

Carer Identification, Demographics and Supports and Services

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

Definition and Use of the Term 'Carer'

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

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

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

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

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

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

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

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

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

1 Carers NSW, Submission No 661, p 6.

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

3 Carers NSW, Submission No 661, p 6.

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

Meaning and Use of the Term Carer in the Inquiry

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

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

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

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

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

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

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

'Hidden' Carers

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

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

Carer Identification

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

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

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

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

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

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

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

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

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

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

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

14 Carers Tasmania, Submission No 671, p 8.

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

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

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

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

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

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

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

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

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

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

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

19 Carers Australia, Submission No 699, p 34.

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

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

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

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

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

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

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

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

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

24 ANGLICARE Sydney, Submission No 769, p 32.

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

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

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

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

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

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

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

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

The Need for Increased Carer Self-Identification

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

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

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

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

31 Siblings Australia, Submission No 701, p 3.

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

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

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

Carer Identification through Surveys

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

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

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

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

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

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

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

Amendments to the Survey of Disability, Ageing and Carers

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

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

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

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

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

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

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

Recommendation 1

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

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

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

The Demographic and Socio-Economic Profile of Carers

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

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

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

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

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

Changing Models of Care and Implications of Demographic and Social Trends

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

48 Carers NSW, Submission No 661, p 6.

49 Carers Victoria, Submission No 652, p 4.

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

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

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

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

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

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

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

50 Carers Australia, Submission No 699, p 8.

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

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

53 Carers Australia, Submission No 699, p 7.

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

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

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

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

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

Consideration of the Implications of Demographics and Social Change

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

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

55 Carers Australia, Submission No 699, p 7.

56 Carers Australia, Submission No 699, p 7.

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

Government Administration of Supports and Services

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

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

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

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

Administration of Government Supports and Services for Carers and Care Receivers

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

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

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

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

Financial Assistance for Carers

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

Concession Cards

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

Australian Government Programs and Services

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

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

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

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

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

Department of Families, Housing, Community Services and Indigenous Affairs

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

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

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

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

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

Department of Health and Ageing

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

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

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

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

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

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

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

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

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

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

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

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

Department of Veterans' Affairs

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

State and Territory Government Programs and Services

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

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

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

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

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

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

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

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

