Aoc 28/7/08

Submission No. 1109
(Inq into better support for carers)

Inquiry into Better Support for Carers

Department of Families, Housing, Community Services
and Indigenous Affairs; Department of Health and
Ageing; and Department of Veterans' Affairs

Submission to the House of Representatives Standing
Committee on Community Affairs, Housing and Youth

July 2008

1 INTRODUCTION

The Australian Government Departments of Families, Housing, Community Services and Indigenous Affairs; Health and Ageing; and Veterans' Affairs welcome this Inquiry into Better Support for Carers.

This submission uses examples from Australia's current evidence base to:

- identify the roles and contributions of carers in society, including the main groups of carers in Australia;
- provide an overview of existing Australian Government support for carers and their families; and
- introduce key topics for consideration.

An outline of other work of relevance currently being progressed jointly at the Australian Government level and individually by the Departments party to this submission is also provided.

2 ROLE AND CONTRIBUTION OF CARERS IN SOCIETY

2.1 THE CARING ROLE

The Australian Bureau of Statistics (ABS) 2003, *Disability, Ageing and Carers, Australia, cat.no.4430.0* (SDAC), is Australia's best source of data on carers and people with a disability. It is a population based survey carried out regularly, most recently in 2003.[1] It provides reasonably well accepted definitions of carers within Australia, which will be used throughout this submission.

The ABS defines:

- "a carer", as a 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;
- "all carers", as people who provide unpaid, informal assistance, to people with disabilities, medical conditions and the frail aged, unless otherwise stated; and
- "a primary carer", as 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]

In addition to SDAC, data and research is provided from other sources throughout this submission. The main sources being:

- Centrelink administrative data for carers who receive an Australian Government payment directed towards carers (Carer Payment and/or Carers Allowance) as at June 2008; and
- The Australian Institute of Family Studies 2008 *Research Report no 16: The nature and impact of caring for family members with disability (AIFS 2008).* This report is based upon data from a nationally representative survey, conducted in 2006, of 1,002 carers who receive an Australian Government payment directed towards carers (Carer Payment and/or Carer Allowance). Carers were selected from a random sample of 5,000 carers from Centrelink administrative data who, at June 2006, were receiving Carer Payment and/or Carer Allowance.

2.2 CARER DEMOGRAPHICS

In 2003, there were nearly 2.6 million carers (12 per cent of the population), providing help or assistance to people in need of care due to disability, medical conditions or age. Of these:

- 20 per cent (or nearly 475,000 people) were primary carers;
- 54 per cent of all carers were female;
- 71 per cent of primary carers were female;
- 4 per cent of primary carers were aged less than 25 years;
- 73 per cent of primary carers were aged between 25 and 64 years;
- 24 per cent of primary carers were aged 65 years and over; and
- 80 percent of primary carers lived in the Eastern states.[3]

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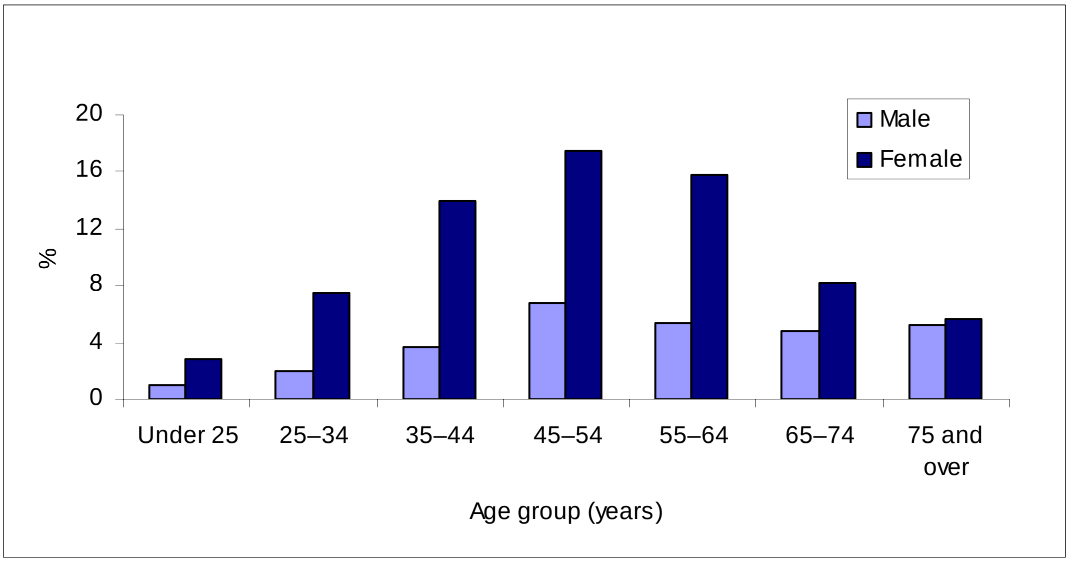
[1] The SDAC is a reliable source of data on the numbers of self-identified carers, however, not all carers may choose to identify themselves as such in surveys, with some seeing their role primarily as spouse, son, daughter, friend etc. This suggests there may be an under-estimation of the number of carers in population based surveys, such as the SDAC, and that there is a cohort of 'hidden' carers that are currently unquantified.

[2] Australian Bureau of Statistics (ABS) 2003, *Disability, Ageing and Carers, Australia: Summary of Findings, cat.no.4430.0*

[3] ibid.

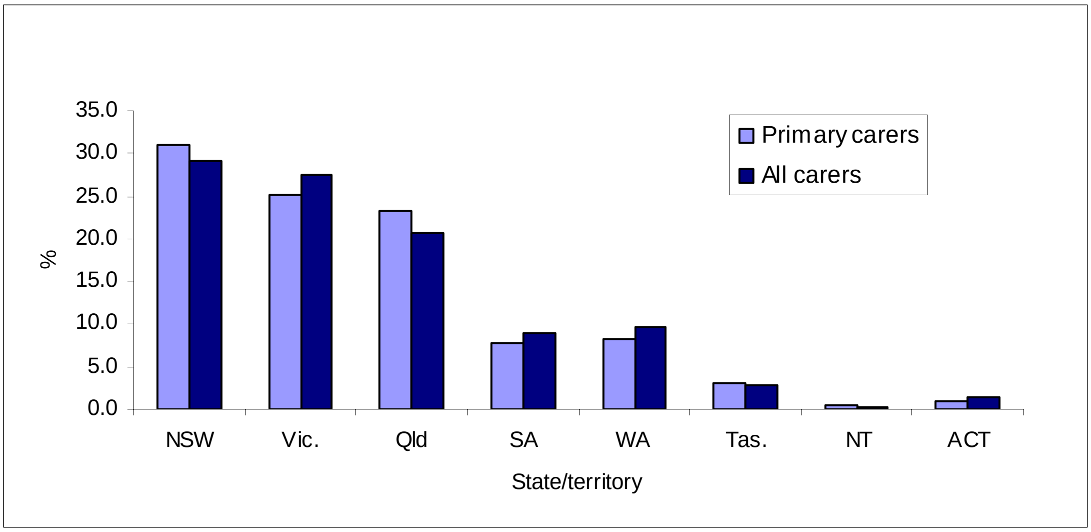
Chart 1: Age distribution of primary carers by gender



Source: ABS, SDAC, 2003

Chart 1 identifies the age distribution of primary carers by gender in 2003. This highlights the significance of women as carers, with the peak age group for women to be in a caring role being 45 to 54 years. Women aged 35 to 64 years comprised 47 per cent of all primary carers. The gender balance of primary carers became more even for older carers with 10 per cent of men and 14 per cent of women aged 65 and over being primary carers.[4]

Chart 2: Location of carers in the states and territories



Source: ABS, SDAC, 2003

Chart 2 highlights the jurisdictional location of all carers and primary carers. In 2003, 80.4 per cent of primary carers lived in the Eastern states with the remaining 19.6 per cent residing in Western Australia (8.3 per cent); South Australia (7.8 per cent); Tasmania (3.1 per cent) and the Northern Territory (0.4 per cent).[5] The jurisdictional location of all carers and primary carers is in line with general ABS population statistics.

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[4] ibid.

[5] ibid.

2.3 ONSET AND DIVERSITY OF CARE SITUATIONS

Each caring situation is different and there is no one way to adequately describe the diverse and complex relationships that exist in caring situations. Some carers provide care for short periods of time, such as for a person with an acute medical condition, or for longer periods, such as a parent caring for a child with a lifelong condition.

Caring situations may evolve over many years, such as caring for a frail, ageing parent with diminishing health and functional ability or they may be co-dependent, such as older couples living and ageing together. Some carers, known as multi-generational or sandwich carers, undertake a dual caring role for both their children and frail aged parents.

The onset of caring situations may also occur quite unexpectedly, at any time. These situations arise from (but are not limited to) car accidents, heart attacks, stroke, birth of a child with a disability or the breakdown of existing care arrangements such as the death or illness of a carer. Caring situations can also be episodic requiring people to care for short periods of time and at different intervals.

2.4 RELATIONSHIP OF CARER AND CARE RECEIVER

Relationships between the person who provides care and the person who receives care are diverse. They occur between people of all ages and at all life stages. AIFS 2008 reported that many carers experience positive results from caring including the benefits of good family functioning and how this can play a protective role for the carer and promote positive outcomes for the person with a disability and other household members.[6]

In 2003, the most common reasons for taking on the caring role were because of family responsibility and a personal belief of carers that they could provide better care in the home than formal or community based care services. In 2003, 78 per cent of primary carers were caring for immediate family members (parent, child and partner) and lived in the same household as the care recipient.[7]

Chart 3 identifies the relationship of primary carers to care recipients. The majority, 41 per cent, provided care to their spouse or partner, whilst the remaining carers provided care to children with a disability (25.8 per cent), their parents (23.4 per cent) or other relatives, friends or neighbours (9.8 per cent).[8]

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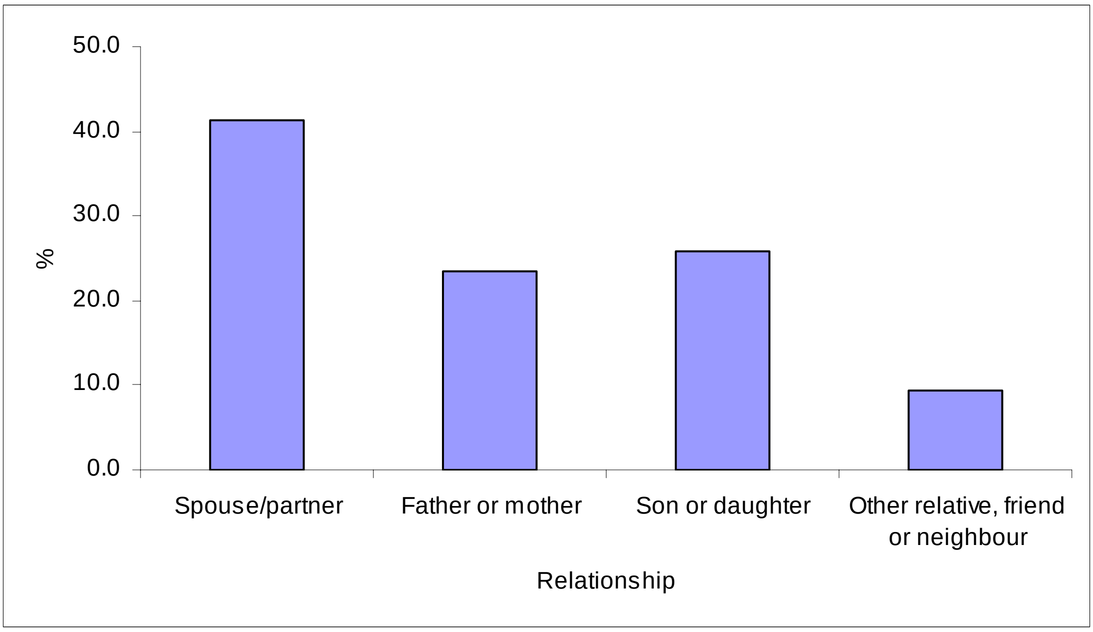
[6] Australian Institute of Family Studies 2008, Research Report no.16: The nature and impact of caring for family members with a disability in Australia, p37

[7] Australian Bureau of Statistics (ABS) 2003, *Disability, Ageing and Carers, Australia: Summary of Findings, cat.no.4430.0*

[8] ibid.

Chart 3: Relationship of primary carer to the care receiver



Source: ABS, SDAC, 2003

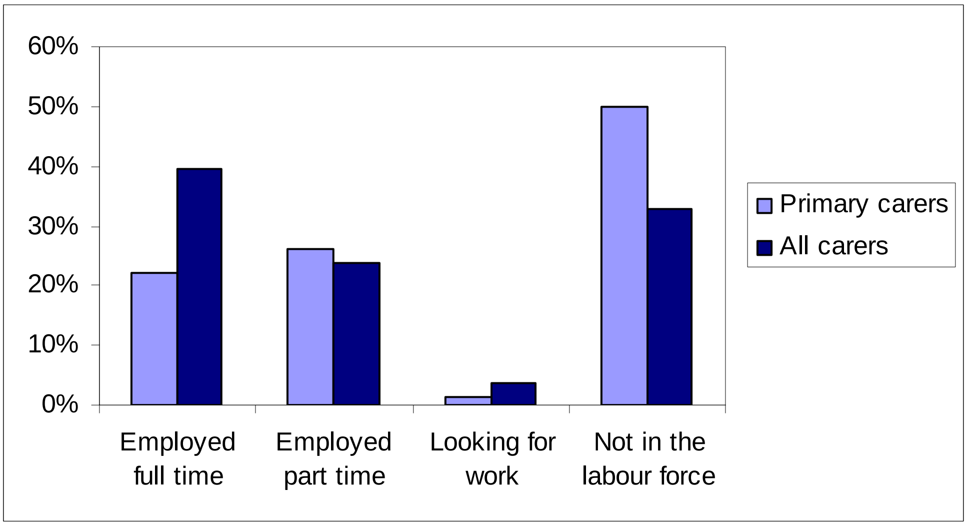
2.5 CARER GROUPS OF INTEREST

The Inquiry will look into the needs of particular groups within the caring population. To assist the Inquiry relevant data and research has been provided on the following carer groups: employed carers; older carers; culturally and linguistically diverse carers; young carers; sandwich carers; and Indigenous carers.

2.5.1 Employed Carers

In comparison to the general population, carers have lower rates of labour force participation than those without caring responsibilities. Primary carers have lower rates of labour force participation than all carers.

Chart 4: Carers' labour force participation



Source: ABS, SDAC, 2003

Chart 4 highlights the employment patterns of all carers and primary carers. It identifies that in 2003, 50 per cent of primary carers were not in the labour force, compared to 33 per cent of all carers. Primary carers were also less likely to be working full-time: 22 per cent of primary carers worked full-time compared to 40 per cent of all carers. The proportion of primary and all carers working part-time was more even. Twenty six per cent of primary carers worked part-time compared to 24 per cent of all carers.[9]

AIFS 2008 highlighted a continuing trend from 2003 that female carers are more likely to be employed on a part-time basis and tend to temporarily give up work to care for a family member with a disability.[10]

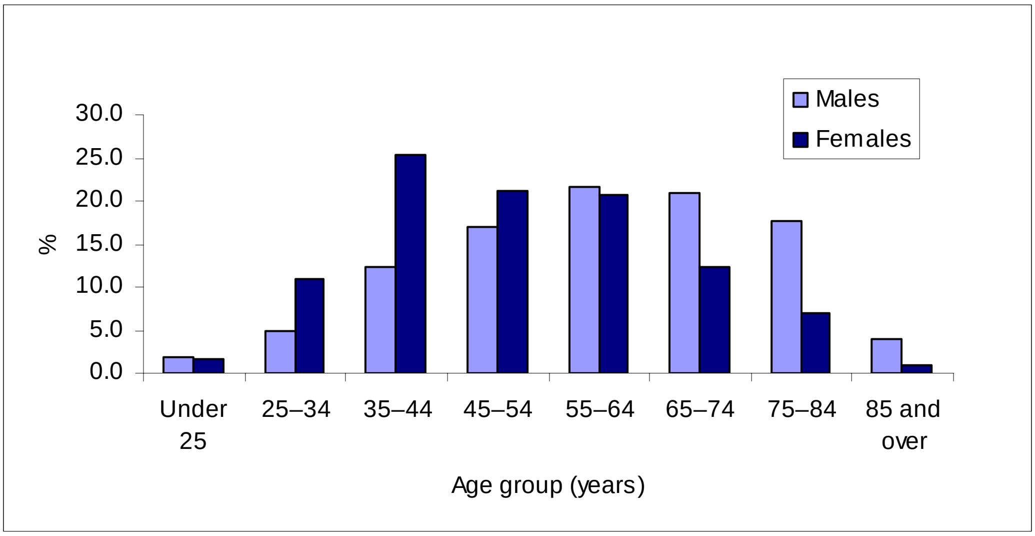
2.5.2 Older Carers

SDAC reported that in 2003, nearly 454,000 carers, or 17 per cent of the carer population, were aged 65 years and over.[11] Approximately four per cent of these carers, or 17,500 people, were primary carers providing between 20 and 40 hours of care each week.[12]

A major difference between older carers and the general carer population was the difference in the gender ratio of primary carers. In 2003, 42 per cent of older primary carers were male.[13] From the age of 65, the ratio of male primary carers increased, with the ratio of male carers becoming almost equal to the ratio of female carers.

