

Chapter 8

Informal carers

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8 Informal carers

At a glance

Who provides care?

- In 2009, 2.6 million Australians (12% of the population) were informal carers. Of these, 771,400 were primary carers (that is, provided the most informal care).
- In 2011, Indigenous Australians were 1.3 times as likely as non-Indigenous Australians to be providing informal care.
- Overseas-born Australians were less likely to be providing informal care than Australian-born residents. In 2011, the carer rate was 11% for people born in non-main English-speaking countries and 9% for those born in main English-speaking countries, compared with 12% for Australian-born residents.
- The majority of informal carers are female (between 55% and 61% depending on the data source), and they are usually the mothers, spouses or daughters of the care recipients.

Carers and care recipients

- In 2009, the labour force participation rate of primary carers aged 15 to 64 (54%) was lower than for other carers (71%) and the general population (79%).
- Primary carers were more likely than non-carers to live in low-income households—in 2009, 26% of primary carers were in households with the lowest equivalised incomes, compared with 15% of non-carers.
- In 2009, around 303,000 primary carers had disability themselves, including 68,200 who needed help with core activities.
- Around 44% of disability support service users in 2011–12 had an informal carer, as did 29% of Home and Community Care clients in 2010–11.

Impact of caring

- In 2009, around one-third (32%) of primary carers reported feeling weary or lacking energy due to their caring role and a similar proportion (30%) reported frequently feeling worried or depressed. Carers who spent an average of 40 hours or more per week providing care were more likely to report these adverse effects than those who spent less than 20 hours per week.
- In 2009, 22% of primary carers reported feeling satisfied due to their caring role.
- In 2011–12, more than 5.1 million hours of respite were delivered under the National Respite for Carers Program.



8.1 Introduction

Informal carers, such as family members and friends, play a vital role in the lives of people who sometimes or always need help or supervision to do tasks because of disability, long-term health conditions or frailty due to ageing. They often help with personal care, transport, housework and other activities. Access to such unpaid informal assistance can improve the care recipient's quality of life, reduce the amount of formal services they require and may also help them delay or avoid entry into residential care.

Reflecting international, national and community values around the inclusion and participation of all members of society, from the 1980s, the focus in Australia shifted from systematic, institutional provision of care for people with disability to community-based care. Greater emphasis has also been placed on 'ageing in place', with home-based care of increasing importance in health care generally, and in palliative care in particular.

8.2 Policy context

The value and importance of informal carers to care recipients, the community and the nation is widely recognised and there is a growing body of evidence on the substantial and increasing economic contribution that they make. The National Health and Hospitals Reform Commission (2009:61) has described 'unpaid primary carers' as the 'invisible' health workforce, in the context of health workforce shortages. The Productivity Commission (2011b) has observed that the economic contribution of informal carers is so great that no insurance scheme would be likely to fully fund its replacement.

The diversity of informal carers and the people they care for, and the growing understanding of the significance of informal carers, is recognised across a range of policy contexts.

Carer-specific policy arrangements

The National Carer Recognition Framework was developed by the Australian Government to improve support for carers and to recognise the vital social and economic contribution that they make to society. This framework has two elements: the Carer Recognition Act (legislated in 2010) and the National Carer Strategy (released in 2011).

The Carer Recognition Act 2010

The *Carer Recognition Act 2010* aims to increase recognition and awareness of the role that carers play in providing daily care and support to people with disability, medical condition or mental illness, or those who are frail aged (Australian Government 2010a; AIHW 2011).

The Act formally recognises the contribution made by unpaid carers, and that carers should have the same rights, choices and opportunities as all Australians. It includes 10 principles that Australian Government agencies and funded organisations need to adopt in developing policies and delivering services for carers or the person for whom they care (Australian Government 2010a).



The National Carer Strategy

The National Carer Strategy recognises that informal carers come from many different walks of life and provide support to a range of care recipients under diverse personal circumstances. The strategy is part of the Australian Government's broader social inclusion agenda and seeks to harmonise approaches to carers and carer support across policy contexts. It has six priority areas for action: recognition and respect, information and access, economic security, services for carers, education and training, and health and wellbeing (Australian Government 2011).

The National Carer Strategy Implementation Plan outlines how the priorities will be implemented. It is based on 3-year action plans, which outline the actions, responsibilities and timelines against each of the priority areas.

Informal carers in different policy sectors

Sectors as diverse as employment, education, community care, health, disability and aged care are playing a part in whole-of-government reforms that will influence the health and wellbeing of informal carers.

Significant reforms and policy that refer to carers include:

- the *Fair Work Act 2009* and the National Employment Standards (Australian Government 2013)
- Community Care Common Standards, 2010 (see Chapter 6)
- the National Strategy for Young Australians, 2010 (Australian Government 2010b)
- National Health Reforms, 2011 onwards (see Chapter 5)
- National Mental Health Reforms, 2011–12 onwards (COAG 2012)
- DisabilityCare Australia (formerly known as the National Disability Insurance Scheme), 2012 (see Chapter 5)
- the revised National Disability Agreement, 2012 (see Chapter 5)
- the draft National Standards for Disability Services, 2012 (see Chapter 5)
- aged care reform package *Living Longer. Living Better*, 2012 (see Chapter 6)
- the forthcoming second National Framework for Action on Dementia.

Factors influencing supply of, and demand for, carers

The AIHW (2009, 2012a) has reported previously on the sustainability of the community care model in the face of demographic and social changes that may affect the demand for, and supply of, carers. These include:

- an ageing population and increasing longevity (as discussed in Chapter 1), which means that in coming years there will be more people with long-term health conditions and disability requiring both formal services and informal care (AIHW 2009, 2012a; see also Chapter 5)

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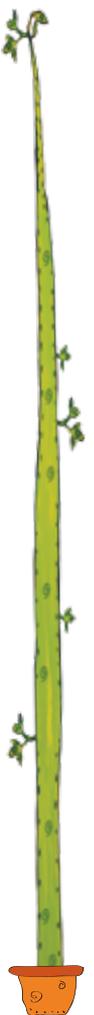
- a reduction in taxation revenue as a smaller proportion of the population is employed (due to the ageing population) and governments may therefore increasingly rely on informal care sources to support ageing Australians and people with disability (AIHW 2009)
- those who traditionally provided informal care, typically middle and older middle-aged women, are more likely to re-enter or have remained in the workforce after child-bearing (AIHW 2012a; OECD 2011)
- pressure on carers to remain in the workforce (for example, through increasing retirement age) which may compromise their ability to provide informal care (AIHW 2009)
- stagnating population growth, coupled with more complex family structures, increasing mobility within families, and looser ties within communities, which means fewer people are able and willing to provide informal care (Hill et al. 2011; Productivity Commission 2011a).

The Productivity Commission (2011b:105) suggested that one of the objectives of a disability insurance scheme would be a 'shift away from an excessive and unfair reliance on the unpaid work of informal carers', which could be measured by, among other things, greater economic and social participation among carers. It recommended finding a sustainable balance between the provision of formal services and informal care that would stabilise the withdrawal of informal care (Productivity Commission 2011b).

8.3 Number of informal carers

The ABS Survey of Disability, Ageing and Carers (SDAC) is the best available data source for estimates of carer numbers and descriptive information about primary carers in the Australian population, including change over time. As explained in more detail in Box 8.1, carers are defined in the SDAC as those who provide informal assistance that is ongoing, or likely to be ongoing, for at least 6 months to people with disability or long-term conditions or people who are aged 60 and over. This chapter summarises key statistics about carers based on analyses of the 2009 SDAC as reported in *Australia's welfare 2011* (see AIHW 2011 for further details). As well, additional information about the physical and emotional wellbeing, and the financial situation of primary carers using 2009 SDAC data, is presented. The most recent SDAC was conducted in 2012, with results due to be released in late 2013.

The ABS 2011 Census collected information about people who, in the 2 weeks before Census night, spent time providing unpaid care, help or assistance to family members or others because of disability, long-term illness or problems related to old age. The Census data are best used for describing informal carer data for small areas and small population groups, as well as for population groups not covered by the SDAC (for example, people living in very remote areas). This chapter presents this type of information and also explores overall changes in the number of informal carers using data from the 2006 and 2011 Censuses. Note that informal carers identified by the Census may not necessarily refer to the same population of informal carers identified by the SDAC.



Box 8.1: Measuring informal carers in the Australian population

Survey of Disability, Ageing and Carers

The SDAC is the best available data source for estimating carer prevalence and analysis of primary carers in the Australian population. More than 70,000 people were surveyed in the ABS 2009 SDAC in all states and territories (except for people living in very remote areas).

The 2009 SDAC defines a carer as a person of any age who provides any informal assistance, in terms of help or supervision, to people with disability or long-term conditions or people who are aged 60 and over. This assistance has to be ongoing, or likely to be ongoing, for at least 6 months (ABS 2010:25). In this chapter, these carers are referred to as 'informal carers'.

A person is a 'primary carer' if they are aged 15 and over and 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 of self-care, mobility and communication (ABS 2010).

The Census of Population and Housing

The ABS 2006 and 2011 Censuses collected data about informal carers aged 15 and over using questions about the provision of unpaid assistance in the previous 2 weeks to a person because of disability, long-term condition or problems related to age. The parts of the definition about the reason for providing assistance are consistent with the SDAC, but reference periods for the two collections are different, and the Census does not refer to ongoing assistance. In this chapter, people who are identified as providing unpaid assistance in the Census are also referred to as 'informal carers', but this group may not necessarily refer to the same population of informal carers identified by the SDAC.

