn Zonca-Post
		1138	Mrs Alison Bennett-Roberts
1111	Mr M & Mrs R Tonissen	1139	Ms Merrelin Robbins
1112	Mr Bill Johnson	1140	Ms Flora Tountzis
1113	Mr D & Mrs S Scrivener	1141	Mr L & Mrs A Hudson
1114	Ms Alena Glaister	1142	Ms Marja Rouse
1115	Ms Katie Adams	1143	Mrs Rose Painter
1116	Mrs Gaye Barclay	1144	Mrs Rijntje Huisman
1117	Ms Claire Hill	1145	Mrs Janelle Dennien
1118	Mr Pat Burgess	1146	Mrs Judith Shearman
1119	Name withheld	1147	Mrs Merle Edwards
1120	Social Issues Executive of the Anglican Church, Sydney	1148	R A Houston
		1149	Mrs Judith Nicholas
1121	Ms Nicola Reid	1150	Mrs Carol Cornish
1122	Mrs Coralie Chetwynd	1151	Mrs Josephine Coulter
1123	Mr Andrew Richard Jary	1152	Mrs Barbara Laycock
1124	Ms Caterina Bortolot	1153	Mr George Pinfold
1125	Ms Rosalie Quaife	1154	Ms Lyn Connell
1126	Mr Jonathon Woodgate		

1155	Ms Margaret Ryan	1183	Ms Judith Rafferty
1156	Ms Liza Roberts	1184	Confidential
1157	Name withheld	1185	Name withheld
1158	Ms Colleen Atkinson	1186	Ms Esther Caprez
1159	Ms Sue Stevens	1187	Ms Dorothy O'Connor
1160	Ms Annie Martin	1188	Mr J & Mrs M Bishop
1161	Mrs Rensie Matthews	1189	Ms Linda Aspinall
1162	Mrs Lyn Harper	1190	Mrs Clare Masolin
1163	Mrs Megan Major	1191	Mr P & Mrs H Coleman
1164	Ms Veronica Wood	1192	Mr Robert McKenzie
1165	Mrs Pauline Simpson	1193	Mr C & Mrs C Howe
1166	Mrs Anne Arnold	1194	Mrs Janette Cooper
1167	Ms Janet Davis	1195	Ms Trudie Shanahan
1168	Mr Peter Aris	1196	Mr S & Mrs H Dodd
1169	Mrs Kali Paxinos	1197	Mrs Kerrie Duff
1170	Ms Leita Boltwood	1198	Name withheld
1171	Mr R & Mrs G McEachern	1199	Ms Susan Minett
1172	Mr Roy Shaw	1200	Mrs Trish McClure
1173	Ms Liz Kelly	1201	Mrs Val Evans
1174	Mr R & Mrs M Hart	1202	Mrs Angela Napthine
1175	Name withheld	1203	Queensland Government - Department of the Premier and Cabinet
1176	Mr Ian Whittingham	1204	Ms Donna Etherington
1177	Name withheld	1205	Villa Maria
1178	Mrs Helen Johnson	1206	Group Home Project (Mackay)
1179	Mrs Beverly Krieger	1207	Ms Caralyn Straw
1180	Mrs Donnelle Curnow	1208	Real Living Options Association Inc
1181	Mrs Nicole Cummings		
1182	Ms Sally Martin		

1209	Mr Gordon Steinberg	1237	Ms Marlene Parker
1210	Name withheld	1238	Mr Adrianus Koelewyn
1211	Ms B Down & Mr S Brown	1239	Mrs Joan Bateman
1212	Mr Frederick Novak	1240	Ms Margaret Cruickshank
1213	Mrs Lynn Driscoll	1241	Mr Kevin Francis Allen
1214	Ms Lynette Allen	1242	Mrs Fay Callum
1215	Ms Robyn Browne	1243	National Network of Adult and Adolescent Children who have a Mentally Ill Parent/s Inc
1216	Ms Wendy M Dempster		
1217	Ms Maria Theodoratos	1244	Ms Sharon Neal
1218	Ms Shohreh Heirati	1245	Mrs Merrian Brown
1219	Ms Deirdre Croft	1246	Ms Jenny Rollo OAM
1220	Ms Elaine Stone	1247	Ms Grace Fava
1221	Mr Roy Page	1248	Name withheld
1222	Confidential	1249	Ms Jenny Clarke
1223	Mrs Joanna Hall	1250	Ms Rhonda Hodges
1224	Mrs Betty West	1251	Mrs Janice Marshall
1225	Mrs Eunice McKelvie	1252	Ms Victoria Bridgland
1226	Ms Lesley Murphy	1253	Mrs Mary Mockler
1227	Mrs Patricia Jones	1254	Mrs Heather Astle
1228	Mrs Flora Duzmath	1255	Ms Helen Van Huet
1229	Mrs Maria Catalano	1256	Mr Ron Egan
1230	Mrs Mary Linder	1257	Mrs Wendy Bakker
1231	Mrs Christine O'Neill	1258	Mrs Jayne Lehmann
1232	Mrs Liza Seubert	1259	Mrs Rhonda Danylenko
1233	Mrs Jacqueline Illingworth	1260	Ms Marianne Jotic
1234	Mrs Julie Crellin	1261	Mr Waclav Rada
1235	Mr Vincent Entwistle	1262	Ms Vicki Njezic
1236	Ms Christine Sykes	1263	Mrs Robyne Rycen

1264	Mrs Meili Su	1288	Mr Brendan Hayward
1265	Mrs Wynn Phillips	1289	Mr M & Mrs T Woodall
1266	Mrs Nerrida Shutt	1290	Ms Julie Hines
1267	Mrs Lena Kelly	1291	Mrs Mary Lou Carter
1268	Ms Belinda Smith	1292	Ms Leona Clothier
1269	Mrs Denise Blackwell	1293	Mr Sean McCandless
1270	Mrs Patsy Hughes	1294	Ms Rachel Gray
1271	Mr Doug Pierce	1295	Name withheld
1272	Confidential	1296	Ms Laura Formosa
1273	Confidential	1296.1	Ms Laura Formosa (Supplementary)
1273.1	Confidential	1297	Mr Joe Stosser
1274	Name withheld	1298	Mr Ken Duncan
1275	Mrs Lee Scriven	1299	Ms Catherine Rowntree
1276	Kapululangu Aboriginal Womens Law and Culture Centre	1300	Canberra Mothercraft Society
1277	Mr Adrian Pederick MP JP	1301	Nerryl Wheatley Counselling
1278	NSW Government	1302	Name withheld
1279	Friends of EACH Action Group	1303	Professor David Peetz
1280	Ms Sue Forster	1304	Name withheld
1281	Mr D & Mrs S Brimblecombe	1305	Mrs Kaylene Evans
1282	Ms Judith Burstyner		
1283	Ms Nouha Jaber		
1284	Name withheld		
1284.1	Name withheld		
1285	Ms Helen Ohlhoff		
1286	National Federation of Parents, Families and Carers		
1287	Mr J & Mrs S Symon		



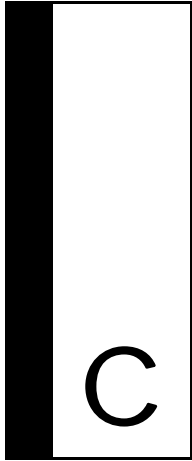
Appendix B – List of Exhibits

- 1 *Submission to Australian Senate Community Affairs Reference Committee: Inquiry into the Funding and Operation of the CSATDA, 28 July 2006.*
Provided by National Carers Coalition (Relates to Submission No. 0571)
- 2 *The Wellbeing of Australians - Carer Health and Wellbeing, Australian Unity Wellbeing Index Survey Report 17.1, 1 October 2007*
Provided by Australian-Polish Community Services Inc (Relates to Submission No. 0654)
- 3 *The Wellbeing of Australians - Carer Health and Wellbeing, Australian Unity Wellbeing Index Survey Report 17.1, 1 October 2007*
Provided by Australian Unity (Relates to Submission No. 0667)
- 4 *A Research Thesis by Elizabeth F Rix, June 2007*
Provided by Ms Liz Rix (Relates to Submission No. 0745)
- 5 *Report of the Mental Health Respite Questionnaire for Mental Health Carers*
Provided by Commonwealth Carer Respite Centre
- 6 *WA Carers Recognition Act 2004 (No.37)*
Provided by the Department for Communities - Government of WA (Relates to Submission No. 0761)
- 6.1 *Western Australian Carers Charter*
Provided by the Department for Communities - Government of WA - (Relates to Submission No. 0761)
- 6.2 *Recognition - Bringing Carers into Focus - March 2007*
Provided by the Department for Communities - Government of WA (Relates to Submission No. 0761)