Chart 5, based on Centrelink administrative data for people receiving Carer Allowance, highlights the age and gender distribution of Carer Allowance recipients. It identifies that at June 2008, more than 25 per cent of Carer Allowance recipients were older carers, aged 65 years and older.

Chart 5: Carer Allowance Recipients by Age and Gender (June 2008)



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[9] Australian Bureau of Statistics (ABS) 2003, *Disability, Ageing and Carers, Australia: Summary of Findings, cat.no.4430.0*

[10] Australian Institute of Family Studies 2008, *Research Report no.16: The nature and impact of caring for family members with a disability in Australia*, p107

[11] Australian Bureau of Statistics (ABS) 2003, *Disability, Ageing and Carers, Australia: Summary of Findings, cat.no.4430.0*

[12] ibid.

[13] ibid.

The Australian Government 2007 *Senate Inquiry into the Funding and Operation of the Commonwealth State/Territory Disability Agreement* highlighted the pressing concern for older carers of what will happen to their loved one when they are no longer able to provide care themselves. [14] Research undertaken by the Centre for Health Service Development in 2007 entitled *Effective Caring: A synthesis of the international evidence base on carer needs and interventions* confirmed that becoming unable to care for a life partner or dependent son or daughter can cause significant anxiety and practical difficulties for older carers, confirming the importance of appropriate psychosocial interventions and the ability to detect depression in this group.[15]

From a health perspective, primary carers over the age of 65 years suffer higher levels of severe or profound restriction in the activities of self care, communication or mobility than their younger counterparts.

Research conducted by Carers Australia and Carers Victoria in 2005[16] indicates that older carers are self reliant with strong values in relation to personal responsibility. As such, they tend to be less reliant on formal services, usually contacting services only at crisis point.

In 2007, the Department of Families, Housing, Community Services and Indigenous Affairs identified similar findings through its implementation of the Transition Support Measure of the

with older carers to identify their future needs; assist them with the development of future care plans (where appropriate); and to talk with them about what supports would be required to enable them to continue providing care in their own homes. The TSWs reported that:

- over a quarter of older carers were ‘hidden carers’, that is, they were not connected or known to service providers;
- a significant number of older carers were struggling in their caring role due to their own failing health and increasing frailty and their own social support needs were neglected due to their caring responsibilities;
- due to the long term nature of the care arrangements, the degree of care required and the intensity of the relationship, there was often an inability on the part of the carer to pursue activities outside of the home, for example with formal work, community activities and friends - this was exacerbated by a lack of service connection and lack of transport;
- the relationship between carer and care receiver was often very complex with interwoven issues of co-dependence, mutual caring and multiple caring situations; and
- a significant number of carers stated they had not thought about, nor did they wish to think about, the future, and therefore future care plans were not in place.

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[14] Australian Government 2007, *Senate Inquiry into the Funding and Operation of the Commonwealth State/Territory Disability Agreement*, p120

[15] Eager K et al. 2007, *Effective Caring: a synthesis of the International evidence on carer needs and interventions.* Centre for Health Service Development, University of Wollongong

[16] Carers Victoria 2005, *Who Will Look After Her When I Die?: Report on the Ageing Carers of People with a Disability Project*; and Carers Australia 2005, *Ageing carers: Succession planning and long term needs, a response to the Federal Government’s Budget Initiative 2005-09*

2.5.3 Culturally and Linguistically Diverse Carers

SDAC reported that in 2003, there were nearly 365,000 culturally and linguistically diverse (CALD) carers. Of these, 76,000 people, or 20 per cent of CALD carers, were primary carers.[17] CALD carers represented 14 per cent of the total carer population. In comparison, people from CALD backgrounds comprised 22 per cent of Australia's population.[18]

CALD carers can also be identified through Centrelink administrative data which shows that in June 2008 there were 97,992, or 23.2 per cent of, Carer Allowance recipients from CALD backgrounds.

The *Supporting CALD Carers* research, undertaken by the Ethnic Disability Advocacy Centre in 2003, provides some insight into the issues and barriers faced by CALD carers of people with a disability. For example, the report found CALD carers were not familiar with the Western notion of disability and care; commonly referred to caring as a "natural duty", as a mother caring for her children, children caring for their parents, brother or sister caring for their siblings; and felt mainstream service providers lacked cultural sensitivity and reported language barriers.[19]

2.5.4 Young Carers

SDAC reported that in 2003, there were 340,000 young people under 25 years providing informal care to people with a disability, approximately 20,000 of these were primary carers. Young carers represented 13 per cent of the total carer population and the majority of young primary carers were female, aged between 18 and 25 years.[20]

Young carers can also be identified through Centrelink administrative data which shows that in June 2008 there were 7,294, or 23.2 per cent of, Carer Allowance recipients under 25 years.

Carers Western Australia's report: *Hopping off the Roundabout: Supporting Young Carers in Western Australia, A report of the findings from the young carers roundtable,* identified that some young carers begin caring from as young as five years of age, although most young carers (18 years or less) were aged between 10 and 13 years. In addition, care responsibilities took, on average, six hours per day with young carers possibly undertaking care for up to 14 years.[21]

In 2002, Carers Australia's *Young Carers Research Project: Final Report* found that in 1999 only four per cent of primary young carers aged between 15 and 24 years were still in education, compared with 23 per cent of other young people.[22] The research also provided examples of other effects of young caring, including poor physical health due to stress, limited sleep and inappropriate lifting and limited capacity to develop meaningful friendships because of social isolation. [23]

The Australian National Youth Roundtable 2006: *A Current Perspective: What services and young people say about best practice and gaps for young carers in Australia,* found many young carers felt that the services offered were not appropriate and that service providers lacked awareness and recognition of their circumstance.[24]

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[17] Australian Bureau of Statistics (ABS) 2003, *Disability, Ageing and Carers, Australia: Summary of Findings, cat.no.4430.0*

[18] Australian Bureau of Statistics 2006, *Census QuickStats: Australia*

[19] Ethnic Disability Advocacy Centre 2003, *Supporting CALD Carers,* pp20-25

[20] Australian Bureau of Statistics (ABS) 2003, *Disability, Ageing and Carers, Australia: Summary of Findings, cat.no.4430.0*

[21] Carers Western Australia 2007, *Hopping off the Roundabout: Supporting Young Carers in Western Australia, A report of the findings from the young carers round table 2007,* p3

[22] Carers Australia 2002, *Young Carers Research Project: Final Report,* p3

[23] ibid., pp11-12

[24] The Australian National Youth Roundtable 2006, *A Current Perspective: What services and young people say about best practice and gaps for young carers in Australia,* p16

2.5.5 Sandwich Carers

Sandwich carers include those carers who provide care for their own dependent children as well as their ageing parents. There are substantial variations in evidence on the number of sandwich carers in Australia.

SDAC reported that in 2003, there were 33,400 primary sandwich carers aged between 25 and 64 years.[25] However, in 2006, the National Centre for Social and Economic Modelling report, *The Cost of Caring in Australia 2002 to 2005* (NATSEM 2005) suggested there were about 720,000 Australians with dual responsibility of caring for children and for another person with a disability or frail aged. About 40 per cent of these carers were aged between 35 and 44 years and likely to be caring for their child and their parent.[26]

In contrast to the other carer groups, sandwich carers have very high rates of full-time employment. An analysis of SDAC data shows that in 2003, 38.9 per cent of primary sandwich carers aged between 25 and 64 years, worked full-time, while another 30 per cent, worked part-time.[27]

The *Household, Income and Labour Dynamics in Australia Survey* (HILDA), *Wave 3*,[28] identifies that adult carers who worked part-time were far more likely to report child dependency as a reason for not working full-time than adult care. HILDA also reported that among those not in the labour force with adult care responsibility, care was the reason for not working for only one in three of these carers.

Conversely, the Human Rights and Equal Opportunity Commission report, *It's About Time: Women, men, work and family* (HREOC 2007) analysed anecdotal evidence to highlight the difficulties faced by sandwich carers in accessing employment and continuing in paid work. [29]

2.5.6 Indigenous Carers

The ABS 2006 *Census of Population and Housing* provides the most comprehensive data on Indigenous carers, however, these statistics should be viewed with caution given the self identification emphasis of the survey. It reported that in 2006 there were 32,581 Indigenous carers providing informal assistance to people with a disability, 20,578 of these were women.[30]

Indigenous carers can also be identified through Centrelink's Carer Payment and Carer Allowance administrative data. **Chart 6** identifies that in June 2008, there were 4,812 Indigenous carers receiving Carer Payment and 9,561 Indigenous carers receiving Carer Allowance. Since 2003, there has been a 128 per cent increase in Indigenous carers receiving Carer Payment and a 78 per cent increase in carers receiving Carer Allowance. Overall increases for Carer Payment and Carer Allowance were 72 per cent and 41 per cent respectively.[31]

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[25] Australian Bureau of Statistics (ABS) 2003, *Disability, Ageing and Carers, Australia: Summary of Findings, cat.no.4430.0*

[26] National Centre for Social and Economic Modelling (NATSEM) 2005, *Income and Wealth Report, Issue 13 May 2006, The Cost of Caring in Australia 2002 to 2005,* p4

[27] Australian Bureau of Statistics (ABS) 2003, *Disability, Ageing and Carers, Australia: Summary of Findings, cat.no.4430.0*

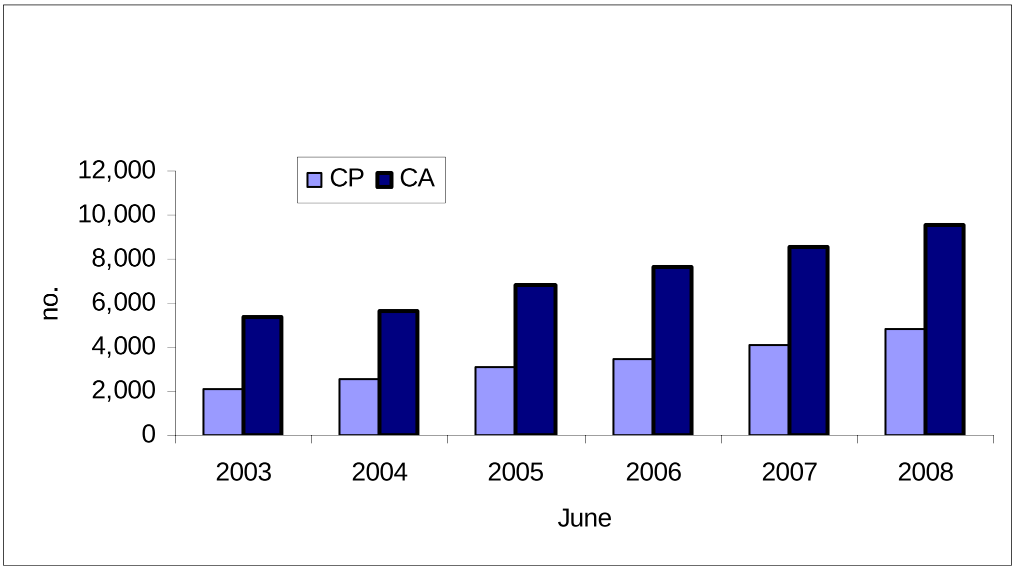
[28] Department of Families, Housing, Community Services and Indigenous Affairs 2003, *Household, Income and Labour Dynamics in Australia (HILDA) Survey, Wave 3*

[29] Human Rights and Equal Opportunity Commission 2007, *It's About Time: Women, men work and family,* p93

[30] Australian Bureau of Statistics (ABS) 2006, *Census of Population and Housing*

[31] Centrelink June 2008, *Carer Payment Administrative Data*; and Centrelink June 2008, *Carer Allowance Administrative Data*

Chart 6: Indigenous Carer Payment and Carer Allowance Recipients



Source: Centrelink Administrative Data, June 2008

There is limited research into the characteristics and needs of Indigenous carers. However, Carers Victoria's 2005 report: *Be with us, Feel with us, Act with us: Counselling and support for Indigenous carers*, provided some insight into the experience of Indigenous carers. The report highlighted that Indigenous carers experience heightened levels of depression, grief, isolation, worsening health and wellbeing. Anecdotally, it also found many older Indigenous people were caring for grandchildren, and that those living in remote communities relied on other family members (not Government services) for assistance.[32]

2.6 VALUE OF INFORMAL CARE

All carer groups referred to above make a valuable contribution to society through the provision of unpaid care to family members, friends and neighbours.

In 2005, Access Economics explored the economic value of informal care for people with a disability, chronic illness or the frail aged. Its study, *The Economic Value of Informal Care* (Access Economics 2005) provides preliminary insight into the issue of the economic value of informal care. The study found that replacing all informal care with formal care would cost the economy $30.5 billion annually.[33]

2.7 CARER RECOGNITION

This Inquiry has been asked to report on the role and contribution of carers in society and how this should be recognised. The *Carer Payment (child)*: *A New Approach, Report of the Carer Payment (child) Review Taskforce*, 2007[34] recommended the Australian Government recognise the role of carers and introduce carer recognition legislation and a national action plan for carers.

Some state and territory government jurisdictions have passed Carer Recognition Acts to set a legislative standard for the treatment of carers by Government services and some have amended their Anti-Discrimination Acts to ban discrimination on the basis of caring duties. Others have introduced action plans that outline a whole of government commitment to recognition and support of carers.

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[32] Carers Victoria 2005, *Be with us, Feel with us, Act with us: Counselling and support for Indigenous carers*, p15

[33] Access Economics 2005, *The Economic Value of Informal Care*, pp10-18

[34] Australian Government 2007, *Carer Payment (child): A New Approach, Report of the Carer Payment (child) Review Taskforce*

HREOC 2007 recommended the introduction of federal legislation to provide labour force protection for employees with family and carer responsibilities and ensure a right for them to seek flexible work arrangements.[35] Also, the Taskforce on Care Costs 2007 report: *The hidden face of care*, recommended a new legislative framework for carers, finding that current federal and anti-discrimination laws did not provide sufficient protection for employees with caring responsibilities, nor promote flexible work practices.[36]

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[35] Human Rights and Equal Opportunity Commission 2007, *It's About Time: Women, men work and family*, pxvii

[36] Taskforce on Care Costs 2007, *The hidden face of care*, p5

3 AUSTRALIAN GOVERNMENT SUPPORT FOR CARERS

The Australian Government's view is that all people should be able to participate as valued members of society. Support provided by the Australian Government to carers is designed to provide financial assistance and services to assist carers to perform their caring responsibilities and to have the choice to participate in the community and labour force.

Australian Government support is provided through two arms:

- the income support system; and
- programs and services.

In reviewing the support needs of carers as part of the Inquiry it is important to consider the respective roles that income support and services can most appropriately play. The role of the income support system is to assist those without the means or opportunity to support themselves to achieve a basic standard of living.

The wider social protection system also encompasses assistance through programs and services to assist with more complex needs.

3.1 INCOME SUPPORT SYSTEM

The Australian Government is responsible for the income support system. Australia's income support system is non-contributory and provides 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.

The Department of Families, Housing, Community Services and Indigenous Affairs has policy responsibility for Australia's income support payments and supplements for carers – Carer Payment; Carer Allowance; Child Disability Assistance Payment; Carer Bonus; and Carer Adjustment Payment. These are delivered through Centrelink, the Australian Government agency responsible for delivering a range of social welfare payments and services.

3.1.1 Income Support and Supplementary Payments

3.1.1.a Carer Payment

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. Like other income support payments, Carer Payment is targeted at those most in need.

There are two streams of Carer Payment available: Carer Payment (adult) and Carer Payment (child). Both are subject to an income and assets test and are paid at the same rate as other social security pensions.

At 1 July 2008, the maximum single rate of Carer Payment was $546.80 and the maximum partnered rate was $456.80 per fortnight. For those below age pension age, the payment is not taxable.