Estimates of the numbers of carers from the Census are lower than the estimates from the SDAC because of a higher non-response rate to the relevant Census questions (ABS 2008). The difference may also be due to different questions and collection methods:

- the Census is based on a self-completion questionnaire, while the SDAC uses trained interviewers to collect responses to the questions
- the Census contains a single question about informal care, while the SDAC uses a set of detailed questions.

For these reasons, Census data should not be used to update the prevalence of carers estimates for the years between the SDAC collections.

Nonetheless, since the Census completely counts (rather than takes a sample of) the whole Australian population, it can provide information about informal carers across small geographic areas and for small population groups, as well as about population groups not covered by the SDAC (for example, people living in very remote areas). Data from the 2006 and 2011 Censuses can also be used to describe change over time in the labour force participation of informal carers, pending the release of the 2012 SDAC data.

Carer rates based on Census data in this chapter are calculated by excluding people who did not respond to the related Census questions.

Note that how informal carers are defined in various administrative data collections is discussed in Section 8.5.

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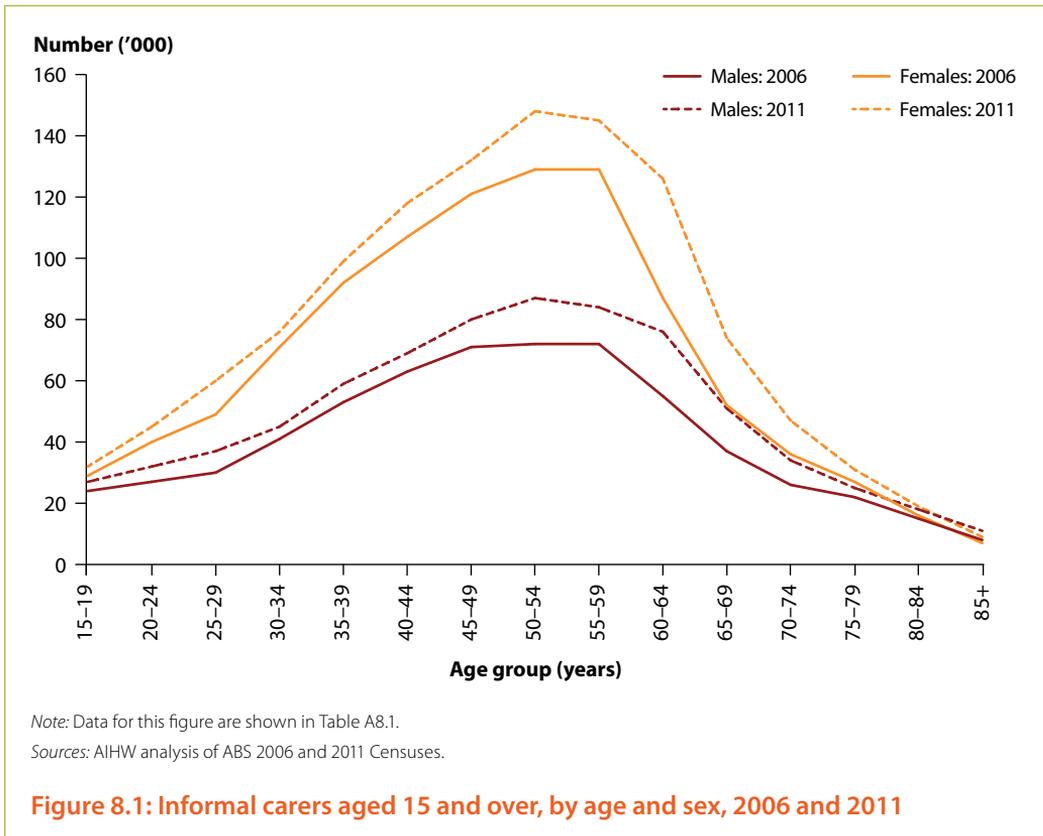


According to the 2009 SDAC, 2.6 million Australians (12% of the population) were informal carers (ABS 2012; AIHW 2011: Table A7.1).

In Australia, informal carers provided the majority of assistance to people with severe or profound core activity limitation living in the community. Based on the 2009 SDAC, 92% of people with severe or profound core activity limitation (see Glossary) received informal help with various activities—38% from informal assistance only and 54% from a combination of informal help and formal services (AIHW 2011).

Based on the Census, the number of informal carers aged 15 and over grew by 18% (290,800 people) between 2006 and 2011, from 1.6 million to 1.9 million (Table A8.1). However, during the same period, the Census estimate of all Australians needing help with core activities rose by 22% (177,000 people) (see Chapter 5).

While the majority of informal carers identified by the Census were female (61%), the number of male carers increased more than the number of female carers between 2006 and 2011 (20% compared with 17%). This trend was observed for all of the age groups, with the exceptions of the 40–44 and 60–69 age groups (Figure 8.1).



The increase in the number of carers between 2006 and 2011 was relatively high among people aged 60 to 69—39% for males and between 41% and 44% for females. High growth rates were also reported among carers aged 85 or over—50% for males and 36% for females.

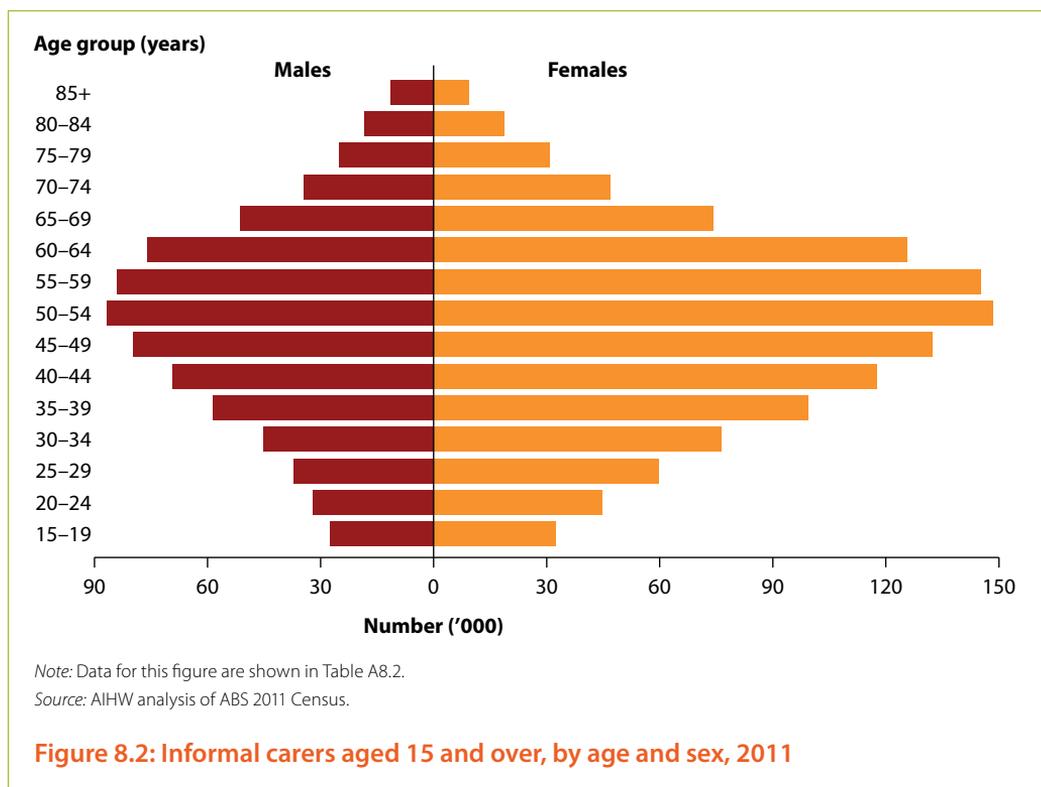


8.4 Who provides informal care?

Age and sex

According to the 2009 SDAC, there were more female (55%) than male carers (45%) (AIHW 2011: Table A7.1). A high proportion (42%) of carers were aged 45 to 64.

Similarly, the 2011 Census indicates that the majority of informal carers were female (61%) and that a high proportion (46%) were aged 45 to 64. Females were more likely to be in a caring role at an earlier age than males and there were more female carers than males across all age groups up to age 79. The sex difference was particularly large among carers aged 30 to 64, where there were 1.7 times as many female carers as male carers (Figure 8.2).



Data from the 2011 Census suggest that there were similar numbers of male and female carers aged 80–84, but slightly more male than female carers among those aged 85 and over (Figure 8.2). The higher number of older male carers may be because life expectancy is shorter for men and because men are often older than their wives. Hence, older men who survive into older ages are likely to be living with a spouse, and have an opportunity to assist them, while many older women have outlived their spouse (ABS 2008).

Primary carers

According to the 2009 SDAC, 771,400 informal carers were primary carers (4% of the Australian population aged 15 and over and 29% of informal carers). Primary carers had a similar age structure to all carers and two-thirds (68%) were female. There were more female primary carers than males across all age groups up to 74, after which there were more male primary carers. Under the age of 45, there were 3.5 times as many female primary carers as male primary carers (AIHW 2011).

