

3 Informal care

3.1 Introduction

Informal assistance provided by family and friends is the main source of non-parental care of children and care for people with a disability. Shifts in the extent to which the responsibility for such care has fallen to the community or the state throughout Australia's history since European settlement have been presented in *Australia's Welfare 1993* (AIHW 1993) and more recently by Fine (1999). In the early colonial days, government-sponsored orphanages cared for the children of 'unsuitable mothers' and working single fathers. Private boarding of children led to the passing of protective legislation for children in the 1870s. Between Federation and 1970, the family was seen as the central institution in the care of children; however, widespread adoption practices and the operation of orphanages and other large-scale residential facilities for children continued until the middle of the 20th century. Formal child care services expanded during the 1970s, beginning with the passing of the Community Child Care Act in 1972 and followed by implementation of a National Child Care Strategy in 1988. Now, family day care and some forms of home-based child care are part of the system of formal child care services along with institutional-based care such as long day care. Informal care of children is the unregulated care of children by other than the non-resident parent, that is primarily provided by grandparents, other relatives and friends.

Institutions run by charitable organisations dominated care arrangements for aged and disabled persons in the fledgling colonies. Adults needing care were viewed as indigent and were institutionalised to facilities for the destitute. Possibly the first public nursing home, the Liverpool Street Asylum, opened in 1849. Between 1860 and 1950, aged care remained a state government responsibility. Specialised community care began to emerge in the 1950s. The 1980s saw the introduction of the Home and Community Care Program and the Aged Care Reform Strategy established residential care benchmarks. Care in the community is now the preferred and most common care arrangement for most people with a disability or age-related frailty.

Informal carers have played a pivotal role in the deinstitutionalisation of aged care and disability services, chronicled in an earlier edition of *Australia's Welfare* (AIHW 2001). The shift to caring for people with a disability in the community depends on the availability of informal carers to take on a caring role. The narratives of carers highlight that, for many, to do so is not a decision as such. For them, being a carer is a natural expression of their relationship with a family member or friend in a time of need, however long that may be. Yet studies of informal care reveal that caring at home may not always be a carer's first choice and can extend well beyond what most people might expect of family life (e.g. CAA 1999; Schofield et al. 1997). There is widespread recognition that, while caring may be rewarding, carers may also experience the stress of social isolation, physical and emotional strain, and reduced education and employment potential. The appointment of the National Family Carers Voice in 2003 is

one of a number of initiatives that represents acknowledgment at the national level of a pressing need for insight and solutions to address the challenges confronting many informal carers.

Informal care has featured as a topic of chapters in previous issues of *Australia's Welfare*. These treatments have suggested that, despite an increased awareness of the role of informal carers in recent decades, there remains some tendency to view the family as a net consumer of welfare—welfare is something provided *to* families rather than being provided *by* families. As such, providers of informal care are sometimes seen as 'dependent' (e.g. because they receive a carer's pension or use respite care services) rather than as contributors to welfare (AIHW 1997:55). A report from the Organisation for Economic Co-operation and Development cautions that informal care 'cannot be simply assumed, or regarded as a free good' (OECD 1996:63).

This dedicated chapter reflects a growing awareness of the importance of informal caring activity. It presents an overview of what we know about carers and their caring activities from existing national data collections and the published literature. Currently, the Australian Bureau of Statistics' Child Care Survey and Survey of Disability, Ageing and Carers are the main sources of national information. The most recent Child Care Survey was conducted in 2002 and the 5-yearly Survey of Disability, Ageing and Carers, last conducted in 1998, is in the field as at date of publication.

Section 3.2 discusses changes in Australia that have raised concerns about the numbers of carers who will be available in the future. Section 3.3 considers the way in which unpaid informal care and formal services are currently used together under the care in the community service delivery model. Section 3.4 looks at informal non-parental care for children. Section 3.5 focuses on those who care for people of all ages with a severe or profound disability. In Section 3.6, the effects that current social trends will have on the availability of carers for people with severe or profound disabilities are examined.

Informal care defined

Caring can be broadly defined as providing assistance and support in response to a need arising in the family or community. As such, it can be provided by workers employed in community service occupations and industries or by volunteers in such organisations (see Chapter 4). However, the vast majority of care for children, and for adults and children who need help in their daily activities because of disability, is provided by family and friends. This ranges from emotional support through financial and practical assistance to supervision and assistance with personal care, mobility and communication for extended periods. This type of care, which is characteristically free of charge and government regulation, is described as 'informal care' and the providers of informal care are referred to as 'carers' for the purposes of this chapter. Other sources might connote 'informal care' and 'carer' differently.

In this chapter, informal care is that provided by an unpaid carer who has assumed responsibility for another's physical, emotional or developmental wellbeing where the care is *not a defining element* of the primary or precedent relationship between the person needing care and the person providing care. There are, inevitably, inconsistencies and ambiguities in this conceptualisation since relationship definitions, and their associated obligations, are subjective. Our scope, therefore, is specified as all informal care *other*

than that provided by a parent to a dependent child without specific special needs (e.g. disability or handicap)—parenting is not included. Section 3.5 further defines ‘primary carer’, an important distinction that needs to be made in the context of informal care of people (including children) with a disability.

3.2 Caring in a changing Australia

Just as national and international awareness of the contributions made by informal carers has been growing, there has emerged a concurrent concern about the sustainability of the current patterns of informal care provision, both in terms of pressures on the supply of carers and factors likely to increase demand for care. Some observers of change in the United States have proposed that the ageing of the population will bring with it a larger proportion of the population with health and personal care needs and that this is occurring at the same time as the traditional supply of paid and unpaid caregivers is shrinking (NHPF 2002). These concerns have been shared by some Australian researchers (Schofield & Bloch 1998) who cite a range of relevant changes in the Australian context, including the shift to deinstitutionalisation of care, the growing number of women in the workforce, increased rates of relationship breakdown, and the tendency toward smaller families. The ageing of carers has also been identified as an issue of concern, particularly in relation to older parents who care for their grown children with disabilities (AIHW 2000).

The ageing of the population

Over the past 30 years, the declining birth rate, in combination with increased longevity, has transformed the Australian population. Moreover, as the baby-boom generation moves into old age in the next two to three decades, this ageing pattern will be accentuated.

Australians are living longer than ever before. While 70% of women born in 1905 survived until age 65, 89% of those born in 1950 are expected to reach age 65. The effect is even more dramatic for those surviving to age 85—just 28% of the 1905 birth cohort survived to this age, compared with the 54% of those born in 1950 who are predicted to reach that age (Gibson et al. 1999). In 1992, 11.5% of the population were aged 65 or over and by 2002 this had grown to 12.7%. It is estimated that in 2016 and 2021 the proportions will be 16.4% and 18.4%, respectively. In 2002, 3.2% of the population were aged 80 or over and this will grow to 4.0% by 2016 and 4.4% by 2021 (ABS 2003a).

Since the proportion of people with a disability increases at older ages, more people are likely to require assistance and care in the future. Demand for personal care services, including home nursing, is likely to increase in line with increasing numbers of people with a severe or profound core activity restriction living in the community. The increasing proportion of older people and the corresponding decreasing proportion of working-age people have been raised as issues that may pose challenges to providing welfare services to Australians, or require changes in the current patterns of social participation and service provision. While this has sometimes been referred to as an ‘ageing crisis’, authors such as Kinnear (2001) have argued that these population changes offer opportunities for progress rather than posing a threat to future sustainability.

Deinstitutionalisation

Over the past three decades, there has been a shift in the system of service delivery for aged care, children in out-of-home care, services for people with a disability, and services for those with mental health problems and those needing acute hospital services. These services have moved from an emphasis on institutional care to one on community-based care and community living (see AIHW 2001:96 for a broadly-based discussion of deinstitutionalisation across these service areas). In 1996 there were 210,186 people living in health and welfare institutions, a decrease of 8% over the decade from 1986. This represents a drop in residency rates from 14.3 people per 1,000 in 1986 to 11.5 per 1,000 by 1996 (AIHW 2001:106).

The shift to community-based care does, however, rely on the unpaid contribution of families and wider social networks. People with varying needs for care are remaining in or returning to the community for care – not just people with a disability and frail older people, but also people with a mental illness and post-acute care patients as well. These changes place multiple demands for support and assistance on a range of community-based programs, home care services, and, importantly for this chapter, on informal carers.

While community family care is preferred by some families, it does not suit all situations and is not the preferred choice of all families. In 2002, the National Disability Administrators commissioned the AIHW to assess the effectiveness of ‘unmet need’ funding allocated under the Commonwealth/State Disability Agreement in 2000–01. The study also sought to identify any remaining unmet need for disability accommodation, in-home support, day programs, respite services and disability employment services. The study estimated that in 2001, 12,500 people needed accommodation and respite services (AIHW 2002:xv, xxi). The study methodology included three discussions with peak organisations of non-government service providers, consumers and carers. It was considered by many participants that the apparent government focus on in-home support ignores ‘the fact that people still need residential accommodation options’, including centre-based respite (AIHW 2002:187).

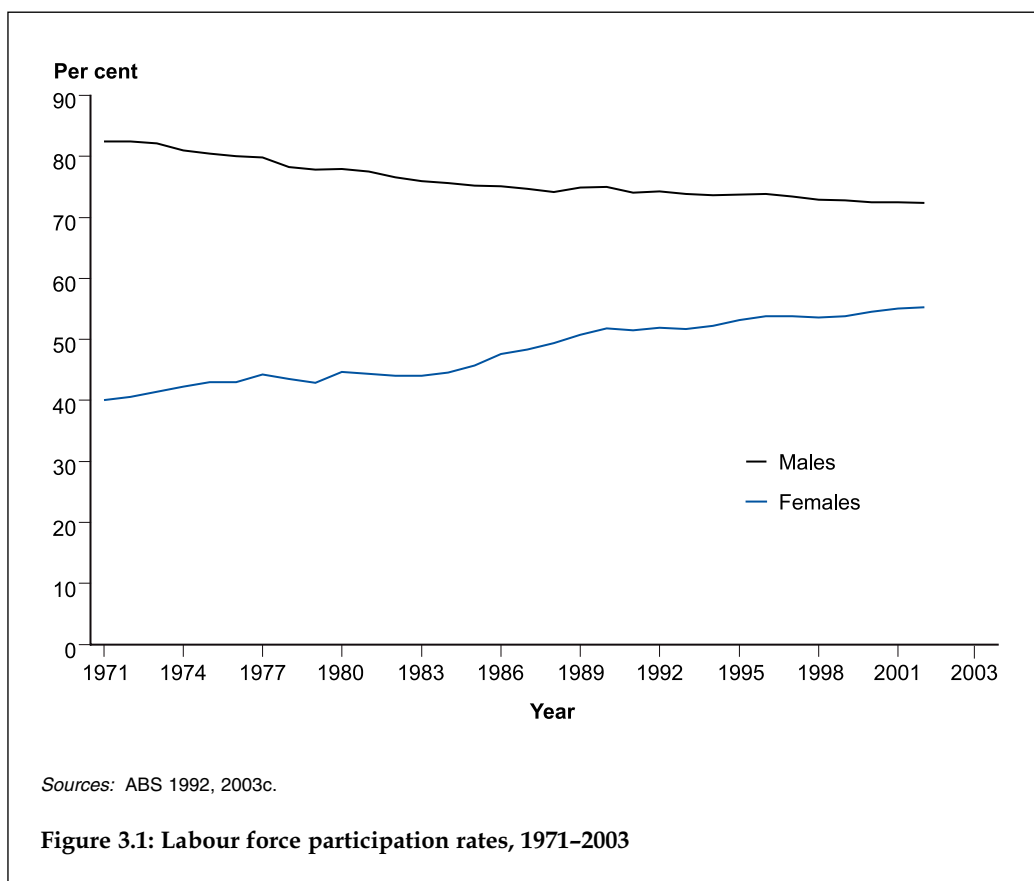
Increased female labour force participation

Female labour force participation grew from less than 40% in 1971 to 55% in 2002 (ABS 1992, 2003c). ABS labour force projections to 2016 indicate a sustained increase in female labour force participation, particularly at ages 45 to 64 which currently comprise over 40% of female primary carers (Table 3.1). At this stage, projections predict that, for 45 to 54 year olds, male and female labour force participation rates will converge from a difference of around 15 percentage points in 2003 to 10 percentage points in 2016.

Table 3.1: Projected labour force participation rates, 2003, 2008, 2013, 2016 (per cent)

	Age group (years)							
	15–19	20–24	25–34	35–44	45–54	55–59	60–64	65+
Males								
2003	57.1	86.5	92.1	91.6	87.5	71.6	47.6	10.0
2008	56.4	85.7	91.4	90.9	87.0	71.1	47.7	10.3
2013	55.8	85.1	90.8	90.2	86.7	70.8	47.7	10.7
2016	55.4	84.7	90.4	89.8	86.5	70.7	47.7	10.9
Females								
2003	56.9	78.8	71.7	74.4	71.9	45.4	19.5	2.7
2008	56.3	79.1	73.1	75.6	74.3	49.3	21.2	2.8
2013	55.7	79.2	74.1	76.3	75.9	53.3	23.0	2.8
2016	55.4	79.2	74.5	76.6	76.7	55.6	24.0	2.9

Source: Labour force projections 1999 to 2016 (ABS 1999b).



Examination of the patterns of women's labour force participation reveals that this trend has not necessarily reduced the provision of care. First, participation rates have levelled off over the past decade. Most of the growth in women's labour force participation occurred in the 1970s and 1980s, with a particularly steep rise of 5 percentage points between 1985 and 1990 (Figure 3.1). By contrast, during the 1990s, there was a growth of less than 3 percentage points. Second, most of the growth in women's labour force participation has been in part-time employment. In fact, successive cohorts of employed women have actually been less likely to work full-time since 1971 (ABS 2003b). Moreover, many people who currently provide care are also in paid employment, often part-time (Table 3.15). As Howe and Schofield (1996) foreshadowed, changes in labour force participation patterns have not been so large as to potentially threaten the availability of carers in the future.

Additionally, it is not clear that increased labour force participation necessarily translates to lower carer availability. While there is evidence that a portion of carers will leave work or reduce their hours of work to care (e.g. Schofield et al. 1997), it is not clear that participation in the workforce reduces carer availability per se. As Cox and Spalding (1996) argue, entering employment does not mean that women are forsaking caring, rather that they are adding to their responsibilities, or as Doty et al. (1998) suggest, making greater use of a wider informal care network. Research conducted in Northern America has indicated that there is little evidence that this increased workforce participation has resulted in reduced care for older people by women (Aytac and Waite, 1995; Chappell 1990).

Increased rates of relationship breakdown

Family resources are reduced by the family network disruption that can occur following divorce or separation and this may have implications for the provision of informal care (Millard 1998). Since most assistance to sustain independence at older ages comes from within generations rather than between them, marital status can be used as an indicator of family resources for care and support (Rowland 2003). Current cohorts of older Australians are the most likely to have been legally married for life. As Rowland (2003:253) puts it: 'In the next few decades, the composition of the older population will begin to change as birth cohorts with disrupted marital histories advance into later life. Australia is on the threshold of a decline in family resources as higher proportions experience marriage breakdown and live their later years without spouses, the main carers and supporters of the aged.'

Figure 3.2 shows the marital status, at age 75–79, of age cohorts born in the first half of the last century over a 20-year period. Data for later cohorts are projections. There is a steady decline in the proportion of age cohorts who were married, or are projected to be married, at this age. In the cohort born between 1926 and 1931, 67% of men and 38% of women were married but these proportions are projected to have fallen to 56% and 26% in the cohort born between 1946 and 1951. Over the same 20-year period, the proportion of birth cohorts divorced or separated has risen sharply, from 11% of men to a predicted 25% and from 6% of women to 17%. The difference in the proportions of men and women is due primarily to the larger proportion of widows among women because men tend to die at an earlier age.

These generations with a history of marital breakdown are less likely to have spouses to care for them at older ages. However, there is a countervailing trend, which is that the gap between male and female life expectancies is closing, potentially reducing the duration of widowhood and hence the proportion of widowed women in the population. In the 1946–51 cohort, 79% of men are projected to reach age 65 and 64% are projected to reach age 75, compared with 60% and 39%, respectively, of men born in 1901–06—a large increase over half a century (Rowland 2003). Levels of cohabitation outside of marriage in later life and improved life expectancy for people in couple relationships will determine the net impact of these emerging patterns of marriage breakdown on informal care.

The proportion of families that are headed by sole parents has risen from 9% of all families with dependent children in 1974, to 15% in 1986 and to 19% in 1996 (AIHW 1997:65). This rise is due to relationship breakdown as well as the higher number of children born outside of continuing relationships. The current divorce rate means that each year 40,000 to 50,000 more children join the pool of Australian people with divorced parents (de Vaus 1997). Once again, the effect that repartnering will have on informal caring resources is unknown.

