



Chapter

7

Informal carers

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7 Informal carers

Key points

- In 2009, 2.6 million Australians (12% of the population) were informal carers of a person with disability or a person who was ageing.
- Around 771,000 people were primary carers: that is, the person who provided the most assistance. Two-thirds of all primary carers were female; one-quarter (196,000) were aged 65 years or over and 3% (23,000) were aged 15–24 years.
- As with the Australian population generally, the population of informal carers is ageing. In 1998, three in five primary carers (60%) were aged 55 years or over. In 2009 this age group accounted for three in four primary carers (74%).
- People aged 45 years or over were most likely to be caring for their spouse or partner; those aged 25–44 years were most likely to be caring for a child with disability; while young carers most often cared for a parent.
- In 2009, half (53%) of all primary carers spent at least 20 hours per week providing care, including one-third (35%) who provided care for 40 hours per week or more.
- One in three primary carers (243,000 people) had been in the caring role for at least 10 years in 2009.
- Providing ongoing informal care can affect carers' employment opportunities. In 2009, 54% of primary carers were in the workforce compared to 79% of the general population. More than 100,000 primary carers were not in the labour force but would like to be employed.
- Almost 300,000 primary carers reported that they needed more support or an improvement in their situation. More financial assistance was the most commonly reported additional support wanted (91,900 primary carers), followed by more respite care (39,400) and more physical assistance (32,100).
- Services that provide support for carers include community care, respite, information and counselling.
- In June 2010, almost 169,000 informal carers received the Carer Payment, an Australian Government allowance for people providing constant, ongoing care. More than 90% of recipients (156,000) were caring for an adult with severe disability while 8% (13,665) were caring for a child.

7.1 The policy context

Governments have recognised the social and economic contribution that informal carers in Australia make, both to the wellbeing of individual care recipients and to the community generally. In recent years, a Parliamentary inquiry (HRSCFCHY 2009) and two Productivity Commission inquiries (PC 2011a, 2011b) have explored the long-term sustainability of caring in the context of population ageing and social change. It has also become the subject of a national strategic approach. Together, these forward-planning initiatives aim to improve the support for, and hence sustainability of, caring.

In addition, several steps have been taken to commence this process of improvement, including carer recognition, as well as streamlining services to care recipients and their carers, along with access to those services.

Box 7.1: Who is an informal carer?

There is no single definition of what makes someone an informal carer. The 2009 ABS Survey of Disability Ageing and Carers (SDAC) defines a carer as

'A person of any age who provides any informal assistance, in terms of help or supervision, to persons with disabilities or long-term conditions or persons who are elderly (i.e. aged 60 years and over). This assistance has to be ongoing, or likely to be ongoing, for at least six months.'

A person is a **primary carer** if they provide 'the most informal assistance, in terms of help or supervision, to a person with one or more disabilities or aged 60 years and over' in one or more of the core activities (communication, mobility and self-care). In the 2009 SDAC, only carers aged over 15 years with whom a personal interview was conducted were included as primary carers (ABS 2011:25, 26, 34).

The *Disability Services–NMDS (DS-NMDS)* defines a carer as

'someone who provides a significant amount of care and/or assistance to the person on a regular and sustained basis. 'Regular' and 'sustained' in this instance means that care or assistance has to be ongoing, or likely to be ongoing for at least 6 months.'

The DS-NMDS also aligns with the 2009 SDAC in its definition of a 'primary carer' (AIHW 2009a:77).

Informal carers do not include paid or volunteer carers that formal services organise (AIHW 2009a:75).

The *Carer Recognition Act 2010* describes a carer as 'an individual who provides personal care, support and assistance to another individual who needs it' because of disability, health conditions or ageing. Carers who are undertaking caring in a paid, training or voluntary capacity are not included (Commonwealth of Australia 2010b). The Act does not differentiate between primary and other carers.

An important consideration for the concept of carers and caring is recognition that the care provided is above and beyond what would usually be expected within a relationship.

Governments have implemented various approaches that seek to have an impact on the lives of carers immediately. This followed from recommendations in *Who cares...? Report on the inquiry into better support for carers* (HRSCFCHY 2009), which proposed a national and whole-of-government approach to carer legislation and policy. The Committee recommended the concept of a National Carer Recognition Framework, comprising both national carer legislation and a national carer strategy (HRSCFCHY 2009).

National Carer Recognition Framework

In October 2009, the Australian Government launched the National Carer Recognition Framework. The framework has seen the development of a National Carer Strategy (see below), which was released in August 2011 (Commonwealth of Australia 2011).

The framework also led to the *Carer Recognition Act 2010*. This legislation seeks to 'increase recognition and awareness of carers and to acknowledge the valuable contribution they make to society' (Commonwealth of Australia 2010a:2). In particular, the Act includes a *Statement for Australia's Carers*, which details 10 principles concerning carers and 'how they should be treated by Commonwealth public service agencies and their funded providers'. This does not, however, create any 'legally enforceable obligations' (Commonwealth of Australia 2010a:6, 7; Parliament of Australia 2010:2).

Most states and territories of Australia enacted carer legislation prior to the Federal enactment, while Victoria implemented a Charter supporting people in care relationships (DoH Victoria 2010).

In addition to the overarching approach to carers, individual sectors are also seeking to recognise and support carers in the context of their specific operations (Box 7.2). This is seen, for example, in the National Disability Agreement (NDA), whose primary objective is that '*people with disability and their carers have an enhanced quality of life and participate as valued members of the community*' (COAG 2008:3).

Box 7.2: Carers and carer support within wide-ranging policy contexts

Carers come from all walks of life and provide care for a diverse range of care recipients. The impact of caring on the lives of those carers can also be wide ranging. For example, employment, education, health and community life are areas in which carer participation and wellbeing may be influenced.

Significant reforms and policy developments are underway in many of these areas, as part of whole-of-government reforms, addressing structural and service issues specific to carers:

- Community Care Common Standards 2010 (see 'Chapter 6 Ageing and aged care')
- National Health Reform (see 'Chapter 5 Disability and disability services')
- The National Disability Agreement (see 'Chapter 5').
- The Fourth National Mental Health Plan released by the National Mental Health Strategy
- The *Fair Work Act 2009* and the National Employment Standards
- The National Strategy for Young Australians (see 'Chapter 4 Children and young people')
- The Productivity Commission's inquiries into caring for older Australians, and a national disability long-term care and support scheme (discussed below).

Planning for the future

National Carer Strategy

In August 2011, the Australian Government released the National Carer Strategy to improve the supports provided to carers through the aged care, disability, mental health, primary health care, hospital and community care systems (Commonwealth of Australia 2011). The strategy aims to provide carers with services and supports that are flexible, coordinated, appropriate, affordable, inclusive and sustainable. It contains six priority areas for action:

- recognition and respect
- information and access
- economic security
- services for carers
- education and training
- health and wellbeing.

The Strategy complements a range of reforms currently underway (Box 7.2).

The Productivity Commission inquiries

National disability long-term care and support scheme

In the inquiry report *Disability care and support*, the Productivity Commission recognised that family and friends provide the majority of all care to people with disability. The size of this contribution is so significant that no insurance scheme could fully fund its replacement. However, informal care arrangements need to move to a 'more equitable and sustainable footing', so that the pressure on carers is lessened (PC 2011b:312, 313). Hence, the Commission recommended that part of the assessment process for an individual with disability entering the scheme would be assessment of informal care that could be '*reasonably and willingly provided by unpaid family carers and the community*' (PC 2011b:339). If in the course of that assessment it becomes apparent that the informal carer provides substantial care, they may elect to have a separate assessment (PC 2011b:331). In the proposed scheme, particular emphasis is put on carer training (PC 2011b:726–728).

Caring for older Australians

The Commission's report *Caring for older Australians* considered in detail the significant role informal carers play in providing the majority of direct care to older people. While supporting the development of the National Carer Strategy, the Commission suggested that there is an 'immediate need to develop additional supports for carers' (PC 2011a:325, 333). In particular the Inquiry recommended that as part of an Australian Seniors Gateway Agency:

'When assessing the care needs of older people, [the Agency] should also assess the capacity of informal carers to provide ongoing support. Where appropriate this may lead to approving entitlements to services for planned respite and other essential services.

Carer Support Centres should ... undertake a comprehensive and consistent assessment of carer needs ... [delivering services] including:

- carer education and training
- planned and emergency respite
- carer counselling and peer group support
- carer advocacy services.(PC 2011a:341)

(See also Chapter 6).

The Australian Government is actively considering the recommendations from these inquiries.