Variations across jurisdictions and remoteness areas

Census data support analysis of informal carers across small geographic areas. The likelihood of a person's need for help with basic daily activities, both for services and assistance, increases with age. States and territories with a relatively high proportion of people aged 65 and over tended to have higher-than-average carer rates than those jurisdictions with a relatively low proportion of older people. After taking into account differences by age structure across jurisdictions, most jurisdictions had an age-standardised rate within 1 percentage point of the national average (12%), except Western Australia and the Northern Territory (Table 8.1). In addition to population age structures, other social and economic factors may also affect the availability of informal carers (AIHW 2009).

Table 8.1: Informal carers aged 15 and over, by state and territory, 2011

Age group (years)	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Aust ^(a)
Age-standardised rate^(b) (per cent)									
15–64	12.1	11.9	10.7	9.9	12.3	11.9	11.0	10.4	11.5
65+	12.5	12.7	11.9	11.3	12.4	12.0	13.9	10.6	12.3
Total 15+	12.2	12.0	10.9	10.1	12.3	11.9	11.4	10.4	11.6
Proportion of population aged 65+									
Per cent	14.7	14.2	13.1	12.3	16.1	16.3	10.7	5.7	14.0

(a) Includes 'other territories' not included in the state and territory totals.

(b) Rates were age-standardised to the Australian population at 30 June 2001. Table A8.3 presents crude rates.

Note: Excludes people who did not respond to the related Census question.

Source: AIHW analysis of ABS 2011 Census.



According to the 2011 Census, the age-standardised carer rate was highest in *Inner regional* areas for both males (10%) and females (15%) and lowest in *Remote* areas (8% and 12% for males and females respectively) (Table 8.2; see Box 1.3 for information about the classification of geographical areas).

Table 8.2: Informal carers aged 15 and over^(a), by remoteness and sex, 2011

	Major cities	Inner regional	Outer regional	Remote	Very remote	Total ^(a)
Number						
Males	505,370	146,751	67,946	8,351	6,341	736,337
Females	797,873	236,401	104,480	12,090	8,004	1,160,628
Persons	1,303,243	383,152	172,426	20,441	14,345	1,896,965
Age-standardised rate^(b) (per cent)						
Males	9.3	9.8	9.2	7.6	9.3	9.3
Females	13.7	14.9	14.0	11.9	14.0	13.9
Persons	11.5	12.4	11.6	9.6	11.4	11.6

(a) Includes persons with no usual address.

(b) Rates were age-standardised to the Australian population at 30 June 2001.

Note: Excludes people who did not respond to the related Census question.

Source: AIHW analysis of ABS 2011 Census.

In *Major cities*, *Inner regional*, *Outer regional* and *Remote* areas, the carer rate was highest in the 55–59 age group for both males and females. In *Very remote* areas, the carer rate was highest for females aged 40–49 and for males aged 35–44 (AIHW analysis of ABS 2011 Census). The peak in these earlier ages was partly related to the younger age structure of Indigenous people who comprise almost half of the population in *Very remote* areas (ABS 2008; see also Chapter 1).

Selected informal carer groups

Many informal carers have particular support needs associated with their own life situations and personal characteristics. Summary data for selected groups of these carers—such as young carers, ageing carers, Indigenous carers and carers of people with disability—are in Table 8.3.



Table 8.3: Selected characteristics of informal carers, 2009 SDAC and 2011 Census^(a)

Selected characteristic	Number	Per cent
2009 SDAC data		
Age group (years)		
Under 25	304,800	11.6
25–64	1,806,800	68.6
65+	520,500	19.8
Total	2,632,100	100.0
Age group of primary carers (years)		
15–24	22,900	3.0
25–64	552,700	71.6
65+	195,900	25.4
Total	771,400	100.0
Carers with disability		
Primary carers with severe or profound core activity limitation	68,200	8.8
Primary carers with disability	303,300	39.3
2011 Census data^(b)		
Age group (years)		
15–24	136,415	7.2
25–64	1,440,399	75.9
65+	320,141	16.9
Total	1,896,955	100.0
Need help with core activities	88,333	4.7
Aboriginal and Torres Strait Islander carers	45,328	2.4
Overseas-born carers	512,264	27.0

(a) See Box 8.1 for information on the differences in the data collection methods used for the Census and the SDAC.

(b) Excludes people who did not respond to the related Census questions.

Sources: AIHW analysis of ABS 2010: Data cube Table 31; AIHW analysis of ABS 2012: Data cube Table 2; AIHW analysis of ABS 2011 Census.

Young carers

Depending on the data source, between 7% (2011 Census) and 12% (2009 SDAC) of all informal carers were aged under 25 (Table 8.3). Most of these young carers were female.

According to the 2009 SDAC, 3% of primary carers were aged 15–24 (22,900) (Table 8.3), and the majority (61%) were the son or daughter of the person for whom they were providing care (see AIHW 2011 for further details).



The estimate of the number of young carers is likely to be an undercount largely because young people may not self-identify as carers or are reluctant to disclose their caring role to others (AIHW 2011). Care recipients could also be reluctant to disclose that they are receiving care from a young person.

An intensive caring role may have a particular impact on younger carers, in terms of education, employment and career development. According to 2003 SDAC data, carers aged 19–24 were less likely to have completed Year 12 or equivalent (66%) than non-carers of the same age (73%) (ABS 2008).

In 2009, a higher proportion of primary carers aged 15–24 were not in the labour force (38%) compared with non-carers of the same age (29%). Less than half (47%) of primary carers aged 15–24 were employed, compared with 64% of non-carers (AIHW analysis of ABS 2009 SDAC).

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Older carers

Depending on the data source, between 17% (2011 Census) and 20% (2009 SDAC) of informal carers were aged 65 and over (Table 8.3), and most of these older carers were female (Table A8.2; AIHW analysis of ABS 2009 SDAC).

According to SDAC data, the proportion of primary carers who were aged 65 and over increased from 21% to 25% between 1998 and 2009. This change partly reflects the large baby boomer generation cohort moving into older age groups.

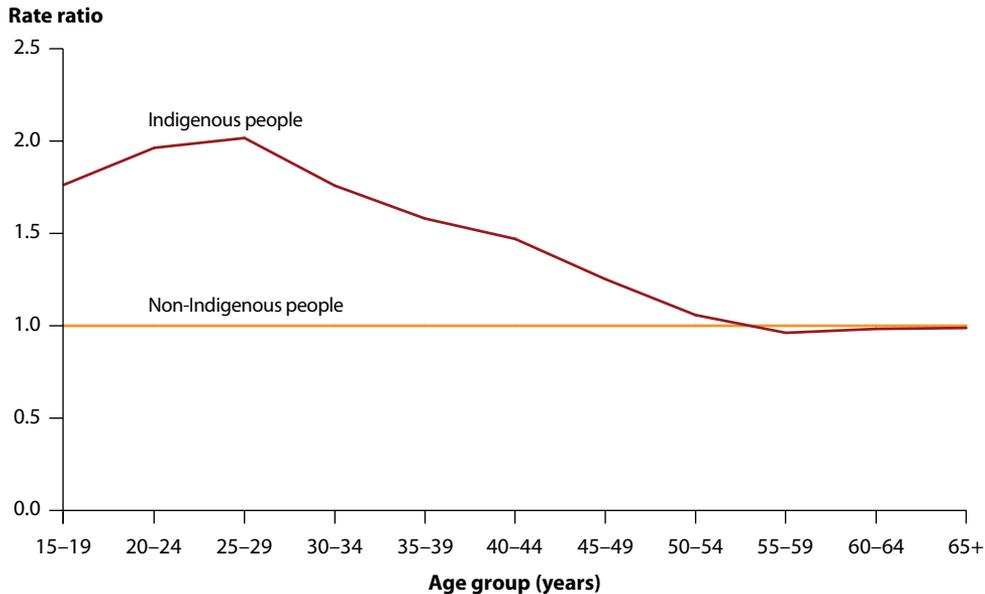
A care recipient's need for help with basic daily activities generally increases with age. Much of the informal care provided to older people living in the community is provided by spouses, who are often older themselves. According to the 2009 SDAC, 77% of primary carers aged 65 and over were caring for their spouse or partner, while 9% were caring for their child and another 9% were caring for their own parent (AIHW 2011).

Indigenous carers

According to the 2011 Census, 15% (around 45,300) of Indigenous Australians aged 15 and over were informal carers (Table 8.3), and the majority of these (63%) were female (AIHW analysis of ABS 2011 Census).

Taking into account differences in age structures across the populations and non-response rates to Census questions, Indigenous Australians were on average 1.3 times as likely as non-Indigenous Australians to be providing informal care. The differences between the two population groups were most evident in younger ages. Indigenous people aged 15 to 34 were around 1.8 to 2 times as likely to be carers as non-Indigenous people in the same age group (Figure 8.3). This may partly reflect the earlier onset of disability-related long-term health conditions and higher birth rates at younger ages (younger parenting) in the Indigenous population (ABS & AIHW 2008; see also chapters 1 and 5). A similar proportion of Indigenous and non-Indigenous Australians aged 65 and over were carers (about 12%).





Notes

1. Rates for non-Indigenous people are taken as the baseline. A rate ratio greater than 1.0 means that Indigenous people were more likely than non-Indigenous people of the same age to be providing informal care. Higher rate ratios mean larger differences.
2. Data for this figure are shown in Table A8.4.