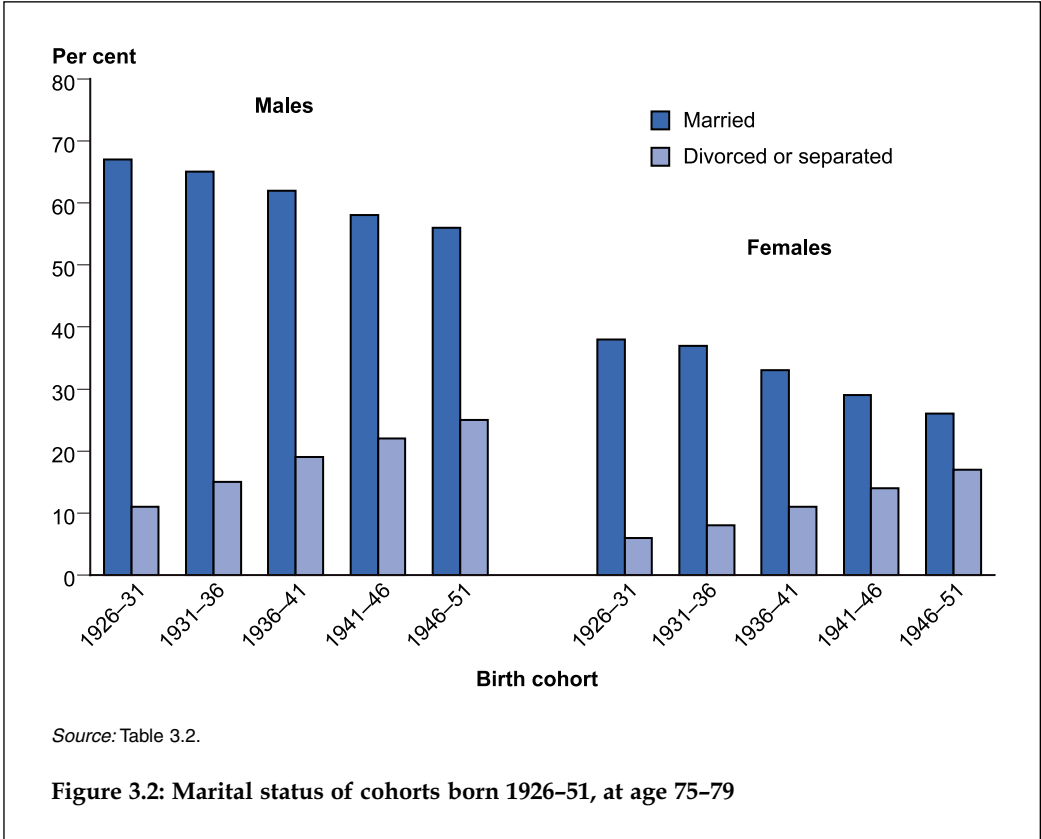


Table 3.2: Marital status at ages 65–69 and 75–79 of cohorts born 1926–51 (per cent)

Birth cohort	Never married		Married		Widowed		Separated or divorced	
	65–69	75–79	65–69	75–79	65–69	75–79	65–69	75–79
Males								
1926–31	7	6	75	67	6	16	12	11
1931–36	6	6	73	65	6	15	15	15
1936–41	6	5	69	62	6	14	19	19
1941–46	6	5	66	58	6	14	23	22
1946–51	6	6	63	56	6	14	26	25
Females								
1926–31	4	5	60	38	27	51	9	6
1931–36	4	5	59	37	26	51	11	8
1936–41	5	5	55	33	25	52	15	11
1941–46	5	5	51	29	25	52	20	14
1946–51	6	6	46	26	24	50	24	17

Source: Rowland 1994.

While the effects of lone parenting will first be felt by the children of these families, in later life the parent may find themselves without the care of their adult children. Very few Australian children do not live with their natural mother (AIHW 1997:66), so it is fathers who are more at risk of losing contact with their children. Even when parents divorce later in life it is father-child relationships that are most likely to be disrupted (Aquilino 1994).

Relationship breakdown also has the potential to affect caring in other ways. Grandparents who are divorced or separated see their grandchildren less often than those who are married or widowed (Millward 1998). Divorce and repartnering of parents or grandparents can lead to dilution of relationships—grandparents, particularly paternal grandparents, may have less contact with their grandchildren and therefore be less likely to provide assistance with child care. In addition, carers often need support to provide assistance to others while living their own lives, and unpartnered carers will go without such support. Being unpartnered often makes parenting harder and potentially increases the need for child care. It can also make it more difficult for people caring for others with a disability. Increased rates of unpartnered Australians have the potential to reduce caring resources.

Smaller families and childlessness

Similar concerns about reduced caring resources have been raised because of the tendency toward smaller families and childlessness. The role of women in social and economic terms has changed substantially over the last 40 years resulting in a marked reduction in child-bearing. Progressively, women have been delaying having children and, partly as a result, having smaller families.

After peaking at 3.55 babies per woman in 1961, the total fertility rate in Australia fell to 1.73 in 2000. The most dramatic decline occurred between 1961 and 1975 when the rate fell by 1.4 children per woman in just 15 years, coinciding with the introduction of the oral contraceptive pill. After a period of relative stability in the 1980s, a steady decline

characterised the 1990s. Women are starting their families later in life and as a result, or by desire, are having fewer children. The median age of Australian mothers at first pregnancy rose from 24 years in 1975 to 29 years in 2001 (ABS 2002b).

Lifetime childlessness began to increase among women who were in their reproductive years from the late 1960s onwards (ABS 2002a). An estimated one in four women of reproductive age in 2003 (24%) are expected to remain childless and rates are predicted to be as high as one in three women in parts of the country. The oldest of these women will turn 65 in 2020 and the youngest in 2050. If they remain childless as predicted, they will not have children who could potentially care for them.

Smaller families mean that, in the future, families will have fewer members to call upon for caring—fewer adult children to provide care for older people, fewer siblings to help with child care or to help care for a family member with a disability. However, past fertility patterns mean that this will not affect the number of available carers in the short to medium term. The effect of current patterns of low fertility will not be felt until around 2040, when those born during the 1960s and in their peak child-bearing years in the 1990s reach ages at which they are likely to be in need of assistance. Indeed for at least the next decade, older generations will be family-rich, since Australia's fertility rate peaked during the baby boom at 3.6 births per woman in 1961. Women turning 80 in 2011 (born in 1931) had an average of 2.3 children (ABS 2002b). Moreover, in the short term, childless people may have more capacity to provide informal care to parents or partners because of the absence of children.

Older parent carers of adult children with disabilities

Ageing parents caring for their child with a severe or profound disability often have a different history from people taking on the caring role as a spouse in later life. Many have been providing care for many years, often decades. Analysis of the 1998 ABS Disability, Ageing and Carers Survey found that an estimated 8,000 co-resident principal carers of people with severe or profound disability were parents aged 65 years and over and a further 25,800 were aged 45 to 64 years. Approximately 57% of parents aged 65 and over had been caring for their children for 25 years or more, and 49% of them for 30 years or more. The recipients of their care are often those with an early onset disability, particularly intellectual disability. The ageing carers often find that the caring role has become more difficult and wish to see alternative arrangements put in place for the future care of the person involved (AIHW: Madden et al. 1996).

Further insight into the experience, knowledge and needs of older parent carers has been gained through recent research by Llewellyn et al. (2003). Through a series of interviews with carers, the researchers identified issues affecting the wellbeing and coping ability of carers, including those factors influencing their use of formal services. While caring may have a toll on older parents that may be physical, emotional or financial, they may also be concerned that alternative care arrangements will not provide care as they had been able.

3.3 Context of care

The trend towards community care has seen a move away from the provision of institutional care and the growth of services that can be used to help people in need of care and assistance to stay living at home. This applies to people of all ages who require assistance as a result of disability, and also to child welfare.

The change of emphasis in child welfare is characterised by government assistance such as Parenting Payment and Family Allowance which aims to assist parents in providing for their children. When it is necessary to remove a child from their home, placement with kin is the preferred option, rather than foster placement or institutional care. Today, there are very few larger institutions left and most residential care for children is provided in family group homes or in smaller residential establishments (AIHW 2001: 127).

It was the awareness of the rapid increase in the proportion of the older population that occurred in the 1980s that prompted the development of the Aged Care Reform Strategy of 1985. The reforms brought about by this strategy reduced the number of nursing home beds per 1,000 people aged 70 and over in the late 1980s. A second wave of major aged care reforms in 1997 saw the continued reduction in provision of residential places. The number of operational residential aged care places has declined from 89.2 per 1,000 persons aged 70 and over in 1997 to 81.6 per 1,000 persons aged 70 and over in 2002 (AIHW 2003). The care needs of residents of aged care services have also been rising over time. For example, the proportion of residents classified in the highest care need categories according to the Resident Classification Scale (RCS 1-4) rose from 58% in 1998 to 63% in 2002 (Table 7.17). Over the last decade, there has also been an expansion of Community Aged Care Packages (CACP). The level of provision increased from 3.9 per 1,000 persons aged 70 and over in 1997 to 14.7 per 1,000 persons aged 70 and over in 2002 (AIHW 2003). The Extended Aged Care at Home program is a new program that, like CACP, offers tailored packages of services to people living at home with complex care needs, but whose level of care need is equivalent to that required by someone in high-level residential care.

For younger people with a disability, the 1980s saw changing policies and services that placed greater emphasis on consumer involvement and integration and an emphasis on moving away from institutional models towards community-based services. The first Commonwealth/State Disability Agreement (CSDA) was signed in 1991 and signalled changes in the care of younger people with disabilities. Initiatives arising from this agreement included the closure of institutional-style services such as special purpose nursing homes and hostels, and the opening of community based services, including group homes and community access/recreation services for clients living in the community. Analysis of the CSDA minimum data set collection has shown that 43% of all accommodation support services received in 2002 were through group homes, although there has not been a clear trend of increase or decrease in regard to this service (Table 8.8). Outreach, in-home and drop-in support services increased steadily over the period from 1996 to 2000 (AIHW 2001:121).

Table 3.3: Living arrangements of people with profound or severe core activity restriction(s), 1981, 1988, 1993 and 1998 ('000)

Living arrangements	People with severe or profound restriction			
	1981	1988	1993	1998 ^(a)
		5–64 years		
Households	244.1	302.5	349.1	606.6
Cared accommodation ^(b)	27.0	24.2	19.2	20.0
Total	271.1	326.7	368.3	626.6
Proportion in cared accommodation (%)	9.9	7.4	5.2	3.2
		65+ years		
Households	168.9	217.8	299.4	396.3
Cared accommodation ^(b)	73.9	113.0	103.1	152.9
Total	242.8	330.8	402.5	549.2
Proportion in cared accommodation (%)	30.4	34.2	25.6	27.8

a) In the 1981, 1988 and 1993 surveys, three levels of severity of handicap (severe, moderate and mild) were applied to both household and establishment components. In 1993 the severe handicap category was further divided into profound handicap and severe handicap, but the severe handicap category was not applied to the establishment component. In the 1998 survey both the profound and severe core activity restriction categories were applied to the cared accommodation component.

(b) Cared accommodation (1998) and establishments (1981, 1988 and 1993) are defined by ABS as hospitals, nursing homes, hostels, retirement villages and other 'homes'.

Source: AIHW analysis of ABS Disability, Ageing and Carers Survey data, 1981, 1988, 1993, 1998.

The shift to caring for people with a range of disabilities in the community has resulted in higher proportions of people with a severe or profound level of activity restriction living in households rather than in institutions (Table 3.3). For those aged 5–64 years with such a restriction, the percentage living in cared accommodation fell from 10% in 1981 to 3% in 1998. For those aged 65 years and over with such a restriction, the notable drop in proportion in cared accommodation occurred between 1988 and 1993 (from 34% to 26%).

Imputed value of informal care

Any description of the Australian welfare system that is limited to government-funded or registered services underestimates total welfare activity and its cost in real terms. The contribution of unpaid carers far exceeds the expenditure of governments and non-government community service organisations (NGCSOs) on welfare services. The System of National Accounts 1993 recommended that 'satellite accounts' be calculated (Commission of European Communities et al. 1993). These are accounting statements which are separate from, but consistent with, the existing national accounts. By imputing a value for unpaid caring work, such a satellite analysis allows caring to be made visible for the purposes of economic policy. The imputed value of unpaid welfare services is calculated in Chapter 4, using time-use survey data to estimate how much households contribute to caring. It must be noted that, in accordance with previous editions of *Australia's Welfare*, this estimate of caring includes care for people with a disability, child care for other people's children, and care for their own children if sick or disabled. The estimates of the size of the community services labour force that are

also in Chapter 4 include volunteers who give unpaid work through organisations, but do not include any other type of unpaid carers.

The imputed value of unpaid welfare work done during 2000–01 is \$28.8 billion, compared with \$13.7 billion in expenditure mostly incurred by governments and NGCSOs (Table 4.24). In terms of type of care provided by this unpaid work, 66.6% (\$19.3 billion) of the gross value was for care provided to other adult family members, friends or neighbours. A further 28.6% (\$8.3 billion) was for child care-related activities and the remaining \$1.4 billion was for voluntary welfare assistance provided through community service organisations. The unpaid workforce was estimated to be about six times the paid workforce in terms of full-time equivalents (AIHW:2001:42). Unpaid caring work plays a large role in improving the quality of life for many Australians and in reducing the need for expenditure on formal services to the extent that informal, unpaid care has been referred to as the ‘invisible welfare state’ (OECD 1996:19).

Interplay of informal care and use of formal services

Among all people living in households in 1998 who received assistance with the core activities (self-care, mobility and communication), 3% said they were assisted only by formal service providers while 46% said they received assistance only from informal carers, and 48% said that they received assistance from both informal carers and formal services (Table 3.4).

There is a vast body of published literature on the interplay between informal care and formal community-based services. Much of the work has focused on how the informal and formal care sectors operate together to help older people with high needs for assistance to remain in the community. Projected increases in the number of people with severe disability over the coming decades means that this is of considerable interest in terms of planning for anticipated growth in demand for services. Does access to informal care reduce demand for formal services? If so, is the effect universal, or does it vary according to service type? What are the respective roles of informal care and formal services in different age groups, and for people of culturally diverse backgrounds?

Early studies of the relationship between informal and formal care centred on the hypothesis of substitution (e.g. Greene 1983). This proposes that informal care and formal community-based services are independent enablers that assist people with disabilities to remain in the community. Accordingly, if an individual in need of assistance does not have access to adequate informal care, then formal services can directly substitute for an informal care network.

Supplementation of informal care with formal services is another widely studied theory (e.g. Jette et al. 1995; Schneider et al. 2003). In some situations, supplementation is observed as specialisation, where informal care and formal services operate in different domains to reflect specialisation in the provision of care. The use of formal services to reduce demand on informal care in one domain, such as domestic assistance, to allow informal care to respond to increasing needs in another domain, such as personal care, is another form of supplementation. Jette et al. (1995) have suggested that increasing supplementation of informal care with formal services reflects the progression of an individual along a care continuum that begins with mainly informal care and

progresses to mixed formal and informal care. For some people, the continuum ends with informal care being largely substituted by formal (institutional) care. If this is true, cross-sectional studies may be unable to demonstrate clear patterns of substitution and supplementation effects because the degree of either depends on where a person is placed on the care continuum.

Data collected recently in Australia reveal patterns that are consistent with both substitution and supplementation effects. The Sydney Older Persons Study (Edelbrock et al. 2003) examined the relationships between the use of formal services and the level of unpaid informal care by 537 community-dwelling older persons in inner Sydney. After adjusting for level and type of disability, the analysis revealed an inverse relationship between the use of formal services for instrumental activities of daily living (shopping, housework, food preparation, etc.) and the level of available informal care. Persons with higher levels of informal care were found to make heavier use of medical and other professional services. Thus, there was evidence of the use of formal services to substitute for unavailable informal network support as well as specialisation and supplementation among people with access to a relatively high level of informal care.

A report compiled by the Lincoln Gerontology Centre at La Trobe University revealed different patterns in the recommendations made by Aged Care Assessment Teams for people living alone, compared to people who live with others (LGC 2002). Aged Care Assessment Teams are multi-disciplinary teams of health care professionals who assess the circumstances of people who may need to enter residential care (see Chapter 7). In 2000–01, clients living at home alone were more likely to be recommended for residential care (38.6%) than those living with others (34.1%) or a spouse only (29.2%). However, clients living alone at home were more likely to be recommended for low-level residential care (26.2%) than for high-level care (12.4%), which is thought to reflect psychosocial factors as well as physical dependency for people who live alone. Clients who were living with only their spouse at the time of assessment were more likely to be recommended for high level residential care (18.1%) than for low-level residential care (11.1%). Likewise, clients who lived with people in addition to, or other than, a spouse were more likely to be recommended for high-level residential care (18.5%) than for low-level residential care (15.6%) (LGC 2002: Table 17a). The authors suggest that ‘the protective effect of being married or living with a family member allows people to remain living in the community until their level of disability requires high-level care’ (LGC 2002:55).

Data collected in the 1998 ABS Survey of Disability, Ageing and Carers reveals some age-related patterns in the mixture of formal and informal sources of assistance reported by people with severe disability. While overall, 46% of this population group said that they received assistance only from informal carers, the proportion is substantially higher among people aged 25 to 64 years (58%), compared with the younger and older age groups (37% and 34% respectively) (Table 3.4).