7.2 Who provides informal care?

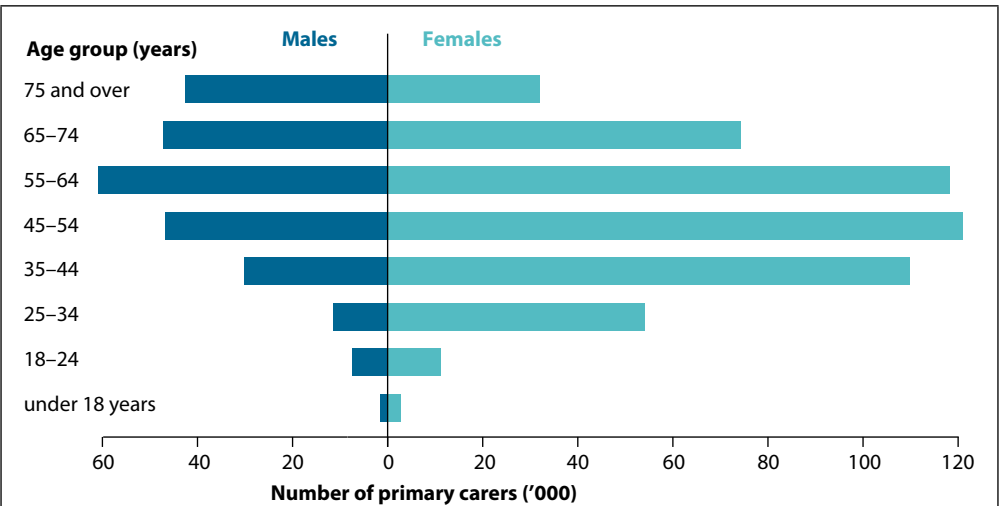
In 2009, over 2.6 million people (12% of the population) were informal carers of people with disability or people who were ageing (Table A7.1). About one-third of these carers (771,400 people or 3.6% of the population) were primary carers (Box 7.1).

More females than males were carers, and this was particularly true for primary carers (Figure 7.1). Over half (55%) of all carers and two-thirds (68%) of primary carers were female (Table A7.1).

Box 7.3: Recognition and identification of informal carers

Some people may not see themselves as ‘carers’ and consider their caring role as a part of family responsibilities. This could lead to an underestimation of carers based on self-reported information (AIHW 2008). The SDAC reported that the number of primary carers increased from 474,600 people in 2003 to 771,400 people in 2009, largely due to the change in the methodology by which carers were identified. The SDAC definition of primary carers has been shown as too narrow for the purpose of representing the diverse circumstances and needs of carers (Schofield et al. 1997, 1998 in AIHW 2008:6). Also, not all carers are eligible to receive carer support payments or services. And while some carers do not seek assistance because they do not consider themselves as carers, along with others they may not be aware of the eligibility criteria for assistance or do not need or want assistance. Therefore, the administrative data often include only a subgroup of the carer population. Failure to identify as a carer affects access to services, as those who do not identify do not seek carer-specific services. Further, data on recipients of disability services will necessarily not reflect the provision of informal care, which itself influences resourcing and availability of services.

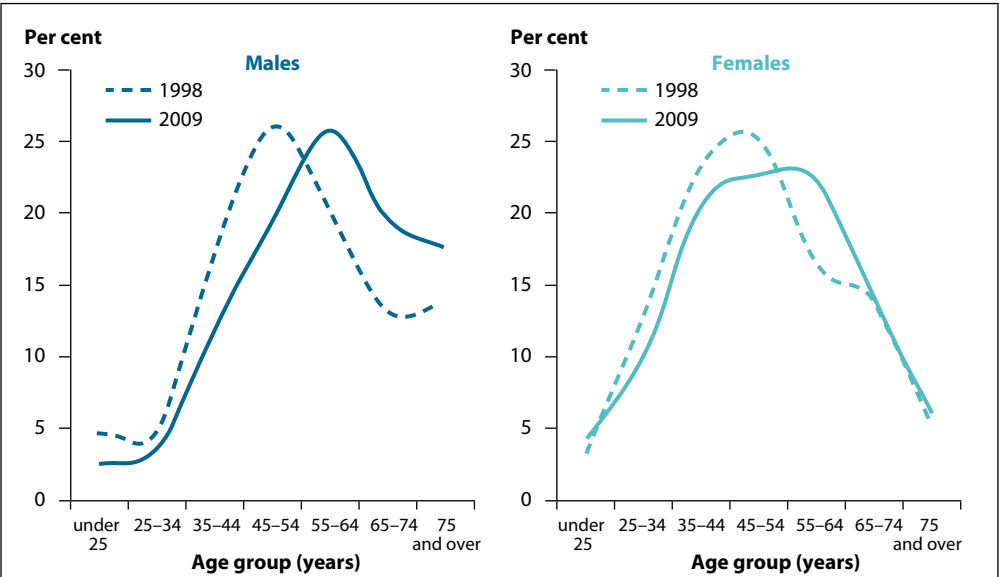
There were more female primary carers than males across all age groups up to 74 years, after which there were more male primary carers (Figure 7.1). The sex differential was particularly large for younger age groups: under the age of 45 years there were 3.5 times as many female carers (177,800) as male carers (50,500). The peak age group for females to be in a caring role was 45–64 years, compared to 55–64 years for males.



Sources: Table A7.1; ABS 2009 Survey of Disability, Ageing and Carers internet version of data table released by ABS in December 2010.

Figure 7.1: Estimated number of primary carers by age and sex, 2009

The impact of population ageing is reflected in the primary carer population (Figure 7.2). Between 1998 and 2009, the proportion of primary carers aged 55 years or over increased from 39% to 49%. The proportion of primary carers aged 65 years or over increased from 21% to 25% over the same period. These changes partly reflected the large cohort of the baby-boomer generation who were moving into the older age groups.



Sources: Table A7.2; ABS 2009 Survey of Disability, Ageing and Carers internet version of data table released by ABS in December 2010; AIHW analysis of the ABS 1998 Survey of Disability, Ageing and Carers confidentialised unit record file.

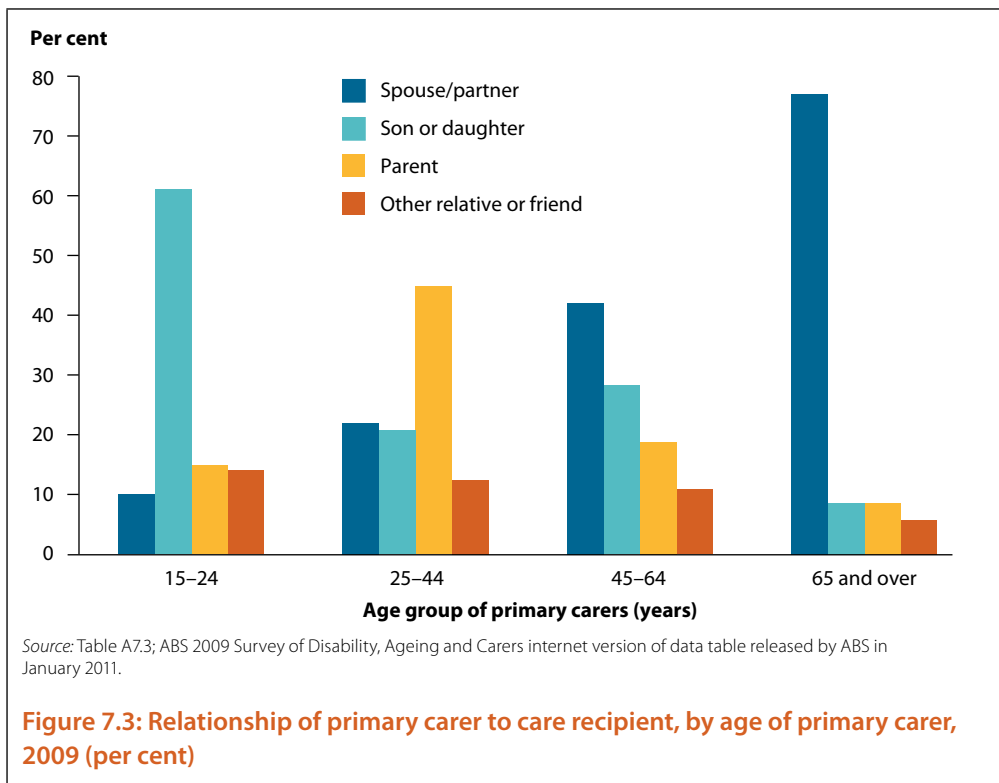
Figure 7.2: Age structures of primary carer populations, by sex, 1998 and 2009

Who do carers provide care for?

Overall, the most common care relationship was one spouse caring for the other. In 2009, 344,600 primary carers were spouses of their care recipients, accounting for 45% of primary carers aged 15 years or over (Table A7.3). Almost one-quarter of primary carers (23%, or 177,800) were parents of their care recipients and 22% (171,400) were children of their care recipients.

Among primary carers aged 15–24 years, a majority (61%) were sons and daughters caring for their parents (Figure 7.3). Carers as parents of care recipients (45%) was the most common care relationship of primary carers aged 25–44 years. Spouse carers accounted for 42% of primary carers aged 45–64 years, and a vast majority (77%) of those aged 65 years or over.