Income testing arrangements mean that carers who participate in the labour force may have their Carer Payment reduced when their income level reaches a prescribed level, and the payment can stop altogether if the carer earns more than the upper level of the income test.

A person on Carer Payment can have other income up to $138 per fortnight before their payment starts to be reduced. This income test free area is adjusted each year in July for increases in the cost of living using the Consumer Price Index. For each dollar of income over this amount, the payment is reduced by 40 cents. Currently a part payment is payable up to an income of $1519.50 a fortnight for a single person.

A couple who are both receiving income support can have other income up to $240 a fortnight (combined) before their payments start to be reduced. This means that for a couple their individual payments are reduced by 20 cents a fortnight for each dollar of combined income that the couple has over the income test free area. Currently, a part payment is payable up to a combined income of $2538.50 a fortnight for a couple both receiving income support.

To be eligible for Carer Payment (adult) a person must be providing constant care to a person aged over 16 years using the Adult Disability Assessment Tool (ADAT). It is designed to provide access to Carer Payment for carers of people with similar levels of disability, even where the cause and type of disability differ. The ADAT measures the amount of help required to undertake activities of daily living, such as mobility, communication, hygiene, eating and a range of cognitive and behavioural areas. This may include supervising and prompting the care receiver to undertake these daily activities.

To be eligible for Carer Payment (child) a person must be providing care to children aged under 16 years who have a profound disability, or for two or more children who, together, require a level of care that is at least equivalent to the level of care required by a child with a profound disability. In broad terms, the child must meet: terminal condition criteria that relate to a life expectancy of not greater than 12 months; three out of seven specific medial and physical circumstances; and at least one of three conditions to do with dangerous, deviant, aggressive or violent behaviour.

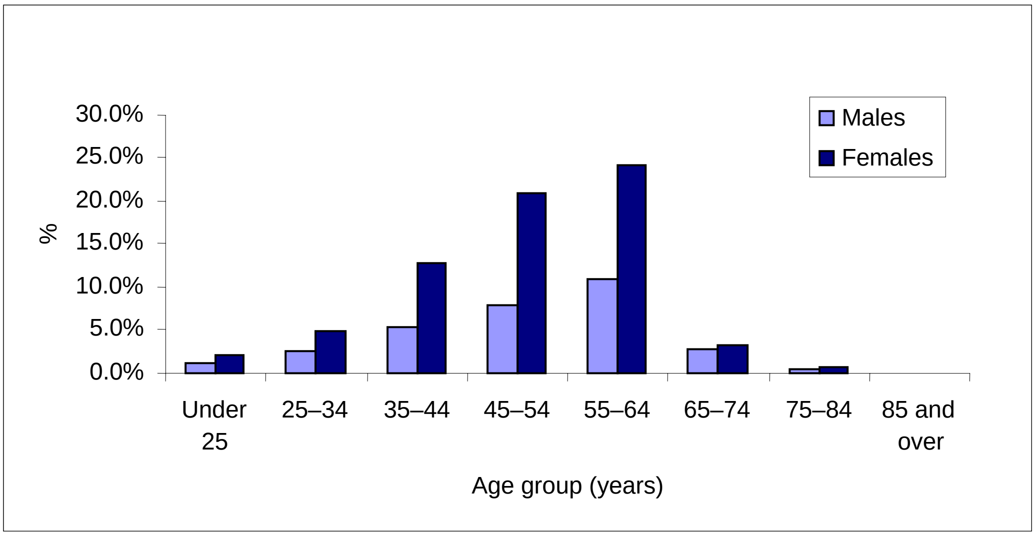
In June 2007, 96 per cent of Carer Payment recipients received Carer Payment (adult) and only four per cent received Carer Payment (child). Last year, the Australian Government established the *Carer Payment (child) Review Taskforce* to investigate this imbalance, examine eligibility for Carer Payment (child) and to determine its effectiveness in providing a safety net for carers of children with a profound disability or severe medical condition.

The Taskforce reported on a number of carers who were caring for one or more children with very high care needs, and whose intensive caring responsibilities prevented them from substantial workforce participation, but who did not meet the eligibility criteria for Carer Payment (child). Some of these carers were in receipt of other income support payments, mainly Parenting Payment.

The Government’s response to the Taskforce’s report, *Carer Payment (child): A New Approach, Report of the Carer Payment (child) Review* is provided at **Appendix 1** and discussed later in this submission. Last year, nearly 4,000 carers described their experiences in submissions to the Taskforce. These submissions inspired The *Carers Storybook* which is dedicated to those families and is provided at **Appendix 2.**

Chart 7 highlights the characteristics of people receiving Carer Payment. In June 2008, the majority of Carer Payment recipients were aged between 45 and 64 years. Like Carer Allowance (see Chart 5), the ratio of male carers becomes almost equal to the ratio of female carers from the ages of 65 plus.[37]

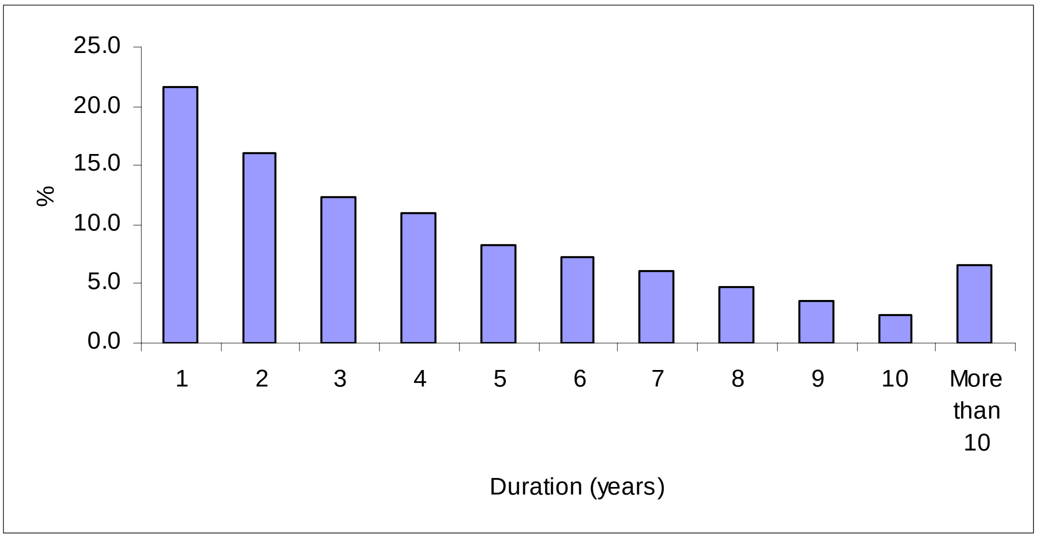
Chart 7: Carer Payment recipients by age and gender



Source: Centrelink Administrative Data, June 2008

Chart 8 illustrates that at June 2008 the majority of Carer Payment recipients had been receiving Carer Payment for one year or less. This percentage then steadily decreased from one year to 10 years of caring. Nearly 70 per cent of Carer Payment recipients had been in receipt of Carer Payment for five years or less, with the average time spent on payment being four years. More than six per cent of Carer Payment recipients were still receiving Carer Payment after 10 years.[38]

Chart 8: Duration on Carer Payment



Source: Centrelink Administrative Data, June 2008

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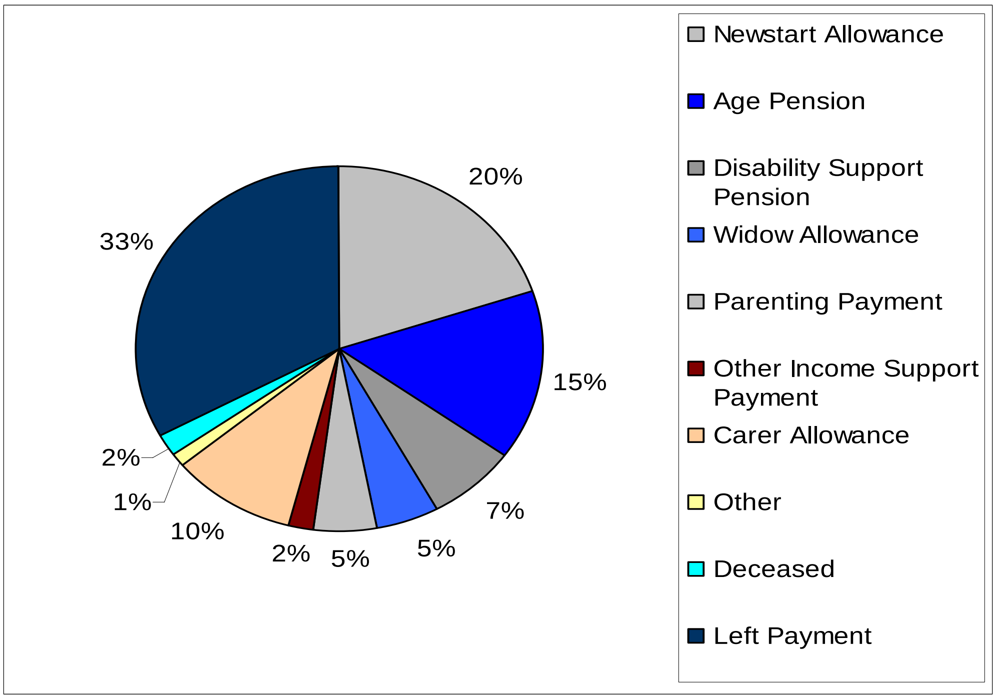
[37] Centrelink June 2008, *Carer Payment Administrative Data*
[38] Centrelink June 2008, *Carer Payment Administrative Data*

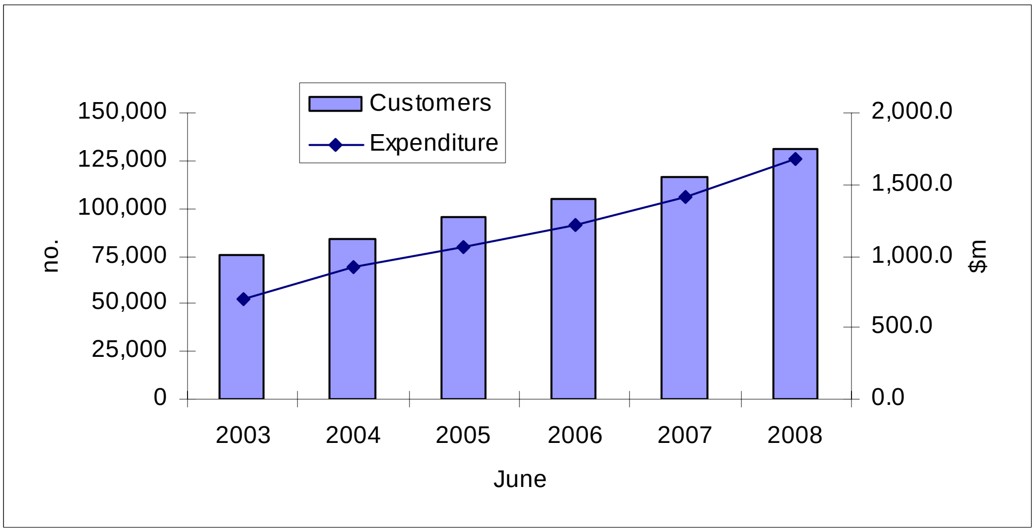
Chart 9: After Caring



Source: Centrelink Administrative Data, June 2007

Chart 9 provides a snap shot of what happens to carers at the end of their caring, when they are no longer eligible for Carer Payment. It is based on administrative data from June 2007.
At 30 June 2006, there were 105,662 people receiving Carer Payment. One year later, at 30 June 2007, 16,797 or 16 per cent, were no longer receiving Carer Payment. Of these, 42 per cent had transferred to other forms of income support: 20 per cent to Newstart Allowance; 15 per cent to Age Pension; and 7 per cent to Disability Support Pension. Thirty three per cent had exited the income support system.

Chart 10: Carer Payment Recipients and Expenditure



Source: Centrelink Administrative Data, June 2008

Chart 10 highlights the large growth in the number of people accessing Carer Payment over the last six years. As a result, expenditure on this payment has also increased significantly. Since 2002-03, the number of people on Carer Payment has grown by 72 per cent (from 75,937 recipients in 2002-03 to 130,657 in 2007-08) and expenditure has increased by 138 per cent (from $702 million in 2002-03 to over $1.6 billion in 2007-08).[39]

These increases reflect:

- demographic changes, such as the ageing of the population, and the associated increase in the incidence of people suffering from a disability;
- an increase in the number of people with a disability and medical conditions being cared for at home;
- changes to qualification criteria that have extended eligibility of this payment to a wider group, and
- greater public awareness of the payment, including through publicity surrounding the payment of carer bonuses in the last five budgets.[40]

The increase in Carer Payment is substantial, especially when compared to growth in the Age Pension and Disability Support Pension over the same period. In contrast, over the last five years, Age Pension recipients have increased by five per cent and Disability Support Pension recipients have increased by six per cent.[41]

3.1.1.b Carer Allowance

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.

Like Carer Payment, two streams of Carer Allowance exist: Carer Allowance (adult) and Carer Allowance (child). Carer Allowance is not taxable, not subject to an income and assets test, and can be paid in addition to Carer Payment or other social security income support payments. At 20 March 2008, the rate of payment was $100.60 per fortnight.

There are different assessment methods for Carer Allowance (adult) and Carer Allowance (child). The assessment process for Carer Allowance (adult) is the same as the assessment process for Carer Payment (adult).

For Carer Allowance (child) there are two stages of assessment, which are different from the assessment processes for Carer Payment (child). First the child is assessed against the Lists of Recognised Disabilities (LORD). The LORD contains certain disabilities and medical conditions that are consistently severe enough to qualify the parent or carer for the allowance. Second, where the child’s medical condition or disability is not on the LORD, they are assessed using the Child Disability Assessment Tool. The tool measures the severity of disability by assessing whether the child functions according to standards appropriate to their age. The child’s ability is measured in a series of functional categories: language skills, self-care skills, social and community skills, and fine and gross motor skills. Additionally, behaviour is taken into account where it is significantly affected by the disability, along with special care needs.

Carer Allowance can only be paid to the same carer in relation to the care they provide for up to two adults with disabilities. However, there is no limit on the number of dependent children in relation to whom a parent can be paid Carer Allowance. A person can receive Carer Allowance for up to two adults and any number of dependant children.

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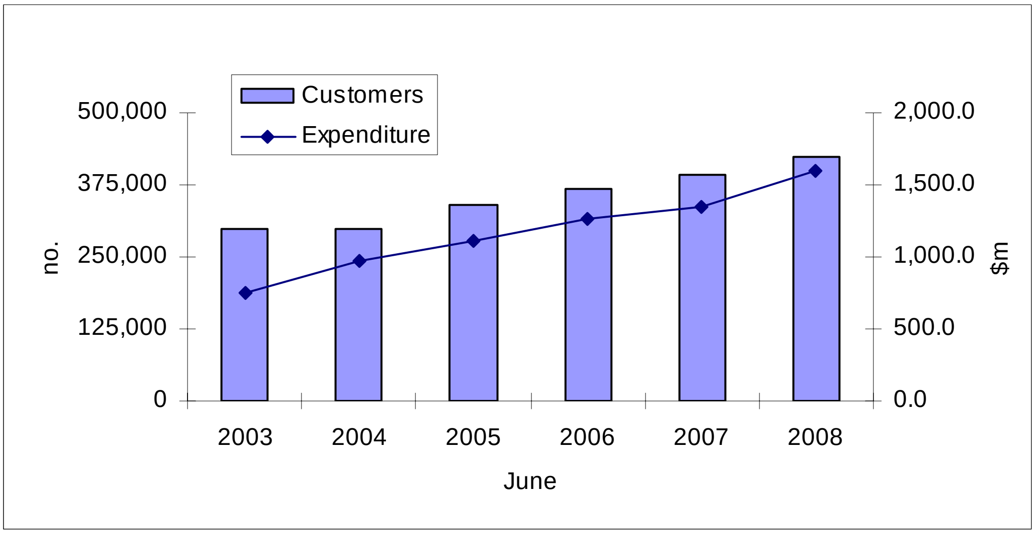
[39] Centrelink June 2008, *Carer Payment Administrative Data*

[40] Australian Institute of Family Studies 2008, *Research Report no.16: The nature and impact of caring for family members with a disability in Australia*, pp7-8

[41] Centrelink June 2008, *Carer Payment Administrative Data*

Like Carer Payment, there has been a significant increase in the number of Carer Allowance recipients and payment expenditure over the last six years. **Chart 11** reveals a 41 per cent increase in Carer Allowance recipients (from 299,609 recipients in 2002-2003 to 422,905 recipients in 2007-2008) and a 114 per cent increase in expenditure (from $744 million in 2002-2003 to $1.6 billion in 2007-2008).[42] In addition, most Carer Allowance recipients remain in receipt of the allowance for five years or less. The average duration on the payment is nearly four years.