- 6.3 *Carer Recognition - Building Tomorrow's Partnerships Today - March 2008*
Provided by the Department for Communities - Government of WA -
(Relates to Submission No. 0761)
- 6.4 *Research Insights - Safe Caring?*
Provided by the Department for Communities - Government of WA -
(Relates to Submission No. 0761)
- 7 *Families as Partners in Mental Health Care - A guidebook for implementing family work*
Provided by the Victorian Mental Health Carers Network Inc
- 8 *Help for you to stay in your own home: Home and Community Care Services for frail older people, people with a disability and their carers*
Provided by Mrs Irene Sullivan
- 9 *Through the Maze 2008 Edition: Information and support for parents of children with a disability in New South Wales*
Provided by Association for Children with a Disability NSW
- 9.1 *Pamphlet and membership form for the Association of Children with a Disability NSW*
Provided by Association for Children with a Disability NSW
- 10 *DVD: Young Carers... A True Story... A True Inspiration*
Provided by Ms Carmel Flavell
- 11 *Carers NSW Dimensions of Caring Presentation*
Provided by Carers NSW
- 12 *For those who carer: A Practical Guide for families of people with Neurological Conditions or Acquired Brain Injury*
Provided by BrainLink Services Limited
- 13 *Family Voices magazine, Vol 1, Issue 1, 2008*
Provided by Australian Association for Families of Children with a Disability
- 14 *Supporting Staff Dealing with Serious Health Conditions*
Provided by Transport Accident Commission
- 15 *Reconciling the patient's right to confidentiality and the family's need to know*
Provided by the Royal Australian and New Zealand College of Psychiatrists

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- 15.1 *Legality of Disclosure by Victorian Psychiatrists of Patient Information to Carers, Psychiatry, Psychology and Law, Vol 14, Number 1 2007, pp 147-167*
Provided by the Royal Australian and New Zealand College of Psychiatrists
- 15.2 *DVD x 3 - Mental Illness "Recovery" A Workshop; "Hypothetical" Working Collaboratively; and Clinicians, Carers and Confidentiality*
Provided by the Royal Australian and New Zealand College of Psychiatrists
- 16 *The Health and Wellbeing of Adult Family Carers in South Australia: An epidemiological analysis 1994-2004, SA Department of Health*
Provided by Ms Anne Stacey
- 17 *Early Intervention for Children with Autism Spectrum Disorders: Guidelines for Best Practice, 2006*
Provided by Mr D & Mrs R Barkhazen
- 17.1 *The Flinders University Early Intervention Research Program, School of Psychology, Flinders University, Adelaide*
Provided by Mr D & Mrs R Barkhazen
- 17.2 *Results of an Autism/Aspergers Parent's on-line support group survey, July/August 2008*
Provided by Mr D & Mrs R Barkhazen
- 18 *Consumer-Directed care: A way to empower consumers? Alzheimer's Australia Paper 11, May 2007*
Provided by Alzheimer's Australia (Relates to Submission No. 1002.1)
- 19 *The Capability Dialogues: A project of Coinda Family Support Group*
Provided by Coinda Family Support Group Inc
- 19.1 *Coinda Information package - Supporting Families to Support Themselves*
Provided by Coinda Family Support Group Inc
- 20 *Provided by Australian Foster Care Association Inc*
AFCA Comparison of State and Territory Forster Care Payments 2000-2008
- 20.1 *Understanding Care and Protection and Out of Home Care at a National Level*
Provided by Australian Foster Care Association Inc
- 20.2 *Supporting Carers of other People's Children: A handbook on support for foster, relative & kinship carers & the children & young people in their care*
Provided by Australian Foster Care Association Inc

- 21 *The Grandparents' Story: A gathering of grandparents parenting grandchildren because of alcohol and other drugs*
Provided by Canberra Mothercraft Society
- 21.1 *Grandparents raising grandchildren because of alcohol and other drug issues, AIFS Family Matters No. 76 2007, pp 70-75*
Provided by Canberra Mothercraft Society
- 21.2 *Grandparents Parenting Grandchildren Report 2006*
Provided by Canberra Mothercraft Society
- 22 *Discussion Paper, Indigenous Carers and Communities, February 2008*
Provided by Carers Australia
- 22.1 *Carers with multiple carer responsibilities*
Provided by Carers Australia
- 22.2 *Supporting older carers - the economic rationale, November 2008*
Provided by Carers Australia
- 23 *Submission to the National Disability Strategy: A national disability strategy for all Australians, November 2008*
Provided by Yooralla (People Helping People Achieve)
- 24 *Powerpoint presentation: The Case for a National Disability Insurance Scheme*
Provided by Yooralla (People Helping People Achieve)



Appendix C – List of Public Hearings

Wednesday, 23 July 2008 - Perth

Private Capacity

Mrs Helen Charlesworth
Mrs Trudi Clough
Mr Thomas Cunningham
Ms Kay De Brett
Ms Janette Dodd
Ms Raynar Foldesi
Mrs Carol Franklin
Mr Anthony Meade
Ms Brenda Pitcher
Mrs Ngoc Thuan Quach
Mr Tony Ramshaw
Mr Charlie Rook
Mr Ken Steele
Mr Andrew Watson
Mr William Wilton

ARAFMI Mental Health Carers & Friends Association (WA)