Of the 195,900 primary carers aged 65 years or over, 16,800 were ageing parents caring for a child, and most (13,600) were mothers (Table A7.4). Some care recipients of these ageing parent carers were those with an early onset disability (ABS 2008). Ageing parents caring for their child with severe or profound core activity limitation have different experiences from people taking on the caring role as a spouse in later life.



Special carer groups

Many carers have particular needs associated with their own life circumstances, in a sense distinct from the person or people for whom they care. This section looks at a number of distinct carer groups with particular needs; it also discusses some issues associated with carer identification, which affect the ability to fully identify and describe these special carer groups.

Young carers

In 2009, there were 304,800 young people (aged less than 25 years) providing informal care, of whom 8% (22,900) were primary carers aged 15–24 years (ABS 2011:10). Primary carers aged 15–24 years were most likely to be the son or daughter of the person for whom they were providing care (61%) or the parent of a child requiring care (15%; Figure 7.3).

Cass et al. (2009) found that young carers were typically providing care for parents, often in single-parent households and over an extended period of time, which frequently had an impact on both education and employment opportunities, as well as personal and recreational activities.

There are concerns that statistical data may not capture “hidden” young carers, as detailed in research on young carers funded by the Australian Government Department of Families, Housing, Community Services and Indigenous Affairs (Cass et al. 2009). This is partly because they may not self-identify as carers (Box 7.3); but also many do not access formal service providers (Cass et al. 2009). This is consistent with evidence given to the Carers inquiry (HRSCFCHY 2009), which noted that young people often either did not see themselves as carers, or were reluctant to disclose their caring role to others.

Ageing carers

The 2009 SDAC estimated that 520,500 informal carers were aged 65 years and older, of whom 195,900 were primary carers (ABS 2011:10). This means that older people account for one in five (20%) informal carers, including one in four (25%) primary carers (Table A7.1). As Figure 7.3 illustrates, ageing primary carers were most likely to be caring for their spouse or partner, although 9% were caring for their child and another 9% were caring for their own parent.

A submission by FaHCSIA and the Departments of Health and Ageing (DoHA) and Veterans' Affairs (DVA) to the Inquiry into Better Support for Carers estimated that:

“over 25% of older carers were ‘hidden’ in the sense that they do not seek assistance and are therefore unknown to service providers” (HRSCFCHY 2009:21).

Another submission also addressed the issue of access to services, suggesting that many ageing carers had been in that role for an extended period and that for some “social isolation and a sense of self-reliance” inhibited access (HRSCFCHY 2009:22).

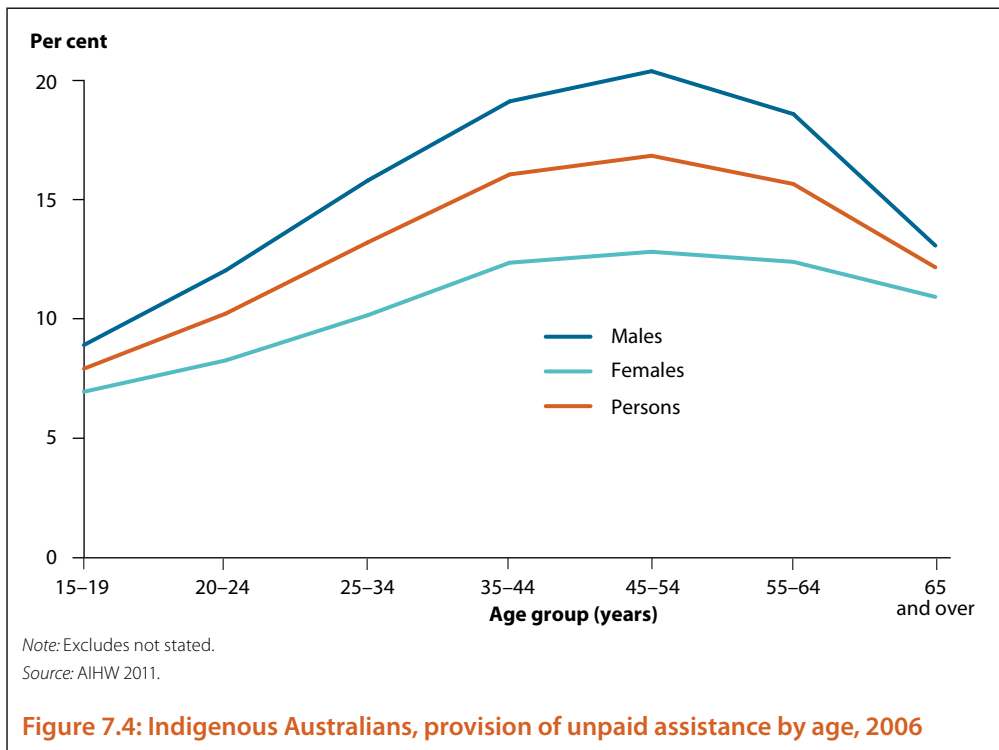
Issues related to the availability of suitable supported accommodation for care recipients are particularly pressing for many ageing carers, as carers face the prospect of their own incapacity and death (HRSCFCHY 2009:192–194). In 2011, the Australian Government committed an additional \$60 million to a new Supported Accommodation Innovation Fund, to build community-based accommodation for people with disability, with priority given to those with ageing carers (FaHCSIA 2010b).

Indigenous carers and carers of Indigenous people

According to the 2006 Census, there were 31,600 Indigenous carers aged 15 years or over. A majority (63%) of these carers were female. Overall, 14% of Indigenous females and 9% of Indigenous males had caring responsibilities, with women aged 45–54 years (20%) most likely to be a carer (Figure 7.4). The number of Indigenous carers may be an underestimate, as about 11% of Indigenous people aged 15 years and over did not answer the Census questions about disability and unpaid care for people with disability (ABS & AIHW 2008). After taking into account the differences in population age structures, Indigenous people were more likely than non-Indigenous people to be informal carers (ABS & AIHW 2008).

The Inquiry into Better Support for Carers specifically noted the absence of available information related to Indigenous carers and called for research into the profiles and specific needs of this group (HRSCFCHY 2009).

One in five (20%) Indigenous carers were young people aged 15–25 years while 4.5% were ageing carers (65 years or over). The median age of Indigenous carers was 37 years, compared to the median age of 49 years for non-Indigenous carers. This reflected the earlier onset of many chronic conditions in the Indigenous population and the tendency for Indigenous parents to have children at younger ages (ABS & AIHW 2008).



Carers with disability

Many primary carers are living with disability themselves. According to the 2003 SDAC, 40% of primary carers (187,500 people) had some form of disability, including 9% (43,400 people) who had severe or profound core activity limitations—higher than the corresponding rates in the wider population (AIHW 2007). In part, this is related to the older age structure of the primary carer population. However, a comparison of age-specific rates shows that primary carers were more likely than the general population to have disability at all ages, including severe or profound limitations (Table 7.1). In particular, the rate of disability among primary carers aged 15–45 years (25%) was more than twice that of the wider population in the same age group (11%).

Table 7.1: Primary carers and the general population aged 15 years or over: disability rates, 2003 (per cent)

Age group (years)	Severe or profound limitations				Total with disability			
	15–45	45–64	65 and over	Total 15+	15–45	45–64	65 and over	Total 15+
Primary carers	8.2	7.7	13.3	9.2	24.7	39.8	58.7	39.7
General population	2.6	6.1	22.5	6.8	11.3	26.8	55.6	22.9

Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers confidentialised unit record file.

The 2006 Census reported that about 2,100 Indigenous carers needed help with core activities themselves. Two-thirds were aged under 55 years of age. Varying across age groups, Indigenous carers were between 1.5 and 3 times as likely as non-Indigenous carers to need assistance with core activities (ABS & AIHW 2008).

Why do people take on a caring role?

While the reasons for caring for someone with disability varied, the most common reasons were family responsibility (54%), to provide better care (41%) and emotional obligation (34%) (Table 7.2). Among primary carers who were parents of the care recipients, one-quarter reported that they had no other choice; 14% found no other care arrangements were available; and 18% considered that alternative care was too costly.

Table 7.2: Primary carers aged 15 years and over: reasons for taking on caring role by relationship to main care recipient, 2009 (per cent)

	Relationship of carer to main care recipient				Total
	Partner	Child	Parent	Other relative or friend	
Family responsibility	49.8	65.7	57.3	41.1	54.2
Could provide better care	46.5	32.8	43.2	30.2	41.1
Emotional obligation	32.0	37.4	36.8	31.3	34.2
No other family or friends available	16.1	29.3	16.2	30.8	20.5
Had no other choice	13.3	10.5	25.5	10.4	15.2
Alternative care too costly	15.9	13.2	17.7	*5.2	14.6
No other family or friends willing	8.3	15.4	10.2	19.6	11.5
No other care arrangements available	7.9	5.9	14.1	*8.5	9.0
Other reason or not stated	17.1	12.2	16.9	17.2	16.0

* estimate has a relative standard error of 25% to 50% and should be used with caution

Source: ABS 2009 Survey of Disability, Ageing and Carers internet version of data table released by ABS in January 2011.