Chart 11: Carer Allowance recipients and expenditure



Source: Centrelink Administrative Data, June 2008

3.1.1.c Child Disability Assistance Payment

The Child Disability Assistance Payment is a $1,000 annual payment for each child with a disability under 16 years who attracts a payment of Carer Allowance for their carer.

The intent of the payment, first paid in October 2007, is to assist families to purchase the support, aids, intervention, therapies or respite that they require for their child with a disability.

The Child Disability Assistance Payment is not subject to income tax, nor does it count as income for social security or family assistance purposes. As at January 2008, 135,920 payments had been made at a cost of $135.920 million.

3.1.1.d Carer Bonus

In each of the Budgets from 2004 to 2008 carers received one-off Carer Bonus Payments:

- $1,000 for carers receiving Carer Payment;
- $600 for carers receiving Carer Allowance, for each eligible care receiver; and
- $1,600 for carers receiving Partner Service Pension from the Department of Veterans' Affairs and Carer Allowance from Centrelink.

Carer Bonus Payments have not been taxable for income tax purposes, and have not been treated as income for social security purposes. They are legislated but not as ongoing payments.

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[42] Centrelink June 2008, *Carer Allowance Administrative Data*

3.1.1.e Carer Adjustment Payment Scheme

The Carer Adjustment Payment scheme is an interim ex-gratia scheme providing one-off financial assistance to families in exceptional circumstances who do not qualify for Carer Payment (child).

The Carer Adjustment Payment scheme is available to families where, following a catastrophic event involving a young child aged 0 to six years, the family is going through a period of significant adjustment as a result of the care needs of the child. Examples of catastrophic events include (but are not limited to) a serious or severe illness or medical condition such as childhood cancer or childhood stroke, or an event such as an accident, fire, fall, poisoning, near drowning or other type of accident.

The Carer Adjustment Payment is a one-off non-taxable payment to families in exceptional circumstances on or after 1 January 2007. The payment amount to a family depends upon each family’s individual circumstances. The maximum amount any family can receive is $10,000 for each child in a single catastrophic event.

3.1.1.f Allowances and Other Assistance

There are a number of allowances and other forms of assistance available to carers and their families depending on their individual and/or family circumstances. **Table 1** outlines these as at 1 July 2008.

Table 1: Allowances and Other Assistance

Payment	Purpose	Amount / Frequency
Rent Assistance	Assists with rent payments. Amounts are determined upon the categorisation of recipients into one of nine family situations.	Fortnightly payment paid at a rate of 75 cents in the dollar for rental payments which fall between the minimum amount and maximum amount payable.
Utilities Allowance	Assists with meeting utility bills such as energy, rates, water and sewerage.	Quarterly payments made in March, June, September and December: $125 per quarter for singles; or $62.50 per quarter for each member of a couple.
Telephone Allowance	Assists with the cost of maintaining a phone and/or home internet service.	Quarterly payments made in January, March, July and September: $22 per quarter for telephone connections; or $33 per quarter for telephone and internet connections.
Pharmaceutical Allowance	Assists with purchase of prescription medicines available through the Pharmaceutical Benefits Scheme.	Fortnightly payment: $5.80 for singles; or $2.90 for each member of a couple.
Pensioner Education Supplement	Assists people improve their chances of finding a job through study.	Fortnightly payment; $62.40 for a 50% study load; or $31.20 for a 25% study load.
Family Tax Benefit Part A (FTBA)	Assists families with the cost of raising children. FTBA is calculated on the ages and number of dependent children in the family.	Fortnightly (FN) or annual payment: Base FN rates $48.30 for children < than 18 years $64.96 for children between 18 and 24 years Maximum FN rates $151.34 for each child < 13 years $196.84 for each child 13-15 years $48.30 for each child 16-17 years $64.96 for each child 18-24 years
Family Tax Benefit Part B (FTBB)	Assists single parent families, and two parent families with one income.	Fortnightly (FN) or annual payment. Maximum FN rates $128.80 for children < 5 years $89.74 for children 5-15 years (or 16-18 years if a full time student)
Child Care Benefit	Assists families with the costs of approved or registered child care. Payment is non taxable, and income tested.	Fortnightly (FN) or annual payment; Maximum FN rates $173.50 for non school aged children for 50 hours of weekly care $147.47 for school aged children; (85% of maximum non school rate)
Child Care Tax Rebate	A taxation rebate to cover 50 per cent of families' out-of-pocket expenses for approved childcare.	Maximum annual payment $7,500, paid quarterly.
Attendant Allowance	Payable to veterans with Disability Pension for certain disabilities, to assist with the cost of an attendant to assist with daily living activities.	Fortnightly payment Maximum FN rate - $264.50 Minimum FN rate $132.10

3.1.1.g Concessions

In addition to income support, allowances and other assistance carers receive concessions that are broadly designed for all income support recipients.

Carer Payment recipients are automatically issued with a Pensioner Concession Card (PCC), while Carer Allowance (child) recipients are entitled to a Health Care Card (HCC), issued in the child's name. These cards tend to be highly regarded by card-holders as they entitle them to receive:

- medicines listed on the Pharmaceutical Benefits Scheme (PBS) at a cheaper rate;
- PBS prescriptions, generally without charge, for the remainder of the calendar year after reaching the PBS safety net;
- bulk-billed General Practitioner (GP) appointments at the discretion of their doctor (the Australian Government provides financial incentives for GPs to bulk-bill concession card holders); and
- reduced out-of-hospital medical expenses, through the extended Medicare Safety Net.

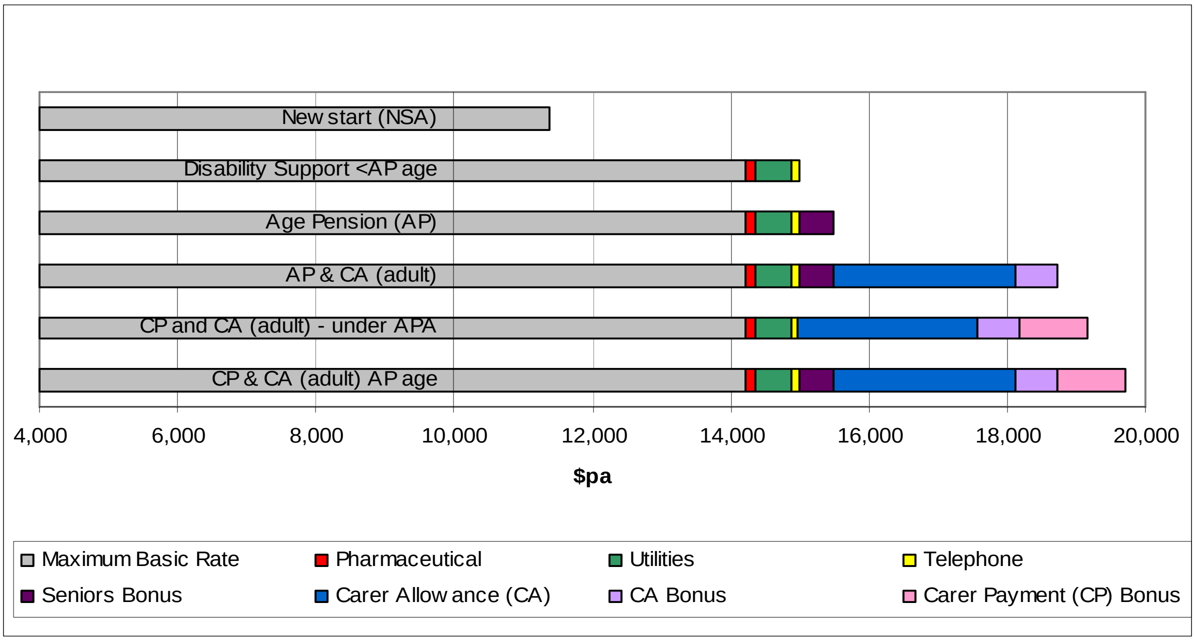
PCC holders also receive free hearing assessments and hearing rehabilitation.

Most other concessions are offered by state/local government or private providers. The range of concessions offered to PCC holders is much larger than those offered to HCC holders.
PCC holders in all states and territories receive reductions on public transport fares, council rates including water, sewerage, electricity and motor vehicle registration.

3.1.1.h Comparison with other income support types

As identified above, carers may be eligible for a range of allowances and other assistance in addition to their base rate of income support. This total package of financial assistance needs to be taken into account when considering the financial support provided to carers by the Australian Government relative to other income support recipients.

Chart 12: Income support packages for selected single recipients, as at 20 March 2008



Source: Department of Families, Housing, Community Services and Indigenous Affairs Modelling

Chart 12 highlights the income support packages for single income support recipients based on the type of payment received, as at 20 March 2008. The income support packages identified include: the basic rate of pension (for example Carer Payment), Carer Allowance, Carer Payment Bonus; Carer Allowance Bonus, Telephone Allowance, Utilities Allowance, Pharmaceutical Allowance and the Seniors Bonus.

Australia's Future Taxation System review, which is commented on later in the submission, will look into the issue of financial assistance provided to income support recipients, including carers.

3.2 PROGRAMS AND SERVICES

The Australian Government funds a broad and diverse range of programs and services for carers. These include community care, direct and indirect respite services, information and referral services, counselling and support. Each state and territory government also administers its own programs and services for carers through individual service delivery mechanisms. Information on state and territory government programs has not been provided as part of this submission.

There are three main Australian Government agencies responsible for the administration of programs and services for carers: the Department of Health and Ageing; the Department of Families, Housing, Community Services and Indigenous Affairs; and the Department of Veterans' Affairs.

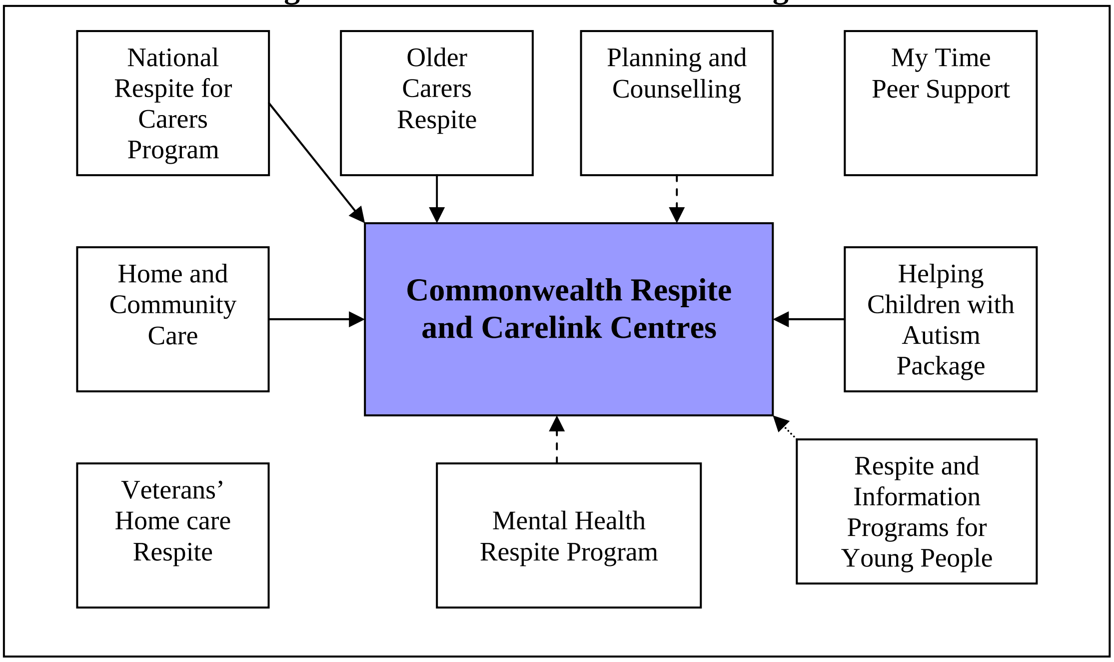
The Australian Government recognises that the current arrangements for the provision of respite, involving a number of different programs across three agencies has an impact on clients, who often find the system confusing and hard to navigate. The Australian Government has made a commitment to streamline respite services across its Departments to create a more sensible system for carers, discussed in more detail later in this submission.

Figure 1 illustrates the breadth and diversity of Australian Government programs and services specifically targeting carers.

A range of other community care programs also provide formal care and other supports to frail older people and younger people with disabilities. These programs are discussed in more detail later in this section.

Central to the carer programs outlined in **Figure 1** are the Commonwealth Respite and Carelink Centres (CRCC's). Along with providing a single point of contact for older Australians, people with a disability and their carers on information about care services available locally, CRCC's assist carers to directly access respite and other supports and have a pool of brokerage funds to respond to emergency respite needs. The Department of Health and Ageing is the main funder of CRCC infrastructure, however, a number of the initiatives funded through the Department of Families, Housing, Community Services and Indigenous Affairs are also implemented through these Centres.

Figure 1: Australian Government Programs



Detailed information about each of the carer programs outlined in **Figure 1** is provided below.

3.2.1 DEPARTMENT OF HEALTH AND AGEING

The Department of Health and Ageing fund a range of programs to directly support the carers of people who are frail aged or people with a disability. These carer support programs are complemented by other care and support programs aimed at keeping frail older people and younger people with disabilities in the community with support for as long as possible. These other programs include: Community Aged Care Packages (CACP) and the Home and Community Care Program (HACC). While not directly targeting carers, the provision of formal care services to people who are frail aged or people with a disability may alleviate the caring responsibility on their informal carers.

3.2.1.a National Respite for Carers program

The National Respite for Carers Program (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.

NRCP funding expended in 2007-08 totalled approximately $188.49 million. This included funding for:

- over 600 community-based respite services across Australia;
- 54 Commonwealth Respite and Carelink Centres nationally; and
- Carers Australia to provide the National Carer Counselling Program (NCCP).

Community-based respite

The 600 community-based respite services are delivered in a variety of settings designed to meet the needs of both the carer and the care recipient. NRCP respite services may be delivered in carers' own homes, day centres, overnight cottages and through host family arrangements.

In 2007-08, around $125 million in NRCP funding was expended, through the provision of respite services across Australia. Respite services funded under the NRCP included:

- 89 services that specifically cater to the needs of employed carers;
- 17 Employed Carer Innovative Pilots;
- 71 overnight respite cottages; and
- 30 demonstration day respite services in residential aged care facilities which showcase innovative models of respite care.

NRCP respite services cater to a wide range of target groups, which can include: frail, older people; people with dementia; people with dementia and challenging behaviour; younger people (under 65, under 50 if Indigenous) with moderate, severe or profound disabilities who are living at home; and/or people with a terminal illness in need of palliative care. A number of NRCP services also cater specifically to the needs of Indigenous carers and carers of people from CALD backgrounds.

Commonwealth Respite and Carelink Centres

The 54 Commonwealth Respite and Carelink Centres across Australia provide a single point of contact to assist carers and other members of the community seeking free and confidential information about community care, aged, disability and other support services available in a local region.

Centres provide information about costs for services, assessment processes and eligibility criteria. Centres maintain an extensive database of services and network with Aged Care Assessment Teams (ACATs), GPs, allied health providers and community organisations. Centres also assist carers with gaining access to appropriate support and services to meet their needs. Centres have a pool of funding that can be used to purchase short term or emergency respite for carers.

In 2007-2008, around $17 million was allocated from the Commonwealth Carelink Program for the role of Centres in information provision and around $49 million was allocated from the NRCP for the role of Centres to assist carers looking at respite options.

Carer Information and Support Program

Overall, the Australian Government expended around $2.2 million to the Carer Information and Support Program (CISP) in 2007-08. The CISP is an Australian Government program that aims to assist carers in their role by providing timely and high quality information, carer education and support that is both culturally and linguistically sensitive. CISP funding supports the development and distribution of national products by the Department of Health and Ageing, as well as funding Carers Australia to deliver specialist services. In 2006–07 around 452,300 items of published information were distributed.

Carers Australia and the National Carer Counselling Program

Carers Australia was allocated 6.4 million in 2007-08 to subcontract the Network of Carer Associations in each state and territory for carer counselling, specialist advice and information services. The National Carers Counselling Program provides counselling, emotional and psychological support services for carers in order to reduce carer stress, improve carer coping skills and facilitate wherever possible, the continuation of the caring role. In 2007-08 an estimated 6,449 individuals received counselling. The Network of Carer Associations also distribute a range of information resources as well as provide community awareness raising for carers and those providing services to them through the CISP program.