Source: AIHW analysis of ABS 2011 Census.

Figure 8.3: Ratios of age-specific rates of informal carers aged 15 and over, Indigenous people compared with non-Indigenous people, 2011

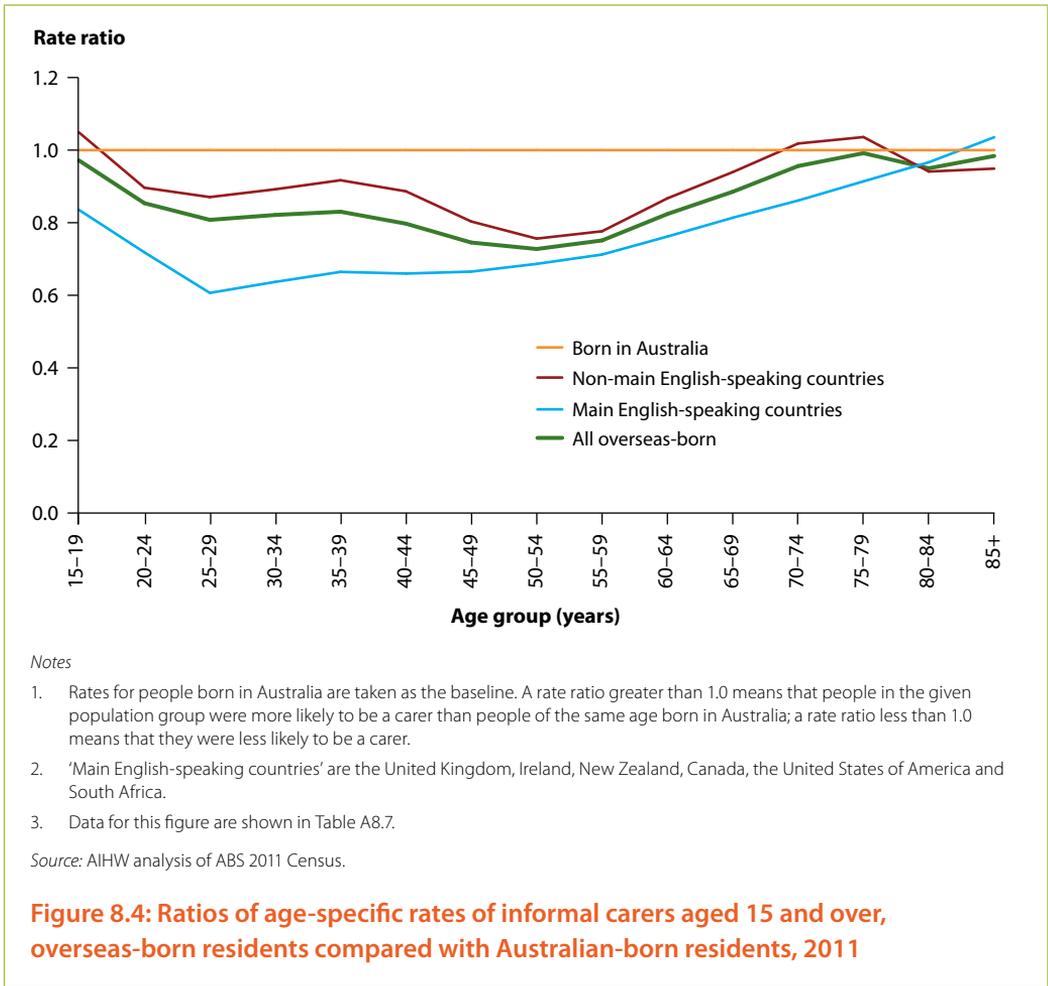
Overseas-born carers

According to the 2011 Census, 27% of all informal carers (512,300) were born overseas (Table A8.5), and the majority of these (66%) were born in non-main English-speaking countries.

Overseas-born Australians were less likely to be providing informal care than Australia-born people. Taking into account differences in age structures and non-response to Census questions, the overall carer rate for Australia-born residents was 12%, compared with 11% for those born in non-main English-speaking countries and 9% for those born in main English-speaking countries (Table A8.6).

The overall carer rate for all overseas-born Australians was lower than Australian-born residents among people aged under 70, except for those aged 15–19. The carer rate for Australians born in main English-speaking countries was lower than both Australia-born residents and people born in non-main English-speaking countries across all ages, except for those aged 80 and over (Figure 8.4).





Carers with disability

Carers often have disability themselves. According to the 2009 SDAC, 33% of carers (867,300 carers) had disability (AIHW analysis of ABS 2012). More than one-third (39%) of primary carers aged 15 and over (303,300) had disability, including 9% with severe or profound core activity limitation (Table 8.3).

Data from the 2011 Census indicate that 5% of informal carers aged 15 and over needed help with core activities themselves. The rate of need for such help increased with the age of carers, from 2% for carers aged 15 to 44 to 12% for older carers aged 65 and over (Table 8.4).

Depending on age, Indigenous carers were between 1.5 and 3 times as likely as non-Indigenous carers to need help with core activities in 2006 (ABS & AIHW 2008).



Table 8.4: Informal carers aged 15 and over who needed help with core activities, by age and sex, 2011

Age group (years)	Males	Females	Persons	Males	Females	Persons
	Per cent ^(a)			Number		
15–44	2.6	2.3	2.4	7,046	9,837	16,883
45–64	4.2	3.6	3.8	13,438	19,778	33,216
65+	12.1	12.2	12.2	16,713	21,521	38,234
Total 15–64	3.5	3.1	3.2	20,484	29,615	50,099
Total 15+	5.1	4.5	4.7	37,197	51,136	88,333

(a) Per cent of carers of that age group and sex.

Note: Excludes people who did not respond to the related Census questions.

Source: AIHW analysis of ABS 2011 Census.

Physical and emotional wellbeing

Providing informal care may have beneficial and adverse effects on a carer's physical and emotional wellbeing. In 2009, 22% of primary carers reported feeling satisfied due to their caring role. About one-third (32%) reported that their 'overall physical and emotional wellbeing' had changed due to their caring role.

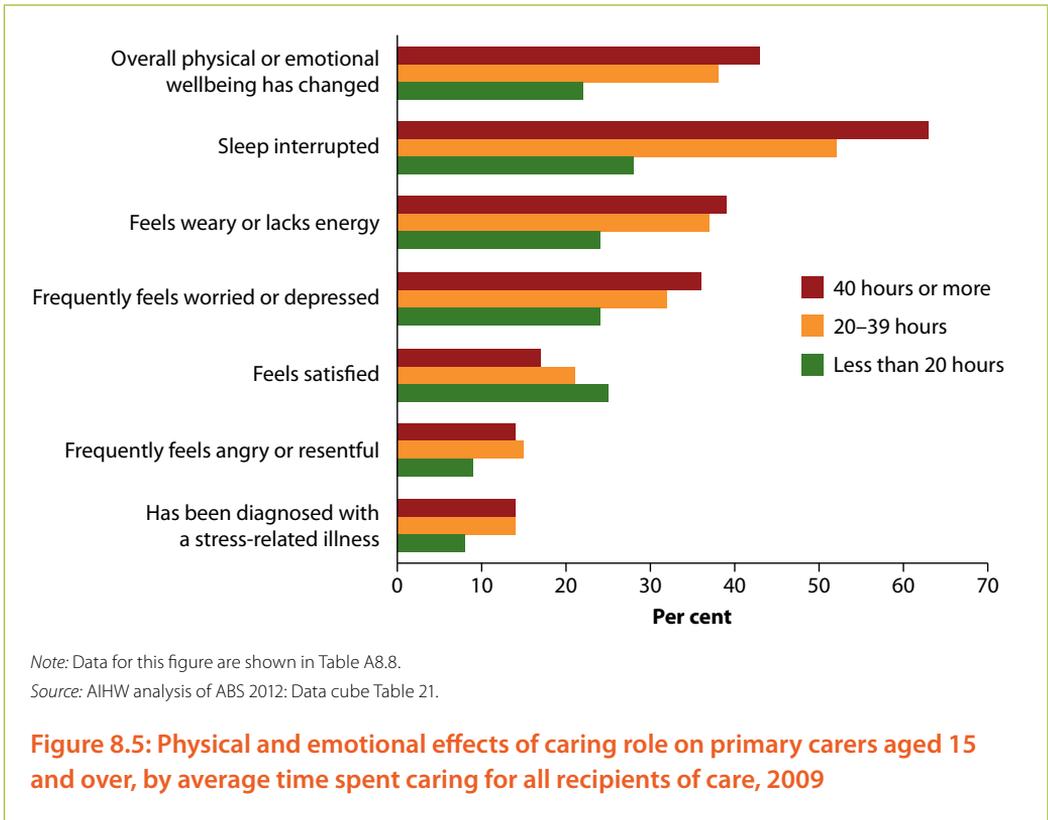
Some specific adverse effects of caring on primary carers include (Table A8.8):

- feeling weary or lacking in energy (32% of primary carers)
- frequently feeling worried or depressed (30%)
- being diagnosed with a stress-related disorder (11%)
- sleep interruption (45%).