Mr David Kernohan, Executive Director
Mr David Hilton, Team Leader – Metro

Australian Red Cross

Mrs Linda Crumlin, Senior Manager, Community Care

Mrs Tina Newman, Manager, South-West Respite & Carelink Centre

Ms Judy Waymouth, Manager, Metro East Respite & Carelink Centre

Carers WA

Mr Paul Coates, Chief Executive Officer

Mrs Lynne McHale, Coordinator, Hospitals Program

Ms Britta Meyer, Manager, Carer Services

Ms Pamela Siu, Carer Advisor

Committed About Securing Accommodation for People with Disabilities

Mrs Irma Brown, Member

Ms Carol Franklin, Co-Founder

Mrs Amanda Simes, Member

Developmental Disability Council of WA

Ms Taryn Harvey, Member

Mrs Dianne Murphy, Member

Mr Shaun Murphy, Member

Ms Di Shepherd, Member

Ethnic Disability Advocacy Centre

Ms Jennifer Au Yeong, Chief Executive Officer

Mrs Maranda Ali, Project Officer

Wednesday, 6 August 2008 - Sydney**Private Capacity**

Mrs Patricia Berrutti

Ms Nell Brown

Mrs Katrina Clark

Ms Beth Daws

Miss Carreen Dew

Miss Lisa Humphries

Ms Lynette MacIver

Miss Maggie Malak

Mrs Irene Sullivan

Ms Johanna Tams

Ms Dianne Thian

Anglicare Diocese of Sydney

Mr Phillip Coller, Assistant Director, Community Care

Mrs Susan King, Policy Unit Manager

Association of Children's Welfare Agencies

Ms Sylvia Ghaly, Manager, Policy and Membership

Mr Andrew McCallum, Chief Executive Officer

Australian Foundation for Disability

Mrs Patricia Berrutti, Carer Support Coordinator

Ms Shirley Crowe, Executive Manager, Client Services

Carers NSW

Ms Sheree Freeburn, Aboriginal Policy and Development Officer

Ms Elena Katrakis, Chief Executive Officer

Disability Council of New South Wales

Mr Dougie Herd, Director

Institute for Family Advocacy & Leadership Development Association Inc

Mrs Belinda Epstein-Frisch, Systems Advocate

Mrs Lesley Light, Member

Mrs Meg Sweeney, Member

Multicultural Mental Health Australia

Ms Vicki Katsifis, CALD Mental Health Carer Advocate

Ms Georgia Zogalis, National Program Manager

University of NSW - Social Policy Research Centre

Professor Deborah Brennan

Professor Bettina Cass, Professorial Fellow

Dr Patricia Hill, Research Fellow

Ms Catherine Thomson, Research Fellow

University of Western Sydney - Centre for Cultural Research

Ms Beatriz Cardona, Research Assistant,

Dr Sharon Chalmers, Research Fellow

Professor Brett Neilson, Research Fellow

Taskforce on Care Costs

Ms Juliet Bourke, Former Chair

Tuesday, 12 August 2008 - Melbourne

Private Capacity

Mr Michael Aldred
Mrs Honnie Aldred
Mr Graham Andersen
Mrs May Andersen
Ms Wai Ling Cheung
Mr Martin Forty
Ms Susan Gambin
Mr John Halford
Ms Helen Johnson
Ms Shirley Matheson
Ms Susan Mina
Mr Aaron Paul
Mr Rolf Regal
Mrs Iris Stockfeld
Mr Terry Stroud
Mrs Lisa Thomas

Association for Children with a Disability NSW

Ms Dianne McCarthy, Manager, Parent Support Team

Australian Association for Families of Children with a Disability

Ms Elizabeth McGarry, Chief Executive Officer
Ms Anne-Maree Newbold, President

Australian Council of Trade Unions

Ms Catharine Bowtell, Industrial Officer
Ms Belinda Tkalcevic, Industrial Officer

Australian Federation of Disability Organisations

Ms Niki Sheldon, National Policy Officer

BrainLink Services Limited

Mr Craig Coleman, Client & Carer

Mrs Greta Parker, Family Services Coordinator

Mrs Sharon Strugnell, Chief Executive Officer

Brotherhood of St Laurence

Ms Jennifer English, Carer

Mr Warren Haynes, Manager

Mr Gordon Moore, Carer

Ms Christine Morka, Senior Manager

Carers Victoria

Ms Maria Bohan, Chief Executive Officer

Mr Ben Chodziesner, President

Mr Ben Ilsley, Policy Advisor

Ms Gill Pierce, Program Manager, Policy and Research

Australian Huntington's Disease Association

Ms Ruth Hertan, Chief Executive Officer

MS Australia

Dr Michael Summers, Senior Policy Advisor

Royal Australian and New Zealand College of Psychiatrists

Dr Julian Freidin, Immediate Past President

Mrs Sarah Gafforini, Manager, Policy and Practice Standards

Dr Margaret Leggatt, Board of Professional & Community Relations

Transport Accident Commission

Ms Rwth Stuckey, OH&S & Injury Management Advisor

Victorian Mental Health Carers Network Inc

Dr Margaret Leggatt, Member of the Executive Committee

Ms Lynne Ruggiero, Child & Adolescent Area Mental Health Services Representative

Wednesday, 13 August 2008 - Adelaide

Private Capacity

Mr Daryl Barkhazen

Mrs Rosina Barkhazen

Ms Vivianna Cagliuso

Mr William Heggblum

Mrs Jayne Lehmann

Ms Paola Mason

Ms Julie Milburn

Mr Doug Nicholas

Ms Sabine Schreiber

Ms Anne Stacey

Ms Dianne Stewart

Ms Helen Thomas

Ms Jeanette Walsh

Mr Kevin Wood

**Australian Infant Child Adolescent and Family Mental health Association -
Children of Parents with a Mental Illness National Initiative**

Ms Christabel Alliston, Consumer and Carer Participation Officer

Ms Elizabeth Fudge, Project Manager

Alzheimer's Australia

Mr Phillip Alderton, Member

Ms Marie Alford, General Manager

Mr Ronald Sinclair, Chairman

Carer Support Network of SA

Mr Robert Haines, Carer

Mr Peter Sparrow, Chief Executive Officer

Mr Gary Vogt, Executive Officer

Carers SA

Mr Philip Saunders, Policy & Projects Officer

Ms Janice Wallent, President

Ms Rosemary Warmington, Chief Executive Officer

Julia Farr Association

Ms Shelley Hoppen, Stakeholder Networking & Consultation

Mr Robbi Williams, Chief Executive Officer

Muscular Dystrophy Association Inc

Miss Lisa Quinn, Client Services Coordinator

Mrs Hilary Rowe, Board Member

Private Mental Health Consumer Carer Network (Australia)

Mrs Judy Hardy, Carer

Ms Janne McMahon OAM, Independent Chair

Siblings Australia Inc

Ms Kate Strohm, Executive Director

Wednesday, 20 August 2008 - Brisbane**Private Capacity**

Mrs Anna Bowlay

Mrs Lynn Collins

Mr Stephen Lopedote

Ms Shirley Macfarlane

Mrs Carolyn McDiarmid

Mrs Desley Payne

Ms Joy Roze

Australian Association of Gerontology

Professor Laurie Buys, National President

Dr Evonne Miller, National Honorary Secretary

Carers Queensland

Ms Toni Cannon, Senior Policy Advisor

Ms Toni Dunshea, President

Mr Brendan Horne, Area Manager, South-East Queensland

Mr Eric Jones, Coordinator, Family Support and Advisory Program

Mr Graham Schlecht, Executive Director

Mental Health Carers ARAFMI Queensland Inc

Ms Marj Bloor, Executive Officer

Mrs Jean Platts, Vice President and Carer

National Seniors Australia

Mr Michael O'Neill, Chief Executive

Mr Geoff Trollip, Chief Operating Officer

Office of the Public Advocate

Ms Michelle Howard, Public Advocate

Mr Marcus Richards, Principal Research Officer

Parent Project Australia Inc

Mrs Helen Posselt, Education Director

Schizophrenia Fellowship, Sunshine Coast Branch

Mrs Jillian Boyle, President and Carer

Mrs Mary Ireland, Carer

Mrs Sharon Plum, Carer

Mrs Beverley Tickner, Vice President and Carer

University of Queensland - School of Social Work & Human Services,

Associate Professor Cheryl Tilse, Director of Postgraduate Research
Studies

Professor Jill Wilson

Friday, 26 September 2008 - Canberra

Private Capacity

Ms Jo-Anne Beattie

Ms Judy Bentley

Mrs Patricia Bodegraven

Miss Tammara Haines

Ms Deborah Hayes

Mrs Bridget Larsen

Ms Stephanie Maxwell

Mrs Carolyn Paisley-Dew

Ms Evelyn Scott OAM

Mr Arthur Skimin

Mrs Kathleen Skimin

Anglicare Canberra Goulburn

Ms Kat Szukalska, Acting Coordinator of CYCLOPS & Litmus

Mr Keith Waters, Chief Executive Office

Ms Shyanne Watson, Manager of Junction, CYCLOPS & Litmus

Carers ACT

Ms Annemarie Ashton, Policy Adviser

Ms Judy Bentley, Carer Representative (voluntary)

Ms Deborah Hayes, Carer Representative (voluntary)
Ms Dee McGrath, Chief Executive Officer
Mrs Carolyn Paisley-Dew, Carer Representative (voluntary)

Tandem

Ms Catherine Bickmore, Family Support Practitioner
Ms Cheryl Daw, Chief Executive Officer
Miss Merrilyn Lowe, Coordinator