What activities do carers provide help with?

Chapter 5 showed that people with disability living in the community most commonly receive assistance from informal sources.

Informal carers provided most of the assistance that people with severe or profound core activity limitation living in the community needed. In 2009, more than nine in 10 (92%) received informal help with a range of activities—38% from informal sources only and 54% from a mix of formal and informal sources (Table 7.3). People were more likely to rely solely on informal assistance for core activities (mobility, self-care and communication) than non-core activities.

More than three in four people with severe or profound limitations who needed help with reading or writing, meal preparation, or transport received assistance from informal sources only.

Table 7.3: People with severe or profound core activity limitation living in households who received informal assistance, by activity in which assistance was needed, 2009 (per cent)

	Informal assistance only	Formal and informal assistance	Total receiving informal assistance
Core activities			
Self-care	71.1	6.9	78.0
Mobility	74.2	12.7	86.9
Communication	50.1	36.6	86.7
Total	67.6	18.3	85.9
Non-core activities			
Meal preparation	80.4	7.0	87.4
Reading or writing	84.5	*2.7	87.2
Private transport	76.6	8.8	85.4
Cognitive or emotional tasks	47.0	38.1	85.1
Household chores	63.0	17.5	80.5
Property maintenance	60.9	14.5	75.4
Health care	42.8	20.4	63.2
Total	39.3	50.0	89.3
Any of these activities	38.1	54.2	92.3

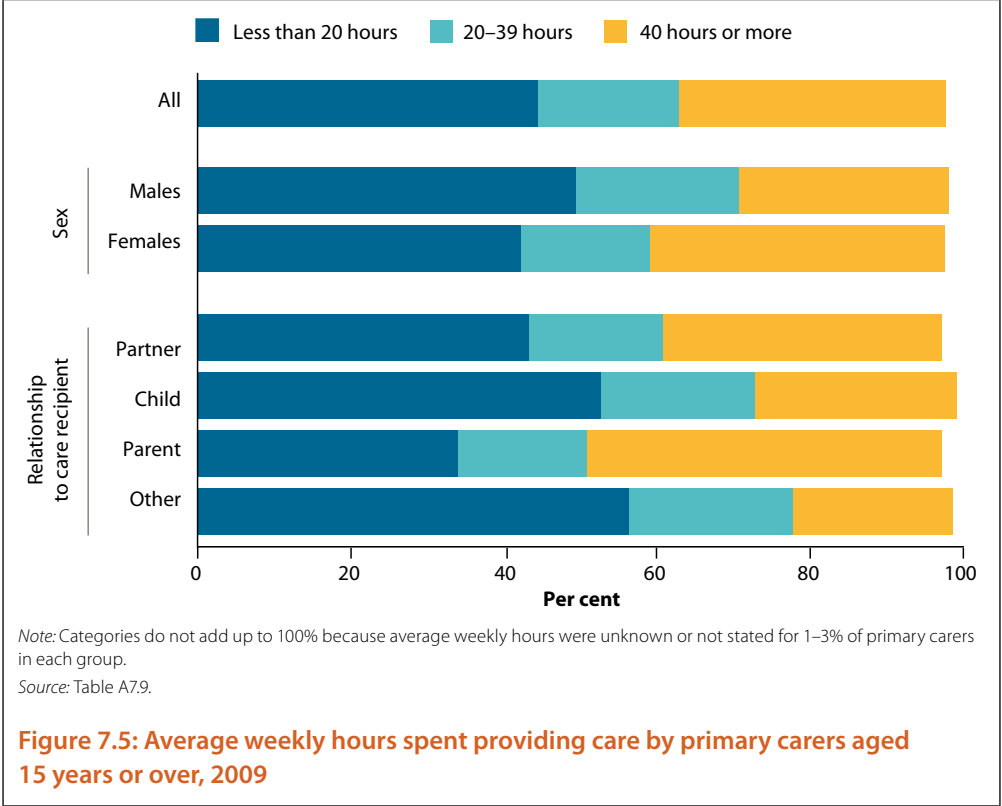
* estimate has a relative standard error of 25% to 50% and should be used with caution.

Source: Table A7.8.

How much time do carers spend caring?

The amount of time spent on caring for a person with disability reflects both the intensity of caring work and high demands on primary carers. In 2009, over half (53%) of primary carers aged 15 years or over spent an average of 20 hours per week or more caring for a person with disability. Over one-third (35%) spent an average of 40 hours per week or more providing care (Figure 7.5).

Primary carers who were parents (47%) or partners (36%) of the care recipients were the most likely to spend at least 40 hours per week on caring, while carers who were children (53%) or other relatives or friends (56%) of the care recipients were the most likely to spend less than 20 hours per week providing care (Figure 7.5). Female primary carers (39%) were more likely than male primary carers (27%) to provide care for 40 hours or more per week.



How long have carers been providing care?

In 2009, one-quarter of primary carers (26%, or 196,700 people) had been in the caring role for 10-24 years, while 6% (46,300) had been providing care for 25 years or more (Table 7.4). Parents of a person with disability were most likely to have been in the caring role for 10 years or more (43%). Around half of all people who were the son or daughter, or other relative or friend of the care recipient (excluding parents), had been providing care for less than 5 years.

Three-quarters of primary carers who had been in the role for at least 25 years were female (Table 7.4).

Table 7.4: Primary carers aged 15 years and over: years in the caring role by relationship to main care recipient, 2009 (per cent)

Relationship to main care recipient	Years in caring role					Total ('000s)
	Less than 5 years	5–9 years	10–24 years	25+ years	Does not know	
Spouse/partner	39.1	27.6	26.3	3.6	*0.7	344.6
Parent	27.7	28.1	29.9	13.4	**0.8	177.8
Son or daughter	47.2	28.4	22.7	**0.9	*0.8	171.5
Other relative or friend	53.2	26.2	18.0	**1.2	0.0	77.6
All primary carers						
Males	44.3	27.8	22.2	4.6	*1.1	248.2
Females	37.6	27.8	27.0	6.7	*1.0	523.2
Total	39.7	27.8	25.5	6.0	*1.0	771.4
Number ('000)						
Total	306.4	214.1	196.7	46.3	8.0	–

* estimate has a relative standard error of 25% to 50% and should be used with caution.

** estimate has a relative standard error greater than 50% and is considered too unreliable for general use.

Source: Unpublished data table of the ABS 2009 Survey of Disability, Ageing and Carers.

Do carers get the help they need?

Types of help needed

Overall, an estimated 293,900 (38%) primary carers needed an improvement or more support in their situation to assist in providing care. Primary carers who had been in a caring role for at least 5 years were more likely to want more support than those who had been caring for less than 5 years (Table 7.5).

More financial assistance was the most commonly reported additional support wanted (91,900 primary carers), followed by more respite care (39,400) and more physical assistance (32,100).

Table 7.5: Primary carers aged 15 years or over: type of improvement or additional support most wanted to assist in the caring role, by years in caring role, 2009 (per cent)

	Less than 5 years	5–9 years	10–24 years	25 years or more	Total
More respite care	4.6	5.1	6.2	n.p.	5.1
More financial assistance	11.4	12.8	12.2	*12.5	11.9
More physical assistance	3.7	5.0	3.7	*6.0	4.2
More emotional support	3.3	*2.8	6.0	n.p.	3.8
An improvement in carer's own health	2.6	3.6	3.1	n.p.	3.0
Other support or improvement ^(a)	5.5	4.1	3.5	n.p.	4.7
<i>All needing an improvement or more support</i>	35.9	39.2	40.9	39.7	38.1
No additional support required	54.4	50.4	48.0	54.6	51.7
Total ('000)	306.4	214.1	196.6	46.3	771.4

* estimate has a relative standard error of 25% to 50% and should be used with caution.

n.p. not published by the data source but included in totals where applicable, unless otherwise indicated

(a) Includes more aids/equipment to help in the role as a carer, more courses available on how to care for persons with particular disabilities, more training on correct use of equipment, more training in correct methods of lifting to prevent injury to carer and none of the above.

Note: Totals do not add up to 100% as some carers did not answer questions about sources of support needed, or length of time in the caring role.

Source: Table A7.10.

Carers of people with disability

More than half (56%) of all primary carers of people with disability aged under 65 years did not receive any assistance in providing care. Most of these reported that they did not need any help; however, in 2009, there were an estimated 29,300 primary carers (7.5%) who reported that they needed assistance but didn't receive any (Table 7.6). Another 54,700 (14%) primary carers received assistance and reported needing further help.

Ageing carers of people with disability were less likely than carers aged under 65 years to receive assistance (36% compared to 45%); however, most ageing carers (60%) reported that they did not currently need assistance. Ageing carers were also less likely than younger primary carers to have a fall-back carer available.