3.2.1.b Residential Respite

Residential respite provides care in Australian Government subsidised aged care homes for people who are in need of short-term care on a planned or emergency basis. Except for emergency situations, to receive residential respite care a person must be assessed by an ACAT as eligible for high or low care.

Funding expended in 2007-08 was $122 million.

3.2.1.c Home and Community Care Program

The HACC Program is jointly funded by the Australian Government and state and territory governments. In 2007-08 total funding expended for the HACC Program was $1.6 billion with the Australian Government contribution totalling more than $1 billion.

The HACC Program provides services such as domestic assistance, personal care as well as professional allied health care and nursing services, in order to support these people to be more independent at home and in the community and to reduce the potential or inappropriate need for admission to residential care.

Access to services in the HACC Program is based on the assessed needs of individuals. Assessments establish the type and extent of support needed and the availability of informal care, and identify HACC services appropriate to meet the person’s needs and circumstances.

3.2.1.d Community Aged Care Packages

The CACP Program provides care at home for frail older people who have complex care needs but are able to live at home with assistance. A CACP is an alternative to low-level residential care.

CACP is tailored to meet the needs of the individual. Services may include personal care, assistance with meals, domestic assistance, care planning, case management and transport to help the person shop or visit a medical practitioner. To be eligible to receive a CACP, the care recipient must be assessed by an ACAT as requiring low level residential care, have expressed a preference to remain at home, and have the ability to do so with some assistance.

As at 30 June 2007, 37,250 CACPs had been allocated nationally.

Temporary in-home respite can be offered through a CACP, allowing carers the opportunity for a break. The provision of services such as personal care and domestic assistance through a CACP can also help ease the caring burden on a carer.

3.2.1.e Extended Aged Care at Home Packages

The Extended Aged Care at Home (EACH) Program provides care to frail older people who are assessed as requiring high level residential care by an ACAT, have expressed a preference to live at home and are able to do so with some assistance. The EACH Program provides coordinated and managed packages of care, tailored to meet the needs of the individual.

Services available through an EACH package may include clinical care, personal assistance, meal preparation, continence management, assistance to access leisure activities, emotional support, therapy services, home safety and modification. Packages are flexible in content but generally include qualified nursing input, particularly in the design and ongoing management of the package.

As at 30 June, 2007, 3,329 EACH packages had been allocated nationally.

A 2002 Census of the EACH program showed that 75 per cent of EACH recipients had co-resident carers and 15 per cent had non-resident carers. Whilst respite care is not included as a specific service available under an EACH package, the level of support that this package provides can assist in reducing the care burden on carers. Emotional support for adjusting to higher care needs and receiving assistance is available for both care recipients and carers through an EACH package.

3.2.1.f Extended Aged Care at Home Dementia Packages

The Extended Aged Care at Home Dementia (EACHD) program provides an alternative to high level residential care in a person's home for older Australians with dementia, who exhibit behaviours of concern and psychological symptoms due to their dementia.

EACHD packages are flexible and services depend on the complexity of care needs of an individual. EACHD packages provide the same range of services as EACH packages including clinical care, personal assistance, meal preparation, continence management, assistance to access leisure activities, emotional support, therapy services, home safety and modification. EACHD packages also offer additional levels of service and service strategies targeted to meet the specific needs of care recipients with dementia who experience behaviours of concern.

To be eligible for an EACHD package, a care recipient must be assessed by an ACAT as requiring high level residential care, and experiencing behaviours of concern and psychological symptoms associated with dementia.

As at 30 June 2007, 1,334 EACHD packages had been allocated nationally.

Respite care is not included as a specific service available under an EACHD package. However, as with EACH packages, the level of support and services available through an EACHD package can assist in reducing the burden on carers. Emotional support for adjusting to higher care needs and receiving assistance is available for both care recipients and carers through an EACHD package.

3.2.1.g Aged Care Assessment Program

Under a cooperative working arrangement, the Australian Government provides funding to state and territory governments specifically to operate the Aged Care Assessment Program (ACAP) and funds 115 ACATs nationally. In 2008-09 the Australian Government contribution to the ACAP is $72.2 million.

The primary purpose of ACATs is to comprehensively assess the care needs of frail older people and assist them to gain access to the types of available services most appropriate to meet their care needs. This may involve referring clients to services, such as HACC services, or approving eligibility for Australian Government subsidised aged care services, including residential aged care, residential respite care, CACPs, and some flexible care services, namely EACH, EACH Dementia and the Transition Care Program.

ACATs work across all regions in each state and territory and work closely with clients, their carers and their families to identify the most suitable services available.

3.2.1.h Dementia Initiative

With the projected rise to Australia's aged population it is estimated the number of people living with dementia will increase to almost 465,000 by 2031[43]. Dementia affects the lives of nearly one million Australians who are involved in caring for a family member or friend with dementia. [44]

The Australian Government made and honoured an election commitment to provide ongoing support for the Dementia Initiative to support people with dementia and their carers.
This includes:

- $90 million per year for EACHD Packages;
- $24 million per year for dementia research, prevention, early intervention and improved care initiatives; and

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[43] Dementia in Australia, January 2007, *National data analysis and development*, Australian Institute of Health and Welfare
44 Pfizer Australia 2004, *Health Report Issue #6 Dementia*, Pfizer Australia, Sydney

- $7 million for training for aged and community care staff, carers and community workers such as police.

People with dementia often need strong support from their carers, family and friends. In order to assist carers in their role, major components under the Dementia Initiative include:

- The National Dementia Support Program which provides a National Dementia Helpline; counselling, information and education services; and, Dementia and Memory Community Centres;
- the national implementation of the Dementia Behaviour Management Advisory Service seeks to improve the quality of care for people with dementia and their carers where the behaviour of the person with dementia impacts on their care;
- the development and distribution of information and resources to assist carers to understand more about dementia and provide advice on the caring role, this includes products such as the *Dementia- The Caring Experience: An essential guide for carers of people with dementia* and the *Dementia Resource Guide*; and
- The Dementia Education and Training for Carers Project, which has provided skill enhancement activities for carers of people living with dementia.

A Minister's Dementia Advisory Group has been formed to provide advice to the Minister for Ageing and the Department on issues relating to the monitoring and evaluation of the Dementia Initiative.

3.2.1.i Community Aged Care Census 2008

During 2007-2008 the Department of Health and Ageing conducted a census of the following four aged and disability care programs – CACP, EACH, EACHD, and NRCP.

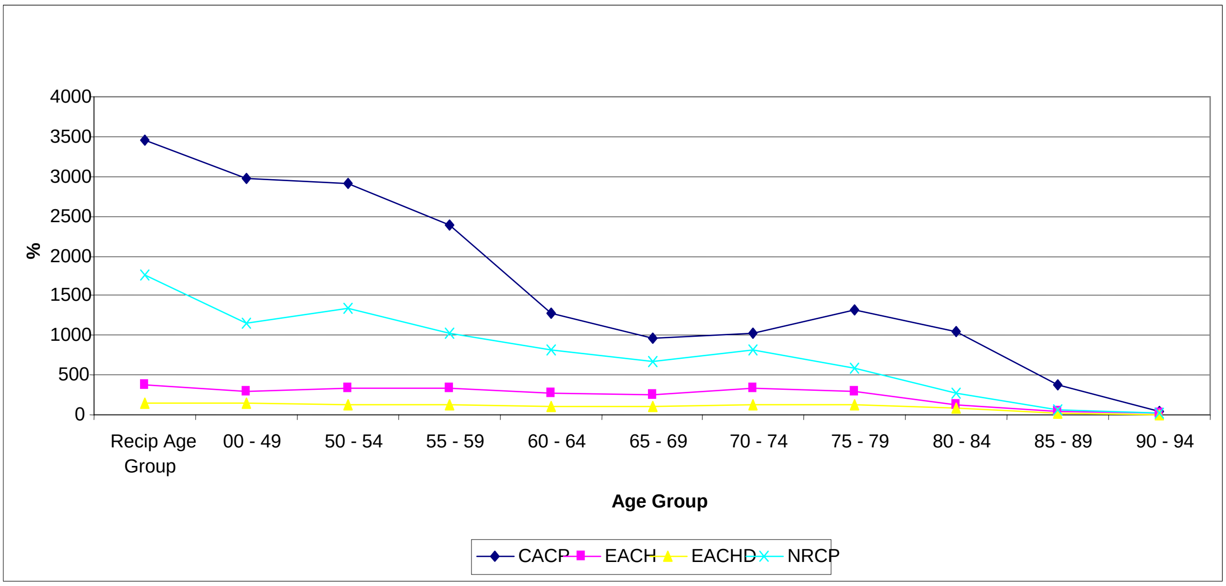
The Community Aged Care Census 2008 provides a snapshot of community care programs which help frail older people or people with a disability continue living in the community. The data collection phase of the census was completed in May 2008, and in depth data analysis and quality checks are continuing. Nevertheless, preliminary findings which may be of relevance to this Inquiry are as follows. Some data from the HACC program are also included in analyses where this enriches information provided through the census.

Analysis of the census data shows:

- 18, 914 of the 34,506 CACP recipients had carers, and 8,520 carers received respite during the census period (corresponding figures for EACH are 2,837 recipients with carers out of 3497; and 1,188 of 1365 EACHD recipients);
- the age profiles of carers in packaged care and respite programs shown in **Chart 13** are similar and show a dip in the 65 to 74 age groups and a rise in the 75 to 84 age groups. This may have implications over the next 15 to 20 years, as the latter group ages;
- the gender composition of carers by each age cohort is comparable across all four programs (CACP, EACH, EACHD and NRCP), with a faster rate of attrition of female carers with increasing age, and greater representation of male carers in the older age groups. The effect is consistent for all packaged care, but is less so for NRCP after age 85-89. Further, there is an increase in the proportion of each age cohort of *care recipients* that is female across the programs.
- the reasons for the changing gender balance as the age of carers increases may be due to the fact that the carer group comprises three main sub-groups with distinct characteristics:

  - Parents of care recipients – very small in number (less than 100), usually associated with younger people with disabilities who have been accepted into packaged care programs in the absence of any more suitable disabilities services;
  - Spouses of care recipients (around 5,300); and
  - Children of care recipients (around 11,000).
- the incidence of parents, spouses and children as carers changes with age of the care recipient. Parents as carers decline from around 10 per cent of all carers for those younger than 50 to virtually nothing by age 70. Spouses as carers decline from a peak of around 22 per cent at age 65-69, to less than 10 per cent at age 95+. On the other hand the proportion of carers who are children rises steadily to peak in the 90-94 age group. From age 60-65 onwards more recipients are cared for by their daughters than by any other family members. By the time these recipients reach their nineties, around 45 per cent are cared for by their daughters;

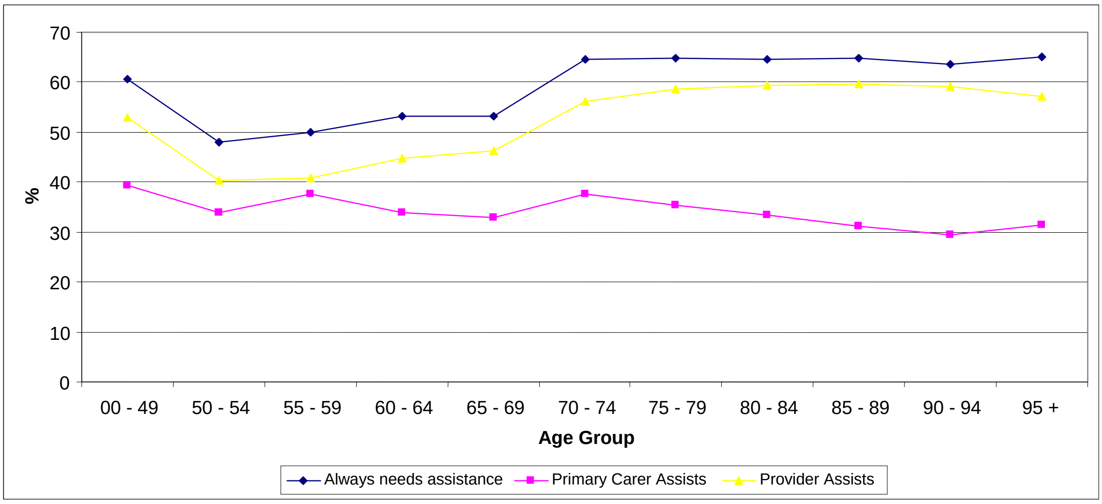
Chart 13: Age Distribution of Carers



Source: Department Health and Ageing, Census of Programs, 2008

- from age 70 onwards the proportion of care recipients with carers changes very little with the age. However, it increases with the intensity of care provided by Program. For HACC care recipients it plateaus at around 35 to 40 per cent. It gradually increases for CACP care recipients within the range 50 to 60 per cent and it ranges between 80 per cent and 90 per cent for both EACH and EACHD care recipients;
- the proportion of care recipients with co-resident carers increases gradually from CACP to higher care programs (EACH, EACHD) and NRCP correspondingly;
- early findings show that irrespective of their age, care recipients with carers have higher levels of dependence and need assistance with more activities of daily living than those without carers. This affect is evident in HACC on ACAT assessment and in CACP; and
- a very high proportion of care recipients' needs for assistance are met by service providers, with a very slight increase in proportion with increasing age shown in **Chart 14**.

Chart 14: Assistance with Housework: The Proportion of Each Age Group who have a Carer, who Always Require Assistance, showing who provides assistance



Source: Department Health and Ageing, Census of Programs, 2008

3.2.2 DEPARTMENT OF FAMILIES, HOUSING, COMMUNITY SERVICES AND INDIGENOUS AFFAIRS

The Department of Families, Housing, Community Services and Indigenous Affairs provides targeted carer programs and services to young carers, older carers, children with autism and carers of people with mental illness, psychiatric and intellectual disability.

3.2.2.a Mental Health Respite Program

The Mental Health Respite Program provides a range of flexible respite options for carers of people with severe mental illness/psychiatric disability and carers of people with intellectual disability. The Program has two components including, a brokerage service model to procure respite on behalf of targeted carers, and a direct funding model to increase the availability of appropriate respite services where demand exceeds supply.

Mental Health Respite Program funding expended in 2007-08 was $4.68 million.

3.2.2.b Personal Helpers and Mentors Program

This program is one of the key initiatives of the Council of Australian Governments (COAG) *National Action Plan on Mental Health 2006-2011*. It provides increased opportunities for the recovery of people with a severe functional limitation as a result of severe mental illness, by increasing their personal capacity and self resilience and increasing their level of community participation. A central theme of the Personal Helpers and Mentors Program (PHaMs) is that wellbeing and positive outcomes for people with a mental illness are improved by involving families and carers in their care and acknowledging that families and carers have a legitimate role in care provision that deserves recognition and respect. In turn, benefits to carers include reduced stress, reduced burden of care and improved understanding of mental illness, treatment and services.

PHaMs funding expended in 2007-08 was $1.6 million.

3.2.2.c Older Carers Respite

This program is targeted at carers aged 60 years and over who are caring for a son or daughter with severe or profound disability aged 25 years or over.

The Older Carer Respite Program will be funded as part of the $901 million in disability funding being transferred to states and territories from 2008-09, as well as the Government's commitment to honour the former government's announcement of $51 million over the three years to 2009-10 for respite capacity building.

3.2.2.d Respite and Information Services for Young Carers

This program provides information, referral, advice and counselling services to support young carers up to 25 years of age in their caring role. It enables young carers who are at risk of leaving education prematurely (and not completing secondary or equivalent education) to access up to five hours in-home respite per week during the school term to attend education or training, and one fortnight of respite each year to undertake activities such as study for exams, training or recreation.

Funding expended in 2007-08 for Respite and Information Services for Young Carers was $7.6 million.

3.2.2.e Respite and Support for Carers of Young People with Severe or Profound Disability

This program provides immediate and short-term respite to carers of young people with a severe or profound disability. It facilitates access to information, respite care and other support or assistance appropriate to the individual needs and circumstances of both carers and care recipients, and supports carers whose needs are not being met through existing state and territory respite care or assistance provided under other Commonwealth Government initiatives.

Funding expended in 2007-08 for Respite and Support for Carers of Young People with Severe or Profound Disability was $7.3 million.

3.2.2.f Helping Children with Autism Package

This package includes a number of initiatives being implemented nationally by the Department of Families, Housing, Community Services and Indigenous Affairs, the Department of Health and Ageing and the Department of Education, Employment and Workplace Relations.
The Department of Families, Housing, Community Services and Indigenous Affairs is overseeing implementation of education and support for families and carers of children aged 0-6 with autism spectrum disorders, and increased access to early intervention programs for children aged 0-6 with autism spectrum disorders. This includes the establishment of advisory services across Australia to assist families and carers to find the best services available.