Primary carers who spent an average of 40 hours or more a week providing care were more likely than those providing care for less than 20 hours a week to report, as a result of their caring role (Figure 8.5):

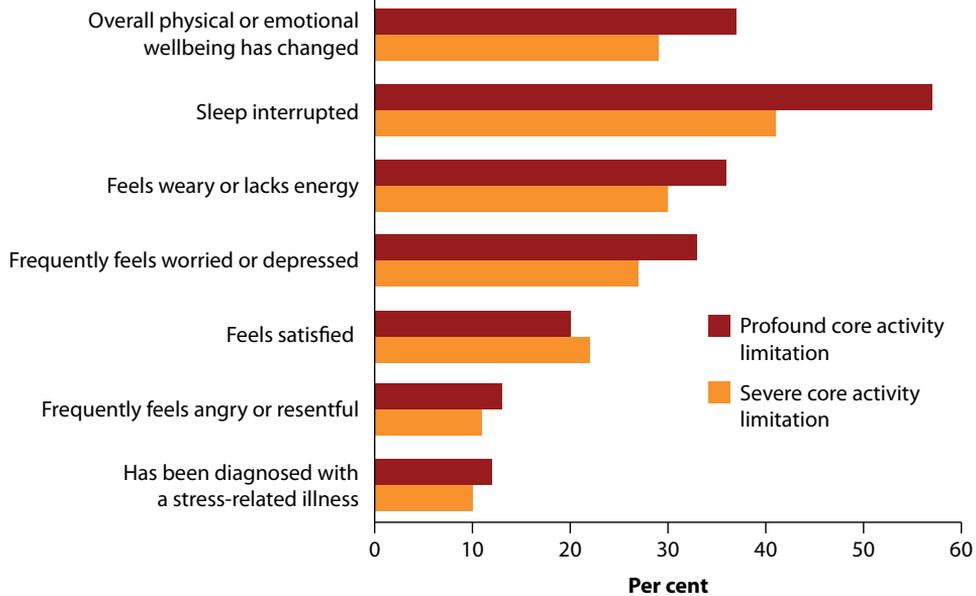
- a changed overall state of wellbeing (43% versus 22%)
- feeling weary or lacking in energy (39% versus 24%)
- frequently feeling worried or depressed (36% versus 24%)
- being diagnosed with a stress-related disorder (14% versus 8%)
- sleep interruption (63% versus 28%).





Caring for a person with severe or profound disability may be an intensely demanding experience. In the 2009 SDAC, information on the disability status of the main recipient of care is only collected for co-resident main recipients of care. Co-resident primary carers of people with profound core activity limitation (that is, a person who *always* needs help or supervision with one or more core activities) were more likely to report a change in their overall state of wellbeing (37%) due to their caring role than those caring for a person with severe core activity limitation (that is, a person who *sometimes* needs help or supervision with one or more core activities) (29%) (Figure 8.6). There were some other differences in the adverse effects of caring between the two groups of co-resident carers. For example, 57% of those caring for a person with profound core activity limitation reported interruptions to their sleep, compared with 41% of those caring for a person with severe core activity limitation.





Notes

1. Disability status of main recipient of care is only collected for co-resident main recipients of care.
2. Data for this figure are shown in Table A8.9.

Source: AIHW analysis of ABS 2012: Data cube Table 23.

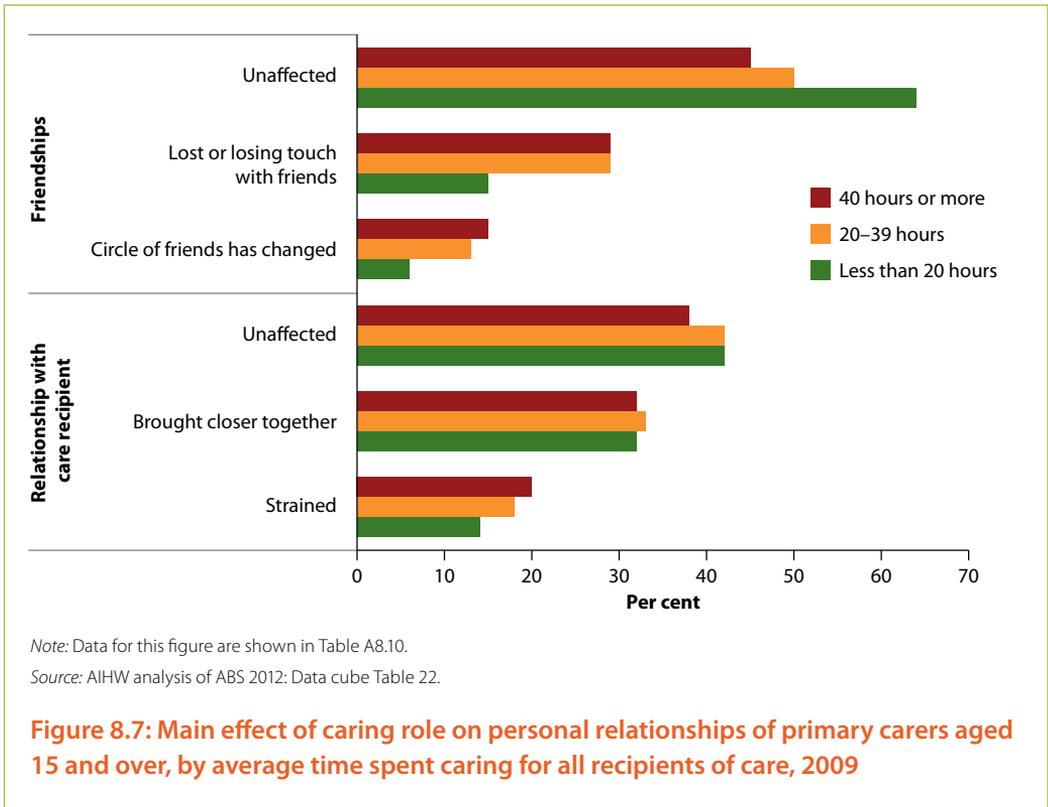
Figure 8.6: Physical and emotional effects of caring role on co-resident primary carers aged 15 and over, by disability status of main recipient of care, 2009

Providing informal care may also affect carers' personal relationships with their care recipients, family and friends. While about one-third (32%) of primary carers felt that caring had strengthened their relationship with the main recipient of care, 17% said that their relationship was strained (Table A8.10). More than half (55%) of primary carers experienced no change in relationships with their friends, while 22% were losing or had lost touch with friends and 11% had changed their circle of friends. Around 17% of primary carers reported that their relationship with their spouse or partner was unaffected and 15% felt that they had been brought closer together, while 7% stated that their relationship was strained.

Primary carers who spent 40 hours a week providing care were more likely than those who provided care for less than 20 hours a week to report that due to the caring role (Figure 8.7):

- the relationship with the main recipient of care was strained (20% versus 14%)
- their circle of friends had changed (15% versus 6%)
- they had lost or were losing touch with existing friends (29% versus 15%).





Labour force participation

Providing informal care may affect the capacity of carers to be involved in paid employment. The 2009 SDAC shows that primary carers aged 15 to 64 had a lower labour force participation rate (54%) than non-primary carers (71%) and the general population (79%). The participation rate of female primary carers (51%) was lower than male primary carers (61%) (AIHW 2011).

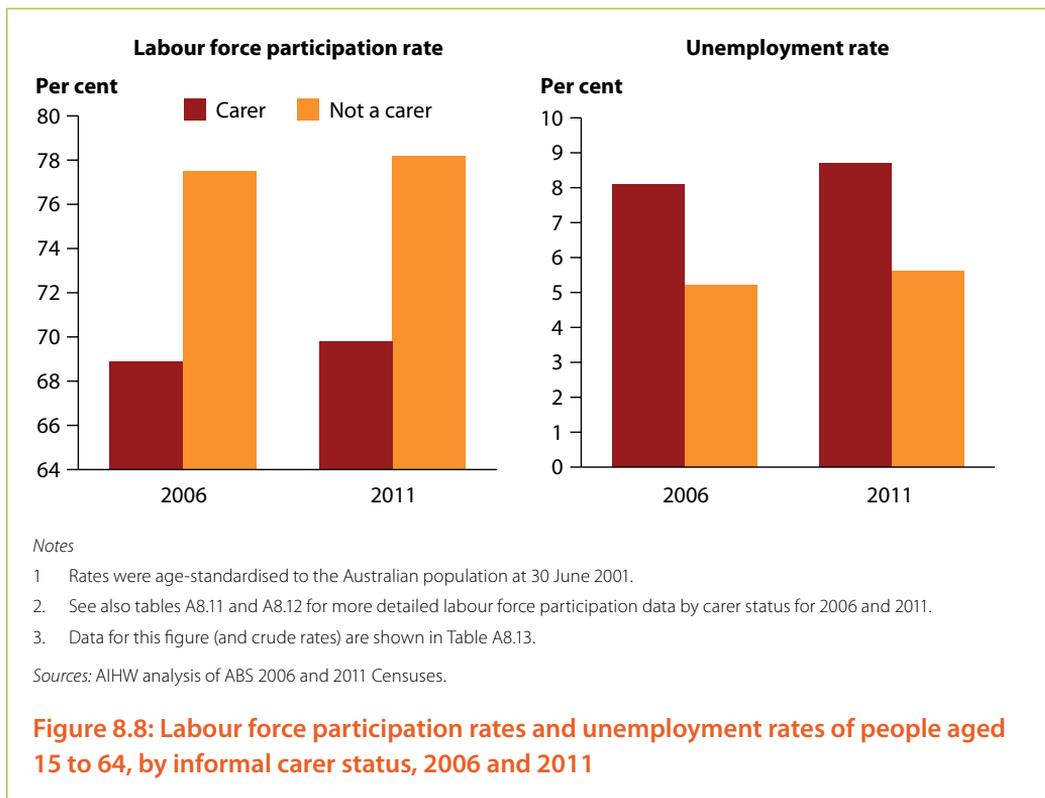
Around 155,000 (20%) primary carers aged 15 and over who were not in the labour force had been in paid employment just before the start of their caring role. Around 21% (95,000) of primary carers who were not in the labour force indicated that they would like to participate in paid work (AIHW analysis of ABS 2012: Data cube Table 15).