Table 7.6: Primary carers of people aged 0–64 years^(a), by need for assistance and age of carer, 2009 (per cent)

	15–64 years	65 years and over	Total
Need for and receipt of assistance			
Receives assistance			
Does not need further assistance	30.3	25.9	30.0
Needs further assistance	14.4	*9.7	14.0
Total	44.7	35.6	44.0
Does not receive assistance			
Needs assistance	7.8	**4.5	7.5
Does not need assistance	47.5	60.0	48.4
Total	55.3	64.5	55.9
Availability of a fall-back carer			
Has a fall-back informal carer	70.1	57.2	69.2
Does not have a fall-back informal carer	23.7	31.0	24.3
Don't know	6.1	*11.7	6.5
Total primary carers ('000)	360.7	29.0	389.7

* estimate has a relative standard error of 25% to 50% and should be used with caution.

** estimate has a relative standard error greater than 50% and is considered too unreliable for general use.

(a) Includes only co-resident recipients of care.

Source: Table A7.11.

Carers of older people

Most people (65%) who were the primary carer of a person aged 65 years or over did not receive assistance in the caring role (Table 7.7). However, 11% (26,200 people) received some assistance and reported needing more, while 6% (15,500) needed assistance but did not receive any. Just half of all co-resident primary carers of older people had a fall-back carer.

As for those caring for people with disability aged 0–64 years, ageing primary carers were less likely to be receiving assistance and less likely to have a fall-back carer available than younger carers.

Table 7.7: Primary carers of people aged 65 years or over^(a), by need for assistance and age of carer, 2009 (per cent)

	15–64 years	65 years and over	Total
Need for and receipt of assistance			
Receives assistance			
Does not need further assistance	31.0	20.0	24.3
Needs further assistance	14.3	8.3	10.7
Total	45.3	28.3	35.0
Does not receive assistance			
Needs assistance	7.3	5.7	6.3
Does not need assistance	47.4	65.9	58.7
Total	54.7	71.6	65.0
Availability of a fall-back carer			
Has a fall-back informal carer	56.9	47.0	51.0
Does not have a fall-back informal carer	34.8	43.7	40.3
Don't know	8.2	9.2	8.8
Total primary carers ('000)	96.2	148.8	244.9

* estimate has a relative standard error of 25% to 50% and should be used with caution.

** estimate has a relative standard error greater than 50% and is considered too unreliable for general use.

(a) Includes only co-resident recipients of care.

Source: Table A7.11.

Impact of the caring role on carers

Caring for a person with disability can be physically, mentally, emotionally and economically demanding. Many factors may impact on the caring role of carers, including personal characteristics of carers and care recipients, as well as environmental factors (AIHW 2004).

According to the 2009 SDAC, only 22% of primary carers felt satisfied as a result of their caring role (Table A7.12). However, a majority of primary carers considered taking on the caring role as a family responsibility (54%) and 41% believed that they could provide better care for the care recipients.

Labour force participation

Providing intensive and ongoing care for a person with disability has an impact on the opportunities for carers to be involved in paid employment. Chapter 3 reported that in 2009 primary carers of traditional working age had a lower labour force participation rate (54%) than the general population (79%), and this rate was the same as that for people with disability (54%).

The lower participation rate among female primary carers (51%) compared to male primary carers (61%) reflects both lower participation of women in the general population, and the generally greater intensity of the caring role undertaken by women, in terms of average weekly hours spent providing care (discussed previously).

While non-primary carers had a higher participation rate (71%), it was still lower than the wider population rate. Differences in labour force participation between primary carers, non-primary carers and non-carers should not simply be interpreted as a result of the caring role. In addition to demographic factors, there are other possible explanations, such as labour market opportunities and decisions as to whether to provide informal care or purchase formal care (Edwards et al. 2008).

Estimates from the 2009 SDAC indicate that there were more than 100,000 primary carers of 'traditional working age' not in the labour force who would like to be employed while in the caring role (Table 7.8). In particular, half (52%) of those who were the mother of the person they cared for desired to combine paid employment with informal care. Perceived barriers to entering the paid workforce while in the caring role included difficulty making suitable alternative care arrangements and difficulty arranging working hours.

Table 7.8: Primary carers aged 15–64 years who were not in the labour force: whether would like to be employed while still in caring role, 2009

	Would like to work	Would not like to work	Total ^(a)	Per cent who would like to work
	'000s			
Husband/male partner	11.9	25.1	37.0	32.2
Wife/female partner	17.4	50.8	68.2	25.5
Father	*2.3	*1.2	*3.5	*65.7
Mother	36.1	33.0	69.1	52.2
Son	7.8	9.8	17.6	44.3
Daughter	17.7	28.2	45.9	38.6
Male relative/friend	*2.4	*6.1	*8.5	*28.2
Female relative/friend	11.0	16.1	27.1	40.6
Total males	24.4	42.1	66.5	36.7
Total females	82.1	128.0	210.1	39.1
Total	106.5	170.1	276.6	38.5

* estimate has a relative standard error of 25% to 50% and should be used with caution.

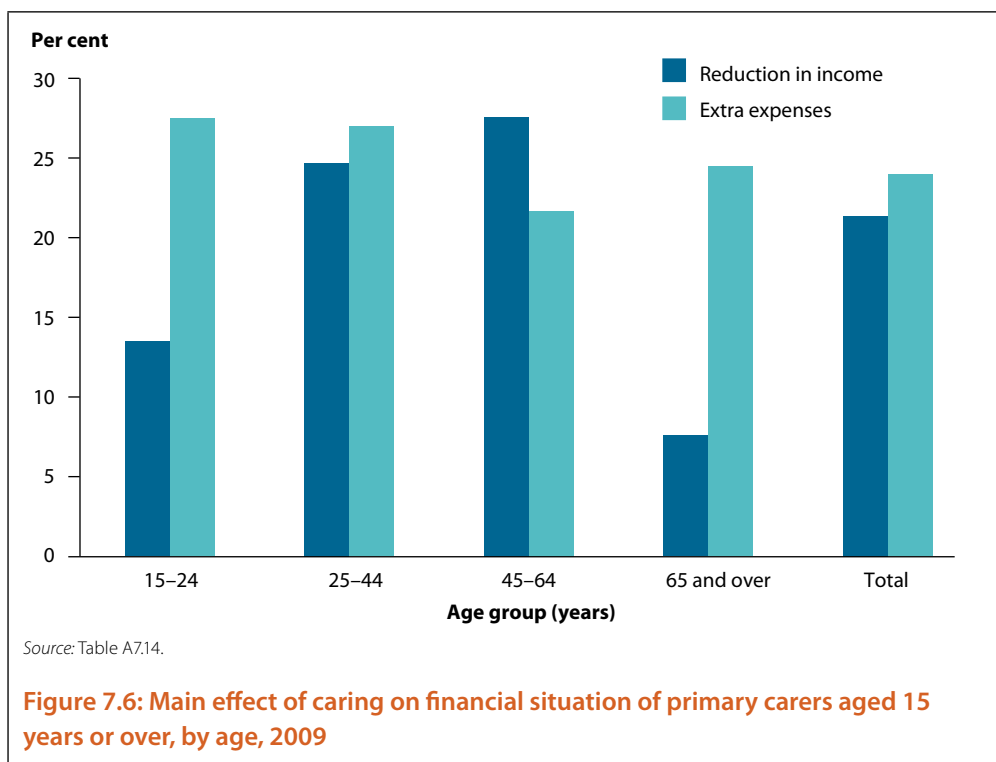
(a) Excludes primary carers who were retired and those in cared accommodation.

Source: Unpublished data table of the ABS 2009 Survey of Disability, Ageing and Carers.

Effect on carers' financial situation

In 2009, 45% of primary carers reported that their caring role either had reduced their income (21%) or created extra expenses (24%). The proportion who said that the main effect was additional expenses did not vary considerably between age groups (Figure 7.6). On the other hand, primary carers of traditional working age (25-64 years) were more likely than younger or older carers to report that the main effect was a reduction in income. Fewer than one in 10 (8%) primary carers aged 65 years or over reported income reduction as the main financial effect, likely because most people in this age group would be retired from the workforce.

Almost half (45%) of primary carers of working age, and four in five (78%) aged 65 years or over, relied on a government pension or allowance as their main source of cash income (Table A7.13).



Effects on carer's physical and emotional wellbeing

According to the 2009 SDAC, 29% of primary carers reported that their overall physical and emotional wellbeing had changed due to their caring role, while an additional 32% reported experiencing one or more specific negative effects of caring on their life despite no overall change to their wellbeing (ABS 2008). Effects of caring included:

- feeling weary or lacking in energy (reported by 34% of primary carers)
- frequently feeling worried or depressed (29%)
- sleep interruption that affects daily functioning (15%)
- being diagnosed with a stress-related disorder (10%).

Regarding their relationship with their main care recipient, 34% of primary carers said that they had been brought closer together, while 18% said that the relationship had become strained (ABS 2008). About 35% of primary carers reported that their relationship with other co-resident family members was strained or that they lacked time together. The same percentage said that they has lost touch with or changed their circle of friends since taking on the caring role (ABS 2008).