Wednesday, 1 October 2008 - Albury**Private Capacity**

Mrs Narelle Hughes
Mrs Anne Manning

Bright Carer Support Group

Mrs Veronika Colyer, Facilitator
Mrs Bevely Miller, Facilitator

Myrtleford Carer Support Group

Miss Cheryl Sanderson, Facilitator

Delatite Community Health Service

Ms Deborah Smith, Community Health Nurse, Carers Support Group

Cooinda Family Support Group Inc

Mr Neil Butterfield, Carer
Ms Kerry Ferguson, Member and Carer
Mr Paul Kirk, Casual staff member and Carer
Mrs Susan Pringle, Coordinator
Mrs Vickie Priscina, Events Coordinator and Carer
Mrs Robyn Raine, Carer
Mrs Beverly Thorpe, Carer
Mrs Naomi Tomkins, Member and Carer

Daughters in Demand Support Group

Mrs Michele Campbell, Coordinator
Mrs Lynette Richards, Coordinator

Dementia Respite Options

Mrs Helen McDougall, Coordinator

Miss Alishya Purss, Carer

Mr Henry Thomas, Carer

Kiewa Valley Carer Support Group

Mr John Lindsey, Facilitator

Thursday, 9 October 2008 - Hobart

Private Capacity

Mr Peter Aris

Mrs Carol Butler

Ms Lesley Field

Mrs Sue Hodgson

Ms Karelle Logan

Mr Geoff Lucas

Mrs Jennifer Parrott

Mrs Robyne Rycen

Mrs Lee Scriven

Mrs Annette Wilson Sturm

Carers Tasmania

Mrs Annemarie Ashton, Policy Consultant

Mrs Maggy Hunter, President

Mrs Janis McKenna, Chief Executive Officer

MS Society of Tasmania

Mrs Jane Hope, Manager, Client Services

Neuro Muscular Alliance Tasmania

Mrs Anne Ashford, Secretary

Parkside Foundation

Mrs Linda Glover, General Manager

Ms Belinda Smith, Service Manager

Wednesday, 15 October 2008 - Canberra**National Carers Coalition**

Mr Robert Gow, Queensland Member

Ms Felicity Maddison, Queensland Liaison

Ms Jean Tops, Victorian Liaison

Wednesday, 22 October 2008 - Canberra**Mental Health Council of Australia**

Mr David Crosbie, Chief Executive Officer

Ms Linda Rosie, Carer Engagement Project Manager

National Council on Intellectual Disability

Mr Mark Pattison, Executive Officer

Wednesday, 12 November 2008 - Canberra**Australian Foster Care Association Inc**

Mrs Bev Orr, President

Canberra Mothercraft Society

Ms Emma Baldock, Counsellor and Community Development Officer

Ms Mary Kirk, Director of Nursing & Midwifery and Executive Officer

Wednesday, 26 November 2008 - Canberra**Carers Queensland**

Ms Suzanne La Fontaine

Group Home Project, Mackay

Ms Lyn Downing

Ms Caralyn Straw

Royal Australian and New Zealand College of Psychiatrists

Associate Professor Robert Parker, Chair of the Board of Professionals and
Community Relations

Ms Tess Narkle, Carer

Friday, 28 November 2008 - Canberra

Alzheimer's Australia

Ms Anne Eayrs, National Policy Officer

Mrs Kaye Pritchard, Volunteer

Mr Glenn Rees, National Executive Director

Mr Ronald Sinclair, Chairman of the National Consumers Committee

Carers Australia

Ms Joan Hughes, Chief Executive Officer

Ms Pam Webster, President of the Carers Australia Board

Department of Families, Housing, Community Services and Indigenous Affairs

Ms Lee Emerson, Branch Manager, Carers Branch

Ms Angela Hope, Section Manager, Carers Branch

Department of Health and Ageing

Mr Andrew Stuart, First Assistant Secretary, Ageing and Aged Care Division

Mr Keith Tracey-Patte, Acting Assistant Secretary, Community Care Branch

Department of Veterans' Affairs

Mr Wayne Penniall, National Manager, Aged and Community Care

Wednesday, 3 December 2008 - Canberra

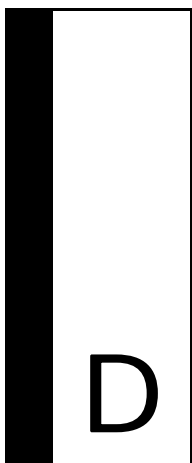
Winnunga Nimmityjah - Aboriginal Health Service ACT

Ms Julie Tongs, Chief Executive Officer

Wednesday, 25 February 2009 - Canberra

Yooralla (People Helping People Achieve)

Mr Bruce Bonyhady, Chairman



Appendix D - Payment costs and recipients 2006-07¹

¹ Australian Government, Department of Families, Housing, Community Services and Indigenous Affairs, *Australia's Future Tax System*, Pension Review Background Paper, August 2008.

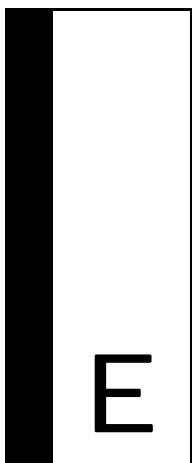
	Expense (\$ million)	Payment description/aim	Labour force criteria	Number of recipients
Aged				
Age Pension	22,598	Income support for people who have reached Age Pension age.	None	1,952,686
Widow B Pension	4	Income support for previously partnered women born before 1 July 1937 or a single parent at age 45 born before 1 July 1942 (closed 20 March 1997).	None	732
Wife Pension (Age)	161	Income support for female partners of Age pensioners (closed 1 July 1995).	None	14,045
Age Pensioners—DVA ^(b)	^(b)	Age Pension paid to eligible service pensioners and their partners. It is paid by DVA as an agent of FaHCSIA.	None	6,068
Service Pension Veterans—DVA ^(b)	2,949 ^(b)	Income support for people who have reached service pension age. Similar to Age Pension paid by Centrelink.	None	113,698
Service Pension (partners)—DVA ^(b)	^(b)	Income support for wives of service pensioners. Similar to Wife Pension paid by Centrelink.	None	96,864
Utilities Allowance	147	Supplementary payment available to income support recipients aged over Age Pension age.	N/A	2,000,000
Seniors Concession Allowance	226	Supplementary payment available to Commonwealth Seniors Health Card holders (CSHC).	N/A	302,583
Telephone Allowance (CSHC only)	12 ^(c)	Supplementary payment available to CSHC holders. (Also available to pensioners and selected allowance recipients and paid quarterly with income support payment).	N/A	292,155
<i>Total</i>	26,097			

	Expense (\$ million)	Payment description/aim	Labour force criteria	Number of recipients
Working age				
Newstart Allowance	4,494	Income support for the unemployed aged between 21 and Age Pension age, including those regarded as unemployed, non-full time students available for and willing to undertake suitable work. Includes <i>people with disability with a partial capacity to work</i> and <i>principal carers of older children</i> (aged 6 or more if partnered or 8 or more if single).	Must satisfy an activity test by seeking and accepting suitable work or participating in agreed activities designed to improve employment prospects (unless exempted). People with a <i>partial capacity</i> to work have requirements that match their assessed capacity to work. <i>Principal carers</i> must seek at least 15 hours work per week (unless exempted).	417,793
Parenting Payment Partnered	1,217	Income support for the principal carer of a child aged under 6 (under 16 if granted payment before 1 July 2006).	Part-time participation requirements (see Newstart Allowance principal carers) if youngest child is over 6 (over 7 if granted payment before 1 July 2006).	144,427
Parenting Payment Single	4,696	Income support for the principal carer of a child aged under 8 years (or under 16 if granted payment before 1 July 2006).	Part-time participation requirements (see Newstart Allowance principal carers) if youngest child is over 6 (over 7 if granted payment before 1 July 2006).	395,495
Sickness Allowance	85	Income support for people who are temporarily incapacitated for work or study as a result of illness.	Must have a job or full-time study (if aged 25 plus) to return to.	7,624
Mature Age Allowance	88	Income support for people aged 60 years to Age Pension age receiving an income support payment for 9 months or more (closed September 2003, phased out by September 2008).	No recent workforce experience at time of claim.	5,032