Data from the 2006 and 2011 Censuses are used to identify recent changes in overall employment and unemployment levels among informal carers, pending the release of the 2012 SDAC data. In the comparisons of informal carers and non-carers, the labour force participation rates and unemployment rates shown are age-standardised rates; these rates take into account differences in the age structures between the two population groups and within the two groups over time. These age-standardised rates should only be compared with other age-standardised rates, not with any crude rates.



Between 2006 and 2011, the age-standardised labour force participation rate for those aged 15 to 64 increased for carers (by 0.9 percentage points from 68.9% to 69.8%) as well as for non-carers (by 0.7 percentage points from 77.5% to 78.2%) (Figure 8.8). The gap between the rate for carers and non-carers was the same in 2006 and 2011—around 8 percentage points lower for carers in both years. In both years, the difference in the participation rate between carers and non-carers was larger for females than males—in 2011, the difference was 8.2 percentage points for females and 4.9 percentage points for males.

During the same period, the age-standardised unemployment rate for people aged 15 to 64 increased for carers (by 0.6 percentage points from 8.1% to 8.7%) and non-carers (by 0.4 percentage points from 5.2% to 5.6%) (Figure 8.8). The gap between the unemployment rate of carers and non-carers remained almost the same between 2006 and 2011, and was around 3 percentage points higher for carers in both years. The difference in unemployment rate between carers and non-carers was larger for males (3.4 percentage points in 2011) than for females (2.9 percentage points in 2011).

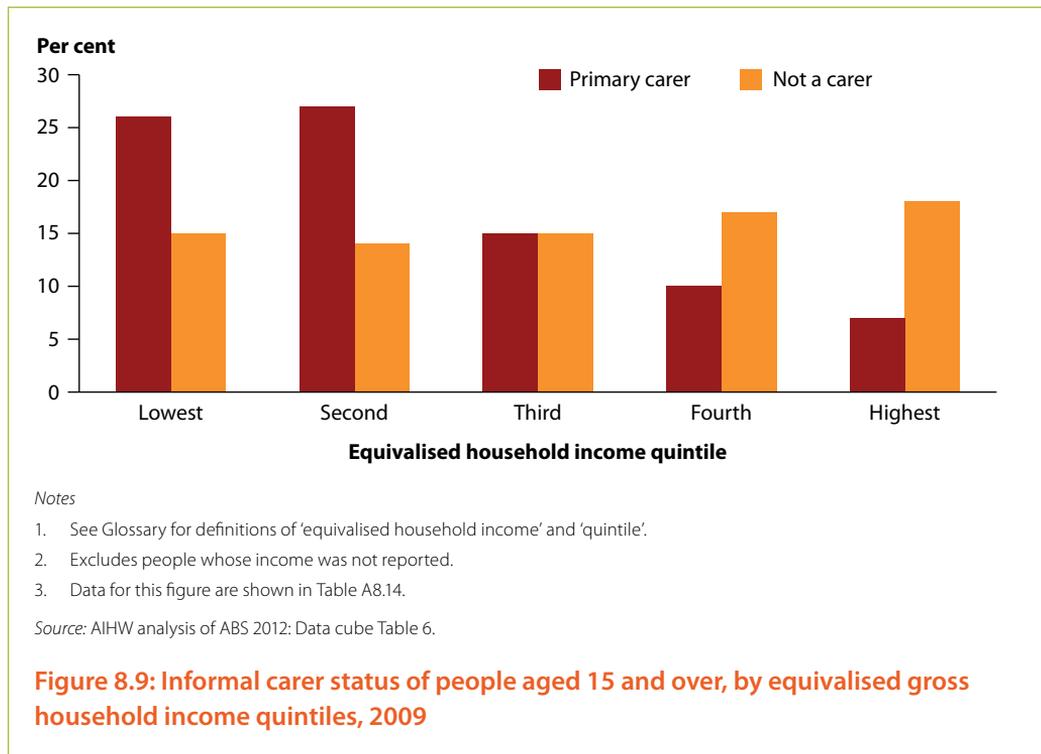


Carers' financial circumstances

The capacity of informal carers to earn income and accumulate wealth may be affected by their caring role. According to the 2009 SDAC, 45% of primary carers reported that their caring role had either reduced their income (21%) or created extra expenses (24%). Around 45% of primary carers aged 15 to 64 and 78% of primary carers aged 65 and over relied on a government pension or allowance as their main source of personal cash income (AIHW 2011).



The 2009 SDAC shows that primary carers were more likely than non-carers to live in low-income households. Among people aged 15 and over, 26% of primary carers were in the lowest equivalised gross household income quintile, compared with 15% of non-carers (see Glossary for definition of equivalised household income). Those not in the caring role were 2.5 times as likely to be in the highest income quintile as primary carers (18% versus 7%) (Figure 8.9).



8.5 Services and payments for informal carers

There are a number of government-funded services available to assist informal carers and their care recipients—see Box 8.2.

Data about informal carers are collected in a number of administrative data sets, as described in Box 8.3. Unlike the SDAC and Census data, the administrative data pertain to various subgroups of the informal carer population—that is, those who are clients of specific programs (or the carers of those clients). Thus these data are not generalisable to the overall population of informal carers. Due to data quality issues, data about carers in the Disability Services National Minimum Data Set (DS NMDS) and the Home and Community Care Minimum Data Set (HACC MDS) should be used with some caution. In particular, data on the age, sex and co-residency of carers was missing in many cases in both collections. As well, data about whether the client had a carer was missing in 7% of cases in the HACC MDS in 2010–11 and in 5% of cases in the DS NMDS in 2011–12. Cases with missing data on the relevant questions were excluded from the analyses shown in this section.



Box 8.2: Services that support informal carers

Services which are funded by the Australian Government and/or state and territory governments that provide information and support for informal carers include:

- Home and Community Care (HACC) services for carers—carer counselling, respite, personal care and domestic assistance for older people, younger people with disability and their carers (note that HACC services are known as Basic Community Care Services from 1 July 2012 for people aged under 65 or, for Indigenous people, aged under 50)
- Aged Care Assessment Program (ACAP)—assessment services (see Section 6.7 for further information)
- Community Aged Care Packages (CACP), Extended Aged Care at Home (EACH) and Extended Aged Care at Home Dementia (EACHD)—‘packaged care’ through which respite can be received (note that EACHD packages will be discontinued under proposed aged care reforms—see Section 6.7)
- Disability support services provided under the National Disability Agreement (NDA)—personal care and respite for people with disability
- Veterans’ Home Care—low-level care services, including respite services, to eligible veterans, and war widows and widowers
- Commonwealth Respite and Carelink Centres—advice and coordination around respite services for relatives and friends caring for someone at home
- National Respite for Carers Program (NRCP)—respite services, information and counselling
- National Carer Counselling Program—short-term counselling and emotional and psychological support services for carers
- Young Carers Respite and Information Services Program—respite and information services to assist young carers who need support to complete their secondary education or vocational equivalent due to the demands of their caring role
- Respite Support for Carers of Young People with Severe or Profound Disability Program—immediate and short-term respite as well as information on respite services
- MyTime Peer Support Groups for Parents of Young Children with Disability—assists parents and carers of children up to the age of 16 with disability or a chronic medical condition
- Mental Health Respite: Carer Support—a range of flexible respite and family support options for carers of people with severe mental illness/psychiatric disability and carers of people with an intellectual disability
- Dementia Education and Training for Carers (DETC)—dementia education
- Dementia Behaviour Management Advisory Service (DBMAS)—dementia behaviour management clinical intervention and training.

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Box 8.3: Data about informal carers in selected administrative data sets

Disability Services National Minimum Data Set

Data on disability support services provided under the NDA are collected annually in the Disability Services National Minimum Data Set. The DS NMDS defines an informal 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'. Under the DS NMDS, informal carers do not include paid or volunteer carers that are organised by formal services. While it is recognised that two or more people may equally share the caring role, for the purposes of this collection, characteristics are only requested for one carer. In the DS NMDS, a 'primary carer' is 'the person who provides the most significant care and assistance related to the service user's capacity to remain living in their current environment' (AIHW 2012b).

HACC Minimum Data Set

Data on HACC clients are collected annually in the HACC Minimum Data Set. In that MDS, an informal carer is defined as 'a person such as a family member, friend or neighbour, who provides regular and sustained care and assistance to another person without payment other than a pension or benefit. The definition excludes formal care services such as care or assistance provided by paid workers or volunteers arranged by formal services'. Sometimes a care recipient may have more than one person who could be described as their carer. In these cases, information on the carer who provides the most significant care and assistance is recorded, that is, the primary carer (DoHA 2006).