Table 3.4: Type of assistance received by people with a severe or profound restriction living in households, 1998

Type of assistance	Age of person with a severe or profound restriction							
	0–24		25–64		65+		All ages	
	'000	Per cent	'000	Per cent	'000	Per cent	'000	Per cent
Informal only	72.8	37.4	257.1	58.3	110.1	33.8	440.0	45.7
Informal and formal	107.1	55.0	160.2	36.3	198.7	61.0	466.0	48.5
Formal only	*8.0	*4.1	*7.4	*1.7	11.5	3.5	26.9	2.8
Not applicable or none specified	*6.8	*3.5	16.5	3.7	*5.3	*1.6	28.7	3.0
Total	194.7	100.0	441.3	100.0	325.6	100.0	961.6	100.0

Source: AIHW analysis of 1998 ABS Survey of Disability, Ageing and Carers confidentialised unit record file.

Table 3.5: Main source of assistance received by people with a severe or profound core activity restriction living in households, 1998

	Under 65 years		65 years and over	
	Number ('000)	Per cent receiving assistance ^(a)	Number ('000)	Per cent receiving assistance ^(a)
Need for assistance				
One of ten daily activities ^(b)	633.4	99.6	324.6	99.6
More than one core activity	264.3	41.5	122.4	37.6
All three core activities	56.0	8.8	17.0	5.2
<i>Total severe or profound</i>	<i>636.0</i>		<i>325.6</i>	
Main source of assistance is a formal service provider				
Self-care	14.5	4.3	17.8	12.6
Mobility	28.6	6.8	22.2	8.6
Communication	18.0	13.6	—	—
Health care	49.8	16.3	95.4	46.6
Housework	18.6	7.6	60.0	27.3
Property maintenance	40.0	13.9	74.9	31.3
Paperwork	*9.0	*7.4	*5.1	*4.8
Meal preparation	*6.0	*5.2	23.7	20.0
Transport	18.9	6.6	22.8	10.4
Main source of assistance is an informal carer (co-resident and non-resident)				
Self-care	320.0	95.7	123.4	87.4
Mobility	391.8	93.2	235.4	91.4
Communication	114.4	86.4	25.5	100.0
Health care	255.5	83.7	109.2	53.4
Housework	225.4	92.4	160.1	72.7
Property maintenance	248.8	86.1	164.6	68.7
Paperwork	112.2	92.6	101.9	95.2
Meal preparation	109.6	94.8	94.6	80.0
Transport	265.8	93.4	196.1	89.6

(a) As a percentage of people of that age group who received assistance with that particular activity.

(b) Daily activities include three core activities (self-care, mobility and communication) plus health care, housework, property maintenance, paperwork, meal preparation, transport and guidance.

Source: AIHW 2000: Tables 19.2, A15.3.

Older people's relatively higher reliance on formal service providers to complement the care provided by informal carers relates largely to their use of health services and forms of domestic assistance. An estimated 47% of people aged 65 years or over in 1998 who had a severe or profound restriction had used formal services for health care, compared with just 16% of people aged under 65 years with this level of disability who had used health care services (Table 3.5). However, across all main categories of assistance, a higher proportion of both age groups nominated informal care as the main source of assistance.

Formal support services and their assistance to carers

In addition to direct care for clients, formal services provide indirect and direct assistance to carers. Care coordination and planning services such as Community Aged Care Packages help carers to access a range of professional and domestic service providers, and coordinate service delivery on behalf of their care recipients if necessary. Respite care is accessible through a range of programs including services under the Commonwealth-State/Territory Disability Agreement, the Home and Community Care Program, Community Aged Care Packages and Veterans' Home Care.

The expansion of the community care sector has seen developments in programs that specifically target the needs of carers (Boxes 3.1 and 3.2). Respite care is a particularly important area of service provision. In 1998, over one-third of primary carers reported that they had no fall-back carer, yet only an estimated 13% of primary carers had used respite care within the previous 12 months (AIHW 2001:301). There are many possible reasons for this low rate of use of respite care which may include difficulty accessing appropriate services. The National Respite for Carers Program, and increasing awareness of services through the operation of Commonwealth Carelink Centres throughout the states and territories (see Chapter 7), are specific recent responses to this issue.

Financial support for carers

Government pensions and allowances were the principal source of cash income for over one-half (56%) of primary carers and 40% of all carers in 1998. The most common type of government pension or benefit was a Family Allowance or Parenting Payment (23%), followed by the Age Pension (15%). Primary carers receiving the Age Pension accounted for about 70% of primary carers aged 65 years and over in 1998 (AIHW 2000:Table 16.6). Centrelink administers special purpose carer payments. In 1999, Domiciliary Nursing Care Benefit was subsumed into Carer Allowance, and Carer Payment replaced the Carer's Pension (Box 3.2).

Ongoing data development will enable comparisons of service use by carer availability for the wider population who receives disability and aged care services in the community. The redeveloped Commonwealth-State/Territory Disability Agreement (CSTDA) national minimum data set (see Box 8.4), for most service types, requires disability service providers to provide information about all service users during the year rather than just those who receive a service on a snapshot day. As well, there are five new items related to the presence of an informal carer who provides support to the service user. These items include existence of informal carer, whether the carer lives in the same household, the relationship between the carer and the service user, and the

age group of carer. The redeveloped collection thus gives new information on carers in Australia, in particular the relationship between formal services and informal care. Data from the 2002–03 CSTDA collection will be available in 2004.

Box 3.1: Commonwealth carer support programs

Commonwealth Carelink Centres

A network of Commonwealth Carelink Centres was established in 2001 to provide an information service to help put older Australians, people with a disability, and their carers in touch with a range of community, aged care and disability services. The network can be accessed by telephoning 1800 052 222, 65 shopfronts in 54 regions throughout Australia, over 90 access points such as free phones in rural and remote localities, or through the Carelink website, www.commcarelink.health.gov.au. During 2001–02, Centres responded to 89,295 requests for information (DoHA 2002b:142).

National Respite for Carers Program

The National Respite for Carers Program, announced in the 1996–97 Federal Budget, funds Commonwealth Carer Respite Centres, state/territory-based Commonwealth Carer Resource Centres, and a number of projects to assist carers of people with dementia, including the National Dementia Behaviour Advisory Service and the Carer Education and Workforce Training Project for dementia. The funding for this program is expected to increase from \$19 million in 1996–97 to an estimated \$88 million in 2002–03 (DoHA 2002a:15). Announcements in the first half of 2003 have allocated \$38.7 million of the 2002–03 Budget to Commonwealth Carer Respite Centres to boost respite services for carers (Andrews K, 2003a; Andrews K, 2003b; Andrews K, 2003c). Some of this funding will specifically target the needs of carers in rural and remote areas (\$13.6 million) and ageing carers caring for younger people with disabilities (\$3.6 million).

Commonwealth Respite Centres work closely with the Carer Resource Centre in their state or territory to provide comprehensive support for carers and access to carer information and training materials. Respite Centres are operated by a variety of community organisations to assist carers by acting as single contact points for information, and by organising, purchasing, or managing respite care assistance packages for carers. Respite care is available on an in-home or residential basis.

In 2001–02, the National Respite for Carers Program funded the 8 state- and territory-based Carer Resource Centres, 62 regional Carer Respite Centres, 423 regional respite services for carers and 3 national projects to assist carers of people with dementia. Commonwealth Carer Respite Centres assisted approximately 38,250 carers in 2001–02 and Commonwealth Carer Resource Centres helped 29,500 carers (DoHA 2002b:127–8).

Residential respite care

An important component of the carer support system, residential respite care provides assistance to carers facing other critical demands, their own health or personal needs, and the opportunity to take a holiday or participate in lifestyle activities. In 2001–02 47% of admissions to residential aged care were for respite care (Table A7.8; see Chapter 7 for further detail on recent trends in residential respite).

Box 3.2: Financial support for carers of people with an ongoing need for assistance

Carer Payment

The Carer Payment (Adult and Child) is an income-support benefit payable to people who, because of their caring responsibilities, are unable to engage in a substantial level of paid work but are not eligible for other income support payments such as the Age Pension. It is set at the same rate as the Age Pension, and is subject to the same income and asset tests. As at 31 December 2002, 71,210 people were receiving Carer Payment (Centrelink unpublished data). Because the Payment is for people who cannot earn an income because of full-time caring responsibilities, the majority of carers receiving Carer Payment are aged between 25 and 64 years (see Tables A7.5 and A7.7 for information on the distribution of Carer Payment in 2001–02).

Carer Allowance

The Carer Allowance (Adult and Child) is payable to co-resident carers who provide full-time care on a daily basis who need substantial amounts of care because of a disability, severe medical condition or age-related frailty (limited to two adults). The Allowance can be paid to carers in receipt of a government pension or benefit, including Carer Payment. It is not income or asset tested, but eligibility is determined according to an assessment of the care recipient's care needs. The level of the Allowance, adjusted on 1 January each year, is designed to help meet additional costs involved in caring for a person with a disability (see Tables A7.6 and A7.7 for information on the distribution of Carer Allowance in 2001–02).

3.4 Caring for children

Children need a great deal of care over many years and this care is usually provided by one or both of the child's parents. There is a range of situations, however, in which children are cared for by people outside of the immediate family and much of this care is provided informally. In the following section two types of informal care are discussed:

- informal substitute care which occurs when children, for various reasons, cannot live with their parents and live with carers in another home; and
- informal child care in which the child lives in the family home with one or both parents, but is sometimes cared for by others, regularly or irregularly, outside of formal care arrangements such as centres and pre-schools.

Informal substitute care

Substitute care refers to care that is provided to children and young people whose parents are unwilling, unable or otherwise deemed unsuitable to care for them. Substitute care by relatives has more favourable outcomes for children than care by non-relatives because it is more stable and provides continuity (Patton 2003). The provision of formal substitute care services in Australia is the responsibility of state and

territory governments and includes situations where the state or territory makes some form of financial payment for the cost of care. However, sometimes a child lives in a home other than that of their parents, but the state or territory government does not contribute to the cost of the care—this is informal substitute care. Families providing informal substitute care for children are potentially more vulnerable than those formally caring for children out-of-home because they are not offered the same level of financial or other forms of support.

As this type of care is provided outside of formal systems, there are few data available about its prevalence. In 1997 there were approximately 12,000 children aged 0–14 who were living with their grandparents but not their parents, and in 1996 there were 20,100 young people aged 15–17 living with relatives other than parents (ABS 1999c). However, these figures include children who have been placed in substitute care by the state which reimburses the costs of looking after these children. The ABS will publish next year more information on the number of grandparents providing care for their grandchildren from its 2003 Family Characteristics Survey.

Centrelink customer data show that, in December 2002, 26,415 people aged over 55 years received payments such as Family Tax Benefit to assist with the costs of raising children, but this group would include older parents as well as grandparent carers. The number of mature age recipients of this benefit grew by 27% in the two years from December 2000 (Wallace-Green 2003), suggesting that older people caring for children is becoming more common. There is also anecdotal evidence that suggests that informal substitute care has increased over the last decade, with the most common reasons for this being substance abuse, relationship breakdown and mental illness (Patton 2003).

Relatives, particularly grandparents, who unexpectedly have to resume parenting either formally or informally, often experience huge life change as a result of assuming full-time care, and this can be distressing. They may become socially isolated from their peers because of the demands of raising children and, as a result, lose important social support networks that they need as they age. Family relationships are also likely to be disrupted in these circumstances. Grandparents may feel a sense of loss for their child-free years. They may also have health concerns that make parenting more difficult. Overseas evidence suggests that relatives caring for children can face financial hardship in taking on the parenting role. Some kinship carers give up full-time employment to care for grandchildren, while others have to return to work from retirement to increase their income (Patton 2003).

Informal substitute carers provide a valuable service that deserves the support of the community. In 2003, the Council on the Ageing (COTA) conducted a series of forums on grandparents who care for their grandchildren. COTA will report to the Minister for Children and Youth Affairs on financial and legal issues facing grandparents in this situation and what support mechanisms grandparents need to assist them in their caring role.

Informal child care

Most families need someone else to look after their children at times, so that parents or guardians can work or do other things. Commonly it is grandparents (often grandmothers), (step) brothers or sisters, and other relatives including non-resident parents, who provide informal child care.

The ABS Child Care Survey provides data on the informal child care provided over a particular week for children aged under 12 years (ABS 2003d). The care was most commonly used for work-related reasons, personal reasons or was care that the parent felt was of benefit to the child. The data do not describe informal carers in detail, but measure how much child care is arranged in Australia, for whom, and who provided that care. This means that where children received care from more than one kind of informal carer in the survey week, they are counted more than once. For example, a child who received care from their grandmother and a neighbour will appear in both care by grandparents and care by other person categories.

Table 3.6: Weekly cost of informal care of children aged 0–11 years, 2002

Informal care provider	Cost of care per child					Total
	No cost	\$1–19	\$20–59	\$60–99	\$100 or more	
			('000)			
Child's grandmother/grandfather	581.0	2.4	7.0	0.6	0.8	591.6
Child's (step) brother/(step) sister	63.9	3.8	2.9	—	—	70.5
Child's non-residential parent	97.3	—	—	—	—	97.3
Child's other relative	102.4	2.2	3.3	1.2	2.6	111.6
Other people						
Family friend	115.7	7.6	11.9	2.3	3.3	140.8
Babysitter	6.2	15.3	20.6	3.6	1.1	46.8
Nanny	0.9	1.6	1.5	2.1	6.5	13.8
Neighbour	17.4	2.3	1.2	0	—	20.8
Other	6.4	1.7	1	0.3	0.6	10.1
<i>Total other people</i>	<i>144.7</i>	<i>26.1</i>	<i>36</i>	<i>8.4</i>	<i>10.7</i>	<i>227.2</i>
			Per cent			
Child's grandmother/grandfather	98.2	0.4	1.2	0.1	0.1	100.0
Child's (step) brother/(step) sister	90.6	5.4	4.1	0.0	0.0	100.0
Child's non-residential parent	100.0	0.0	0.0	0.0	0.0	100.0
Child's other relative	91.8	2.0	3.0	1.1	2.3	100.0
Other people						
Family friend	82.2	5.4	8.5	1.6	2.3	100.0
Babysitter	13.2	32.7	44.0	7.7	2.4	100.0
Nanny	6.5	11.6	10.9	15.2	47.1	100.0
Neighbour	83.7	11.1	5.8	0.0	0.0	100.0
Other	63.4	16.8	9.9	3.0	5.9	100.0
<i>Total other people</i>	<i>63.7</i>	<i>11.5</i>	<i>15.8</i>	<i>3.7</i>	<i>4.7</i>	<i>100.0</i>

Note: Children may appear in more than one category.

Source: Unpublished data from 2002 Child Care Survey.

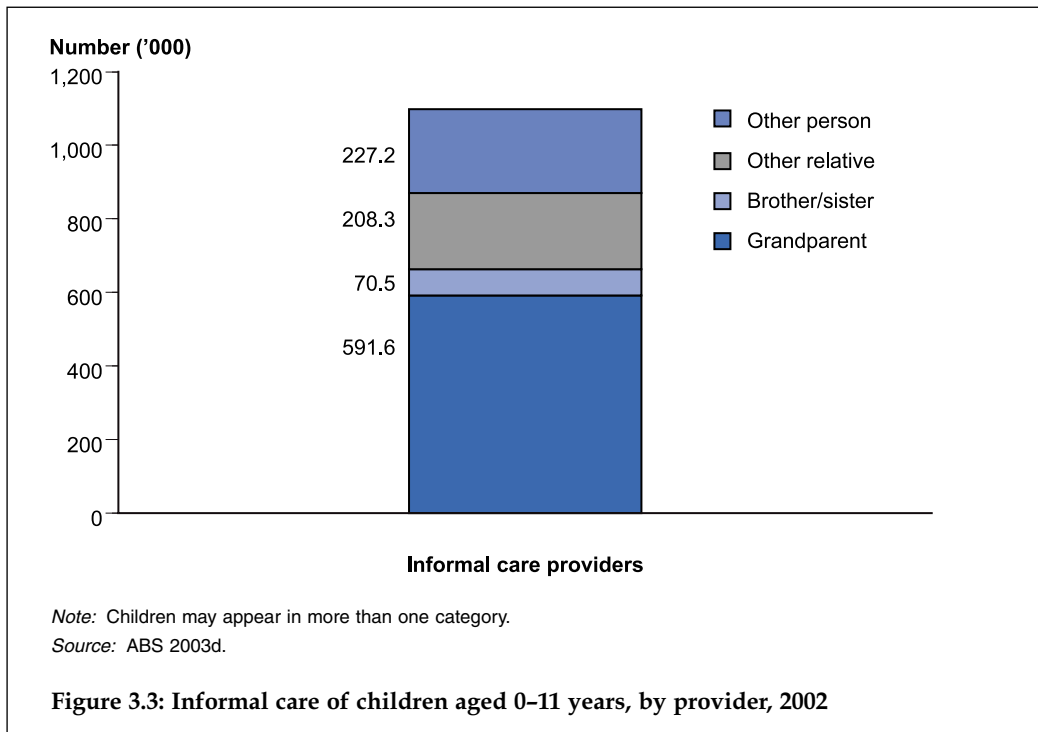
Most informal care in 2002 (89%) was unpaid (Table 3.6). For example, 98% of care by grandparents, 91% of care by (step) brother or sister and 84% of care by neighbours was done at no cost. Almost all of the remainder was paid for at minimal cost. The care by 'other people' category includes a mixture of carer types: care by other organisation, child looked after self, family friend, babysitter, nanny, neighbour, and other. A breakdown of this category reveals that almost all care by family friends and neighbours was free of charge, but the majority of care that nannies provided was paid for at market rates – almost half (47%) cost \$100 or more.