7.3 Services and supports

A range of services and supports is available to carers. While some are carer-specific, they generally occur within the context of services being provided to a care recipient. Some provide services and support primarily to people who are aged and their carers to help them stay in their own homes, rather than entering low-level residential aged care. Others provide support to younger people with disability and their carers. They include personal care, domestic assistance, social support, transport and meal preparation, as well as respite, information and counselling.

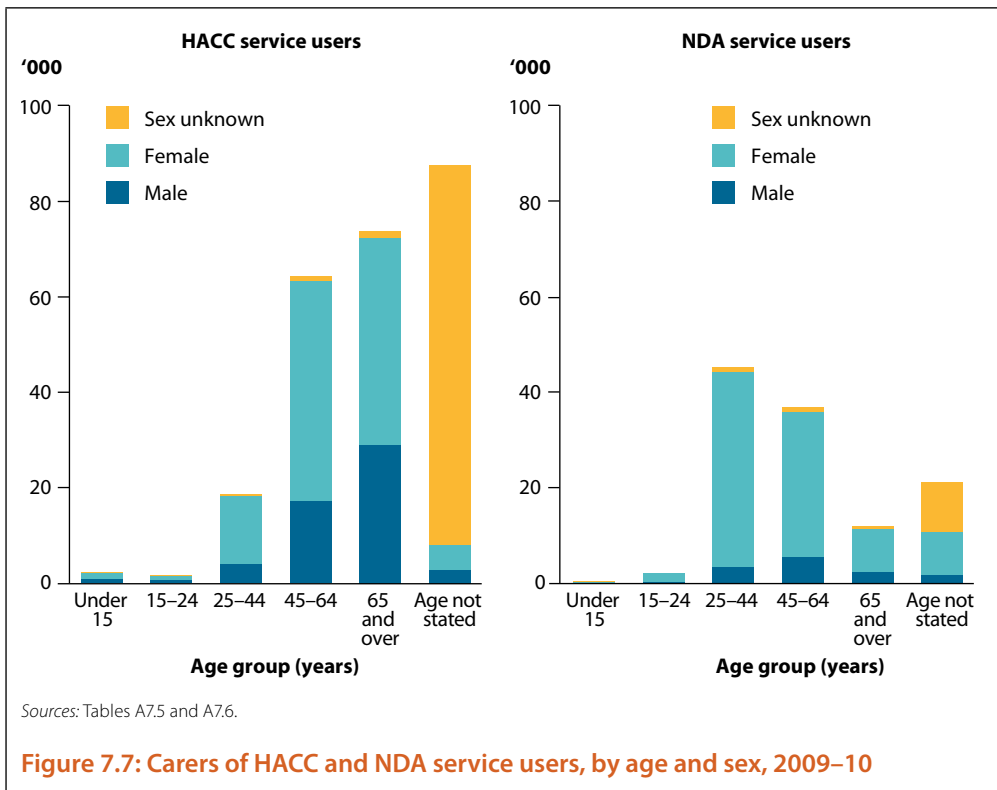
Carers of disability and community care service users

Even though most services under both HACC and the NDA are directed at care recipients (see 'Chapter 5'), the Carers Inquiry observed that 'the needs of carers and those they care for are inextricably bound' (HRSCFCHY 2009:194). Hence services provided to care recipients also support the carer. For example, ageing carers are said to particularly value in-home assistance (HRSCFCHY 2009:179).

In 2009–10, nearly 250,000 HACC clients with a carer received services (Table A7.5). Such services have been described as having a 'respite effect' for carers (ADHC 2007). Carers aged 65 years and over (around 73,800 people) were the largest single age group receiving carer-specific services under the HACC program in 2009–10, among those where the carer's age was stated (Figure 7.7), followed by carers aged 45–64 years (64,300 people). Male representation was highest among the oldest age group of carers of HACC service users: 39% of those aged 65 years or over were male, compared to 21% of those aged 25–44 years. This mirrors the age and gender patterns observed in the broader population of informal carers (discussed previously).

Around four in 10 users of NDA services (see 'Chapter 5') reported having a carer (117,754 carers). In contrast to HACC service users, carers of NDA-funded service users were most likely to be aged 25–44 years (45,149 carers), reflecting the program's generally younger target population (Figure 7.7).

The large number of carers for whom sex and/or age is unknown in both the HACC and Disability Services data sets constitutes a significant data gap.



In addition to HACC, the main community care program, a number of smaller community care programs were also legislated under the *Aged Care Act 1997*:

- Extended Aged Care at Home (EACH)
- Extended Aged Care at Home Dementia (EACH D) and
- Community Aged Care Packages (CACAP).

These are sometimes described as ‘packaged care’—for further information see ‘Chapter 6’ (AIHW 2010; DoHA 2010a, 2010c). Some community care clients eligible for packaged care are now able to employ ‘consumer directed care—(CDC) packaged care’, which aims to give the individual and his or her carer greater choice in service types used and providers (DoHA 2010b).

Of the roughly 179,000 ACAP clients living in the community in 2008–09, 83% (134,000) had a carer—an increase from 74% in 2003–04 (Table 7.9). The percentage of clients living in the community without a carer fell steadily from 22% in 2004–05 to 16% in 2007–08. Two-thirds (66%) of these carers in 2008–09 were female (Table A7.15).

Table 7.9: ACAP clients living in the community, by carer status, 2003–04 to 2008–09 (per cent)

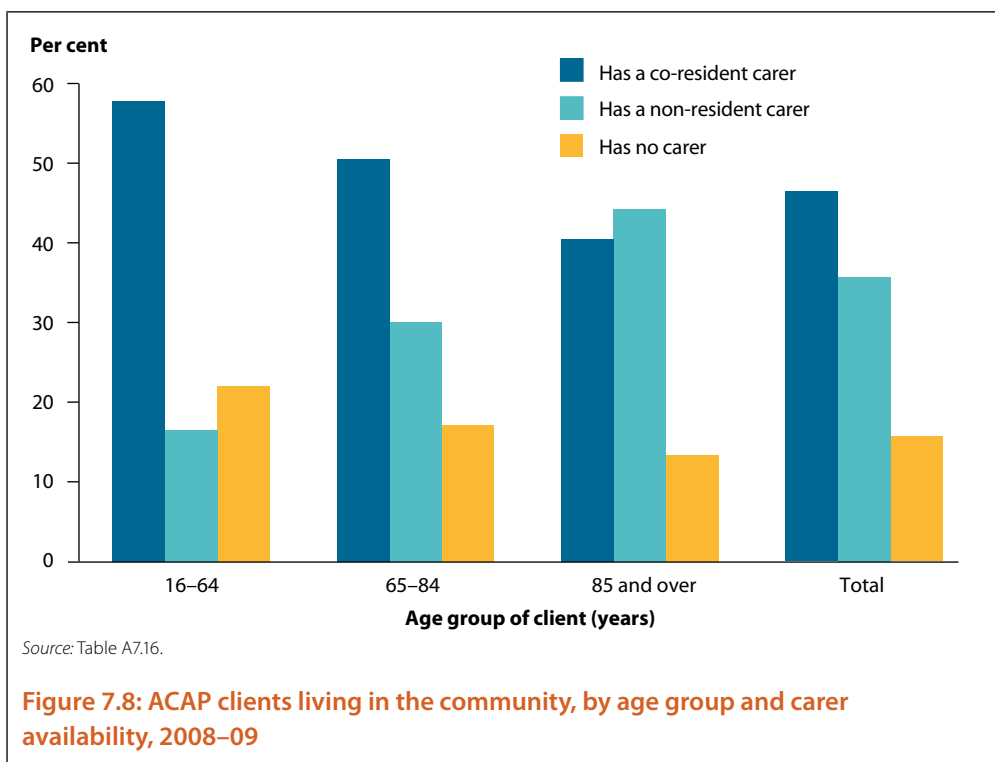
	2003–04	2004–05	2005–06	2006–07	2007–08	2008–09
Has a carer	74.0	74.6	77.6	79.3	80.9	82.6
Has no carer	19.8	21.6	19.6	18.3	17.0	15.7
Carer presence unknown	6.2	3.7	2.8	2.3	2.1	1.7

Source: Table A7.15.

The percentage of ACAP clients without a carer decreased with age. More than one in five (22%) clients aged 16–64 years living in the community in 2008–09 did not have a carer, compared to 17% of clients aged 65–84 years and 13% of those aged 85 years and over (Figure 7.8).

Almost half (47%) of all ACAP clients living in the community in 2008–09 had a co-resident carer—that is, a carer who lived at the same address—while 36% had a non-resident carer. Older clients were most likely to have a carer who was not a resident of the same household (Figure 7.8): 44% of clients aged 85 years or over had a non-resident carer, while 41% had a co-resident carer. The ill-health and death of spouses, who would normally be co-resident carers, increasing with age partly explains this trend.