The Helping Children with Autism Package funding is $190 million over five years.

3.2.2.g MyTime Peer Support

This program provides peer support groups for parents and carers of young children with disabilities or a chronic medical condition throughout Australia. By 2009-10 the program is expected to benefit over 2,500 families, participating in a national network of over 300 MyTime Peer Support Groups.

MyTime Peer Support Groups are supported by two workers; a facilitator for parents and a play helper for children. The play helper organises play activities and provides support for the children while parents participate in activities and discussions.

Funding for MyTime Peer Support is $9 million over four years.

3.2.2.h Companion Card Scheme

The Australian Government is progressing an election commitment jointly with the states and territories to introduce a national companion card scheme. This initiative would aim to deliver a nationally recognised Companion Card across all jurisdictions. It is anticipated that the scheme will be administered by the states and territories.

Currently no national approach exists to enable eligible people with a disability, dependent on full-time care, to be accompanied to events and supported by their carer for the price of a single ticket.

A Companion Card has already been introduced in Victoria, Tasmania, Western Australia and South Australia. Queensland and New South Wales have announced that they plan to launch a Companion Card in late 2008. A National Companion Card is a positive vehicle for businesses and service providers to meet some of their obligations under the *Disability Discrimination Act 1992.*

3.2.2.i Family Relationship Services for Carers

Family Relationship Services for Carers provide mediation and counselling to assist families who are: concerned about the future care of their family member with a disability; thinking about making 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. The program provides an impartial person to assist families to take into account the needs and interests of the whole family unit when considering future care arrangements.

Funding expended in 2007-08 for Family Relationship Services for Carers was $1.6 million.

3.2.2.j Future Planning, Special Disability Trusts

Special Disability Trusts offer means test concessions to encourage families to financially provide for their family member with a severe disability. Immediate family members and carers who have the financial means to do so, can make private financial contributions to the trust for the current and future care and accommodation needs of their family member with a severe disability. The Special Disability Trust concession applies to families receiving income support under the *Social Security Act 1991* and the *Veterans' Entitlements Act 1986.*

The Senate Community Affairs Committee is currently conducting an Inquiry into Special Disability Trusts. This Inquiry, discussed in more detail later in this submission, will examine why more families caring for people with disabilities are not making use of the current provisions to establish Special Disability Trusts, and possible amendments to the relevant legislation.

3.2.3 DEPARTMENT OF VETERANS' AFFAIRS

The Department of Veterans' Affairs provides carer programs to veterans, war widows and widowers.

3.2.3.a Veterans' Home Care Program

The Veterans' Home Care (VHC) program provides low level home care services, based on assessed need, to eligible veterans and war widows and widowers who are Gold or White Card holders. It is part of a broader Department of Veterans' Affairs strategy to ensure veterans and war widows/widowers maintain optimal health, well being and independence. The program consists of a range of home care services that include domestic assistance, personal care, respite care and safety-related home and garden maintenance.

In addition to VHC, The Department of Veterans' Affairs provides a range of programs to support veterans and war widows/widowers in their homes including Community Nursing, Rehabilitation Appliances Program, Homefront (safety inspections) and medical transport. These programs are formally for the veteran client but can also support the carer's ability to provide care.

Funding expended in 2007-08 for VHC core services (domestic assistance, personal care and safety related home and garden maintenance) was $97.8 million and for VHC Respite was $23.3 million.

4 TOPICS FOR CONSIDERATION

The topics highlighted in this section of the submission include:

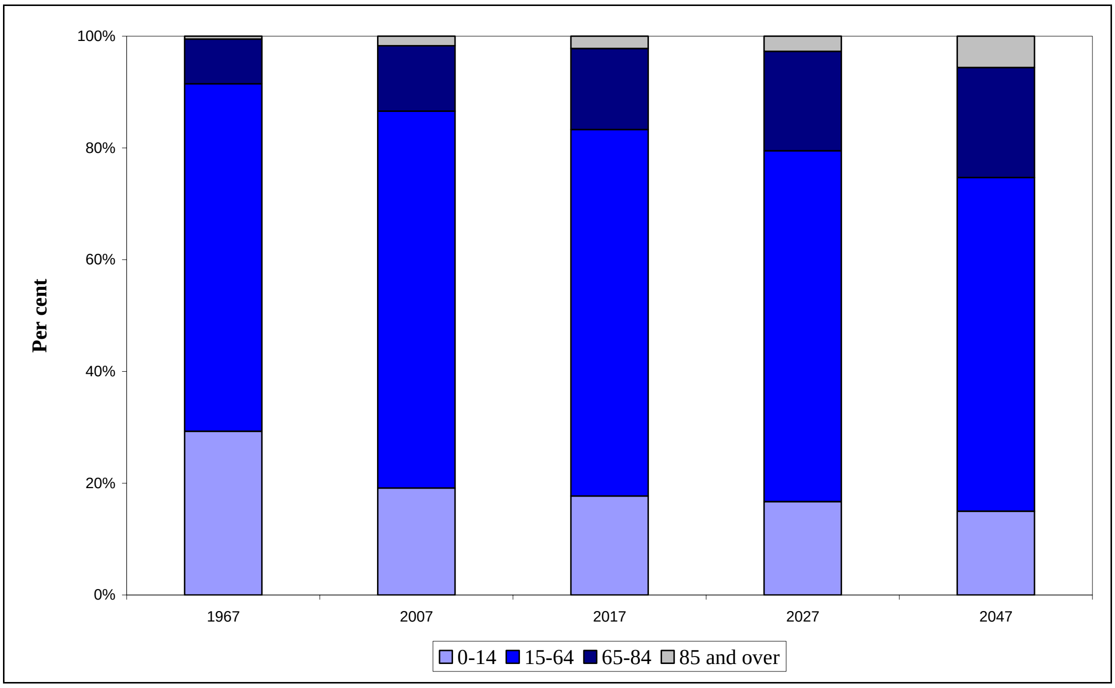
- ageing population and care supply and demand;
- caring and labour force participation;
- carer health and wellbeing; and
- carer support needs.

4.1 AGEING POPULATION AND CARE SUPPLY AND DEMAND

The *Intergenerational Report 2007 (IGR2)* provides useful contextual information that impacts on carers. It is projected that over the next 40 years Australia's population will continue to increase in size, with a higher proportion of older people.

Chart 15 highlights the continuing growth in the proportion of older people. In June 2007, the proportion of those aged 65 and over was projected to reach 13.4 per cent, rising from only four per cent a century ago. By 2047, just over 25 per cent of Australia's population is projected to be aged 65 and over. The proportion of the very old (aged 85 and over) is projected to rise from 1.7 per cent in 2007 to 5.6 per cent in 2047.[45] Note also that a significant proportion of the Department of Veterans' Affairs veteran community are aged i.e. 77 per cent are over 65 and 68.6 per cent are over 75.

Chart 15: Proportion of the Australian population in different age groups



Source: IGR2

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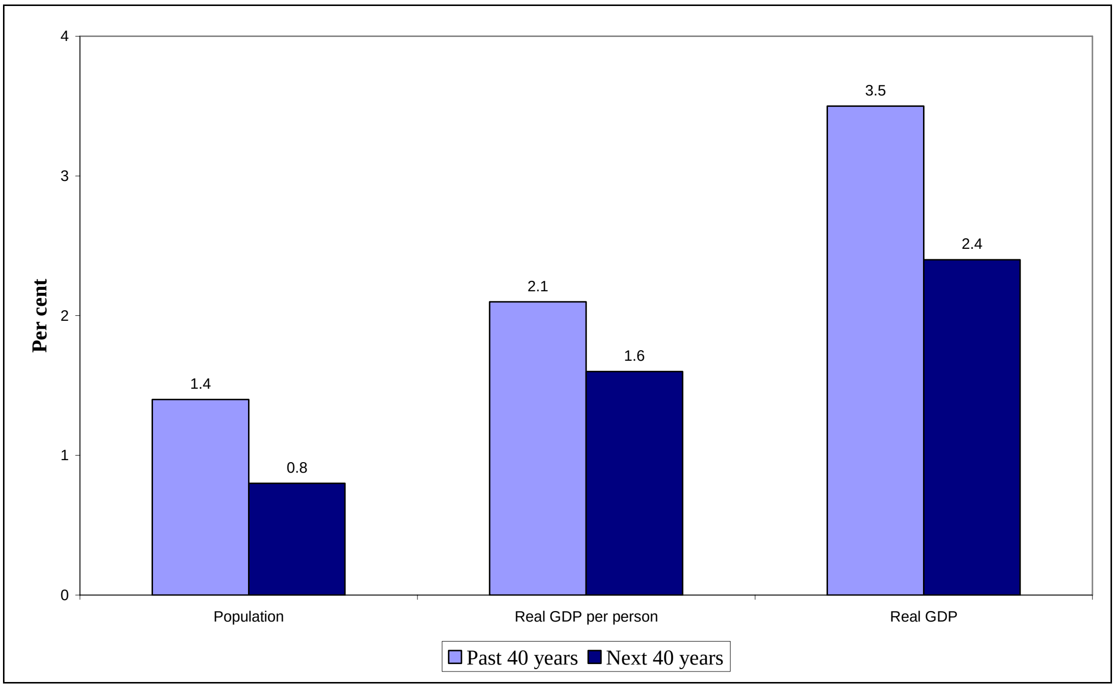
[45] Treasurer 2007, *Intergenerational Report, 2007*, Part 2, p4

The population of traditional working age (15-64 years) is projected to grow by over 20 per cent by 2047, but to fall as a proportion of the total population. The fastest growing group of working age people is that aged 55-64, rising by nearly 50 per cent over the next 40 years. In 2007 there were five people of working age to support every person aged 65 and over. By 2047, there will only be 2.4 people of working age supporting each person aged 65 and over.[46]

The IGR2 projected that the growth rate of real Gross Domestic Product (GDP) per person is projected to slow because of the ageing of the population. Real GDP is the product of the total population and real GDP per person. Over the past 40 years, the population grew at an average annual rate of 1.4 per cent. When added to growth of real GDP per person of 2.1 per cent, this gave annual average real GDP growth of 3.5 per cent.[47]

Annual population growth is projected to slow to around 0.8 per cent over the next 40 years. **Chart 16** highlights that as a consequence, annual average real GDP growth is projected to slow to 2.4 per cent.[48]

Chart 16: Real GDP and real GDP per person



Source: IGR2

The IGR2 also projected substantial fiscal pressures will emerge due to projected increases in spending, particularly in the areas of health, age pensions and aged care as a proportion of GDP over the next 40 years.

The structural ageing of the population means that carers are getting older and providing care for longer. The demand for informal care for older Australians is projected to grow, however, the number of people available to provide that care is reducing.

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[46] ibid., p8
[47] ibid. p31
[48] ibid.

A range of population characteristics may have bearing on the availability of informal carers into the future, including: increasing rates of relationship breakdown; estrangement of parents from adult children; reduced family formation among young adults; widespread altered role perception among women; and a large increase in lone person households.

Both the Australian Institute for Health and Welfare and the National Centre for Social and Economic Modelling (NATSEM) have recently conducted modelling on possible future trends in the number of informal carers by extrapolating out from the 1998 SDAC and adjusting for possible social trends such as those listed above. Given the uncertainty about the effect of social trends on people's need for and propensity to provide care, these alternative projections are best seen as possible scenarios, rather than predictions. Nevertheless, these projections are extremely useful.[49]

NATSEM's 2005 report *The Cost of Caring in Australia 2002 to 2005,* projects that by 2031 the number of people requiring care is estimated to increase considerably, with older Australians with a disability over 65 years of age projected to increase from 350,000 to 882,000 (150 per cent), and those over 85 years of age projected to increase from 80,000 to 260,000 (more than 200 per cent). In contrast, the number of younger people with a disability (under 65 years) is projected to increase by only 25 per cent.[50]

Over the same period the growth of carer supply is projected to only increase from 208,000 to 363,000. This will result in a gap of around 500,000 between the number of people who will need care and the number of people available to provide the care required.[51]

There will be a dramatic fall in the ratio of people most likely to provide care (females aged between 50 and 64 years) to the ratio of people most likely to need care (people aged 80 years and older). In 2000, this stood at around 2.5. Over the next 50 years the ratio is projected to fall to below one.[52]

4.2 CARING AND LABOUR FORCE PARTICIPATION

The Australian economy requires people to participate in the labour force to improve Australia's growth prospects, but informal carers are also required to care for the growing number of people needing care. This creates a tension between the dual goals of labour force participation and the supply of informal care.

4.2.1 Employment Prior to Caring

In 2003, SDAC reported that 31 per cent of primary carers had worked before commencing their caring role.[53] AIFS 2008 identified that 45 per cent of female carers on Carer Allowance and 47 per cent of female carers on Carer Payment were employed just prior to commencing the caring role.[54]

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[49] Eager K et al. 2007, *Effective Caring: a synthesis of the International evidence on carer needs and interventions,* Centre for Health Service Development, University of Wollongong

[50] National Centre for Social and Economic Modelling (NATSEM) 2005, *Income and Wealth Report, Issue 13 May 2006, The Cost of Caring in Australia 2002 to 2005,* p19

[51] ibid.

[52] ibid.

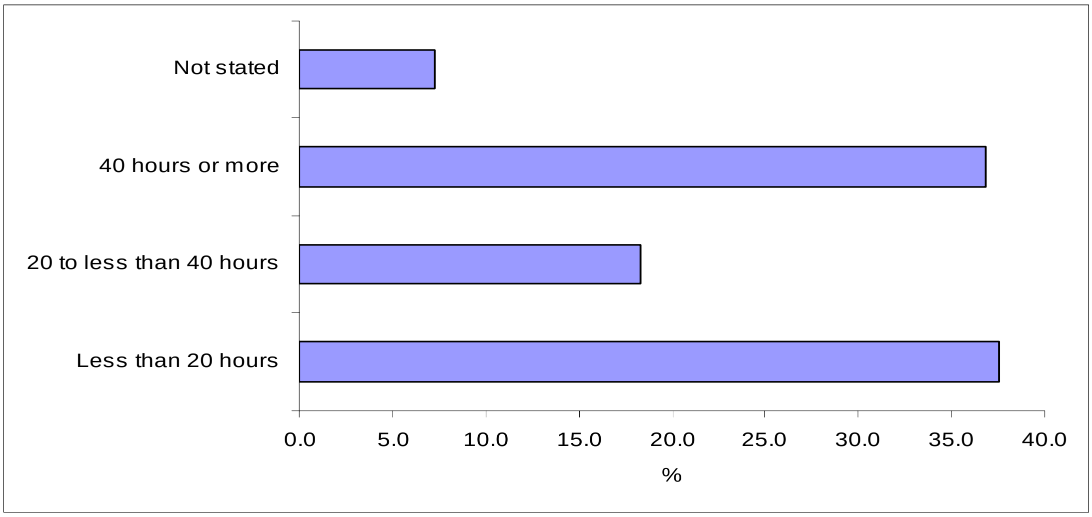
[53] Australian Bureau of Statistics (ABS) 2003, *Disability, Ageing and Carers, Australia: Summary of Findings, cat.no.4430.0*

[54] Australian Institute of Family Studies 2008, *Research Report no.16: The nature and impact of caring for family members with a disability in Australia,* p104

4.2.2 Impact of Caring on Employment

Chart 17 highlights that in 2003, 37 per cent of primary carers spent, on average, 40 hours or more each week providing care.[55] However, a similar portion, 38 per cent of primary carers, provided care for less than 20 hours a week.