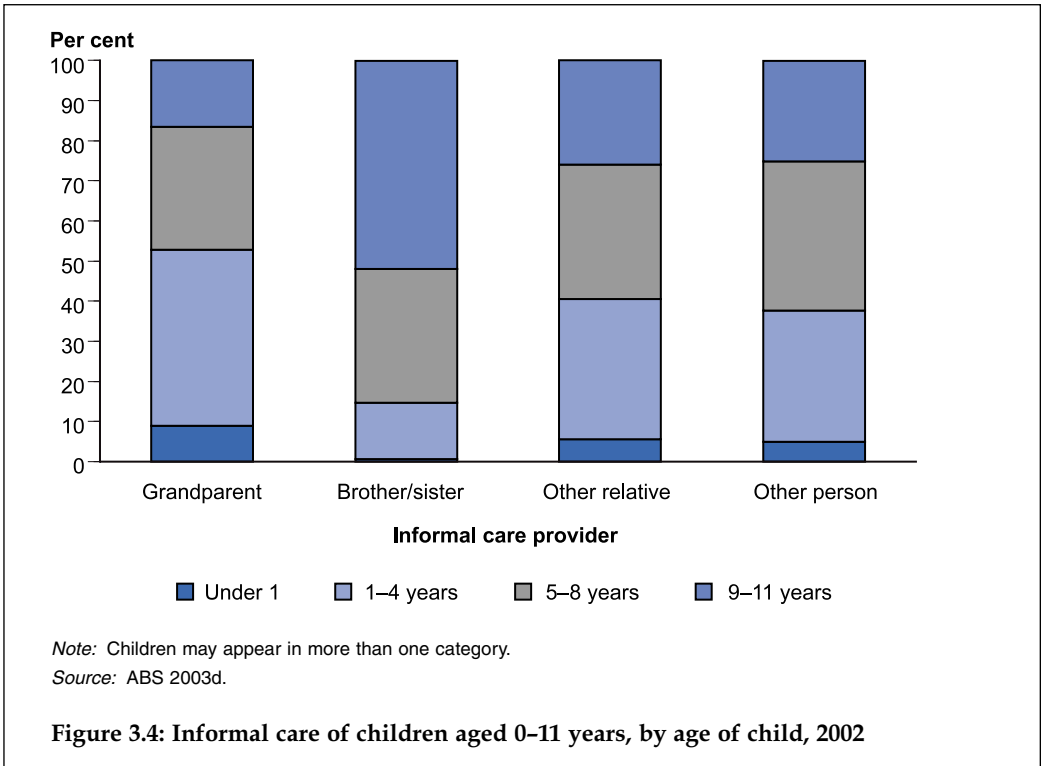
Informal child carers

This section describes who provided care for the 1,019,200 children using informal care, (either alone or in combination with formal care) – one-third (33%) of children aged under 12 years (ABS 2003d).

Over half of all care (58%) was provided by grandparents, 22% was provided by other people, 20% was provided by other relatives, and 7% was provided by brothers and sisters (Figure 3.3).

Over half (53%) of care by grandparents was for children aged under 5 years, with 9% being for babies aged less than 1 year (Figure 3.4). Care by other people and other relatives was less often for children aged under 1 year (5% and 6%) but more often for children aged 5 or over – 62% and 59% of children, respectively. Siblings most commonly cared for older children, with 52% of care being for children aged 9–11 years.

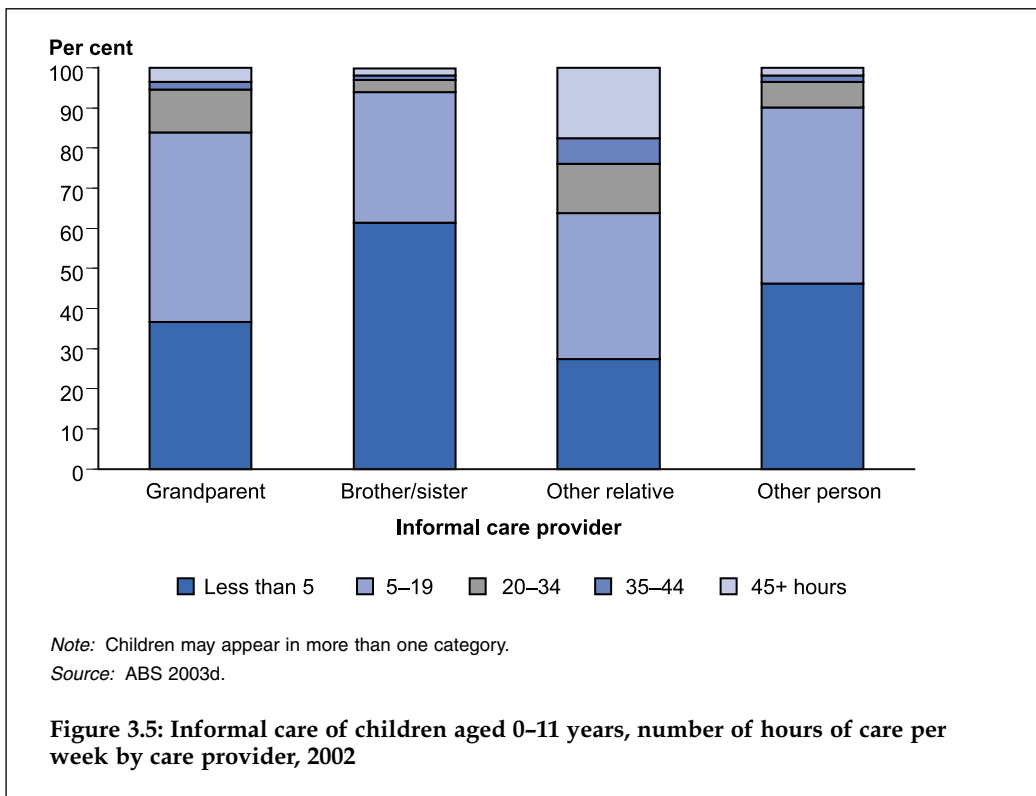




Amount and frequency of care provided

The number of hours of care per week varied between carers (Figure 3.5). Siblings and other people tended to provide fewer hours of care per week—for 19 hours or less in 94% and 90% of cases, respectively. In fact, 61% of (step) brother and sister care was for less than 5 hours per week. Grandparents also tended to care for shorter amounts of time, though some provided extensive care—in 11% of cases, children being cared for by grandparents were looked after for 20-34 hours per week. A quarter of care provided by other relatives (24%) was for 35 hours or more, which included care for 45 hours or more in 18% of cases.

Almost half (46%) of all children using informal care received care on 1 day a week, and a further quarter (25%) received care on 2 days a week. One in 10 children received informal care on more than 4 days a week.



Trends in informal child care provision

The number of children who used informal child care in Australia declined by 12.6% between 1993 and 2002 (Table 3.7). This fall coincided with increased accessibility of formal child care services—the total number of children using Commonwealth-supported child care services more than doubled between 1991 and 2002, from 262,200 to 623,900 (Table 6.12).

Prior to the 1999 child care survey, care by grandparents was not given its own category, so Table 3.7 has care by grandparents included in the 'other relatives' category. The biggest percentage reduction between 1993 and 2002 was in care by (step) brothers and sisters which halved (down by 56%) coinciding with a big expansion in outside school hours care services, the use of which doubled between 1993 and 2002. Care by other people also fell steadily over this time, down by 42%. Care by other relatives (including grandparents) peaked in 1999 at 884,100 children, before settling back to 766,400 children in 2002 (ABS Child Care Survey unpublished data).

Nevertheless, the number of children using informal care is greater than the number using formal care—just over three-quarters of a million are in formal care, compared with just over a million in informal care. Furthermore, just over half of all children (51%) did not use any form of child care in the survey reference week.

Table 3.7: Number of children aged 0–11 years using informal care, 1993 to 2002 ('000)

Informal care provider	1993	1996	1999	2002	% change
					1993 to 2002
Brother/sister	159.1	165.1	74.2	70.5	–55.7
Other relative ^(a)	707.1	726.0	884.1	766.4	13.1
Other person	389.1	318.0	294.0	227.2	–41.6
Total children using informal care	1,166.2	1,128.3	1,162.1	1,019.2	–12.6

(a) Includes grandparents.

Source: ABS Child Care Surveys, 1993, 1996, 1999, 2002.

Box 3.3: ABS 1998 Survey of Disability, Ageing and Carers: informal assistance and carers

Informal assistance

Informal assistance is unpaid help or supervision that is provided to a person with one or more disabilities or persons aged 60 years or over living in households. It includes only assistance that is provided for one or more of the specified tasks comprising an activity because of a person's disability or because they are older.

Carer

A carer is 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 or over). The assistance must be ongoing, or likely to be ongoing, for at least 6 months. Assistance to a person in a different household relates to 'everyday types of activities', without specific information on the activities. Where the care recipient lives in the same household, the assistance is for one or more of the following activities: communication; health care; housework; meal preparation; mobility; paperwork; property maintenance; self-care; transport.

Primary carer

A primary carer is a person of any age who provides the most informal assistance, in terms of help or supervision, to a person with one or more disabilities. The assistance must be ongoing, or likely to be ongoing, for at least 6 months and be provided for one or more of the core activities (communication, mobility and self-care).

Source: ABS 1999a:65, 71.

3.5 Caring for people of all ages with a disability

This section examines the role of informal carers of people of all ages with a disability who require assistance with certain activities (see Chapter 8 for a discussion of the conceptualisation of disability in the International Classification of Functioning, Disability and Health). Material in this section draws largely on the results of the 1998 ABS Survey of Disability, Ageing and Carers and the findings of other key studies of informal care. It focuses on primary carers, who individually provide the most help to a person who needs assistance. The section begins with a demographic profile of primary carers. This is followed by a description of the needs of care recipients and the translation of those needs into caring activity. The section concludes with a discussion

of the impact that caring has on carers. Detailed information on primary carers and their care recipients is collected in national surveys of disability, ageing and carers conducted by the ABS (1988, 1993, 1998).

Carers and caring

In the context of disability services and aged care, the term 'carer' loosely applies to anyone engaged in caring for a person in the community who has a disability or age-related health condition. However, the literature distinguishes 'principal' or 'primary' carers as those who individually provide the most informal assistance to a person. While definitions vary and some are more inclusive than others, most embody aspects of care intensity and duration. The definition of primary carer used here is consistent with that employed in the 1998 ABS Survey of Disability, Ageing and Carers, hereafter referred to as 'the ABS survey'. Accordingly, a primary carer is the main provider of assistance with the core activities to someone with a disability (Box 3.3). This definition and the method used to identify carers in the 1998 ABS survey has generated detailed national data on a well-defined group of carers.

Box 3.4: ABS 1998 Survey of Disability, Ageing and Carers: core activities and associated level of restriction

Disability

For ABS survey purposes, a person has a disability if he/she has a condition that restricts everyday activities and lasts for 6 months or longer. Impairments include, but are not limited to, loss of sensory perception (sight, hearing, speech), chronic pain, respiratory conditions, loss of limb or motor function, learning difficulties, intellectual impairment, mental illness, disfigurement and deformity, and disorders of the nervous system.

Core activities are:

- self-care – bathing or showering, dressing, eating, using the toilet, and managing incontinence;*
- mobility – moving around at home and away from home, getting into or out of a bed or chair, and using public transport; and*
- communication – understanding and being understood by others: strangers, family and friends.*

A core activity restriction may be

- profound – unable to perform a core activity or always needing assistance;*
- severe – sometimes needing assistance to perform a core activity;*
- moderate – not needing assistance, but having difficulty performing a core activity; or*
- mild – having no difficulty performing a core activity but using aids or equipment because of disability.*

Note: In the text of this chapter, a 'severe or profound core activity restriction' is sometimes referred to as a 'severe or profound restriction'.

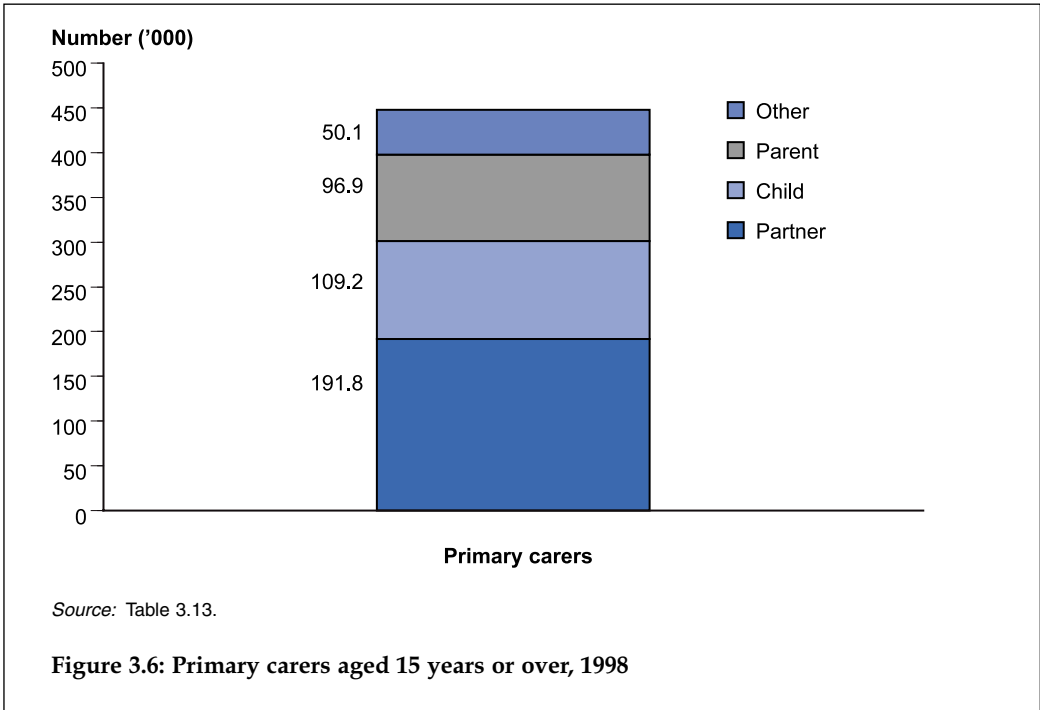
Source: ABS 1999a:66.

According to the ABS survey, 19% of all informal carers of people with a disability were primary carers. Primary carers assist one or more persons with a severe or profound core activity restriction who always or sometimes need assistance with the core activities of self-care, mobility and communication (Box 3.4). Primary carers typically function within an extensive network of family and social exchanges (Howe et al. 1997). Many are close relatives of the person they care for and the assistance they provide is an extension of family relationships. Carers distinguish their role as being 'beyond that of wife, husband, mother, father, daughter, son, sibling and friend' (Schofield et al. 1997). They feel a deeper sense of responsibility that is associated with caring for someone with a disability or long-term health condition.

Who are carers of people with a disability?

According to the ABS survey, approximately 450,900 people were informal primary carers in 1998. In 2002, approximately 2.5 million people would have performed informal caring, excluding child care, including an estimated 490,700 primary carers.¹

In 1998, 43% of primary carers were the partners of their care recipient. Children gave care to their parents (24% of primary carers) and parents gave care to their children (22%). Around 11% of primary carers were other relatives or friends (Figure 3.6).



1 Based on 1998 age-specific prevalence rates, by sex, of carers and primary carers applied to ABS estimates of the population as at 30 June 2002.

Primary carers are predominantly women—in 1998, 70% of primary carers were female. Among primary carers aged 15 years or over in 1998:

- 43% were spouses or partners of the care recipient;
- 44% of spouse or partner carers were male;
- 89% were immediate family of the care recipient (partner, parent or offspring);
- 69% of primary carers aged 60 or over were caring for a spouse or partner;
- 79% lived with their care recipients; and
- 67% were aged between 25 and 59 and 29% were aged 60 or more.

The person a carer is most likely to be caring for depends largely on the carer’s age (Figure 3.7). Of co-resident primary carers aged 15–34 years in 1998, 44% were parents caring for a child with a disability. Over one-quarter (28%) of this age group were people caring for their spouse or partner. This latter proportion is higher among carers in older age groups: 36% of carers in the 35–64 year age band and 75% of carers aged 65 or older were caring for a spouse or partner. Only in the 35–64 year age band did children commonly provide care to their parents—about 1 in 3 carers (31%).