The majority of ACAP clients living in the community with a carer required assistance with self-care (59%) and moving around at home or elsewhere (51%), while 18% required assistance with communication (Table A7.17). The recommended long-term care setting of ACAP clients who needed help or supervision with these core activities varied according to whether the client had a carer. While 51% of ACAP clients with a carer were recommended for a private residential setting, 38% of clients without a carer were recommended for that setting. On the other hand, 45% of clients with a carer were recommended for a residential aged care setting, while 56% of clients without a carer were recommended for that setting (Table A7.17).



Flowing from ACAP assessment processes, as at 30 June 2010, there were an estimated 42,728 Community Aged Care Packages (CACP) allocated nationally. DoHA also estimated that there were 5,584 EACH places, during 2009-10, and 2,583 EACH D places. (DoHA 2010a:164, 178). It is not clear however, from available data, how many recipients of these packages have carers and the characteristics of the caring relationships. Further data on packaged care are reported in Chapter 6.

Respite

According to the 2009 SDAC, the large majority (89%) of primary carers reported that they had never used respite care services. Some 46,700 (6%) primary carers had used respite services in the three months prior to survey and 38,800 (5%) used respite services, but not in the last three months (Table 7.10).

About 454,700 primary carers (59%) had never used respite care because they did not need it. For 21,900 primary carers, the main reason for not using respite services was that no respite service was available in their areas or the available service did not suit their needs. One in five (156,100) primary carers reported that they preferred not to use respite services, or the main care recipient did not want it.

Spouse or partner carers were more likely than other carers to report that they had never used respite services because they did not need it. Primary carers who were a son or daughter of the main care recipient were more likely than other carers to report that they preferred not to use respite care or the recipient did not want it.

Table 7.10: Primary carers aged 15 year or over: the use of respite services and reason for not using respite services, by relationship to main care recipient, 2009 (per cent)

	Spouse/ partner	Parent	Son or daughter	Other relative or friend	Total
Primary carer use of respite care					
Used respite care in the last three months	3.7	10.5	7.5	*3.5	6.1
Used respite care but not in the last three months	2.8	7.6	6.2	*6.4	5.0
Never used respite care	93.5	81.8	86.4	90.0	88.9
Main reason primary carer has never used respite care					
Does not need service	69.5	48.7	51.5	52.1	58.9
Not available in area or available respite is not suited to needs	*1.5	6.4	*2.0	*2.4	2.8
Recipient does not want it or carer prefers not to use it	18.0	18.0	26.0	22.7	20.2
Other reason ^(a)	4.6	8.9	6.9	12.9	6.9
Has used respite care	6.5	18.1	13.6	9.9	11.1
Total ('000)	344.7	177.9	171.4	77.7	771.4

* Estimate has a relative standard error of 25% to 50% and should be used with caution.

(a) Other reason also includes no affordable respite available.

Source: Table A7.18; unpublished data table of the ABS 2009 Survey of Disability, Ageing and Carers.

National Respite for Carers Program (NRCP)

The Australian Government funds the National Respite for Carers Program (AIHW 2009b; DoHA 2010a) to support those who are caring for people with disability or who are frail aged at home. The program assists carers to access respite through:

- Commonwealth Respite and Carelink Centres which have funding to purchase short-term or emergency respite. The centres can also coordinate access to community-based agencies offering respite.
- Community-based agencies providing a range of respite services delivered in various settings: in-home; respite cottages and in aged care homes.

In 2009–10, NRCP provided assistance to 143,387 carers. This includes 37,076 carers assisted with short-term or emergency respite and 100,273 carers assisted to receive respite coordinated through Commonwealth Respite and Carelink Centres. It is estimated that respite services funded under the NRCP provided over 5 million hours of respite in 2009–10, delivered through over 650 respite services. (DoHA 2010a:165). Funding for the NRCP overall was budgeted in 2009–10 at just over \$200 million (DoHA 2009).

Respite provided by specialist disability services

The recipients of carer respite services are people with disability under specialist disability services. In 2009–10, 12% of service users (36,000) accessed respite services under the NDA, with flexible respite being the most commonly used service type. See 'Chapter 5' for more information.

The Respite Support for Carers of Young People with Severe or Profound Disability Program provides immediate and short-term respite to carers of young people with severe or profound disability under 30 years of age, or up to 65 years of age where the carer is suffering from

extreme stress. The program facilitates access to information, respite care and other support or assistance appropriate to the individual needs and circumstances of both carers and care recipients. It supports carers whose needs are not being met through existing state respite care or assistance provided under other Government initiatives.

Under the HACC program, some services are provided directly to carers as well as care recipients. Carer-specific services are respite and counselling. In 2009–10, 61% (28,000) of people receiving a carer service received respite care (Table A7.19).

Care recipient engagement in activities not theoretically designated as 'respite', such as transition to employment and education, may also be considered to provide a respite effect for carers (ADHC 2010).

Information and counselling

National Respite for Carers Program

In addition to respite, the Australian Government also funds the NRCP to provide other support such as information and counselling. This occurs through the Commonwealth Respite and Carelink Centres' Carer Information Support Program, and under the Carers Advisory Service and the National Carer Counselling Program, the latter two being provided through a network of state and territory Carers Associations (Carers Australia 2007; DoHA 2010a).

In 2009–10, DoHA funded 54 Commonwealth Respite and Carelink Centres through the National Respite for Carers Program, to provide information on community, aged care and support services available locally or across Australia (DoHA 2010a). The centres reported 209,028 client episodes in the same period, being the number of times that carers were assisted through telephone calls, emails, facsimiles and visits to a centre (DoHA 2010a:158). Almost 375,000 items of information were provided to carers in 2009–10 under the Carer Information Support Program—an increase from 276,000 in 2008–09. (DoHA 2010a:158, 159).

DoHA also funded the Dementia Education and Training for Carers Program in 2009–10, which delivered 40 education and training programs providing information on living with dementia and access to services, through 36 Commonwealth Respite and Carelink Centres (DoHA 2010a:157). Counselling services under this program were provided to 6,038 carers in 2009–10.

HACC

Under the HACC program, carers are able to receive assistance in 'understanding and managing situations, behaviours and relationships associated with the caring role, including advocacy and the provision of advice, information and training' (DoHA 2007:33). During 2009–10, 44% of carers receiving a carer service (20,517) received counselling (Table A7.19).

Services directed at special carer groups

Young carers

Young carers are eligible for services on the basis of the demands of their caring role. In addition, a targeted Young Carers Respite and Information Services program aims to assist young carers 'who need support to complete their secondary education or vocational equivalent due to the demands of their caring role' (FaHCSIA 2010c). It provides flexible respite and carer support services for school-aged carers who are at risk of not completing secondary education. The respite services component of the program enables school-aged young carers to access

respite and age-appropriate support: for example, time off to study for exams, tutoring, skills development or activities during the school holidays. Information services for all young carers up to 25 years are also available providing support, information, referral and counselling (FaHCSIA 2010a, 2010c).

In 2009–10, the program provided 3,688 school-aged carers with respite and support to manage educational and caring responsibilities. The program also provided information, advice and referral services to 1,924 carers aged 25 years and younger. Some carers accessed both respite and information services (FaHCSIA 2010a).

Young carers comprise only a very small proportion of carers of clients of the Home and Community Care (HACC) program and NDA services (tables A7.5, A7.6). Data on whether they receive services under the National Respite for Carers Program (NRCP) are not available.

Indigenous Australians

Indigenous people with disability and their carers received particular attention in the Productivity Commission's Inquiry into long-term care and support for people with disability, which observed the cultural significance of caring within Indigenous families (PC 2011b:540–541). However, because caring is considered a natural part of family life, Indigenous carers may be less likely to seek help (HRSCFCHY 2009). In recognition of this, Centrelink recently launched a DVD in a number of Indigenous languages about Carer Allowance, explaining the concept of caring and the support available for people having a caring role (Centrelink 2010a).

Among specialist disability service users 50% of Indigenous people have a carer, compared with 41% of non-Indigenous people. Among both Indigenous and non-Indigenous people mothers most frequently assume the role of carer (31% of Indigenous service users and 29% of non-Indigenous service users; Table A7.7). It should be noted, however, that the Indigenous status of the carer is not recorded in the DS NMDS.

7.4 Payments and allowances

Carer Payment

Carer Payment is a means-tested income support payment provided to informal carers. Recipients also qualify for a Pensioner Concession Card or Health Care Card. Pension Supplements are also paid to some pensioners as an additional payment to the base pension. Australian Government expenditure on Carer Payment in 2009–10 amounted to \$2.3 billion (FaHCSIA 2010a: Table 10.4).

Carer Payment (adult) is paid to carers of people aged 16 years and over who have a disability or medical condition or are frail aged, where the demands of caring severely restrict or prevent the carer from undertaking substantial paid employment (Centrelink 2010b; FaHCSIA 2010a). The adult care recipient must undergo an assessment with the Adult Disability Assessment Tool, demonstrating that significant levels of assistance are required in activities of daily living, such as mobility, communication and hygiene (Edwards et al. 2008). In some cases Carer Payment is payable where a person cares for an adult with moderate care needs and care is also provided for their dependent child.