	Expense (\$ million)	Payment description/aim	Labour force criteria	Number of recipients
Partner Allowance	522	Income support for partners of income support recipients (at time of claim) born on or before 1 July 1955 (closed 20 September 2003).	No recent workforce experience at time of claim.	45,988
Widow Allowance	505	Income support for older women (phased out from 1 July 2005 with new grants from that date limited to women born on or before 1 July 1955) who were widowed, divorced or separated prior to turning 40.	No recent workforce experience at time of claim.	40,247
Youth Allowance (Other)	482	Income support for young people aged 16 to 20 seeking or preparing for work or temporarily unable to work.	Must seek and accept suitable work or participate in agreed activities (unless exempted).	68,698
Exceptional Circumstances Relief Payment	260	Income support for farmers in drought affected areas.	None	28,601
Utilities Allowance	7	Supplementary payment paid to Mature Age, Partner and Widow Allowance recipients who are not of Age Pension age. (From March 2008 also paid to Carer Payment, Wife Pension, Disability Support Pension, Widow B Pension and Bereavement Allowance recipients).	N/A	n.a.
Pensioner Education Supplement	73	Supplementary payment for certain pensioners (and former pensioners) undertaking study.	Must be undertaking an approved course.	44,802
Education Entry Payment	16	Supplementary lump sum payment to assist with the cost of commencing an approved study course (available annually if continuing study and receiving Pensioner Education Supplement).	Must be commencing or continuing (PES recipients) an approved course.	76,394
Mobility Allowance	106	Supplementary payment for people with disability who are aged 16 or over and who are unable to use public transport without substantial assistance.	None	54,492
<i>Total</i>	12,551			

	Expense (\$ million)	Payment description/aim	Labour force criteria	Number of recipients
People with disability				
Disability Support Pension	8,651	Income support payment for people aged 16 and over (new entrants must be under Age Pension age) with a physical, intellectual or psychiatric impairment with at least 20 points on the Impairment Tables. Special rules apply for the blind.	Because of their impairment, unable to work or be reskilled to work, at least 15 hours a week (or 30 hours if on payment at 10 May 2005) at or above the minimum wage for at least the next two years.	714,156
<i>Total</i>	8,651			
Carers of people with disability				
Carer Payment	1,408	Income support for a person providing constant care for an adult or child with disability or a medical condition, or who is frail aged.	None	116,614
Wife Pension (DSP)	234	Income support for female partners of Disability Support Pensioners (closed 1 July 1995).	None	21,228
Carer Allowance	1,349	Supplementary payment for people who provide daily care and attention at home to an adult or child with disability or a medical condition.	None	393,263
<i>Total</i>	2,291			
Students				
Youth Allowance (Student)	1,591	Income support for full-time students aged 16 to 24 years in secondary or tertiary education or training and apprentices aged 16 to 24.	Must be undertaking an approved course of study.	263,257
Austudy	218	Income support for people aged 25 and over who are studying or training full-time, including full-time apprentices.	Must be undertaking an approved course of study.	28,269

	Expense (\$ million)	Payment description/aim	Labour force criteria	Number of recipients
Abstudy	156	Income support for full-time secondary and tertiary students and apprentices who are Aboriginal or Torres Strait Islander.	Must be undertaking an approved course of study.	34,134
<i>Total</i>	1,965			
Special				
Special Benefit	67	Income support for people who are not eligible for any other type of payment and who are in financial hardship.	As for NSA.	6,244
Bereavement Allowance	1	Income support for a recently widowed person following the death of their partner. Paid for up to 14 weeks.	None	553
<i>Total</i>	68			



Appendix E - Income support payments as at 1 July 2008¹

¹ Australian Government, Department of Families, Housing, Community Services and Indigenous Affairs, *Australia's Future Tax System*, Pension Review Background Paper, August 2008.

Rates (per fortnight)	Income test (per fortnight)	Assets test
Pensions — includes Age Pension, Disability Support Pension, Carer Payment, Parenting Payment Single, Bereavement Allowance, Wife Pension, Widow B Pension and Service Pension		
<p>Single: \$546.80 Partnered: \$456.80 (each)</p> <p><i>Single DSP under 21, no children</i> (Youth Allowance plus Youth Disability Supplement of \$100.60, total cannot exceed adult DSP rate):</p> <p><18, at home: \$295.10 18-20, at home: \$334.50 16-20 independent: \$456.00 Member of a couple: \$456.00</p> <p>Rates are adjusted each March and September in line with increases in the CPI. Single adult rates are also benchmarked against 25% of MTAW, with a proportional flow-on to partnered rates. Pensions are taxable, except for Disability Support Pension and Invalidity Service Pension paid to people under Age Pension age, and Carer Payment and Wife Pension spouse where the person being cared for or the spouse is receiving a non-taxable pension.</p>	<p>Free Area: \$138 (single) \$240 (couple) plus \$24.60 per child</p> <p>Taper:</p> <p>Singles: 40% of income above free area Couples: 20% of combined income above free area for each member of couple.</p> <p>Working Credit* available if aged under Age Pension age.</p> <p>Income test does not apply to a permanently blind person receiving Age, Service or Disability Support Pension.</p> <p>Some income types are subject to different arrangements (for example, compensation payments may be deducted directly from the rate otherwise payable).</p>	<p><i>Homeowners for full pension:</i> Single \$171,750 Partnered (combined): \$243,500</p> <p><i>Non-Homeowners for full pension:</i> Single: \$296,250 Partnered (combined): \$368,000</p> <p>Assets over the limit reduce pensions by \$1.50 per fortnight for every \$1,000 above the threshold.</p> <p><i>Homeowners for part pension:</i> Single: \$540,250 Partnered (combined): \$856,500</p> <p><i>Non-Homeowners for part pension:</i> Single: \$664,750 Partnered (combined): \$981,000</p> <p><i>(Amounts are higher if receiving RA or separated due to illness)</i></p> <p>For Parenting Payment Single, see Allowances.</p> <p>Assets test does not apply to a permanently blind person receiving Age, Service or Disability Support Pension.</p>

Rates (per fortnight)	Income test (per fortnight)	Assets test
Allowances — excluding student and youth payments. Includes Newstart Allowance, Parenting Payment Partnered, Sickness Allowance, Mature Age Allowance, Widow Allowance and Partner Allowance		
<p>Higher single rate: \$472.80 Lower single rate: \$437.10 Partnered: \$394.40</p> <p>Higher single rate applies to: a person with a dependent child; or a person aged 60 or more and on income support for at least 9 months; and to partnered people separated due to ill-health, infirmity or because the partner is in gaol.</p> <p>Lower single rate applies to singles not covered by the higher rate.</p> <p>Rates are adjusted each March and September in line with increases in the CPI. Payments are taxable.</p>	<p>Free Area: \$62 Tapers: 50% of income \$62-\$250, 60% of income above \$250</p> <p><i>Partner income test:</i> Free Area: \$751 Taper: 60%</p> <p>If partner is a pensioner, then a joint income test applies. Individual income is calculated as half the combined income of the couple. This amount is then subject to the person's individual income test.</p> <p>If partner is not a pensioner, a sequential income test applies. Individual income test is applied to own income. Partner income over the partner income free area is subject to a 60% taper.</p> <p>Working Credit* applies.</p>	<p><i>Homeowners ineligible for allowance if assets exceed:</i> Single: \$171,750 Partnered (combined): \$243,500</p> <p><i>Non-Homeowners ineligible if assets exceed:</i> Single: \$296,250 Partnered (combined): \$368,000</p>