Chart 17: Primary carers by hours of care provided per week



Source: ABS, SDAC, 2003

AIFS 2008 reported much higher weekly proportions of hourly care than SDAC. It found that 60 per cent of carers were caring for people with a disability for more than 100 hours per week. The time spent caring included time associated with direct care as well as indirect care such as time spent monitoring the person with a disability (i.e. being on call).[56]

AIFS 2008 also provides data on changes to the employment patterns of female carers who were working prior to caring. **Table 2** demonstrates that over 70 percent of Carer Payment and Carer Allowance recipients had changed jobs or their working arrangements in order to provide care for a person with a disability. A significant number of carers, nearly 60 per cent of those on Carer Payment and 40 per cent of those on Carer Allowance, had to give up work to provide care.[57]

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[55] Australian Bureau of Statistics (ABS) 2003, *Disability, Ageing and Carers, Australia: Summary of Findings, cat.no.4430.0*

[56] Australian Institute of Family Studies 2008, *Research Report no.16: The nature and impact of caring for family members with a disability in Australia*, pxv

[57] ibid., p105

Table 2: Employment changes as a consequence of caring by female carers

Changes to employment of employed female carers, made as a consequence of caring responsibilities	Payment Type	
	Carer Allowance Only	Carer Payment Only
	%	%
Had to give up work to provide care for the person with disability	39.3	58.8
Changed jobs or working arrangements in order to provide care for the person with disability	72.4	79.4
Taken periods of leave to provide care	66.7	58.8

Source: AIFS, 2008

Research into employed carers undertaken by the 2007 *Australian Longitudinal Study on Women's Health (ALSWH)* on behalf of the Department of Health and Ageing also sheds some light on changing patterns of employment and caring. The ALSWH commenced in 1995 and surveys 40,000 women sampled from the Australian population in three cohorts (young, middle aged and old). Each group is surveyed every three years about their health, and well being and social circumstances. To date there have been four surveys, and Survey five is currently in progress.

An examination of the middle aged group across both Survey three and four resulted in the following findings:

- women who did not provide care at either survey were more likely to work full-time and less likely not to be in the labour force than those who did provide care at either survey;
- carers at both surveys were more likely not to work, or to work part-time compared to non carers;
- women who started caring were more likely to cut down on working than those who did not start caring; and
- women who stopped caring were more likely to increase working than those who did not stop caring.

The findings also indicate that more than half of those providing care in the two surveys did not do so at both surveys, suggesting that caring roles are transient and changeable.[58]

4.2.3 Barriers to Labour Force Participation

AIFS 2008 provides some insight into the employment barriers faced by female carers not in the labour force (but who would like to work).[59] **Table 3** highlights that the most common barriers reported where there were no alternative disability care arrangements available (22.4 per cent for Carer Allowance recipients and 21.6 per cent for Carer Payment recipients); and difficulties in arranging working hours (23 per cent for Carer Allowance recipients and 15.7 per cent for Carer Payment recipients). Another significant barrier was that undertaking employment would be too disruptive to the person with a disability.

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[58] Berecki J., et al July 2007, *Changes in Caring Roles and Employment in Mid-life. Findings from the Australian Longitudinal Study on Women's Health Report 2*, Women's Health Australia, The University of Newcastle and The University of Queensland

[59] ibid., p106

Table 3: Main employment barriers identified by female carers

Main Employment Barriers	Payment Type	
	Carer Allowance Only	Carer Payment Only
	%	%
No alternative disability care arrangements available	22.4	21.6
Would be too disruptive to the person with the disability	12.7	17.6
Difficult to arrange working hours	23.0	15.7
Loss of skills from being out of the labour force	3.0	2.0
Age	6.7	17.6
Cost of paying for disability carer while at work	2.4	2.0
Other	27.3	23.5
No difficulties expected	2.4	0.0

Source: AIFS, 2008

In 2005-06 the Department of Health and Ageing funded the establishment of 17 pilot programs to test and develop innovative and sustainable models of respite support for employed carers of the frail aged. These pilots are due to conclude in December 2008. Evaluation of the pilots to date identified some difficulty in attracting employed carers to take up the services. Some of the key reasons cited for this were that employed carers do not identify as carers and demonstrate reluctance to identify in the workplace as having a formal caring role.

4.3 CARER HEALTH AND WELLBEING

SDAC reported that people caring for people with a disability were more likely to be older than non carers and have a disability themselves. Of those living in households with care recipients, the disability rates were 40 per cent for primary carers; 35 per cent for all carers; and 20 per cent for non carers.[60]

4.3.1 Reliance on Income Support

Compared to families within the general population, a higher proportion of carers rely on an Australian Government pension for their main source of income. **Chart 18** highlights that in 2003, 40 per cent of all carers and 55 per cent of primary carers received their main source of cash income from Australian Government pensions.

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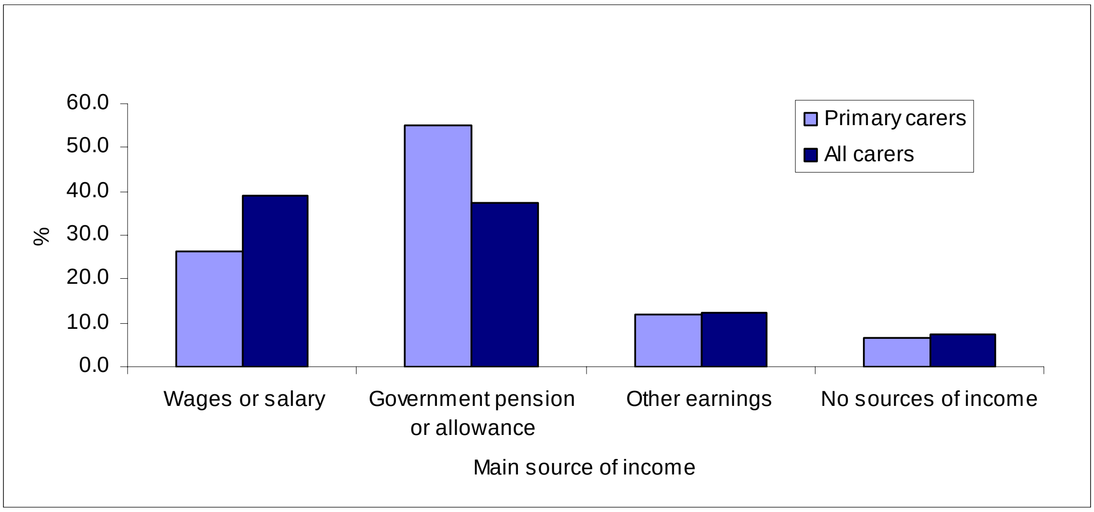
[60] Australian Bureau of Statistics (ABS) 2003, *Disability, Ageing and Carers, Australia: Summary of Findings, cat.no.4430.0*

Chart 18: Primary carers' main source of income



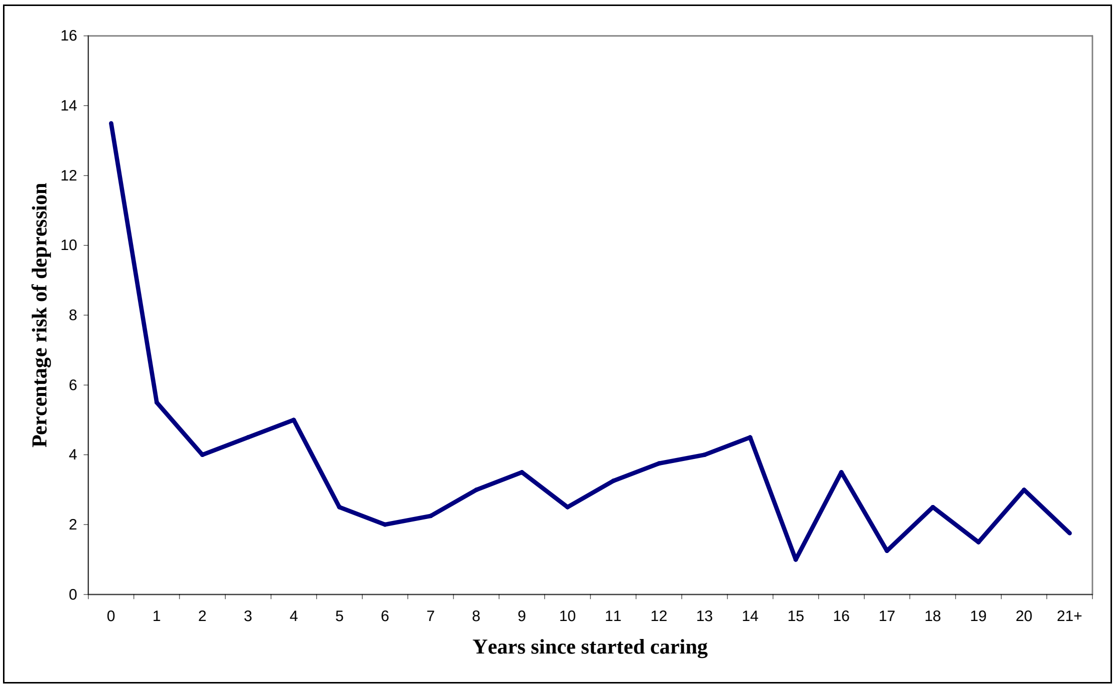
Source: AIFS, 2008

4.3.2 Emotional/Psychological Wellbeing

AIFS 2008 provides some insight into the emotional/ psychological wellbeing of carers. For example, the report highlighted carers had significantly worse mental health and vitality and higher rates of depression than the general population.

Chart 19 from AIFS 2008 shows the greatest risk of experiencing a depressive episode appears to be in year 0, the first year of caring.[61]

Chart 19: Reports of carers' first depressive episode since starting caring



Source: AIFS, 2008

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[61] Australian Institute of Family Studies 2008, *Research Report no.16: The nature and impact of caring for family members with a disability in Australia*, p xiii

ALSWH also highlighted that levels of physical and mental health were highest in the non-carers. The study compared women who quit work or reduced work when starting care with carers who maintained hours of paid employment and suggests a therapeutic effect of employment for carers. The results indicated that women who left or reduced work were more likely to be stressed, to report only poor to fair health and report frequent visits to a GP compared to women who maintained hours of paid employment when starting care.[62]

4.3.3 Physical Wellbeing

The 2007 Australian Unity Wellbeing Index survey, *Special Report: The Wellbeing of Australians: Carer Health and Wellbeing* found that carers were more likely to experience chronic pain, carry an injury and suffer from significant medical or psychological conditions. It also reported carers were less likely to seek or receive treatment for their condition(s).[63]

AIFS 2008 also reported that almost twice as many carers were in poorer health than the general population. These elevated rates of poor physical health were not the result of carers being older than the general population, as female carers had poorer physical health than females in the general population for all age categories, except when aged 65 years or more.[64]

4.4 CARER SUPPORT NEEDS

4.4.1 Need for Support

Access Economics 2005 reported that almost 40 per cent of all primary carers felt they needed more support in their caring role. However, the need for more support varied on the diagnosis of the care recipient. Carers of people with an intellectual disability and a psychological disability were more likely to report needing additional assistance. Carers of people with a sensory, speech or physical disability were the least likely to report needing additional support.[65]

AIFS 2008 explored the use of support services by families and found that almost half of carers' families did not use any support services. Of those that did use support services, the most commonly used services were respite care (13 per cent) and visits to GPs (11 per cent). The report found that three out of five families used respite for less than 20 hours a month and close to one in five used it for more than 50 hours per month.[66]

4.4.2 Type of Support

Chart 20 uses SDAC data to highlight the type of supports most desired by primary carers and their families. In 2003, the type of support or improvements most desired by primary carers to assist in their caring role focused on financial assistance, respite care, improvements in their own health and emotional support.

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[62] Berecki J., et al July 2007, *Changes in Caring Roles and Employment in Mid-life. Findings from the Australian Longitudinal Study on Women's Health Report 2*, Women's Health Australia, The University of Newcastle and The University of Queensland

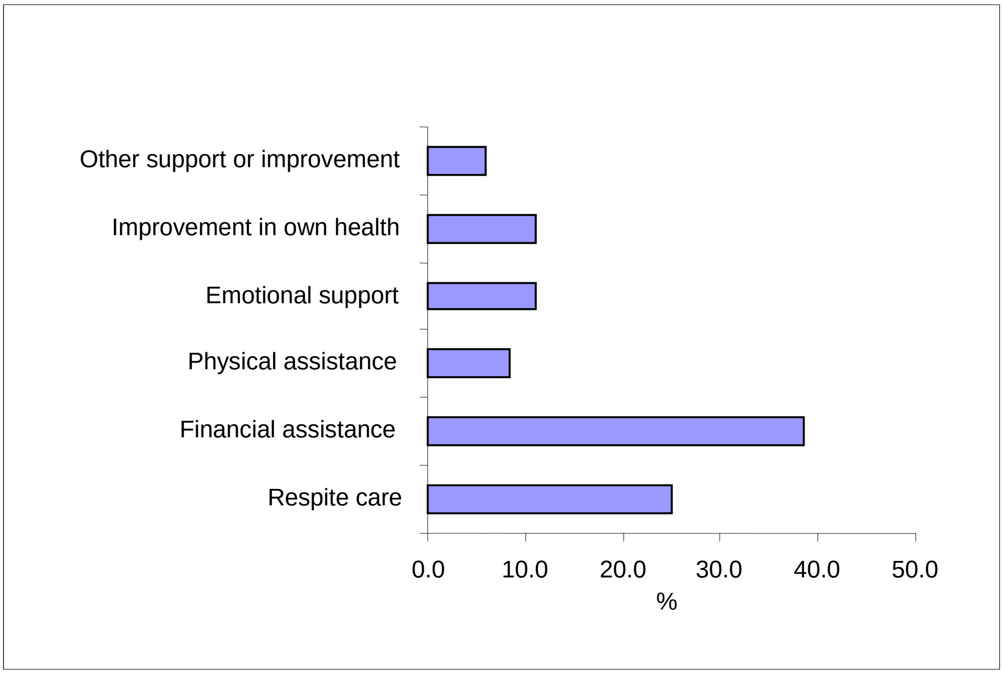
[63] Australian Unity Wellbeing Index October 2007, *Survey 17.1, Special Report: The Wellbeing of Australians: Carer Health and Wellbeing*, p v11

[64] Australian Institute of Family Studies 2008, *Research Report no.16: The nature and impact of caring for family members with a disability in Australia*, p94

[65] Access Economics 2005, *The Economic Value of Informal Care*, p38

[66] Australian Institute of Family Studies 2008, *Research Report no.16: The nature and impact of caring for family members with a disability in Australia*, p xvi

Chart 20: Type of support or improvement most desired by Primary Carers



Source: ABS, SDAC, 2003

4.4.3 Effectiveness of Support

In 2007, the Department of Health and Ageing engaged the Centre for Health Service Development, to identify the needs of carers, including the factors that sustain carers in their caring role; to identify effective interventions; and to develop and set out a prioritised research agenda in this area. The results are compiled in the final report, *Effective Caring: a synthesis of the international evidence on carer needs and interventions* December 2007. The report is available on the Department's web-site.[67]

The strongest evidence in Centre for Health Service Development's findings was presented for counselling, case management and tailored carer interventions. Positive findings were identified for educational and psycho-educational interventions and good evidence was identified for the impact of multi-component interventions, whereby a range of carer interventions are made available.

The Department of Health and Ageing has also commissioned an evaluation into carer support measures for the NRCP, which was undertaken by Campbell Research and Consulting.

Key findings of the evaluation showed carers see many benefits of respite and other support services provided under the NRCP. Two of the most commonly reported respite types sought by carers were in-home respite and centre-based respite, both highly rated for the appropriateness and convenience of the services to carers. Residential respite rated the highest in giving the carer a proper break, yet rated low in carer's view of being good for the care recipient. In comparison in-home respite was favoured amongst carer's for being good for the carer recipient and given at a convenient place and time, being their home. In-home respite was identified as the area of greatest demand, with many carers expressing a need for support in the home that went beyond the presence of a paid carer.

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[67] Effective Caring Report Website address: http://www.health.gov.au/internet/main/publishing.nsf/Content/ageing-publicat-effective-caring-v1.htm

5 OTHER CURRENT WORK OF RELEVANCE

Current work of relevance that is being pursued by Australian Government agencies has been highlighted in this section of the submission.

5.1 WHOLE OF AUSTRALIAN GOVERNMENT

5.1.1 Streamlining Respite Services

As highlighted in this submission, all levels of Government and various portfolios contribute to a mix of services and supports for carers. The Australian Government recognises the difficulties this poses for carers and their families and the complexities they face in navigating the service delivery system. The Australian Government has made a commitment to streamline respite services across its departments to create a more sensible system for carers.

The Departments of Health and Ageing; Families, Housing, Community Services and Indigenous Affairs; and Veterans' Affairs are working together on options for structural reform that will lead to a simpler, more accessible and more effective respite system that better meets the needs of both carers and care recipients. This process is being informed by previous consultations across the sectors and will incorporate key principles for reform including:

- more consumer-focused arrangements that support improved continuity and responsiveness of care;
- simplified arrangements for service providers that enable better planning and distribution of services and improved capacity to respond to consumer need; and
- simpler and more streamlined program arrangements that better integrate respite care with other community care.

5.1.2 Council of Australian Governments – Commonwealth-State Specific Purpose Payments

Reforms to Commonwealth-State funding arrangements by the COAG will enable states to deploy Commonwealth-State Specific Purpose Payments more efficiently, with the current 92 Specific Purpose Payments being reduced to five or six new national agreements, one of which will cover disability. The new arrangements are to commence from 1 January 2009.