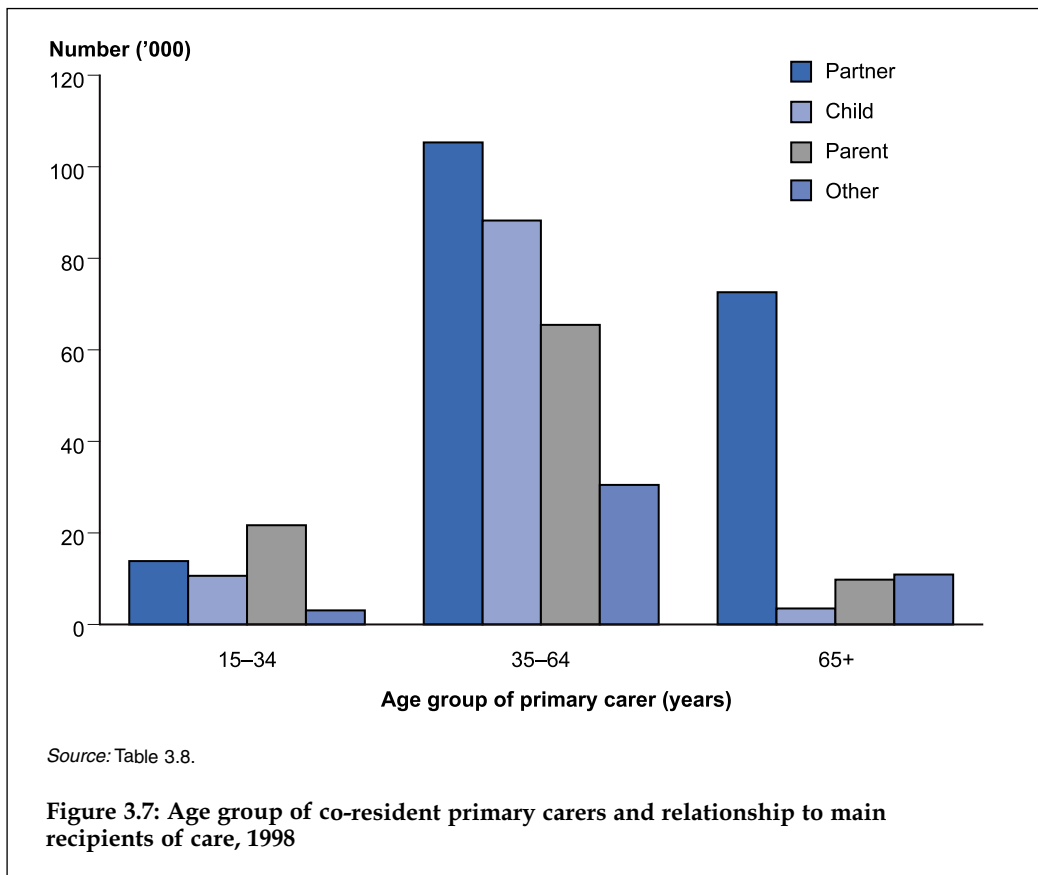
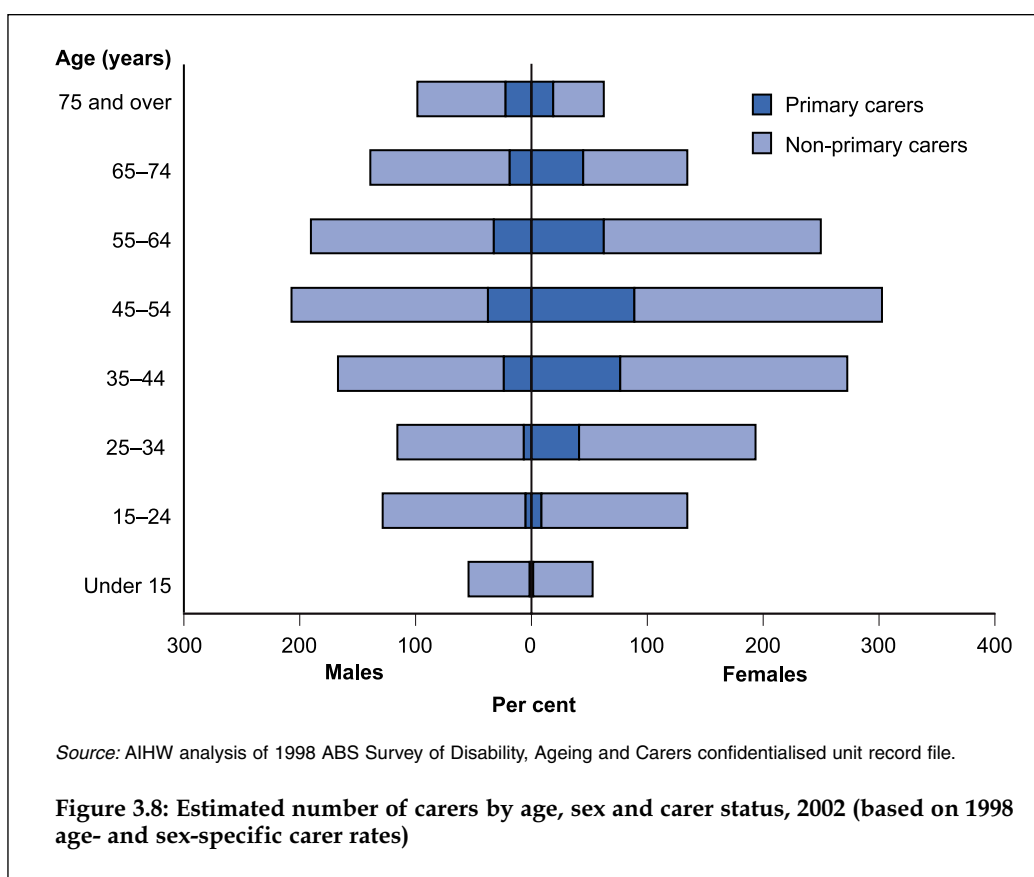


Table 3.8: Relationship of co-resident primary carers to main recipients of care, 1998

Age group of primary carer (years)	Main recipient of care				Total
	Partner	Child	Parent	Other	
	('000)				
15–34	13.8	10.6	21.6	*3.0	49.0
35–64	105.3	88.2	65.5	30.4	289.6
65+	72.6	*3.5	9.7	10.9	96.7
Total	191.8	109.2	96.9	50.1	447.9
	Per cent				
15–34	28.2	21.6	44.1	*6.1	100.0
35–64	36.4	30.5	22.6	10.5	100.0
65+	75.1	*3.6	10.0	11.3	100.0
Total	42.8	24.4	21.6	11.2	100.0

Source: ABS 1998.



Female carers were more likely than male carers to be in a primary caring role at all ages except 75 years and over (Figure 3.8).

The peak age group for women to be in a caring role is 45–64 years. In this age group, around 24% of women in 1998 were carers and approximately 7% were primary carers. Women aged between 35 and 64 years comprised 47% of all primary carers in 1998. Men were more likely to be found in a caring role at older ages: 22% of men aged 75 or over were carers and 5% of men in this age group were primary carers.

Overall, 79% of primary carers aged 15 years or over lived with their care recipient. Most partner and parent primary carers lived with their care recipient. Although other categories of primary carers were less likely to reside with their care recipient than spouse, partner or parent carers, 46% of children (including adult children) caring for a parent and 40% of other relative or friend primary carers were co-resident carers.

Age and co-residency of carers and care recipients

In 1998, one in five primary carers were caring for two or more people with a disability. In these cases, identification of the care recipient who received the most assistance as the ‘main care recipient’ allows a cross-reference of care recipient details with demographic information for all primary carers. Two-thirds of primary carers in 1998 had a main recipient of care aged 45 years or over (Table 3.9).

Over one-half of primary carers aged 25–44 (32% of all primary carers) had a main recipient of care aged under 45 years, and 23% were caring for someone aged 65 or over. This distribution represents a mix of parent, spouse or partner, and adult offspring carers in this age group. In the 45–64 age group, 36% of primary carers were caring for a person also aged 45–64 and 44% cared for a person aged 65 or over, reflecting a mix of mainly partner or spouse, and adult offspring carers. Older primary carers, aged 65 or over, were predominantly caring for another older person (82%); 17% of older carers were caring for a person aged 25–64 years. This group of primary carers consists mostly of spouses or partners, or parents of the main care recipient.

Table 3.9: Age of co-resident and non-resident primary carers ('000), by age of main care recipients, ^(a) 1998

Age of care recipient	Age of primary carer										Total
	15–24		25–44		45–64		65+		All ages		
	Co-res	Non-res	Co-res	Non-res	Co-res	Non-res	Co-res	Non-res	Co-res	Non-res	
Under 15	**0.6	—	51.2	—	10.4	—	**0.9	—	63.1	—	63.1
15–24	**2.2	—	*6.9	**0.5	*8.1	**1.3	—	—	17.2	**1.8	19.0
25–44	*4.9	—	30.7	**2.8	15.8	*3.1	*5.5	**0.9	56.9	*6.8	63.7
45–64	*3.9	*0.8	10.9	*6.3	65.6	*3.2	10.0	**0.3	90.5	10.7	101.2
65+	—	**1.0	9.6	25.5	44.0	41.9	70.9	*8.1	124.5	76.5	201.0
Total	11.6	**1.8	109.2	35.1	143.9	49.6	87.4	*9.3	352.2	95.8	447.9

(a) Each primary carer may care for more than one person, but nominates only one as the main care recipient.

Source: AIHW 1999: Table A7.6.

Non-resident carers were more likely than co-resident carers to have a main care recipient aged 65 years or over: 80% of non-resident primary carers cared for an older Australian, compared with 35% of co-resident carers. Co-resident carers comprised 76% of primary carers aged 25–44 years and 74% of primary carers aged 45–64 years. In contrast, 90% of primary carers aged 65 years or over lived with their care recipient, reflecting the predominance of spouses and partners among older carers (as seen in Figure 3.7).

Of primary carers who had a main care recipient aged 65 or over, 17% (35,100) were aged 25–44 years and 43% (85,900) were aged 45–64 years. Thus, around 60% of primary carers who cared for an older person were of working age and 56% of this group were non-resident carers.

The reasons for taking on a primary caring role

The reasons for caring for someone with a disability are undoubtedly complex. The ABS Survey of Disability, Ageing and Carers allowed carers to give one or more reasons for taking on a primary caring role. Frequent responses included family responsibility (57%), a desire to provide the best possible care (44%), and emotional obligation (39%) (Table 3.10). Individuals often care *for* people because they care *about* them. It is also evident that many individuals feel a responsibility to care for family members – factors such as there being no choice, no other family or friends willing or able to care, and no other care being available or affordable, also figured in decisions to care.

There were some differences in responses depending on the relationship of the carer and care recipient. Spouse and parent carers exhibited similar response patterns. They were more likely than offspring carers to report a desire to provide the best possible care (53% and 49% versus 33%). Fifty per cent or more of each relationship group cited family responsibility as a motivating factor and this was the most frequent response of offspring carers (in 72% of cases). Around half of other relative or friend carers cited family responsibility (51%) and emotional obligation (44%) as prime motivating factors.

Table 3.10: Reasons for primary carers (15 years and over) taking on the caring role,^(a) 1998 (per cent)

Reasons	Relationship to main recipient of care				Total
	Partner	Offspring	Parent	Other friend or relative	
Can provide better care	52.6	33.3	49.3	24.3	43.9
Family responsibility	49.8	72.4	58.6	50.5	57.4
No other family or friends available	23.5	30.1	17.8	34.6	25.2
No other family or friends willing	11.1	18.6	14.0	21.1	14.7
Emotional obligation	36.8	43.2	35.2	44.1	38.8
Cost of alternative care	26.4	16.7	21.6	*11.7	21.3
No other care arrangements available	9.2	8.9	16.9	*7.4	10.5
No choice	21.2	13.7	35.2	*13.5	21.2
Other reason/not stated	9.4	*7.9	16.4	*14.1	11.0
Total carers ('000)	192.1	111.7	94.4	49.7	447.9

(a) Carers may report more than one reason.

Source: AIHW analysis of 1998 ABS Survey of Disability, Ageing and Carers; ABS 1999a:Table 36.

While the literature cites examples of intense caring in the absence of love and affection, relationship history is an important determinant of the impact and outcome of caring for both carer and care recipient (Cahill 1999). Cahill's work suggests that wives tend to perceive caring as a natural extension of their marriage relationship, whereas daughter (or daughter-in-law) carers had more complex reasons. They more often felt that external factors meant that they had no real choice but to take on the role of primary carer: 'Their motivation seemed shaped by several different structural and contextual constraints including gender, labour market positioning, the availability of others within the kinship network, and commitment to other family care responsibilities' (Cahill 1999:243).

The Later Life Families Study in 1996 examined intergenerational exchange in interviews of 721 people aged between 50 and 70 years. The help that is given in families depends on a range of factors (Millward 1998). Important among these are the structural dimensions of family cohesion, such as family structure, proximity of relatives and the frequency of contact between family members. Interpersonal factors such as satisfaction with the quality of the parent-child relationship, and beliefs about intergenerational obligations, were also important predictors of the exchange of assistance. It is likely that such factors also impact on the propensity of individuals to take on the more extensive role of primary carer. Many Australians accept that adult children have some responsibilities and obligations for the wellbeing of their elderly parents, but this acceptance is by no means universal, unequivocal or without qualification (de Vaus 1996). There was a strong acceptance that adult children should keep in contact with older parents, do things with them wherever possible, and help them where needed, but not at any cost. Few people agreed that adult children should be prepared to have elderly parents live with them, that they should live near parents so that they can help out or that a daughter should give up her job to care. There was considerable variation in the preparedness to take on such extensive caring.

The type of assistance given by carers

Just over 1,000 carers who took part in the 1999 National Survey of Carer Health and Wellbeing (CAA 2000) volunteered information on how they spent time on caregiving activities. They broadly divided caring time into:

- direct personal care (34.3%);
- support activities such as organising health services, transport, financial management, laundry and meal preparation (30.6%); and
- supervision to prevent self-harm and harm to others, emotional support and companionship, and arranging activities for the development of children with certain disabilities (35.1%).

For a carer to be identified as a primary carer in the 1998 ABS survey, they must have been providing ongoing assistance to their care recipient(s) with at least one of the three core activities of self-care, mobility and communication. Results show that over 60% of primary carers helped their care recipients with self-care tasks such as dressing, bathing, using the toilet and managing incontinence; three-quarters (74%) helped with mobility; and just under half (45%) assisted in communication (Table 3.11).

Table 3.11: Primary carers (5 years and over) who assist with core activities of daily living,^(a) 1998

	Age of main recipient of care ^(b)								All ages	
	<15		15–44		45–64		65+			
	'000	%	'000	%	'000	%	'000	%	'000	%
Whether carer usually assists with self-care										
Usually assists	60.5	74.0	68.1	45.4	60.7	66.6	92.0	73.4	281.3	62.8
Does not usually assist	21.2	26.0	81.9	54.6	30.4	33.4	33.2	26.6	166.8	37.2
<i>Total</i>	<i>81.7</i>	<i>100.0</i>	<i>150.0</i>	<i>100.0</i>	<i>91.1</i>	<i>100.0</i>	<i>125.2</i>	<i>100.0</i>	<i>448.1</i>	<i>100.0</i>
Whether carer usually assists with mobility										
Usually assists	40.3	49.3	119.3	79.5	71.8	78.8	101.9	81.4	333.3	74.4
Does not usually assist	41.4	50.7	30.7	20.5	19.3	21.2	23.3	18.6	114.8	25.6
<i>Total</i>	<i>81.7</i>	<i>100.0</i>	<i>150.0</i>	<i>100.0</i>	<i>91.1</i>	<i>100.0</i>	<i>125.2</i>	<i>100.0</i>	<i>448.1</i>	<i>100.0</i>
Whether carer usually assists with communication										
Usually assists	48.7	59.6	76.8	51.2	26.5	29.1	48.5	38.7	200.5	44.7
Does not usually assist	33.0	40.4	73.2	48.8	64.7	70.9	76.7	61.3	247.6	55.3
<i>Total</i>	<i>81.7</i>	<i>100.0</i>	<i>150.0</i>	<i>100.0</i>	<i>91.1</i>	<i>100.0</i>	<i>125.2</i>	<i>100.0</i>	<i>448.1</i>	<i>100.0</i>

(a) See Box 3.4.

(b) Where a primary carer provides assistance to more than one person the person who receives the most care is called the main care recipient.

Source: AIHW analysis of 1998 ABS Survey of Disability, Ageing and Carers confidentialised unit record file.

Some differences appear with respect to the age of the main care recipient. For example, higher proportions of primary carers with young (under 15) and old (65 or over) care recipients helped with self-care than carers of people in the middle age groups, whereas primary carers with younger care recipients were less likely to report assisting with mobility. Relatively more primary carers with care recipients aged under 15, or 15–44 years, reported assisting in communication than carers of middle-aged and older people. To some extent, these results reflect the predominant main disabling conditions of the different age groups (see Box 3.5). Primary carers were also the main providers of assistance with higher level activities such as health care, shopping, meal preparation, housework and paperwork. Few people with a severe or profound core activity restriction living in the community in 1998 relied solely on formal providers, but almost half received assistance from informal carers as well as formal service providers.

Who receives the caring?

Estimates based on results from the 1998 ABS Survey of Disability, Ageing and Carers suggest that approximately 3.7 million people with a disability, as broadly defined in the survey, were living in households in 2002 (Table 3.12). However, neither disability nor advanced age automatically implies a need for assistance. According to the survey, 43% of people with a disability, and 54% of older persons (65 years or over) living in households had no need for assistance beyond that which people routinely exchange (ABS 1999a: Tables 12 and 23). Among the estimated 3.7 million people with a disability in the community, approximately 1 million, or 5.4% of the household population, always or sometimes required assistance with core daily activities because of a severe or profound level of restriction. People aged 65 or over accounted for an estimated 35% (369,000) of the household population with a severe or profound restriction in 2002. Of the remainder, around 30% (316,700) were aged 45–64 years; 21% (221,900) were aged 15–44 years and approximately 14% (146,900) were children under the age of 15 (Table 3.12).