Rates (per fortnight)	Income test (per fortnight)	Assets test
Allowances - youth and student payments. Includes Youth Allowance (Student), Austudy and Abstudy.		
<p><i>Youth Allowance (YA)</i></p> <p><18, at home: \$194.50 18 +, at home: \$233.90</p> <p><i>YA and Austudy</i></p> <p>Partnered, no children; and Away from Home: \$355.40 Single, with children: \$465.60 Partnered, with children:\$390.20</p> <p>Higher rates are available to long-term income support recipients aged 21 or over commencing full-time study or an apprenticeship.</p> <p>YA with partial capacity to work receive YA rates plus Youth Disability Supplement of \$100.60 (total is capped at adult Newstart rates).</p> <p>Rates are adjusted each January in line with increases in the CPI.</p> <p>Payments are taxable.</p>	<p><i>Personal income test</i></p> <p>Free Area: \$236</p> <p>Tapers: 50% of income \$236-\$316; 60% of income above \$316</p> <p>Student Income Bank** available.</p> <p><i>Partner income test as for other allowances.</i></p> <p><i>Parental income test</i></p> <p>YA for non-independent young people is paid subject to a parental income test, unless a parent receives income support or holds a low-income Health Care Card. The family actual means test applies to specified families.</p>	<p>YA for independent young people and Austudy payment are assets tested as for other allowances.</p> <p>YA for non-independent young people is paid subject to a family assets test, unless a parent receives income support or holds a Health Care Card.</p>

Rates (per fortnight)	Income test (per fortnight)	Assets test
Income support — veterans (does not include payments of a compensatory nature)		
<p>Income Support Supplement (ISS) is payable to eligible war widow(er)s with a maximum fortnightly rate of \$163.20.</p> <p>Indexed in March and September with reference to CPI and MTAW.</p> <p>ISS is not taxable when recipient is aged less than 65, but is taxable otherwise.</p>	<p>Free area for ISS: \$1,097 (single). ISS Taper: 40% of income above free area. Different ISS free areas and taper rates apply for members of a couple.</p>	<p><i>Homeowners for full ISS*:</i> Single: \$427,500</p> <p><i>Non-Homeowners for full ISS*:</i> Single: \$552,000</p> <p>Assets over this limit reduce the ISS by \$0.375 per fortnight for every \$250 above the threshold. Different thresholds apply for members of a couple.</p>
Safety net		
<p>Special Benefit rate is discretionary but cannot exceed Newstart or Youth Allowance rates otherwise applicable.</p>	<p>No Free Area. \$1 for \$1 withdrawal rate. Plus strict liquid asset limits.</p>	<p>As for allowances.</p>

- 1 Veterans and their dependents are entitled to a further range of payments which are of a compensatory nature, and as such are not detailed here.
- * Working Credit: a credit accrues for each \$1 of unused free area (up to \$48 per fortnight) up to a maximum of 1,000 credits. Credits can be used to reduce the amount of earned income subject to the personal income test.
- ** Student Income Bank: students can accrue up to \$6,000 of unused free are to reduce income in other periods.

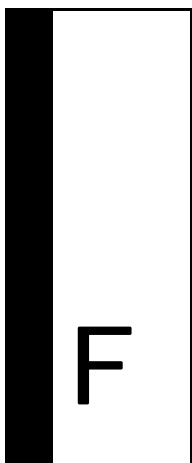
Family assistance payments as at 1 July 2008

Payment type	Rate/s	Income test (no assets test)								
Family Tax Benefit (FTB)										
<p><i>FTB Part A</i></p> <p>Must have a dependent child aged under 21 or qualifying dependent full-time student aged 21-24. Child is not a dependent child (not an FTB child) if they receive an income support payment; or they are a non-full time student aged 5-15 or aged 16-24 years with income at or exceeding the FTB Child Income Limit.</p> <p><i>Rent Assistance</i> is paid as part of the maximum rate of FTB Part A for families with children under 16.</p> <p>Families eligible for the maximum rate of FTB Part A (prior to the application of the Maintenance Income Test) are also issued a <i>Health Care Card</i>.</p>	<p><i>Maximum rate per fortnight:</i></p> <table> <tr> <td>0-12</td> <td>\$151</td> </tr> <tr> <td>13-15</td> <td>\$196.84</td> </tr> </table> <p><i>Base rate per fortnight:</i></p> <table> <tr> <td>Under 18:</td> <td>\$48.30</td> </tr> <tr> <td>18-24:</td> <td>\$64.96</td> </tr> </table> <p><i>FTB Part A supplement per child:</i> \$686.20 per annum</p> <p><i>Large Family Supplement</i> paid for third and each subsequent child: \$10.36 per fortnight, \$270.10 per annum</p> <p><i>Multiple Birth Allowance:</i></p> <p>Triplets: \$125.58 per fortnight, \$3,274.05 per annum</p> <p>Quads or more: \$167.44 per fortnight, \$4,365.40 per annum</p>	0-12	\$151	13-15	\$196.84	Under 18:	\$48.30	18-24:	\$64.96	<p><i>Maximum rate income test per annum</i></p> <p>Lower income threshold:\$42,559</p> <p>Taper rate: 20%</p> <p><i>Base rate income test per annum</i></p> <p>Higher income threshold:\$94,316</p> <p>Additional Child Amount:\$3,796</p> <p>Taper rate: 30%</p> <p>FTB Child Income Limit:\$12,287 per annum</p> <p>FTB Part A income test does not apply if parent receives an income support payment.</p> <p>Income for the FTB Part A income test is the 'adjusted taxable income' (ATI)* of the person claiming payment and their partner for the financial year FTB is claimed.</p> <p>The Maintenance Income Test applies to FTB Part A above the base rate (including Rent Assistance).</p> <p><i>Maintenance income-free areas per annum:</i></p> <p>Single parent, or one of a couple receiving maintenance: \$1,292.10</p> <p>Couple, each receiving maintenance: \$2,584.20</p> <p>For each additional child: \$430.70</p> <p>Maintenance over these amounts may reduce FTB Part A by 50 cents in the dollar, until the base rate of FTB Part A is reached.</p>
0-12	\$151									
13-15	\$196.84									
Under 18:	\$48.30									
18-24:	\$64.96									

Payment type	Rate/s	Income test (no assets test)				
<p>FTB Part B</p> <p>Must have a dependent child (FTB child) aged under 16 or qualifying dependent full-time student aged 16-18.</p>	<p><i>Maximum rate per fortnight:</i></p> <table border="0"> <tr> <td>Under 5</td> <td>\$128.80</td> </tr> <tr> <td>5-18 years</td> <td>\$89.74</td> </tr> </table> <p><i>FTB Part B supplement per family:</i></p> <p>\$335.80 per annum</p>	Under 5	\$128.80	5-18 years	\$89.74	<p><i>Second earner income test:</i></p> <p>Income threshold: \$4,526 per annum</p> <p>Taper rate: 20%</p> <p>For couples, the second earner income test applies to the ATI of the lower income earner. The second earner income test does not apply to single parents.</p> <p>FTB Part B income limit: payment only available if primary earner ATI is \$150,000 or less.</p>
Under 5	\$128.80					
5-18 years	\$89.74					
Baby Bonus						
<p>Paid following birth (including stillbirth) or adoption of a baby. From 1 January 2009 will be extended to the adoption of children aged under 16.</p> <p>Parents are required to formally register the birth of their child.</p>	<p>\$5,000 per child. Paid by 13 fortnightly instalments for claimants aged 17 and under.</p> <p>Others recipients can be paid as a lump sum, or a combination of lump sum and fortnightly payments. From 1 January 2009, all customers will be paid by fortnightly instalment paid from the date of claim.</p>	<p>Baby Bonus income limit (from 1 January 2009) — family must have income of \$75,000 or less in the six months following birth or adoption.</p>				
Maternity Immunisation Allowance						
<p>Paid for children aged 18-24 months who are fully immunised, or have an approved immunisation exemption.</p>	<p>One-off payment of \$236.70.</p> <p>From 1 January 2009, payment will be made as two instalments - one made for children aged 18 months and 2 years, the other made for children aged between 4 years one month and 5 years.</p>	<p>No income test.</p>				