HACC data presented in this chapter were derived from the HACC MDS National Data Repository for all jurisdictions except New South Wales. Data for that state were provided separately by the New South Wales State Data Repository. The AIHW collated those data with data for the other states. Consequently, HACC data published in this chapter may differ from those published in other reports.

Aged Care Assessment Program

Data on Aged Care Assessment Program clients are collected through the ACAP MDS. In that collection, a carer is defined as someone, such as a family member, friend or neighbour, (excluding paid or volunteer carers organised by formal services) who has been identified by the individual, carer or significant other as providing regular and sustained care and assistance to the person without payment other than a pension or benefit (DoHA 2011a). The carer may or may not live with the person for whom they care. Information is only collected about one carer in this collection, who is referred to as the main carer. The main carer is the person who is identified by the client and/or a carer as providing the most significant amount and type of care and assistance related to the client's capacity to remain living at home.

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How many service users had a carer?

According to data from the DS NMDS, around 133,800 (44%) disability support service users had an informal carer in 2011–12 (an increase of 24% from 108,100 in 2007–08). The proportion of all service users with a carer has remained relatively steady since 2008–09 (at 43% to 44%) (Table A8.15; AIHW 2013).

Data from the HACC MDS indicate that both the number and proportion of HACC clients who had an informal carer have decreased in recent years—250,400 (29%) had an informal carer in 2010–11, compared with 272,200 (39%) in 2006–07, a decrease of 8% (Table A8.16).

Data from the ACAP MDS suggest that the proportion of ACAP clients with an informal carer has increased from 119,200 (81%) in 2006–07 to 125,200 (85%) in 2010–11 (Table A8.17).

Characteristics of carers

Age and sex

Women provide the majority of informal care to recipients of disability support, HACC and ACAP services, often as the mother of young care recipients, or the child or spouse of older care recipients (tables A8.18 to A8.21). However, there are some differences between programs—the proportion of male carers of recipients of HACC (around 32% in 2010–11) and ACAP services (33% in 2010–11) was higher than that for disability support service users (around 14% in 2011–12) (tables A8.17, A8.18 and A8.19).

Age patterns and care relationships among carers vary between programs. For example, in 2011–12, the majority of disability support service users' carers were aged under 65. Of these, most were women aged 25–44, and many were caring for their child (Table A8.19). In contrast, within the HACC program in 2010–11, carers tended to be older, with most aged 45 and over, and they were often caring for either a spouse or a son or daughter (tables A8.18 and A8.20).

Co-residency status

The majority of informal carers of disability support service users (83% in 2011–12) and HACC clients (77% in 2010–11) were co-resident carers (that is, living in the same household as the care recipient) (tables A8.15 and A8.20). However, the co-residency pattern is different for ACAP, with clients only slightly more likely to have a co-resident carer (53%) than a non-resident carer (47% in 2010–11). This balance has shifted from 2006–07, when it was 58% co-resident and 42% non-resident carer (Table A8.17).

Services for informal carers

Home and Community Care program

The HACC program provides two types of services directly to informal carers: counselling and respite care. In 2010–11, around 47,600 (19%) HACC clients with an informal carer received counselling (22,600) and/or respite services (28,100), an increase of 3% from around 46,300 in 2009–10 (Table A8.22; AIHW 2011).



National Disability Agreement

The NDA provides respite services to service users, which is also of direct benefit to informal carers. In 2011–12, around 37,000 people with disability who were receiving services under the NDA used respite services—an increase of 17% since 2007–08 (AIHW 2013: Table 5.2). Most respite services were provided as ‘flexible respite’ (22,200), which may include any combination of ‘own home and host family/peer support respite’ (Table A5.13).

National Respite for Carers Program

The NRCP provides respite, information and counselling to primary carers of people who are unable to care for themselves. NRCP services are targeted to assist carers of:

- frail aged Australians (aged 65 and over, or aged 50 and over for Indigenous people)
- people with dementia
- people with dementia and challenging behaviours
- younger people with disability (people under the age of 65, or under the age of 50 for Indigenous people)
- people with a terminal illness requiring palliative care
- people with high-care needs
- employed carers (DoHA 2012e).

In 2011–12, the NRCP provided assistance to 109,200 primary carers. Services were delivered through:

- 54 Commonwealth Respite and Carelink Centres, which provided information and access to emergency respite—accessed by 73,200 carers
- 650 respite services, which provided planned respite in a variety of settings, including in the person’s home, by host families, at day centres, and at community overnight respite cottages—accessed by 30,900 carers
- the National Carer Counselling program (through Carers Australia), which provided short-term emotional and psychological support services to carers—accessed by around 5,100 carers
- the Carer Information Support Service (through Carers Australia) (DoHA 2011b, 2012a, 2012d, 2012e).

As noted above, the NRCP provided 30,900 primary carers with respite services in 2011–12 (Table 8.5). Although this was less than in the previous 2 years, the number of actual hours of respite delivered remained at more than 5.1 million (Table A8.23; DoHA 2010, 2012a). The most common form of respite was ‘day care centre-based’, which had both the greatest number of care recipients and the greatest number of respite hours (Figure 8.10).

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Table 8.5: Respite services provided by the National Respite for Carers Program to primary carers, by selected characteristics, 2008–09 to 2011–12

Selected characteristic ^(a)	2008–09	2009–10	2010–11	2011–12
New carers receiving support	12,453	12,811	12,267	11,656
Carers from an Aboriginal or Torres Strait Islander background	1,435	1,583	1,577	1,567
Carers from a culturally and linguistically diverse background ^(b)	5,733	6,415	6,229	6,227
Carers from rural areas	7,471	7,890	7,566	7,489
Carers from remote areas	2,216	2,053	2,632	2,328
Employed carers	8,698	10,304	10,116	10,364
Carers with financial or social disadvantage	9,499	10,371	10,502	10,692
Carers receiving emergency respite	3,397	3,429	3,026	3,030
Primary carers supported in a 12-month period	29,992	37,220	31,862	30,906

(a) Primary carers may have more than one of the characteristics listed so the columns do not sum to the total number of primary carers supported.

(b) For the purposes of the NRCP, carers are defined as from a 'culturally and linguistically diverse background' when they have particular cultural or linguistic affiliations due to their: place of birth or ethnic origin, main language other than English spoken at home, and/or proficiency in spoken English.

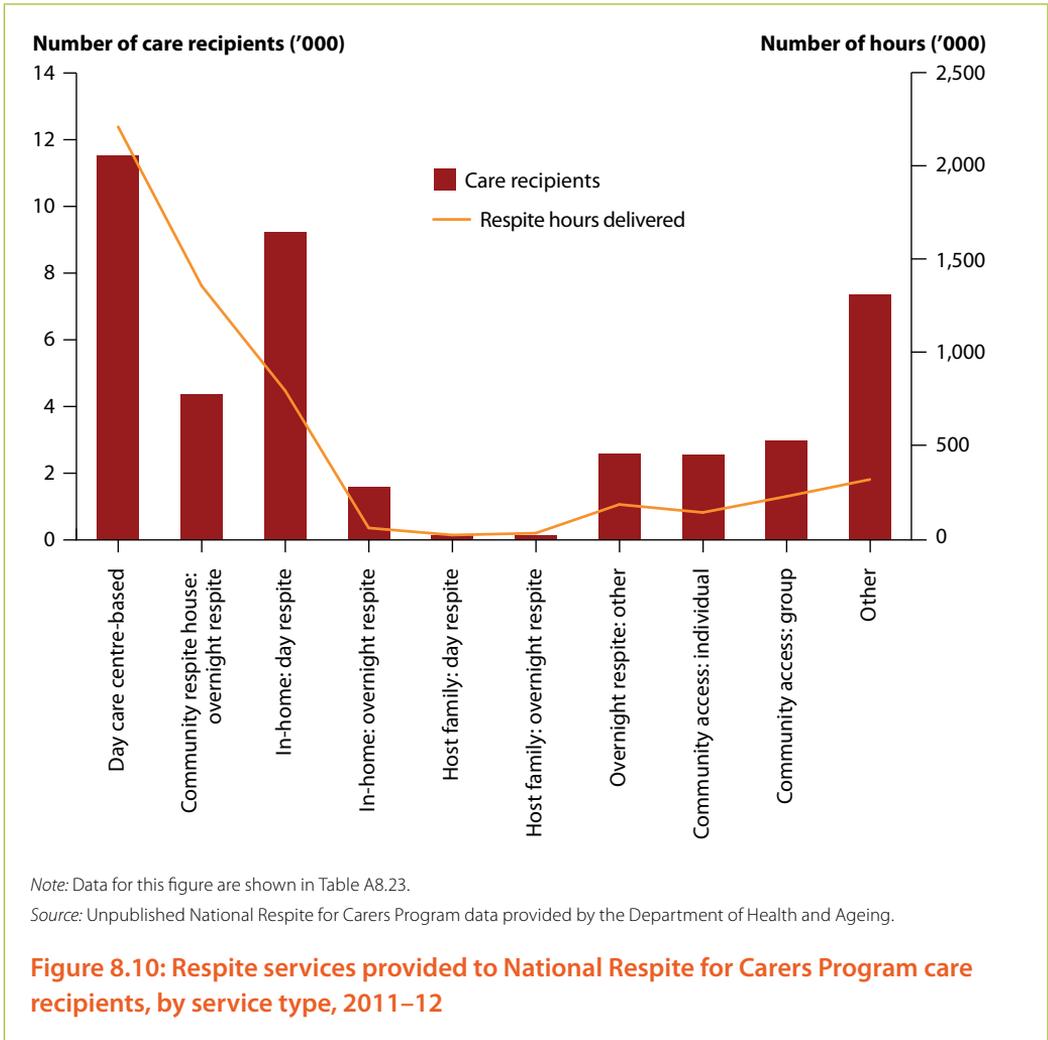
Source: Unpublished National Respite for Carers Program data provided by the Department of Health and Ageing.