Table 3.12: Estimated number of people with a disability living in households, 2002^{(a)(b)}

Age/sex	Profound or severe core activity restriction		All with a disability	
	'000	Per cent of age group	'000	Per cent of age group
Males				
0–14	99.2	4.9	197.6	9.7
15–44	106.6	2.5	526.2	12.2
45–64	150.2	6.5	645.5	28.0
65+	135.1	12.2	548.4	49.6
<i>Total</i>	<i>491.1</i>	<i>5.0</i>	<i>1,917.7</i>	<i>19.7</i>
Females				
0–14	47.8	2.5	105.9	5.5
15–44	115.2	2.7	462.2	10.8
45–64	166.7	7.3	624.3	27.2
65+	233.1	16.3	624.1	45.1
<i>Total</i>	<i>562.8</i>	<i>5.7</i>	<i>1,816.5</i>	<i>18.3</i>
Persons				
0–14	146.9	3.7	303.4	7.6
15–44	221.9	2.6	988.8	11.5
45–64	316.7	6.9	1,269.3	27.6
65+	369.2	14.8	1,171.3	47.0
Total	1,054.7	5.4	3,732.8	19.0

(a) ABS preliminary estimates of total population as at 30 June 2002.

(b) Based on 1998 prevalence rates: people living in households who reported a severe or profound core activity restriction, or any disability, as a proportion of the survey population.

Source: AIHW analysis of ABS 1998 Survey of Disability, Ageing and Carers Confidentialised Unit Record File.

Prevalence and nature of severe or profound disability in the household population

Rates of severe or profound disability are quite low in the household population aged under 65 years and are similar for males and females, except at very young ages where males aged 5–14 years experience a higher rate of severe and profound core activity restriction than females (AIHW 2000:Table 12.1). Rates of severe and profound restriction among people of both sexes aged 65 or over and living in households are double those of the 45–64 age group. At older ages, women were more likely to report a severe or profound restriction than men (16% versus 12%), owing in part to the older age structure of the female population in this age group. Although 65% of people with a severe or profound restriction who are currently living in the community are aged under 65 years, high rates of severe and profound restriction at older ages in a rapidly ageing household population have implications for future needs for assistance in the community.

The ABS survey collected information on a possible array of activity restrictions and disabling conditions for each person with a disability and asked care recipients to identify the disabling condition and consequent activity restriction that caused most problems in everyday life, the so-called 'main disabling condition' and 'main activity

restriction'. The need for assistance is a complex function of many factors that is rarely explained by just one medical condition or type of restriction (see Chapter 8 for a full discussion of the conceptualisation of disability). However, it is reasonable to assume that conditions and restrictions underlying the most serious or frequently encountered problems are closely associated with the nature and intensity of care. Information on the prevalence of disabling conditions among all people with a severe or profound restriction can be found in Chapters 7 and 8 and in other AIHW publications (see, for example, AIHW 2001:263–4; 2000:Tables 14.5, 14.6). The main interest here is on disabling conditions and restrictions in people with a primary carer, who represent a subset of all people with a severe or profound restriction. The main disabling condition and main activity restriction recorded in survey data can be determined for people who had a co-resident primary carer. Although this precludes a description of care recipient characteristics for people with a non-resident carer, the profiles presented here give an insight into the nature of caring, hence its potential impact on primary carers.

Main disabling conditions and main restrictions in people with a co-resident primary carer

People with a co-resident primary carer in 1998 reported a diverse range of main disabling conditions so that, individually, each condition accounts for a low proportion of care recipients. Main disabling conditions in care recipients with a co-resident carer vary according to age, with markedly higher prevalence of intellectual and developmental disorders in young care recipients and a predominance of musculoskeletal disorders in the older age groups (Box 3.5). In terms of main activity restrictions, chronic, recurring pain or discomfort affected 5% or more care recipients in every age group. Restriction in physical activities or work was a main restriction for 5% or more care recipients in all but the youngest age group, 0–14 years. Age-related patterns are evident for certain types of main restriction. Learning and speech difficulties and mental illness were more common main restrictions in the younger age groups of care recipients (0–14 and 15–44) in 1998. Incomplete use of feet or legs was a common main restriction in care recipients aged 15 or over with a co-resident carer, and was particularly prominent in the older age groups of care recipients.

These results do not reflect the prevalence of certain conditions and restrictions among people with a primary carer, since each condition and type of restriction can also be reported as secondary to the main condition or restriction. Rather, they highlight the types of conditions and restrictions that care recipients associate with the problems that they frequently encounter.

Need for and receipt of assistance

Within the 1998 household population:

- 958,000 people with a severe or profound core activity restriction reported a need for assistance with at least one of ten daily activities (see Boxes 3.3, 3.4) and two-thirds of these people were aged under 65 years;
- 386,700 people with a severe or profound restriction reported a need for assistance with more than one core activity; and
- 73,000 people required assistance with all three core activities of daily living (AIHW 2000:104–6).

Box 3.5: ABS 1998 Survey of Disability, Ageing and Carers: care recipient main disabling conditions and main restrictions

The 'main disabling condition' is the condition reported by each care recipient to be associated with most of the problems that he or she experienced. The 'main restriction' is the area of activity that caused most problems for each care recipient. Main disabling conditions and main restrictions are listed below if they were recorded for 5% or more care recipients, by age, with a co-resident primary carer in 1998 (358,200 care recipients). Main restriction categories of memory loss, reading difficulty and incontinence were excluded from the analysis due to survey data limitations.

Care recipients aged under 15 years

Main disabling conditions: cerebral palsy; attention deficit disorder or hyperactivity; mental retardation or intellectual disability; autism and related disorders; other developmental disorders.

Main restrictions: slow at learning or understanding; speech difficulties; mental illness; incomplete use of arms or fingers; chronic, recurring pain or discomfort.

Care recipients aged 15–44 years

Main disabling conditions: back problems (dorsopathies); mental retardation or intellectual disability; cerebral palsy; Down syndrome.

Main restrictions: chronic, recurring pain or discomfort; slow at learning or understanding; restriction in physical activities or work; incomplete use of feet or legs; incomplete use of arms or fingers; nervous or emotional condition; mental illness; loss of hearing.

Care recipients aged 45–64 years

Main disabling conditions: back problems (dorsopathies); arthritis and related disorders; other diseases of the nervous system including transient ischaemic attack; stroke.

Main restrictions: chronic, recurring pain or discomfort; restriction in physical activities or work; incomplete use of feet or legs; incomplete use of arms or fingers; mental illness.

Care recipients aged 65 or over

Main disabling conditions: arthritis and related disorders; stroke; back problems (dorsopathies); sight loss.

Main restrictions: incomplete use of feet or legs; restriction in physical activities or work; chronic, recurring pain or discomfort; loss of sight; breathing difficulties; incomplete use of arms or fingers; loss of hearing; difficulty gripping or holding things.

Source: AIHW analysis of 1998 ABS Survey of Disability, Ageing and Carers confidentialised unit record file.

People under 65 with a severe or profound restriction were more likely than older people to require assistance with the three core activities (9% versus 5%). Almost one in four children aged under 15 years with such restriction needed help with three core

activities (AIHW 2000:106). Differences in the type of assistance received by younger and older people with severe or profound restrictions reflect constraints related to predominant disabling conditions and the circumstances of different stages of life.

Those in need of assistance because of severe or profound activity restriction typically received help from a combination of formal services and informal carers, mainly family and friends. Unpaid informal carers were the main source of all types of assistance for people with severe and profound restrictions living in the community. For persons with a primary carer, formal services were often used to supplement the assistance provided by the carer and provide direct carer support. In cases where a primary carer was not available, formal services might be accessed to complement more casual forms of assistance from informal carers by substituting some forms of care that would otherwise be performed by a primary carer (Howe & Schofield 1996). In this context, formal services include those funded by government welfare programs, and privately organised for-profit and not-for-profit services, including volunteer organisations.

Of people who received assistance from a co-resident primary carer in 1998, approximately 65% needed help at times with five to nine activities of daily living, 60% always needed help with up to four daily activities and a further 27% always needed help with five or more activities (Table 3.13). Youth and old age can compound the need for assistance as seen in similar proportions of the youngest and oldest age groups reporting a constant need for help with five or more activities (40% and 31% respectively). The next section examines in greater detail the characteristics of people who provide this on going care and the impact of the caring role on their lives.

Table 3.13: Main care recipients^(a) with a co-resident primary carer,^(b) number of daily activities for which assistance was needed, 1998

	Age of main care recipient									
	0–14		15–44		45–64		65+		Total	
	'000	%	'000	%	'000	%	'000	%	'000	%
Number of activities for which assistance was needed										
1–4	32.7	52.2	19.6	25.4	29.2	31.9	24.6	19.6	106.0	29.8
5–9	27.9	44.5	50.0	64.9	60.4	66.0	94.6	75.5	232.8	65.3
10+	—	—	*4.7	*6.1	**0.7	**0.8	*5.2	*4.2	10.6	3.0
Not applicable	**2.1	*3.4	**2.8	*3.6	**1.2	**1.3	**0.8	**0.7	*6.9	*2.0
Total	62.7	100.0	77.0	100.0	91.5	100.0	125.2	100.0	356.4	100.0
Number of activities for which assistance was always needed										
1–4	28.7	45.7	43.6	56.6	62.2	68.0	77.6	62.0	212.1	59.5
5–9	19.9	31.7	15.8	20.6	15.8	17.2	35.4	28.3	86.9	24.4
10+	*5.2	*8.2	**2.2	**2.9	—	—	*3.1	*2.4	10.4	2.9
Not applicable	*9.0	*14.3	15.3	19.9	13.5	14.8	*9.1	*7.3	47.0	13.2
Total	62.7	100.0	77.0	100.0	91.5	100.0	125.2	100.0	356.4	100.0

(a) In cases where a carer provided assistance to more than one person, the care recipient who received the most care was designated the main care recipient (i.e. table does not report on all care recipients).

(b) The 1998 ABS survey collected information on the needs of all people with a disability, but these can be reliably associated with an informal carer only when the carer is a co-resident primary carer (see Box 3.3 for a definition of primary carer).

Source: AIHW analysis of 1998 ABS Survey of Disability, Ageing and Carers confidentialised unit record file.

Impact of the caring role

Many factors influence the impact of the caring role on carers, including the personal characteristics and circumstances of caregiver and receiver, the nature and strength of their relationship, and the level of social support available to them.

Caring intensity varies according to the severity and nature of activity restrictions and age of the care recipient, living arrangements, availability of secondary carers and access to affordable formal support services. In 1998, informal caring occupied one in three primary carers aged 15 years or over for 40 or more hours per week (Table 3.14). On average, older carers reported spending more time caring than younger carers, with one-half of primary carers aged 65 or over indicating that they performed caring activities for 40 hours or more per week. The higher caring load among older carers is associated with a higher rate of co-residency. Co-resident primary carers report higher caring loads on average than non-resident carers.

The constancy and time consuming nature of long-term caring have been cited as specific causes of carer stress (CAA 2000:30). Three-quarters of primary carers in 1998 had spent at least 5 years in the caring role, and 40% had been caring for at least 10 years (AIHW 2000:Table 16.4). Among those caring for a person aged 15 or over, 177,700 primary carers could not leave their main care recipient for more than a few hours without supervision and 63,800 carers could not leave their care recipient unattended for an hour or more (ABS 1999a:Table 33).

Table 3.14: Primary carers (15 years and over): hours of caring for main care recipients,^(a) 1998

	Amount of time per week									
	<20 hours		20–39 hours		40+ hours		Not stated		Total	
	'000	%	'000	%	'000	%	'000	%	'000	%
Co-resident primary carers										
15–44	48.0	39.6	23.5	19.4	42.0	34.6	*7.8	*6.4	121.4	100.0
45–64	48.5	33.4	24.3	16.8	66.9	46.1	*5.3	*3.7	145.0	100.0
65+	21.9	25.1	13.5	15.5	46.7	53.5	*5.2	*6.0	87.3	100.0
All ages	118.4	33.5	61.3	17.4	155.7	44.0	18.3	5.2	353.6	100.0
All primary carers										
15–44	77.8	49.3	27.3	17.3	44.3	28.1	*8.5	*5.4	158.0	100.0
45–64	88.5	45.7	28.8	14.9	69.1	35.7	*7.3	*3.8	193.7	100.0
65+	27.1	28.2	15.1	15.7	48.6	50.5	*5.5	*5.7	96.4	100.0
All ages	193.5	43.2	71.2	15.9	162.1	36.2	21.3	4.8	448.1	100.0

(a) A primary carer may care for more than one person with a disability, but nominates one person as the main recipient of care.

Source: AIHW analysis of 1998 ABS Survey of Disability, Ageing and Carers confidentialised unit record file.

Caring times observed in the Victorian Carers Program longitudinal study of carers and care recipients, reported in Schofield et al. (1997), ranged from the minimum qualifying time for inclusion in the study (4 hours per week) to 168 hours per week. Twenty-seven per cent of these carers reported spending over 100 hours per week in direct care. Duration of care ranged from 1 month to 50 years, with carers of children most likely to have provided care for 5 years or more. These and similar findings from the ABS survey highlight the importance of carer support from informal networks and formal respite care services.

Carer health and wellbeing

AIHW analysis has shown that age-specific rates of disability are significantly higher for primary carers than for the total population at most ages under 65 years (AIHW 2000:141). Of those surveyed in 1998, just over 39% (177,500) had a disability and 9% (41,900) had a severe or profound core activity restriction. Many primary carers are themselves older people, so that a higher rate of disability might be expected. Consequently, many primary carers are providing support for someone who is severely restricted in their activities, while also coping with their own, often serious, health conditions and activity restrictions. The physical and psychological demands of the caring role itself can lead to adverse health outcomes for carers.

The ABS survey asked primary carers to assess the impact of caring on various aspects of their physical and emotional wellbeing. High numbers of primary carers reported that their caring role had resulted in a changed overall state of wellbeing (29%); feelings of dissatisfaction (67%); fatigue and weariness (34%); and feelings of worry or depression (31%) (AIHW 2000:Table 16.10). Many said that caring had taken a toll on personal relationships. While one in three primary carers felt that caring had strengthened their relationship with the care recipient, 22% said that the relationship was strained. Nearly a quarter of primary carers said that they had lost or were losing touch with friends because of caring commitments.

Younger carers in the Victorian Carers Program study, particularly adult daughters and daughters-in-law, were more negative about their circumstances than older spouse carers (reported in Schofield et al. 1998). The study found that female carers in general experienced more psychological distress and overload than male carers. Self-reported measures of health and wellbeing for female primary carers were compared to those for a representative random sample of women with usual household and parenting responsibilities. Overall, carers reported lower life satisfaction, higher overload and poorer self-rated health status. Relinquishing primary caring responsibilities during the study period was associated with improved life satisfaction, reduced feelings of overload and lower levels of family conflict.

Bergquist and others (1993) have highlighted the strain that caring for aged parents can place on people in their fifties and sixties because of competing priorities and family responsibilities. At this stage of life many people experience changing life patterns while continuing to work and provide support to adult children and possibly grandchildren. Two factors said to contribute most to a positive experience of caring for an elderly parent are having the support of other family members and a sense that there was some choice in the decision to provide care (Millward 1999).

Carers who took part in the 1999 National Survey of Carer Health and Wellbeing reported declines in physical, mental or emotional health as a result of their caring responsibilities (CAA 2000). Providing mobility assistance (lifting or transferring) presented difficulties for 38% of long-term carers. Around 60% of carers reported major negative effects on their life choices including restrictions in their ability to take part in paid work, education or other career opportunities. The survey reported on the emotional and physical demands faced by families caring for children with severe or profound disabilities, highlighting parents' anxiety about the future welfare of their disabled children. Responses to questions about personal wellbeing referred to the physical demands of caring, constant responsibility, and the emotional and psychological impact of behavioural disorders in care recipients as specific causes of carer stress.

The Young Carers Research Project (CA 2001) revealed that many young carers feel a sense of isolation and alienation from their peers because the caring role varies considerably from usual adolescent experience. Caring responsibilities can interrupt education and make the transition from home to independent living more difficult for some young carers.

Labour force participation of carers

Given the time demands of caring for someone with a disability it is not surprising that patterns of labour force participation among carers differ from those of the wider population. Carers of working age are less likely than non-carers to be in paid employment. Part-time employment rates are similar for primary carers (23%), non-primary carers (21%) and non-carers (20%) (Table 3.15). However, carers report lower rates of full-time employment—22% of primary carers and 41% of non-primary carers in 1998 were employed full-time, compared with 51% of non-carers. To some extent, these results are confounded by differences in the age and sex distribution of carers when compared with the general population of workers aged 15 to 64 years.