Payment type	Rate/s	Income test (no assets test)
Child Care Benefit		
<p>Child must attend approved or registered care. Claimant or partner must be liable for the payment of child care fees. Child aged under 7 must have age appropriate immunisation, or have an exemption.</p> <p>All families eligible for up to 24 hours of approved care per week paid subject to family income test.</p> <p>For approved care parents must meet work/study/training test during the week child care is used to receive more than 24 hours and up to 50 hours of CCB per child.</p> <p>For registered care, parents must meet the work/training/study test sometime during the week child care used to receive up to 50 hours CCB.</p> <p>Special rules apply to grandparents with the primary care of a grandchild(ren).</p>	<p><i>Maximum rate — approved care:</i> \$3.47 per hour (\$173.50 for 50 hour week) for a non-school child.</p> <p><i>Minimum rate — registered care:</i> \$0.581 per hour (\$29.05 per week) for a non-school child.</p> <p>Rates for school children 85% of non-school rates.</p>	<p><i>Income test on maximum rate:</i></p> <p>Income threshold: \$36,573</p> <p>Taper rates:</p> <p>One child: 10%</p> <p>Two children: 15% then 25%</p> <p>Three or more children: 15% then 35%</p> <p>Income test does not apply to families on income support.</p> <p>CCB for approved care no longer available when family income reaches, per annum:</p> <p>One child: \$126,793</p> <p>Two children: \$131,457</p> <p>Three children: \$148,452 (plus \$28,028 for each child after the third)</p>
Child Care Tax Rebate		
<p>Child must have attended approved care. Claimant must be assessed as eligible for CCB.</p> <p>Claimant and partner must have passed the CCB work/study/training test (for the purposes of the rebate).</p>	<p>50 per cent of out-of-pocket child care expenses for approved care, up to \$7,500 for 2008-09.</p> <p>Payment made quarterly from October 2008 (for July to September).</p>	<p>No income test.</p>

*Income for FTB and CCB purposes is 'adjusted taxable income' (ATI) for the financial year FTB is claimed. ATI is 'taxable income' plus the value of adjusted fringe benefits, target foreign income, net rental property loss, and tax free pension or benefit, less deductible child support paid. Family assistance payments are non-taxable.



Appendix F - Supplementary payments as at 1 July 2008¹

¹ Australian Government, Department of Families, Housing, Community Services and Indigenous Affairs, *Australia's Future Tax System*, Pension Review Background Paper, August 2008.

Supplements included as part of the maximum rate of income support		
Payment type	Payment rates	Other features
<p>Rent Assistance (RA)</p> <p>Is additional financial assistance to private renters paying private rent.</p> <p>RA is paid at the rate of 75 cents for each dollar of private rent above specified minimum rent thresholds until the maximum rate is reached.</p> <p>RA is paid as part of the maximum rate of income support for people without dependent children aged under 16.</p> <p>RA is paid as part of the maximum rate of FTB Part A for families with dependent children aged under 16.</p>	<p>RA WITH INCOME SUPPORT</p> <p>Maximum rates</p> <p>Single: \$107.20 pf</p> <p>Single, sharer: \$71.47 pf</p> <p>Couple: \$101.00 pf</p> <p>Rent thresholds</p> <p>Single: \$95.40 pf</p> <p>Couple: \$155.20 pf</p> <p>Maximum RA paid if rent is more than:</p> <p>Single: \$238.33 pf</p> <p>Single, sharer: \$190.69 pf</p> <p>Couple: \$289.87 pf</p> <p>RA PAID WITH FTB PART A</p> <p>Maximum rates:</p> <p>One or two children: \$125.86</p> <p>Three or more children: \$142.38</p> <p>Rent thresholds:</p> <p>Single: \$125.44</p> <p>Couple: \$185.64</p> <p>Maximum RA paid if rent is more than:</p> <p>Single, one or two children: \$293.25</p> <p>Single, three or more children: \$315.28</p> <p>Couple, one or two children: \$353.45</p> <p>Couple, three or more children: \$375.48</p> <p>Taper rates</p> <p>RA is not separately income tested but is subject to the income test of the payment it is included in. This is 20% (FTB Part A), 40% (pension), 60% (allowance). (RA paid with FTB Part A can also be reduced by receipt of child support — at a MIT rate of 50%).</p>	<p>RA is not generally available for income support recipients aged under 25 (under 21 for DSP) living with a parent or guardian.</p> <p>To get RA you must be receiving an income support payment or more than the base rate of FTB Part A. Unless eligible to receive the Rent Assistance component of FTB Part A for a regular care child(ren) (that is, at least 14 % and less than 35% care).</p> <p>To receive RA, a level of proof of rent expenditures is required.</p> <p>People in retirement villages, aged care homes and community housing can receive RA (subject to a range of conditions). Government tenants are not eligible.</p> <p>Maintenance income can reduce RA paid with FTB Part A but not RA paid with income support.</p> <p>Disability Support Pension and Carer Payment recipients are not subject to the reduced sharers' rate, nor are people in some forms of group accommodation such as boarding houses.</p> <p>RA is non-taxable.</p>

Payment type	Payment rates	Other features
<p><i>Pharmaceutical Allowance (PhA)</i></p> <p>Is automatically paid to pensioners and recipients of Mature Age and Sickness Allowances.</p> <p>PhA can also be paid to other allowance recipients, depending upon their circumstances (see details in third column).</p>	<p>PhA is paid at a rate of \$5.80 per fortnight for single people (and illness separated) and \$2.90 per fortnight for each eligible member of a couple.</p> <p>PhA is paid in addition to the base pension or allowance.</p> <p>Non-taxable.</p>	<p>PhA can be paid to recipients of allowances if they are in certain special circumstances, such as: being temporarily incapacitated, or having a partial capacity to work, or being a single 'principal carer' of a dependent child, or being aged over 60 years in receipt of income support continuously for at least nine months.</p>
<p><i>Remote Area Allowance (RAA)</i></p> <p>Provides additional assistance to income support customers residing in remote areas. It recognises that many customers do not get the full benefit of zone tax offsets. RAA makes a contribution towards some of the costs associated with living in particularly remote areas.</p>	<p>\$18.20 per fortnight for a single person.</p> <p>\$15.60 per fortnight for each eligible member of a couple.</p> <p>\$7.30 per fortnight for each dependent.</p> <p>RAA is in addition to the relevant pension or payment.</p> <p>RAA is not indexed, and while it is not taxable, it does reduce the amount of any Tax Zone Offsets otherwise available.</p>	<p>RAA is payable to pensioners and allowees (and Abstudy recipients) who usually reside in ordinary Tax Zone A (including, with certain exceptions, Special Tax Zone A) and Special Tax Zone B.</p> <p>RAA is not reduced under the income and assets tests, it is added to any pension or payment after the income and assets tests have been applied.</p>
<p><i>Telephone Allowance (TAL)</i></p> <p>Is a payment to assist with the cost of maintaining a telephone service. It is paid to pensioners, certain allowees and CSHC holders who are telephone subscribers.</p> <p>A higher rate of TAL is payable for income support recipients of Age Pension age, CSHC holders, and DSP and CP if a person, or their partner, has a home internet connection.</p>	<p>\$88.00 per annum (\$22 per quarter) for singles and couples combined.</p> <p>The higher rate of TAL for home internet subscribers is \$132.00 per annum (\$33 per quarter) for singles and couples combined.</p> <p>Non-taxable.</p>	<p>TAL is paid quarterly with the customer's regular income support payment. Eligibility test dates are 1 January, 20 March, 1 July and 20 September.</p> <p>TAL is adjusted annually for increases in the CPI.</p>