Carer Payment (child) is paid to carers who provide care for a child with severe disability or medical condition, where the care severely restricts or prevents them undertaking substantial paid employment (Centrelink 2010b; FaHCSIA 2010a). In some cases the payment may also be made to a person caring for more than one child with a disability whose combined care needs are equivalent to one child with severe disability or medical condition (Centrelink 2010b, 2011).

Recipients of Carer Payment can participate in paid employment, study and/or volunteer work. However, to maintain eligibility for the payment, these activities cannot exceed 25 hours per week (including travel time).

The Centrelink website provides detailed information about Carer Payment eligibility and payment rates (www.centrelink.gov.au).

In June 2010, there were almost 169,000 recipients of Carer Payment, of whom 92% (156,000) were caring for an adult (Table 7.11). Around half (49%) of all adult payments were made in respect of people caring for their partner, while one-quarter (23%) were made in respect of a parent caring for a child.

Table 7.11: Carer Payment recipients, as at June 2010

	Adult		Child ^(a)	
	Number	Per cent	Number	Per cent
Carer Payment recipients				
Males	50,705	32.5	1,497	11.6
Females	105,453	67.5	11,258	88.4
Persons	156,158	100.0	12,755	100.0
Relationship of care recipients to carer				
Child	18,645	11.9	12,973	94.9
Parent	36,709	23.5	21	0.2
Partner	77,077	49.3	<20	n.a.
Other relation	15,233	9.7	268	2.0
Unrelated	8,197	5.2	195	1.4
Total^(b)	156,255	100.0	13,684	100.0

(a) Includes 'two children combined care' (in which the care of two children with disability is considered equivalent to the care of one child with profound disability).

(b) Total includes categories such as step-parent with fewer than 20 care recipients, and care recipients whose relationship to the Carer Payment recipient was not specified.

Notes

1. The number of care recipients is greater than the number of Carer Payment recipients as some payment recipients cared for more than one person.
2. From 1 July 2009 changes were made to the way qualification for Carer Payment (Child) is assessed. This table shows both recipients who qualified for Carer Payment prior to 1 July 2009 and those who qualified under the new rules.

Source: Australian Government Department of Families, Housing, Community Services and Indigenous Affairs.

The most common condition of care recipients in respect of whom Carer Payment (adult) was paid was osteoarthritis (12% of recipients), followed by major depression (8%). Among care recipients in respect of whom Carer Payment (child) was paid, 28% had autistic disorder or Asperger syndrome (Table A7.20).

Carer Allowance

Carer Allowance is a supplementary payment that is not subject to an income or assets test. Carers who qualify for a Carer Payment (child) generally receive Carer Allowance (Centrelink 2010b). It may include a Health Care Card alone, or Health Care Card plus fortnightly payment (Centrelink 2010b, 2011; FaHCSIA 2011). In 2009–10, expenditure on Carer Allowance amounted to around \$1.5 billion (FaHCSIA 2010a).

Carer Allowance (adult) is provided to carers of people with a disability or medical condition aged over 16 years who need additional care and attention. The care must be provided in the carer's home, the home of the care recipient or in hospital. The care recipient is assessed using the Adult Disability Assessment Tool (Centrelink 2010b, 2011; Edwards et al. 2008). Carer Allowance (child) is provided to carers of children with a disability or medical condition, who provide care in the child's home or hospital additional to what would ordinarily be provided.

The Centrelink website provides detailed information about Carer Allowance eligibility and payment rates (www.centrelink.gov.au).

In June 2010, there were 496,000 recipients of Carer Allowance payments (Table 7.12), with an additional 13,000 people receiving the Health Care Card only. Just over half of the care recipients in respect of whom Carer Allowance (adult) was paid were partners of carers (54%), with the next largest group of care recipients being parents of carers (19%), followed by children of carers (14%). The profile of conditions reported for care recipients in respect of whom Carer Allowance was paid was similar though not identical to Carer Payment (Table A7.20).

Table 7.12: Carer Allowance recipients^(a), as at June 2010

	Adult		Child ^{(a)(b)}	
	Number	Per cent	Number	Per cent
Carer Allowance recipients				
Males	116,045	32.0	9,387	7.0
Females	246,041	68.0	124,161	93.0
Persons	362,086	100.0	133,548	100.0
Relationship of care recipients to carer				
Child	53,602	14.0	148,576	97.5
Parent	72,189	18.8	—	—
Partner	208,438	54.3	—	—
Other relation	31,088	8.1	2,101	1.4
Unrelated	18,319	4.8	1,688	1.1
Total^(c)	383,646	100.0	152,365	100.0

n.a. not available

(a) Excludes people receiving the Health Care Card only, and cases where adult/child category is unknown.

(b) Includes payment recipients receiving Carer Allowance for both adult and child care recipients.

(c) Total includes care recipients whose relationship to the Carer Allowance recipient was not specified, and categories such as step-parent with fewer than 20 recipients.

Note: The number of care recipients is greater than the number of Carer Allowance recipients as some payment recipients cared for more than one person.

Source: Australian Government Department of Families, Housing, Community Services and Indigenous Affairs.

Child Disability Assistance Payment

The Child Disability Assistance Payment is a single annual payment of \$1,000 made to recipients of Carer Allowance (child under 16 years) to assist in the purchase of therapy, aids and equipment, among other things (FaHCSIA 2009). In 2009–10, payments were made to 133,548 carers (for 152,365 children), being just over \$152 million in expenditure (FaHCSIA 2010a:96).

Carer Supplement

The Carer Supplement was introduced in the 2009–10 Federal Budget as part of the ‘Secure and Sustainable Pension Reform package’ (FaHCSIA 2009:103), aimed at providing financial security and alleviating financial pressures that informal carers face (FaHCSIA 2010a).

It is as an annual payment of \$600 for recipients of a range of income support payments including Carer Allowance, Carer Payment, Wife Pension and some DVA pensions.

The first Carer Supplement was paid in June 2009, but as subsequent payments take place on 1 July each year from 2010, no payments were made in the 2009–10 financial year (FaHCSIA 2010a). In the 2008–09 financial year, just over \$408 million was expended in Carer Supplements (FaHCSIA 2009).

7.5 Data development

The AIHW has previously reported in detail regarding the quality of data about carers and gaps in what is known about carers, their characteristics and needs in various data sets (AIHW 2009b).

Population survey data

In terms of informal carers, the **2009 SDAC** provides:

- estimates of the number of people who provide assistance to older people and people with disability and long-term health conditions, including primary carers providing ‘the majority of the informal help’
- a demographic and socioeconomic profile of carers compared with the general population
- information about the care provided, need for support and the support available, personal assessment of health and wellbeing, and the impact of caring (ABS 2011).

In future the SDAC will be conducted at 3-yearly intervals, with the next survey expected to be run in 2012. This change will provide more frequent and more timely data than in the past, when the survey was conducted every 5–6 years.

Administrative data

In addition to statistical estimates of the caring population, data based on carers receiving benefits and services both directly and indirectly, is also available:

- The Disability Services – NMDS collects data on both specialist disability service recipients and their carers. It is the only data set that distinguishes between ‘primary’ and other carers in a manner that is conceptually equivalent to SDAC (AIHW 2009b:231).
- Home and Community Care – Minimum Data Set (HACC – MDS) – is a ‘set of nationally agreed data items collected by all HACC service providers about their clients’. HACC provides specific services to carers (DoHA 2007:32, 33). Support provided directly to the care recipient

also alleviates carer burden to a degree, however this is more difficult to measure as a service to carers.

- FaHCSIA-Centrelink – Carer Allowance—Eligibility for Carer Allowance is not based on the ABS definition of primary carer (FaHCSIA 2010a), influencing its comparability with other data.
- FaHCSIA-Centrelink – Carer Payment—Because some clients who might otherwise be eligible choose a different Centrelink payment (AIHW 2009b; Centrelink 2010b, 2011), these data cannot be used for ascertaining the eligible population, that is, carers whose caring role precludes them from substantial paid employment. Also, eligibility for Carer Payment is not based on the ABS definition of primary carer (FaHCSIA 2010a), influencing its comparability with other data.
- DoHA oversees various Australian Government-funded community care programs, described under *Community care* in respect of which data are available. However there are some limitations in these data for understanding carers and their characteristics as the ‘data sets have remained fragmented to a large extent, in part because of inconsistency in the way in which carers are identified’ and the way carer definitions are operationalised. The use of ‘primary carer’ in these data sets is not always consistent with its use in DS NMDS and SDAC (AIHW 2009b:230, 231).
- In 2009, DoHA commissioned the AIHW to investigate the feasibility of establishing a Carers National Data Repository, as a way of ‘improving the evidence available about carers, using existing data’ (AIHW 2009c:vi). The study presented three models of repository, and while the AIHW viewed a physical data repository as the one holding the most promise for developing the quality and visibility of evidence about carers, it was not considered viable at the time. This issue may benefit from being revisited in the light of the streamlining that may result from the national health reforms, which may, in turn, affect various data sets incorporating information on carers.

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