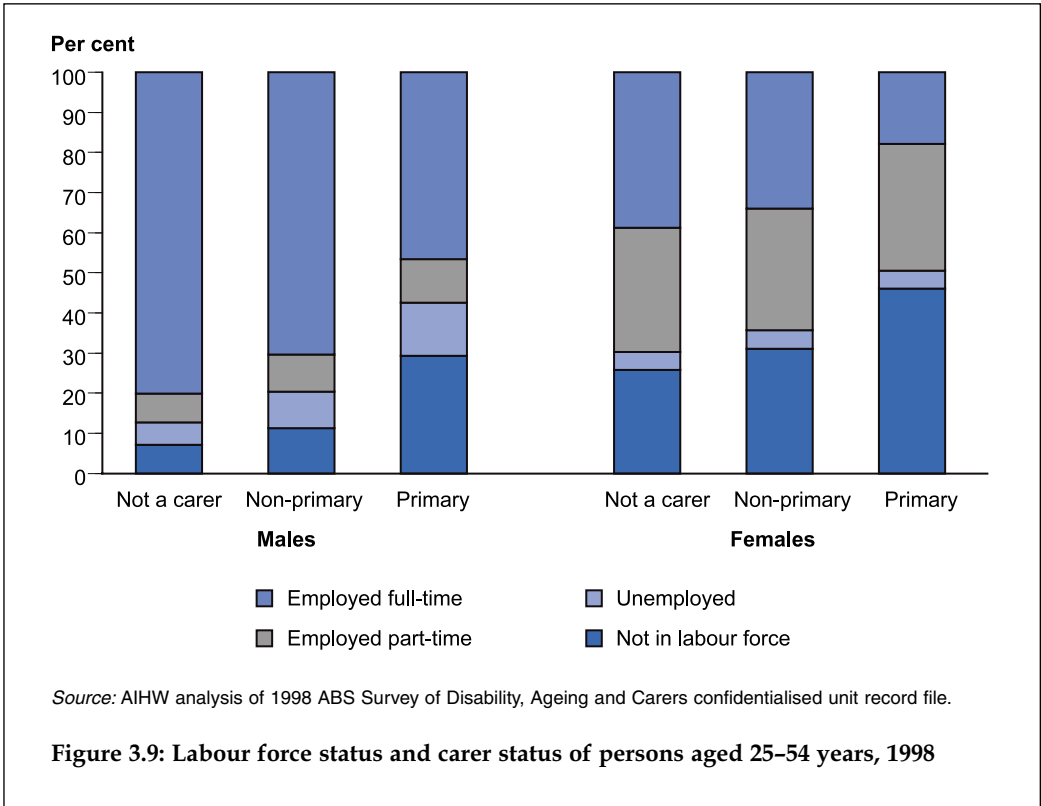
Table 3.15: People aged 15–64 years living in households, carer status by labour force status and source of income, 1998 (per cent)

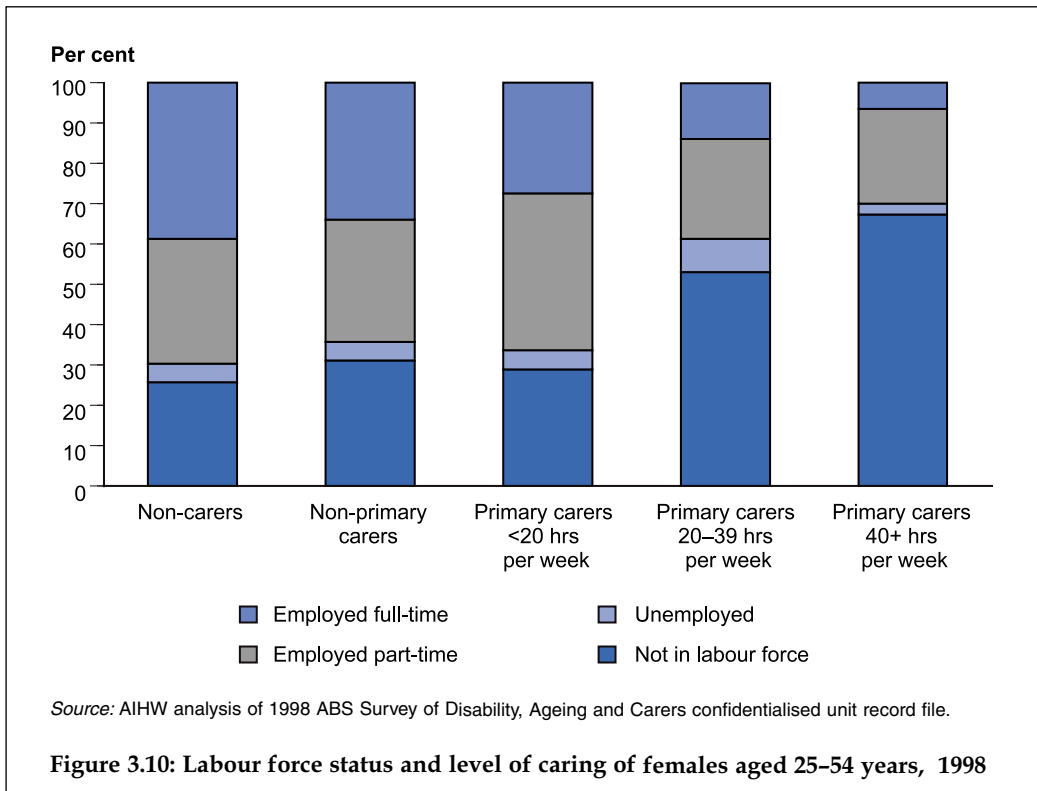
	Carer status			Total ('000)
	Primary carer	Carer (not primary)	Not a carer	
Labour force status				
Employed full-time	21.6	41.4	51.1	49.1
Employed part-time	23.0	21.3	20.0	20.2
Total employed	44.6	62.7	71.1	69.3
Unemployed	6.0	7.7	6.1	6.3
Not in the labour force	49.4	29.6	22.9	24.4
<i>Total</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>
Principal source of cash income				
Wages or salary	33.2	49.7	58.6	56.8
Own business or partnership income	6.1	7.7	8.3	8.2
Other private income	5.5	5.2	3.9	4.1
Government pension or allowance	49.2	29.7	20.3	22.2
Not stated	5.9	7.8	8.9	8.7
<i>Total</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>

Source: AIHW 2000:Table 16.5.

Narrowing the focus to persons of prime working age confirms lower labour force participation among male and female primary carers compared with other (non-primary) carers, and those without caring responsibilities (Figure 3.9). Reduced participation is mainly at the expense of full-time employment. Approximately 47% of male primary carers were employed full-time in 1998 versus 80% of men not involved in informal caring. Similarly, 18% of female primary carers aged 25–54 were in full-time paid employment versus 39% of women who did not perform informal caring.

For females at least, ABS survey data on labour force participation in relation to weekly hours of caring are sufficiently reliable to examine the relationship between these variables. Labour force participation among female primary carers aged 25–54 years who provided fewer than 20 hours of informal assistance was similar to that of non-primary carers (71% and 69% respectively) (Figure 3.10). Primary carers providing assistance to someone for 20 hours or more per week reported lower rates of part-time and full-time employment. Among female primary carers age 25–54 years performing 40 hours or more per week, 30% were employed and 67% were not in the labour force, compared with 70% and 26% respectively of women aged 25–54 without caring responsibilities. In 1998, 31,200 primary carers (6,800 men and 24,400 women) reported being in paid employment while performing 40 hours or more of informal caring per week.





Paid employment could have a protective effect from the negative aspects of caring. Schofield and colleagues (1998) identified caring and not having full-time work as significant predictors of major health problems in the past year. Table 3.16 summarises income, living costs and employment outcomes reported by primary carers in 1998. Further breakdown by sex is not possible due to the high sampling error associated with small numbers of male carers in detailed reporting categories. According to the ABS survey, 11% of primary carers aged 25-54 years and 17% of those aged 55-64 years had left work in order to commence caring or increase their hours of care. Around 21% of employed primary carers had reduced their hours of paid work, and the same proportion of employed carers reported a reduction in income associated with caring.

The impact of ceasing or reducing paid employment to perform informal caring can extend well beyond the actual or intended period of caring. Among 108,700 primary carers aged 25-54 who were not in the labour force at the time of the 1998 ABS survey, 57% (61,600) said that return to work was not relevant and a small proportion (2%) did not anticipate any difficulty. The remaining 47,100 primary carers expected to face problems that could prevent a return to paid employment. Making suitable alternative care arrangements was the most commonly reported specific difficulty in a list that included inflexible work hours, disruption to care recipient, and loss of skills while caring. However, almost one-third of this group (15,700) cited 'other reasons', suggesting that more research is needed if such problems are to be addressed (AIHW analysis of 1998 ABS survey confidentialised unit record file).

Table 3.16: Primary carers (aged 15 and over), impact of caring on hours of work, income and living costs, 1998 (per cent)

	Age group				Total
	15–24	25–54	55–64	65+	
Effect on income					
Income not affected	71.5	39.3	49.2	57.2	45.9
Income has increased	**2.4	*2.8	**2.0	**1.9	2.5
Income has decreased	**5.4	27.2	18.8	*6.8	20.7
Has extra expenses	**16.7	25.5	26.0	28.1	25.8
Not applicable/not stated	**4.0	5.2	**4.0	*6.0	5.2
	100.0	100.0	100.0	100.0	100.0
Effect on living costs					
Difficulty meeting costs	**14.5	34.6	28.3	17.1	29.1
No difficulty meeting costs	**7.6	17.5	16.3	15.8	16.6
Not applicable/not stated	77.9	47.9	55.4	67.2	54.3
	100.0	100.0	100.0	100.0	100.0
Effect on hours paid work					
Applicable	42.8	51.4	22.4	*3.7	35.8
No effect	*86.4	71.5	64.9	*76.6	71.4
Reduced hours	—	21.8	*22.7	**10.4	20.9
Increased hours	**13.6	*6.7	**12.3	**13.0	7.7
Not applicable	*57.2	48.6	77.6	96.3	64.2
	100.0	100.0	100.0	100.0	100.0
Reason left work					
To commence or increase care	—	11.4	17.2	*4.4	10.6
Total number ('000)	13.6	259.0	79.1	96.4	448.1

Source: AIHW analysis of 1998 ABS Survey of Disability, Ageing and Carers confidentialised unit record file.

The ability to remain employed while caring and to return to employment after a prolonged period of caring could become an increasingly important factor in women's predisposition to provide ongoing informal care. Flexible working arrangements and the availability of affordable support are likely to also impact on the extent to which employed men can take on a greater share of informal caring. Conversely, the moral imperative to care for disabled family members will influence many older workers' employment decisions. Structural and numerical ageing of the population will see a shrinking labour force supporting growing numbers of people in need of assistance. For governments aiming to maximise labour force participation over the coming years, the need to also realise the 'carer dividend' in the large cohort of older working-age baby boomers could prove to be a significant policy challenge (OECD 1996:298).

3.6 The future availability of carers

Concerns have been raised about the future availability of people to care for those who need assistance in the light of changes in Australia: the ageing of the population, declining fertility rate, and increased rates of female labour force participation and of relationship breakdown (see Section 3.2). There are changes that might counteract these trends: male longevity and healthy ageing. At all ages, women have historically enjoyed

greater average life expectancy than men and, while this remains the case, the gap between male and female life expectancies is closing. Conceivably, gains in male longevity will produce relatively higher numbers of older, co-resident spouse and partner carers, compared with those observed in 1998. In addition, the National Strategy for an Ageing Australia emphasises ways of ensuring that more Australians are active and healthy in their later years, giving them a great capacity to contribute to the community, including caring for others. These factors may ameliorate the need for primary carers in the future.

Here an analysis is presented that attempts to consider the effects of these trends on the numbers of primary carers available over the next 10 years. This analysis was prepared as part of a collaborative project with the Department of Health and Ageing.

Effects of social trends on future numbers of primary carers

There is considerable conjecture about the impact of these social trends on the future provision of informal care. Given the paucity of data to support or refute such propositions, the AIHW undertook an analysis to compare the effect of emerging social trends on future numbers of primary carers. The objective was not so much to forecast the number of primary carers, as to gauge the relative impact of factors, among those discussed in this chapter, on the community's capacity to provide primary carers. Specifically, the analysis considered the likely impact of:

- an overall decline in the propensity of people to care;
- a decrease in the availability of primary carers that could result from a reduced propensity of women to reduce paid employment in order to provide care; and
- an increase in the availability of carers that could result in higher numbers of co-resident spouses and partners at older ages (owing to converging male and female average life expectancy).

These scenarios are compared against a 'baseline propensity to care' scenario. This scenario adopts the 1998 rates of carers by age, sex, labour force participation category and living arrangement for the projections to 2013. It assumes that the proportions of people in similar life circumstances who become carers will be the same in the future as were reported in 1998.

A summary of the scenarios is provided in Box 3.6 and full details of the methods and analytical results of each stage of calculations are provided in an AIHW information paper (AIHW: Jenkins et al. 2003). Projections were separately calculated for each of the age groups 10–24 years, 25–59 years, and 60 years or over. Caring rates in these age groups reflect the propensity to care among the young, working-age, and older populations respectively. The effect of these factors on the number of primary carers was examined at 5-year intervals, commencing in 1998 through to 2013.

This scenario modelling approach uses the results of the 1998 ABS Survey of Disability, Ageing and Carers and population projections by age, sex and labour force participation category supplied by Department of Treasury, and consistent with those in

the *Intergenerational Report* (Costello 2002). Projected population proportions by living arrangement category, taken from the ABS *Household and Family Projections* (ABS 1999) were used in conjunction with the Treasury population figures.

To adopt the 1998 results as a starting point is to assume that caring in the community is primarily driven by the number of people who are available and willing to provide care. This places little emphasis on the interaction between the provision of care and changing levels in the need for care. It would be an extreme theoretical position to propose that the supply of informal care bears little relation to demand. This would be to assume that the drivers of social change will act to increase or decrease the number of carers as the case may be, regardless of the growing needs of those affected by disability or illness in an ageing household population. Nevertheless, it has been observed that many people with very considerable care needs do not have a primary carer so that, clearly, the relationship between demand and supply is complex and multi-faceted. The scenario projections are based on the numbers of people responding to the care needs of others by acting in a primary caring role in 1998, with future projections based on specified changes in behaviour that have been hypothesised to affect the likelihood of people becoming a primary carer. The past, if not current, impact of the prevalence of disability on population rates of informal care (measured as proportions of primary carers in given population groups) is reflected in the 1998 survey results. By assuming that disability prevalence in the household population does not alter markedly over the next decade, a key factor that might otherwise influence supply was held constant. This section summarises the methods and main results of the scenario projections (AIHW: Jenkins et al. 2003).

A baseline ‘propensity to care’ scenario

The 10–24 age group was broken down only by sex because further stratification produced 1998 population estimates, hence carer rates, that are subject to high sampling error. Thus, the baseline ‘propensity to care’ for 10–24 year olds was measured in terms of the proportions of this age group, by sex, who were primary carers in 1998.

The overall baseline scenario incorporates changing patterns in the age and sex structure of the population, changing patterns of labour force participation in the working-age population (including increasing female labour force participation), and changing patterns in spouse and partner cohabitation at older ages that are all built into the underlying population projections.

In the baseline scenario, population dynamics alone, with respect to age, sex, labour force participation and living arrangement according to age group, are seen to increase the number of primary carers from 450,900 in 1998 to 573,900 in 2013 (Table 3.17). In this scenario, 59,900 additional carers will be sourced from the working-age population and 62,300 additional carers will be aged 60 years or over. The proportion of primary carers who are of working age, 25–59 years, will fall from around 67% in 1998 to a projected 63% in 2013. While the proportion of carers who are employed males is projected to be stable at around 17%, throughout the projection period, employed women as a proportion of all primary carers are projected to decrease from 49% in 1998 to 46% in 2013. People aged 60 years and over are projected to rise from 29% of all primary carers in 1998 to 34% in 2013.

Table 3.17: Estimated (1998) and projected (2003, 2008, 2013) numbers of primary carers, according to baseline 'propensity to care' scenario

Sex/age	1998	2003	2008	2013
Males				
10–24	*6,200	6,500	6,600	6,700
25–59	78,700	87,000	92,900	96,400
60+	48,600	55,200	63,700	72,700
<i>Total</i>	<i>133,500</i>	<i>148,700</i>	<i>163,200</i>	<i>175,800</i>
Females				
10–24	10,100	10,400	10,600	10,600
25–59	223,100	243,100	257,200	265,200
60+	84,200	90,500	103,700	122,400
<i>Total</i>	<i>317,300</i>	<i>344,000</i>	<i>371,500</i>	<i>398,200</i>
Persons				
10–24	16,300	16,900	17,300	17,300
25–59	301,700	330,100	350,100	361,600
60+	132,800	145,700	167,400	195,100
Total	450,900	492,700	530,800	573,900

Scenarios to assess the impact of emerging social trends

Questions about the impact of a reduced willingness of women to reduce paid employment to care, an increase in older people in couple relationships, or an overall decline in the propensity to care were expressed as three scenarios for the future of informal care: the 'overall decreasing propensity to care' scenario, the 'women's career preference' scenario and the 'converging life expectancies' scenario (Box 3.6). An arbitrary choice of a 20% effect size, whether it be an increase or decrease, is common to all scenarios. This effect was applied linearly throughout the projection period. For example, a 20% decrease in carer rates by 2013 was modelled as a 6.7% decline in propensity to care between 1998 and 2003, a 13.3% decline between 2003 and 2008, and a full 20% decline in the final 5 years to 2013.