Payment type	Payment rates	Other features
Supplements paid in addition to income support or concession card entitlement		
<p><i>Utilities Allowance (UA)</i></p> <p>Is a payment to people of Age (or Service) Pension age in receipt of an income support payment, and to recipients of Mature Age, Widow and Partner Allowances, Disability Support Pension, Carer Payment, Bereavement Allowance, Widow B Pension, Wife Pension, Invalidity Service Pension and Income Supplement regardless of age.</p>	<p>\$500 per annum (\$125 per quarter) for singles.</p> <p>\$250 per annum (\$62.50 per quarter) for each eligible member of a couple.</p> <p>Non-taxable.</p>	<p>UA is paid quarterly. Eligibility test dates are 20 March, 20 June, 20 September and 20 December each year.</p> <p>UA is adjusted twice a year for increases in the CPI.</p> <p>UA is intended to provide assistance towards regular household bills and is paid regardless of whether a person is liable for utilities bills.</p>
<p><i>Seniors Concession Allowance (SCA)</i></p> <p>Is a similar payment to UA paid to Commonwealth Seniors Health Card and Department of Veterans' Affairs Gold Card holders of pension age who do not already receive UA.</p>	<p>\$125 per quarter for each recipient of SCA, whether single or partnered.</p>	<p>Similar to UA.</p>
<p><i>Pensioner Education Supplement (PES)</i></p> <p>Is paid to the following income support customers if they are studying: Parenting Payment Single, Disability Support Pension, Carer Payment, Special Benefit (in some circumstances), Widow Allowance, Widow B Pension, Wife Pension (in some circumstances), Newstart Allowance/Youth Allowance (previously received PES while on Parenting Payment), and certain other allowees transferred from Disability Support Pension who previously receiving PES.</p>	<p>PES is paid at two rates: \$62.40 per fortnight or \$31.20 per fortnight.</p> <p>Rate depends on study load and the person's income support payment.</p> <p>A person can get the \$62.40 per fortnight rate if their approved study load is 50% or more of a full time study load; or they are a Disability Support Pensioner or an Invalidity Service Pensioner with an approved study load of at least 25%; or they are a War Widow(er) Pensioner with a dependent child with an approved study load of at least 25%.</p> <p>A person can get the \$31.20 per fortnight rate if their approved part-time study load is at least 25% of a full-time study load.</p>	<p>To receive PES, a person must be enrolled in an approved course of secondary or tertiary study.</p> <p>Part-time study load students can usually get the supplement for twice the minimum period it takes to finish their course as a full-time student.</p> <p>Fares Allowance is payable to tertiary PES students who live away from a partner or child to study.</p>

Payment type	Payment rates	Other features
<p><i>Education Entry Payment (EdEP)</i></p> <p>Is a lump-sum payment to assist with the cost of beginning approved study (available annually for continuing study if receiving PES).</p> <p>It is available to income support recipients who qualify for PES, and to recipients of Mature Age Allowance, Newstart Allowance, Parenting Payment Partnered, Partner Allowance and Widow Allowance if they have been on income support for at least 12 months.</p>	\$208 per annum.	<p>Only one EdEP payment per calendar year is payable.</p> <p>EdEP is a taxable payment.</p>
<p><i>Work for the Dole Supplement</i></p> <p>Is a fortnightly supplement to assist Newstart Allowance and Youth Allowance recipients with the cost of participating in Work for the Dole programs.</p>	\$20.80 per fortnight.	
<p><i>Language, Literacy and Numeracy Supplement</i></p> <p>Is a fortnightly supplement to assist people on eligible income support payments with the costs associated with participating in the Language, Literacy and Numeracy program.</p>	\$20.80 per fortnight.	
<p><i>Pension Bonus Scheme</i></p> <p>Pays a one-off lump sum to people who defer receipt of Age Pension and continue to work. A number of qualification rules apply.</p>	<p>The maximum rate is \$33,409.50 (singles) and \$27,910.50 (each member of a couple).</p> <p>The maximum amount is paid if the person has accrued 5 full years of bonus periods and receives maximum rate of Age Pension when they eventually claim.</p>	<p>Non-taxable.</p> <p>The scheme is funded through the Age Pension appropriation.</p>

Payment type	Payment rates	Other features
<p><i>Pension Bonus Bereavement Payment</i></p> <p>Is a one-off lump sum paid to the surviving partner of a deceased Pension Bonus Scheme member who did not make their claim for a Pension Bonus before their death.</p>	<p>See Pension Bonus Scheme.</p>	<p>Non-taxable.</p> <p>Commenced from 1 January 2008.</p> <p>Funded from the Age Pension appropriation.</p>
<p><i>Crisis Payment</i></p> <p>Is a one-off payment to help people who are in severe financial hardship. It is available to social security income support recipients who are forced to leave their own home due to extreme circumstances, such as natural disaster, or who are victims of domestic violence, newly released prisoners or newly arrived humanitarian entrants.</p>	<p>Equivalent to one week's payment of the person's income support payment without add-ons.</p>	<p>Must claim within 7 days after the event leading to the Crisis Payment claim.</p>
Other supplementary payments		
<p><i>Mobility Allowance</i></p> <p>Is a non-means tested income supplement for people with disability who are aged 16 or over and who are unable to use public transport without substantial assistance.</p>	<p>There are two rates of Mobility Allowance.</p> <p>Basic rate: \$75.90 per fortnight</p> <p>Higher rate: \$106.20 per fortnight</p> <p>Non-taxable.</p>	<p>Standard rate — must be engaged in approved activity for at least 32 hours every four weeks (combination of employment, voluntary work or vocational training).</p> <p>Higher rate — must be in receipt of DSP, NSA, YA (other) and working at least 15 hours a week or looking for such work.</p>

Payment type	Payment rates	Other features
<p><i>Carer Allowance</i></p> <p>Is for people who provide daily care and attention at home to a person with disability or medical conditions who is: aged 16 or over with substantial functional impairment; or a dependent child under age 16 who needs substantially more care than a child without disability.</p> <p><i>Child Disability Assistance Payment (CDAP)</i> is available to recipients of CA (child) at 1 July each year.</p>	<p>\$100.60 per fortnight.</p> <p>Child Disability Assistance Payment (CDAP): \$1,000 per annum.</p> <p>Non means-tested.</p> <p>Non taxable.</p> <p>Carer Allowance is indexed annually. CDAP is not indexed.</p>	<p>The child and the carer must live together in the same private residence, or if the child is hospitalised, there must be an intention for the child to return home to live with the carer.</p> <p>CDAP is intended to help with the purchase of support, aids, intervention, therapies or respite care.</p>
<p><i>Carer Bonus Payments</i></p> <p>Carer Payment — one-off lump sum bonus paid to recipients of: Carer Payment; DVA Carer Service Pension; or Wife Pension and Carer Allowance; or DVA Partner Service Pension and Carer Allowance.</p> <p>Carer Allowance — one-off lump sum bonus paid to Carer Allowance recipients.</p>	<p>\$1,000 - Carer Payment recipients.</p> <p>\$600 - Carer Allowance recipients.</p> <p>Non-taxable.</p>	<p>Paid by June 30 after the following Budget speeches:</p> <p>2004-05</p> <p>2005-06</p> <p>2006-07</p> <p>2007-08</p> <p>2008-09</p>
<p><i>Seniors Bonus payments</i></p> <p>Eligible recipients vary between years.</p> <p>In 2008, eligible recipients include: income support recipients of Age (or Service) Pension age; recipients of Mature Age, Partner and Widow Allowances; and people who qualify for Seniors Concession Allowance. In 2008, the one-off payment was extended to recipients of Wife Pension and Widow B Pension.</p>	<p>In June 2008, the Seniors Bonus payment was \$500.</p> <p>Non-taxable.</p>	<p>Bonus (or similar bonus) paid by June 30 after the following Budget speeches:</p> <p>2006-07</p> <p>2007-08</p> <p>2008-09</p>