In 2011–12, carers from an Indigenous background comprised 5% of primary carers receiving NRCP respite services, while those from culturally and linguistically diverse backgrounds comprised 20% (Table 8.5).

In 2011–12, people with dementia comprised the largest group of NRCP care recipients, at 13,400—92% of whom were aged 65 and over (Table A8.24). Around 6,000 recipients were identified as having dementia and challenging behaviour, of whom 89% were aged 65 and over. People with disability were the next largest group of respite care recipients, at just under 7,900—59% of whom were aged 65 and over.

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The Dementia Education and Training for Carers program is administered through Commonwealth Respite and Carelink Centres. This program aims to increase the competence and confidence of carers of people with dementia by providing skill-enhancement activities such as driving lessons, education about dealing with challenging behaviours, and personal care skills (DoHA 2012b). The program assisted 3,700 family carers in 2011-12 (DoHA 2012c).

Under the National Health Reforms, and in particular the proposed aged care reforms, the NRCP will be rolled into a Commonwealth Home Support Program from 1 July 2015, along with the HACC program for older people, the Day Therapy Centres program and the Assistance with Care and Housing for the Aged program (DoHA 2012a).



Dementia Behaviour Management Advisory Service

The DBMAS provides clinical interventions to help aged care staff and family carers improve the care of people with dementia where the person's behaviour affects their care. The DBMAS provides education and tailored information workshops, assessment and short-term case management, clinical supervision, and mentoring and modelling of behaviour management techniques (DoHA 2012c).

Multi-disciplinary DBMAS teams may include registered nurses, occupational or diversional therapists, social workers and other health or aged care professionals. In 2011–12, DBMAS teams received around 1,100 referrals for assistance from informal carers and provided 1,536 in-home clinical interventions. Around 1,200 family carers also received training and/or education (DoHA 2012c).

Payments

Selected payments made to eligible informal carers by the Australian Government are listed in Box 8.4 and include: Carer Payment (caring for a child or an adult), Carer Allowance (caring for a child or an adult), Child Disability Assistance Payment and Carer Supplement.

Box 8.4: Financial assistance for informal carers

Australian Government-funded payments for informal carers include:

- Carer Payment—a means-tested income support payment made to informal carers who are unable to maintain substantial paid employment due to caring responsibilities for a person with severe disability or medical condition, or who is frail aged.
- Carer Allowance—a supplementary payment made to informal carers of people with disability or a severe medical condition. It is not subject to an income or assets test, nor is it included as income for social security or family assistance purposes. Those receiving Carer Payment for a child generally automatically receive Carer Allowance.
- Child Disability Assistance Payment—a single, annual payment of \$1,000 to recipients of Carer Allowance (caring for a child under the age of 16), to assist with the purchase of therapy, aids and equipment, among other things.
- Carer Supplement—a single, annual payment of \$600 paid to recipients of Carer Allowance for each person they care for. An additional \$600 Carer Supplement is paid to recipients of one of the following income support payments: Carer Payment, Department of Veterans' Affairs (DVA) Carer Service Pension and those recipients of Wife Pension and DVA Partner Service Pension who also receive Carer Allowance.

Sources: DHS 2012a, 2012b; FaHCSIA 2012.



In 2011–12, Australian Government expenditure on these payments comprised:

- \$3.18 billion on Carer Payment. At June 2012, around 205,600 people received this payment (AIHW 2011; FaHCSIA 2012; Table 8.6).
- \$1.75 billion on Carer Allowance, including both Carer Allowance (adult) and (child). At June 2012, 549,600 people received this allowance (AIHW 2011; FaHCSIA 2012; Table 8.6).
- \$164 million on the Child Disability Assistance Payment. At June 2012, 148,900 carers received this payment (AIHW 2011; FaHCSIA 2012).
- \$480 million on the Carer Supplement. At June 2012, 557,200 people received this supplement (FaHCSIA 2012).

Carer Payment and Carer Allowance

The majority of recipients of Carer Payment and Carer Allowance were female: 69% and 74% respectively in June 2012 (Table 8.6).

Table 8.6: Recipients of the Carer Payment and/or Carer Allowance, by sex, June 2012

Sex	Carer Payment		Carer Allowance ^(a)	
	Number	Per cent	Number	Per cent
Males	63,641	31.0	143,639	26.1
Females	141,924	69.0	405,999	73.9
Persons	205,565	100.0	549,638	100.0

(a) Excludes those who received a Health Care Card only.

Source: Unpublished data provided by the Department of Human Services.

At June 2012, most people who received Carer Payment and/or Carer Allowance were caring for an adult (defined as a person aged 16 or over) rather than a child (aged under 16) (Table 8.7). The most common care relationship for people caring for an adult was 'partner' (around half of these recipients). Other common relationships were caring for their adult child and caring for their parent. Not surprisingly, the most common care relationship for carers caring for a child is parental.



Table 8.7: Relationship of Carer Payment recipients and Carer Allowance recipients to their care receivers^(a), June 2012

	Carer caring for adult		Carer caring for child	
	Number	Per cent	Number	Per cent
Carer Payment				
Child	43,707	23.5	<20	n.a.
Parent	21,867	11.8	19,694	94.0
Step parent	<20	n.p.	n.p.	n.p.
Partner	90,427	48.6	<20	n.a.
Other relation	17,556	9.4	444	2.1
Unrelated	11,496	6.2	308	1.5
Not specified	n.p.	n.p.	487	2.3
Total	186,084	100.0	20,964	100.0
Carer Allowance				
Child	85,876	19.7	n.p.	n.p.
Parent	63,893	14.6	154,469	97.4
Step parent	<20	n.p.	—	—
Partner	228,469	52.4	n.p.	n.p.
Other relation	34,514	7.9	2,281	1.4
Unrelated	23,418	5.4	1,813	1.1
Not specified	<20	n.p.	<20	n.p.
Total	436,184	100.0	158,564	100.0

(a) Data are based on the number of care receivers, not the number of carers.

Source: Unpublished data provided by the Department of Human Services.



8.6 Where to from here?

Data issues

There are several sources of national data about carers in Australia, including the Survey of Disability, Ageing and Carers, the Census and various administrative databases. Data limitations include:

- no consistent definition of an 'informal carer' and a 'care recipient' across various data collections
- the methods of identifying carers vary in different data collections and often change over time within a collection
- administrative data collections are, by definition, restricted to the scope of service program clients, and cannot be used to estimate the total number of carers
- although the SDAC distinguishes between 'carers' and 'primary carers', detailed data are collected only about primary carers
- the SDAC definition of 'informal carers' excludes intermittent or short-term carers
- data collections based on self-reported responses may have a high non-response rate for some data items, resulting in the number of carers being underestimated.

Disability Services National Minimum Data Set redevelopment

The AIHW is in discussions with the Disability Policy and Research Working Group (a national advisory group on disability) about redeveloping the DS NMDS to provide a better evidence base for the administration, planning and management of specialist services for people with disability and their carers. In 2012, the AIHW produced a revised disability data dictionary that includes most of the items in the current DS NMDS, and proposes new items to enable collection of:

- more sociodemographic information about carers
- more information on the capacity of carers, and the nature of supports they provide
- information on carers' involvement in the planning, delivery and assessment of support services.

ABS population survey and Census data developments

Results from the 2012 SDAC are due to be released in late 2013. The ABS is reviewing the SDAC survey content for the 2015 collection, including information about informal carers.

In preparation for the 2016 Census, the ABS is reviewing the questions on disability and unpaid assistance provided to a person with disability. The review will look at the topic of 'core activity need for assistance' and related topics on unpaid work, including unpaid care of others due to disability, illness or old age.



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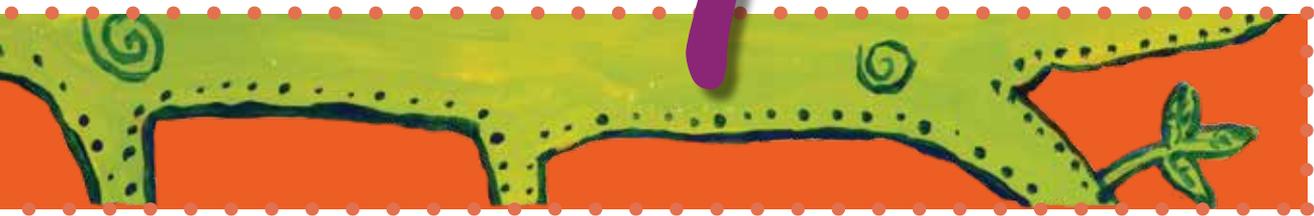
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Chapter 9



Community services workforce

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