The Commonwealth State Territory Disability Agreement will be replaced by the new National Disability Agreement as the vehicle for funding state and territory governments for the administration of services for people with a disability. The national agreement will contain a clear, mutually-agreed statement of policy objectives, specified as far as practicable in terms of outcomes to be achieved, and the accountabilities of each government. These policy objectives and outcomes will take into account the funding provided by both levels of government in supporting people with a disability and their carers.

5.1.3 Agreement for funding Disability Services

At a meeting on 30 May 2008, State and Territory Disability Ministers agreed to deliver $900 million in funding on top of the Australian Government's $900 million, from the Disability Assistance Package. This funding, together with the Budget amount of $100 million for supported accommodation will provide a total of over $1.9 billion in additional support for disability services across Australia over the next four years.

The combined funding will provide more than 24,500 places, including 2,300 in-home support places, 2,300 supported accommodation places, 9,900 individual support packages and 10,000 much needed respite places. The $100 million will deliver 309 new supported accommodation places.

5.1.4 Social Inclusion Agenda

The Australian Government is strongly committed to the progression of a significant Social Inclusion Agenda. The aspiration is 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. In pursuing this aspiration there is a recognition that despite 17 years of economic growth there are disadvantaged Australians who are missing out on these, and other benefits, of Australian society.

In this context the Australian Government has already identified five immediate priorities for the Social Inclusion Agenda: homelessness; Indigenous disadvantage; employment for people with mental health and disability concerns; children at risk; and jobless families. It has also established a Social Inclusion Unit and a Social Inclusion Board, chaired by Ms Patricia Faulkner, to offer advice on developing the long term Social Inclusion Agenda, including addressing locational disadvantage and engagement with the third sector.

Social isolation in particular emerged as a major policy theme for carers in their individual submissions to the *Carer Payment (child) Review 2007*. Carers reported social isolation contributed to their levels of depression and stress. It also affected the socialisation of their children who experienced isolation, bullying and rejection when attending school.

5.1.5 Australia’s Future Tax System Review

Australia’s Future Tax System Review, announced by the Treasurer on 11 May 2008, will take into account the relationship of the tax system with the transfer payments and other social support payments, rules and concessions with a view to improving incentives to work, reduce complexity and maintain cohesion. The review will provide a final report to the Treasurer by the end of 2009.

As part of the review, the Secretary of the Department of Families, Housing, Community Services and Indigenous Affairs, Dr Jeff Harmer, will complete an investigation into measures that might be adopted to strengthen financial security of carers and seniors.

The report, which is to be provided to the Treasurer and Minister Macklin through the Chair of the Tax Review, Dr Ken Henry, no later than 28 February 2009 will address:

- the appropriate levels of income support and allowances, including the base rate of the pension, with reference to the stated purpose of the payment;
- the frequency of payments, including the efficacy of lump sum versus ongoing support; and
- the structure and payment of concessions or other entitlements that would improve the financial circumstances and security of carers and older Australians.

5.1.6 Mental Health and Disability Employment Strategy

The Australian Government announced the Mental Health and Disability Employment Strategy as part of the Government’s broader social inclusion agenda. The Hon Brendan O'Connor MP, Minister for Employment Participation and the Hon Bill Shorten MP, Parliamentary Secretary for Disabilities and Children’s Services, will jointly drive the strategy. The Mental Health and Disability Employment Strategy will form part of the National Disability Strategy and will address the barriers to gaining and maintaining work that people with a disability and/or mental illness confront in the community.

It will look at ways to create direct links between employers and people with a disability and mental illness while exploring innovative ways to support people to find and retain work.

The strategy will be developed in consultation with people with a disability and/or mental illness, employers, employment service providers, peak bodies, state and territory governments and experts.

A discussion paper for the strategy was launched on 14 April 2008.

5.2 DEPARTMENT OF FAMILIES, HOUSING COMMUNITY SERVICES AND INDIGENOUS AFFAIRS

5.2.1 2008-09 Budget Implementation

The Australian Government is committed to increasing the participation, social inclusion and well being of people with a disability and their carers and allocated $293.6 million in this year's Budget to carers.

A large component of this year's Budget measures were in response to the Carer Payment (child) Review. The most significant change is to the eligibility criteria and assessment process for Carer Payment (child) at a cost of $273.6 million over four years. In 2009-10 around 19,000 carers of children under 16 years of age with a disability or severe medical conditions are expected to benefit from the new arrangements. The changes will be implemented from 1 July 2009 and 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);
- 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.

The remainder of the package includes around $20 million over four years for carers who have experienced a catastrophic event involving a young child

Other Budget measures that will assist carers and their families include:

- $428.1 million in 2007-08 for Carer Bonuses to be paid to eligible carers;
- $100 million in 2007-08 to state and territory governments to support older carers through accommodation for their children with a disability;
- all Carer Payment recipients being eligible for a Utilities Allowance of $500 per year; and
- the rate of Telephone Allowance increasing from $88 per year to $132 per year for Carer Payment recipients with a home internet connection.

5.2.2 National Disability Strategy

The National Disability Strategy will provide the opportunity to develop an overarching policy statement and action framework that will support the creation of innovative policy. It will set the direction of future disability policy in Australia and deliver outcome focused initiatives that aim to maximise inclusion, consistency and responsiveness to the needs of people with a disability, their families and carers. Key components of the National Disability Strategy include the new Disability Agreement and ratification of the United Nations Convention on the Rights of Persons with Disabilities.

5.2.3 Senate Inquiry into Special Disability Trusts

Special Disability Trusts assist families with the financial means to make private provision for the current and future care and accommodation of a family member with severe disability. The Special Disability Trust provides social security and veterans' entitlement means test concessions to eligible contributors and beneficiaries.

On 15 May 2008, the Senate referred matters relating to Special Disability Trusts to the Community Affairs Committee for Inquiry and the report is due by 18 September 2008. The Terms of Reference for the Inquiry are as follows:

- why more families of dependents with disabilities are not making use of the current provisions to establish Special Disability Trusts;
- the effectiveness of Part 3.18A of the *Social Security Act 1991*;
- barriers in the relevant legislation to the establishment of Special Disability Trusts; and
- possible amendments to the relevant legislation.

5.2.4 Disability Investment Group

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 to explore innovative funding ideas from the private sector that will help people with a disability and their families access greater support and plan for the future. The Department provides secretariat and other support to the Disability Investment Group which reports directly to the Parliamentary Secretary.

The Disability Investment Group provides a vehicle for a group of experts to assist in identifying ways to encourage private investment (including from families) and avenues for new products and services to assist families make financial provision and plan for the future care of a family member with a disability.

5.2.5 Economic Model on Care Provision

An *Economic Model on Care Provision* is being developed to assist with the assessment of options for the provision of care for people with a disability or severe medical conditions, or those who are frail aged. The model will provide information on the full economic costs of alternative options in care provision, including whole of government care options.

The model will deliver:

- projections of the supply of formal and informal care and demand for care;
- the relative costs of alternative options of care provision; and
- impacts of different policy options on different agents (care givers, care receivers, their families, the economy and the Australian Government).

5.3 DEPARTMENT OF HEALTH AND AGEING

5.3.1 Program Reviews

The Department of Health and Ageing has progressed two key reviews into the system of community care and the programs directly funded through Health and Ageing in recent years. These reviews are: A Review of Subsidies and Services in Australian Government Community Aged Care Programs; and the Review of Community Care: *The Way Forward (2004).*

A key area for consideration in both reviews was to identify opportunities to reduce system fragmentation, gaps and overlaps in the system, including in relation to carer support programs, so as to enhance outcomes for clients and their carers. Key consideration has also been given to exploring opportunities for better integration between carer support programs and broader community care supports in recognition of the needs of carers being intimately linked to the needs of care recipients.

Review of Subsidies and Services in Australian Government Community Aged Care Programs

A Review of Subsidies and Services in Australian Government Community Aged Care Programs was established by the previous government in September 2006. The review examined the levels and types of care required by older people in the community, how well current services meet these requirements, and how arrangements could be improved to ensure equity, choice and value for money. It also examined the relationship between programs funded by the Department of Health and Ageing and the jointly funded Home and Community Care Program.

The review examined a range of information on the operation of community care programs, including the views of consumers, community care providers and other stakeholders through a public call for submissions.

The call for submission process, conducted from November 2006 to February 2007, sought key stakeholder views on:

- the structure and funding of programs supporting the frail aged and their carers;
- the range and diversity of community care services required for this target group; and
- future service requirements.

More than 50 submissions were received from key stakeholders, including peak bodies, service providers, consumer and industry organisations and several state, territory and local government agencies. Most submissions included comment on respite and provided useful insight into carer issues and the operation of current respite arrangements.

Themes in the submissions relating to carer supports included:

- The value of carers, the critical role they play in supporting frail older people and those with disabilities and reducing social isolation across the community care spectrum and the significance of respite care in maintaining the efficacy of community care were common themes in the majority of submissions. The emergency and short-term respite service provided through Australia’s NRCP was strongly supported.
- There was also a high level of agreement on the issues that need to be addressed to improve the provision of respite services and meet future need. In general stakeholders see respite as oriented around programs, rather than client focused, and overly complex, with gaps and overlaps in service provision and inconsistencies between program arrangements contributing to service inequities and inefficiencies.

- There was less agreement on the changes that could be made to improve respite arrangements for carers and care recipients. There was strong support for consumer-centred care, closer alignment of respite for carers of frail older people with the broader community aged care arrangements and integration of respite with other carer supports.
- There was also general support for improved continuity of care and consumer access through comprehensive assessment, simplified eligibility arrangements, a reduction in the number of disparate programs, removal of program boundaries and increased flexibility and levels of service provision to better meet community need. Several submissions suggested that respite provision be amalgamated into a single program though there was no agreement on whether this would be a dedicated respite program or form part of a broad community care program.

The Review of Community Care: *The Way Forward (2004)*

A 2002 review of community care programs identified that the current system:

- was complex and confusing for individuals and carers to navigate;
- had service gaps and overlaps in service delivery; and
- assessed clients multiple times and in a variety of ways.

A New Strategy for Community Care: *The Way Forward (2004)* set out a range of action items to improve community care services from client/carer and service provider perspectives by adopting a nationally consistent approach (known as common arrangements) across all community care programs in key areas such as entry into community care and access to services, assessment practices, planning, fees, financial reporting, quality assurance and information management.

The common arrangements aim to strengthen the community care system and identify strategies that would simplify and streamline current arrangements for the administration and delivery of community care services.

The common arrangements have been developed in partnership with state and territory governments, industry (including carer organisations) and the community care sector.

The Department of Health and Ageing continues to regularly communicate with the sector and industry bodies on progress made and opportunities for involvement in developing the details of the common arrangements, and ways of implementing the reform initiatives.

A key piece of work underway is the development of a Carer Eligibility and Needs Assessment (CENA) tool. Community and Aged Care Officials, a forum established to progress the reforms, and a number of multi-jurisdictional working groups, regularly meet to guide this work.

The COAG decision of 10 February 2006 in relation to “simplifying access to care services for older people, people with disabilities and people leaving hospital”, confirmed the commitment by all jurisdictions to key common arrangement components such as access, eligibility, assessment and referral in the HACC Program.

Implementation of the COAG initiative has seen the identification of 14 demonstration projects to trial and model different arrangements for simplified Access Points into community care.

5.3.2 Building the Evidence Base

The Centre for Health Service Development Research, *Effective Caring: a synthesis of the international evidence on carer needs and interventions,* includes the following observations on the evidence of carer needs:

- the lack of a standardised approach to defining, collecting and sharing common information about carers is a barrier to greater coherence in the approach to carer support; and
- available evidence on the effectiveness of carer interventions is not conclusive due to outcome measures not being sufficiently sensitive to change; the elements of the carer interventions not being specific enough to meet carer needs; and an incapacity to determine which elements of an intervention are more or less effective.

The report provides a broad range of questions for future research. A few of the areas the report suggests more evidence is required are:

- identifying carer needs of specific groups such as CALD and ATSI;
- the “dose” and type of respite that is most effective for different types of carers (spouses, parents, children, resident, non-resident, employed, young, old etc);
- the “dose” and type of counselling and psychosocial interventions that are effective for different types of carers;
- evaluated pilots on support groups;
- identifying a range of profiles on carers based on statistical information from available data sources e.g. ABS, SDAC; and
- identifying unmet need and defining this. (See Support Needs section for further information on the Centre for Health Service Development report).

The report outlines a proposed research agenda which provides useful direction regarding how research can be translated into practice. The report suggests that services may benefit in training in local service/program evaluations and in researchers sharing their expertise in these evaluations. Additionally, the report suggests a need to improve processes for the dissemination of research findings regarding evidence-based practice in carer support such as through a clearing house.

The Department of Health and Ageing is involved in two key projects that will improve the availability of standardised carer data:

- (i) The Australian Institute for Health and Welfare, the Department of Health and Ageing and the Department of Families, Housing, Community Services and Indigenous Affairs are contributing to an Australian Bureau of Statistics Working Group tasked with improving the carers data in the ABS Survey of Disability, Ageing and Carers. The Australian Institute of Health and Welfare and the Department of Health and Ageing are exploring ways of developing a clear and consistent definition and description of the caring relationship and of carers and their experiences; and
- (ii) The Department of Health and Ageing has commissioned the development of a national carer assessment tool for use by the Department’s carer related programs and services and potentially other programs that support carers. A consistently applied assessment tool provides a key plank in standardising carer data. This is discussed more fully later in this section.

5.3.3 Carer Eligibility and Needs Assessment Tool

There is currently no nationally consistent approach to assessing the needs of carers seeking assistance from government programs, such as the NRCP. The value of such a tool is multi-faceted, including ensuring equity of access to support by carers with similar needs; reducing the need for multiple assessments when carers access a range of programs and, as highlighted previously, developing a common language for defining carers and their needs.

The Department of Health and Ageing has commissioned the development of a national assessment tool for the assessment of carer needs intended to be used by the Department's carer related programs and services. The "Carer Eligibility and Needs Assessment" (CENA) is an assessment process that both identifies the activity that a carer or carers undertake to support their "care recipient" and any areas of potential need or support the carer may have and the information aims to support the broader research agenda relating to carer needs.

Development of the CENA was a key outcome of the Australian Government initiated review of all community care programs, A New Strategy for Community Care: *The Way Forward (2004).* This review identified that the community care system was confusing and complex for clients and carers to enter or navigate, and that there were gaps and overlaps in service delivery and clients were being assessed multiple times in a variety of ways.

In response to this, a key action of A New Strategy for Community Care: *The Way Forward (2004),* was to develop a nationally consistent intake assessment process for care recipients and carers.

Following initial research and development during 2006 the University of Wollongong constructed and field tested two questionnaires, the Australian Community Care Needs Assessment (ACCNA) and the CENA. Applied Aged Care Solutions is now enhancing and further developing the ACCNA and CENA in line with field testing recommendations.

The CENA has been designed to assess carers' needs for services, supporting the principle that an assessment process should consider the needs of both the care recipient and the carer. The CENA is a new assessment based on available research. Whilst it may be used as a telephone interview by skilled, experienced interviewers, it is recommended that the depth of questioning and the sensitive areas covered make it more suitable for a face to face interview. The CENA will undergo further refinement, testing and validation before progressing to full implementation.

This further development will consider the potential impact of the CENA on organisations providing services to carers. For some services, a focus on carers may be a new way of thinking. It may require a considerable shift in how to identify and appropriately respond to carers' needs.

Some elements of the CENA include:

- the extent of care hours required to assist the care recipient;
- an estimate of carer health;
- 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.

The ACCNA and CENA are currently under development and are expected to be available for full implementation in 2009.

5.4 DEPARTMENT OF VETERANS' AFFAIRS

The Department of Veterans' Affairs is aware of the changing needs of its veterans and war widows/widowers. An independent review of the Veterans' Home Care Program was commissioned in early 2007 to identify what changes, if any, may be necessary to continue to meet the needs of veterans and war widows/widowers over the coming years. The final report, entitled *Options for the Future of Veterans' Home Care*, was received in early March 2008 and is available on the Department of Veterans' Affairs website - www.dva.gov.au/health/homecare/mainvhc.htm.

The review highlighted opportunities to expand and improve the program to cater for future needs. The options are currently being examined, including the best way to meet the respite requirements of veterans and their carers.

The Department of Veterans' Affairs is participating in the Community Care Review: *The Way Forward* with a view to improving the provision of services to both veteran clients and their carers.

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