The overall decreasing propensity to care scenario assesses the impact of a decline in carer rates across all combinations of age, sex, labour force participation category (for the working-age population), and living arrangement (for the older population), that reaches 20% by 2013. Similarly, the career preference scenario measures the impact of a decline in carer rates across combinations of age and labour force participation category for the population of women aged 25–59 years. In this scenario, it is assumed that the projected populations at other levels of age, sex, labour force participation category or living arrangement experience baseline propensities to care. That is, the number of carers in categories other than working-age women, continue to be influenced by population dynamics with respect to age, sex, labour force participation and living arrangement as defined for this study. This approach was repeated in the converging life expectancies scenario, in which a 20% linear increase in the proportion of spouse and partner carers was applied to population projections for the 60 years and over age group by 5-year age group to 80 years and over, sex, and living arrangement, while baseline propensities were assumed for all other projection categories.

Box 3.6: Scenarios for the projection of informal carers to 2013

Baseline propensity to care scenario

The baseline propensity to care scenario assumes that 1998 patterns of care continue, in relation to each combined level of age group, sex, labour force participation category (for ages 25–59 years) and living arrangement category (for ages 60 years and over). The proportions of male and female primary carers recorded in each age group by labour force participation category or living arrangement, depending on age, in the 1998 ABS Survey of Disability, Ageing and Carers were applied to corresponding Treasury population projections. The driving forces of change in the number of primary carers according to this scenario are thus the changing age and sex structure of the population and changing patterns of labour force participation that are implicit in the Treasury projections. For example, if 3% of men aged between 55 and 64 years, who were not in the labour force or were unemployed in 1998, were primary carers, then that rate is applied to the projected population for the same group in 2008. The result is an estimate of the number of male primary carers aged 55–64 years, unemployed or not in the labour force in 2008. Although there is a change in absolute number of primary carers, it still represents 3% of men in this projection category.

Overall decreasing propensity to care scenario

The 'overall decreasing propensity to care' scenario evaluates the impact of an across-the-board 20% decrease in the proportion of primary carers by age, sex, and labour force participation (at ages 25–59 years) or living arrangement (at ages 60 years or over) category, by 2013. This scenario is an attempt to quantify the relative impact on future numbers of primary carers if a range of social factors conspired to reduce the propensity of people across all projection categories to act as carers. The absolute number of carers may still increase under these conditions because of increasing numbers of people moving into age groups that have relatively high proportions of primary carers. The resulting change in primary carer numbers, relative to the baseline propensity to care scenario, measures the impact of an overall decline in the propensity to care, taking into account anticipated population dynamics.

Women's career preference scenario

In 1998, 7% of female primary carers aged 25–59 years said that they had reduced paid employment, or left work altogether, to take on a role as primary carer. There is considerable debate as to whether working-age women of the future will make that choice. The 'women's career preference scenario' assesses the impact of an arbitrary 20% reduction over the projection period in the proportion of women who reduce paid employment to care. The 1998 patterns of care are assumed to continue in relation to other age, sex and labour force participation (or living arrangement) categories. The figure of 20% is arbitrary, thus a sensitivity analysis using alternative reductions of 10% and 30% was undertaken.

Converging life expectancies scenario

The 'converging life expectancies' scenario assesses the impact of an arbitrary 20% increase over the projection period in the proportion of primary carers aged 60 years or

(continued)

Box 3.6 (continued): Scenarios for the projection of informal carers to 2013

over who are the spouse or partner of their care recipient. A sensitivity analysis was undertaken, by applying alternative increases of 10% and 30%. For this scenario, Treasury-projected populations by 5-year age group, at ages 60 years or over, were classified into spouse/partner in a couple family, or 'other living arrangement' groups using ABS household and family projections (ABS 1999b). The 1998 patterns of care were assumed to continue in relation to other age, sex and labour force participation categories.

A projected total carer pool was calculated by aggregating primary carer numbers across the three broad age groups, consistent with the assumptions of each scenario. For the baseline propensity to care scenario, baseline propensity projections in each of the age groups 10–24, 25–59 and 60 years or over were summed. Likewise, for the overall decline in propensity to care scenario, projections based on a decreasing rate of primary carers, by projection category in each age group, were summed. Total carers in the career preference scenario are the sum of projected female carers aged 25–59 years in this scenario, and baseline propensity to care projections for both sexes at ages 10–24 years, males aged 25–59 years, and both sexes at 60 years or over. Finally, total carers in the converging life expectancies scenario are the sum of baseline propensity to care projections for males and females at ages 10–24 years and 25–59 years, and the scenario projection for the 60 years and over age group, based on higher proportions of cohabiting couples. The results reveal that, of these single-effect scenarios, only an overall decline in propensity to care would have a marked impact on the number of primary carers in 2013 (Table 3.18).

Table 3.18: Scenario projections of numbers of primary carers (10 years and over), by sex, 2003, 2008 and 2013

Scenario	2003	2008	2013
		Males	
Baseline propensity to care	148,700	163,200	175,700
Overall decreasing propensity to care	138,800	141,400	140,600
Women's career preference	148,700	163,200	175,700
Converging life expectancies	151,900	170,600	188,500
		Females	
Baseline propensity to care	344,000	371,600	398,200
Overall decreasing propensity to care	321,100	322,000	318,600
Women's career preference	342,400	368,100	392,900
Converging life expectancies	347,600	379,600	412,200
		Persons	
Baseline propensity to care	492,700	534,800	573,900
Overall decreasing propensity to care	459,900	463,500	459,200
Women's career preference	491,100	531,300	568,600
Converging life expectancies	499,500	550,200	600,700

Scenario projections in the context of future need

But what of the relationship between projected numbers of primary carers and the projected population in need of assistance? To answer this question, the projected number of primary carers in 2013 for each scenario was expressed as a rate per 100 persons with a severe or profound core activity restriction. Assuming 1998 rates of severe or profound restriction by age and sex, this latter population is projected to be in the vicinity of 1.4 million persons by 2013 (AIHW: Jenkins et al. 2003). In 1998, there were an estimated 450,900 primary carers and just over 1 million people with a severe and profound restriction (living in households, retirement homes, hospitals or cared accommodation). However, around 20% of primary carers in 1998 assisted more than one person with a severe or profound restriction and a large number of people in need of assistance received help from informal care networks but did not nominate any one person as a primary carer. For these reasons, a 'care ratio' facilitates a comparison of the scenarios taking into account potential need for care, without actually measuring the level of informal care in the community. The 1998 ratio of 43 primary carers per 100 persons with a severe or profound core activity restriction provides a benchmark against which to compare the 2013 scenario care ratios.

There is little difference between the 2013 care ratios of the baseline propensity to care, women's career preference and converging life expectancies scenarios. All fall slightly below the 1998 estimate. Under the baseline scenario of 1998 propensities to care by age, sex, labour force participation and living arrangement, there are projected to be 40 primary carers per 100 persons with a severe or profound restriction, or a care ratio of 0.40. Baby boomers who survive the projection period will age from between 37 and 51 years in 1998 to between 52 and 66 years in 2013. In 1998, people aged between 35 and 64 accounted for 64% of all primary carers (ABS 1999a:Table 28). Despite projected high growth in the population for age groups that register relatively high proportions of primary carers, 1998 carer rates will not quite keep pace with growth in the population with a severe or profound restriction. The women's career preference scenario also generates a care ratio of 0.40 in 2013. During this particular projection period, a 20% reduction in the proportion of women aged 25 to 59 who are willing to forgo hours of paid employment relative to 1998 is largely offset by high numerical growth in traditional primary carer age groups due to ageing of the baby-boomer generation. The converging life expectancies scenario, with a care ratio of 0.42, appears to maintain the 1998 status quo, suggesting that a 20% increase in the proportions of co-resident spouse and partner carers at older ages could offset higher numbers of people needing assistance. Each of these three scenarios describes a situation in which the demand for formal services increases mainly as a result of the increase in the number of people needing and providing assistance, rather than in any dramatic shift in the provision of informal care.

In contrast, an overall decline in the propensity to care, by 20% in 2013, would reduce the care ratio to just 32 primary carers per 100 persons with a severe or profound core activity restriction. A reduction in care potential of this magnitude would compound the effect of growth in the population in need of assistance on demand for formal care. It suggests that, under these conditions, a significant number of people who might have had a primary carer if the 1998 propensity to care were maintained would instead be relying on formal services and more casual forms of informal care.

Discussion of scenarios

Social commentators have been preoccupied with the impact on informal care capacity of increasing labour force participation among women, particularly at ages 45 and over. The scenario posed here examines a situation in which, within each population group of employed women, by age and labour force status, the proportion who would cease or reduce paid employment actually reduces by 20% over the projection period. The proportions to which this reduction applies are those observed in each age and labour force category in 1998. Overall, 7% of female primary carers aged 25–59 years in 1998 reported having resigned or reduced hours of paid work to provide care; however, the proportion varies across age and labour force categories. A reduced willingness of women to sacrifice employment that results in a 20% reduction in these proportions by 2013 could be regarded as a pessimistic outlook. While it is not unreasonable to expect female workforce participation (particularly women aged 55 and over) to continue to rise over the next decade in line with current trends, it is less likely that all of those continuing or returning to work will not provide care in some capacity. Other research has suggested that women are more likely than men to arrange their working hours to fit with other family caring responsibilities (Fine 1994). In this respect the scenario presented here is somewhat of an extreme position. Yet under the proposed conditions, the ratio of carers to people with a severe or profound core activity restriction would be the same as if there were no change in carer rates over the projection period (both 0.40).

These results emphasise that a large proportion of female carers is actually in the labour force, highlighting the need to specifically consider employed carers in the ongoing development of carer support programs. Employed women made up 34% (102,400) of all primary carers in 1998. The ability of many women to balance paid work and family caring responsibilities and to continue to do so into the future will no doubt depend upon the availability of other family and community supports. As the 1999 National Survey of Carer Health and Wellbeing reports, respite care and other services are seen by carers as an integral part of their lives and essential to their ability to continue in their role as carers (CAA 2000).

The projections also indicate that an increase in the number of older co-resident spouses and partners is likely to be only a small source of additional carers over the next decade. A 20% increase in the rate of caring among co-resident spouses and partners is perhaps an optimistic scenario. While life expectancies are improving, particularly for men, and, as Mathers (1996) reports, severe disability-free life expectancies are increasing in line with life expectancies, these factors are only two of a multitude of variables influencing the availability of people to care for their spouse or partner. The scenario assumes that surviving partners will remain married rather than become divorced or separated and that, in addition to physical capability, these partners will have the necessary skills and emotional ability to undertake the caring role. These assumptions may not always find support in reality. For example, Sammut (1996) describes some of the difficulties faced by carers of those with dementia who can sometimes exhibit disturbing symptoms that are physically exhausting for their carers.

The projections suggest that a considerable decline in the proportion of working age women who reduce workforce participation to care, or increase in the rate of older spouse and partner carers, do not have major implications for the future availability of

informal carers. However, even given the one-off effect of large numbers of baby boomers entering age groups with traditionally high rates of primary carers, a 20% decline in the propensity to care across all categories of age, sex, labour force participation and living arrangement would not go unnoticed. The plausibility of a scenario in which there is a broad decline in carer availability is difficult to assess, not least because of the multitude of variables relevant in determining carer supply, many of which are not well understood.

The scenario projections are based on data for primary carers: that is, individuals providing the most assistance to persons with a disability. Many people with a disability receive help from more than one person, usually other family members (Miller & McFall 1991). This group of additional carers is not included in the projections. Thus, the scenarios presented above which project a decline in primary carers do not allow for the possibility that these carers will be replaced by carers in other circumstances beyond those identified in the model. A survey of carers by Braithwaite (1990) found that 25% of primary carers took on the role because there was no one else to do so, and for 28% other potential carers had refused. According to the 1998 ABS survey (ABS 1999a), 30% of carers of parents felt that there were no other family or friends available and 19% felt that no one else was willing to take on the role of primary carer. In contrast, Miller and McFall (1991) have observed that additional informal assistance varied in intensity and size (in terms of the number of additional carers) as a function of, among other things, the need of the recipient, with greater care needs finding more support from an additional carer network. The contribution of additional carers and the implications of this for future care needs are difficult to assess and were beyond the scope of the analysis.

Carer accessibility, in terms of geographic location, is a further consideration in the interpretation of the scenario projections. There is an assumption that additional primary carers will be available in a practical sense. Thus, the phenomenon of geographic ageing and the tendency of many people to retire to coastal destinations will play a part in future patterns of informal care.

While these limitations are important to note, they do not detract from the strength of the conclusions. The scenarios presented here offer an empirical base for some likely projected future trends, indicating the likely scope of changes over the period from 1998 to 2013. Shifts in carer responsibility that results from the changing availability of the group identified as primary carers will have implications for formal services and for the caring responsibility placed on others in informal networks. The effectiveness of these extended networks is related to the availability of relevant formal services and programs and to policies which facilitate broader community support.

3.7 Conclusion

This examination of caring reveals the enormous contribution that Australians make to the welfare of those who need special assistance. Most of the care provided to children, and to people with a disability, is provided by parents, spouses, adult children, grandparents, siblings, aunts and uncles, and friends and neighbours. They perform a range of tasks including personal care, assistance with mobility and communication, domestic assistance, the provision of meals and transport, and advocacy and social

support. People are supported in their caring role by formal assistance from governments and other organisations—assistance comes in the form of financial support and the coordination and provision of services. However, the vast majority of care is given by those close to the care recipient—their family and friends.

When parents *are* unable, for whatever reason, to raise their children, other relatives, often grandparents, step in and provide out-of-home care, sometimes informally, ensuring some continuity and stability for children.

When individuals need assistance due to disability, primary carers make a huge contribution to their care. Almost three-quarters (70%) of primary carers are women, many in their mid- to later life. Partners and spouses often care for one another, particularly in later years, and close to half (44%) of partner or spouse carers are men. Parents provide ongoing care to children with a disability. For some, the primary caring role imposes a considerable burden, but it is a role that people take on out of a sense of responsibility and the desire to provide the best possible care. They report fewer hours of paid employment than others, and almost half of all primary carers who were not in the labour force reported difficulties that would prevent them from returning to paid employment.

Families are changing. Women are more likely to work, people marry later, have children later and have fewer children, and childlessness has increased. Divorce rates are high and there are more blended and step-families, and families tend to be more mobile. As the analysis of the future availability of primary carers showed, some of these changes may signal a lower ratio of potential carers to those in need of ongoing assistance in the future. Women are most likely to be affected by a lack of informal carers because they are more likely to survive into old age, more likely to have related physical and psychological impairments and more likely to be financially vulnerable. Others for whom the availability of informal care may be reduced include divorced fathers, the childless, those geographically isolated from their families, and those on low incomes. However, these changes are occurring gradually over a very long time frame, allowing for gradual change in government policies and service provision.

The 'ageing' experience is also changing. As the National Strategy for an Ageing Australia notes, the needs and expectations of the current aged population will not be the same as the needs of the aged in 2010. Greater numbers of people are ageing in a better state of health. Roles of older Australians are changing, with less acceptance of traditional ideas of what old age means. Retirement patterns are changing—men used to have continuous periods of full-time employment while women had very little, but now, both sexes are more likely to work part-time or intermittently. This means that more people have superannuation coverage in Australia than ever before, but that a growing proportion are covered part-time. Traditionally, there has been a sharp division between paid work and retirement. Now the division is becoming more blurred, with high rates of part-time and self-employment both before and after traditional retirement ages (Rosenman 1996). All of these factors will affect the need for and provision of informal caring.

The ageing of carers is an urgent current issue both for families in which a family member has a disability and for governments and service providers. AIHW's 2002 study on the effectiveness of 'unmet need' funding for disability support services,

estimated that, in 2001, 12,500 people needed accommodation and respite services (AIHW 2002:xxi). The peak organisation discussions conducted as part of this study highlighted the fact that, particularly for ageing carers, while respite services are useful and appreciated, centre-based respite is also needed. Furthermore, many ageing carers were very mindful that they need to 'hand over'. The fundamental question for many ageing carers, mainly parents, are: 'When can I retire? And if I can't, what happens when I die?' For these people, a policy focus on in-home support does not fully meet their needs (AIHW 2002:ix).

One thing seems clear from this analysis: the provision of informal caring will increasingly depend upon people's ability to combine work and family responsibilities. A wide range of policies will be required to support carers. Family-friendly workplace policies will need to be extended to apply to people who are caring for people with a disability or frail older people, and not just to those with dependent children.

The Stronger Families and Communities Strategy announced in 2000 gives the federal government a vehicle to work in partnership with other levels of government and community agencies in new and innovative ways to support families and to work within communities to build capacity. A component of the strategy is the Longitudinal Study of Australian Children. Data collected between 2003 and 2010 will add to our knowledge of the provision of unpaid informal care of children and how care arrangements change over time. This longitudinal perspective will complement the now triennial Child Care Survey, which was first conducted by the Australian Bureau of Statistics in 1969 as a supplement to the Monthly Population Survey.

Convened in 2003, the National Family Carers Voice is an organisation of individuals with a commitment to and personal experience of caring for adults and children with disabilities. Its charter is to 'gather information about the nature, location, and circumstances of family carers to provide the Government with advice and options for addressing the longer term needs of these important individuals' (Vanstone 2003). The Department of Health and Ageing provides funding to carers organisations such as Carers Australia, the national peak carer organisation. Carers Australia promotes the recognition of carers and provides information and resources to carers through initiatives such as the National Carers Counselling Program. This program operates through the eight state and territory Commonwealth Carer Resource Centres.

More and more Australians are likely to become involved in the ongoing giving and receiving of unpaid care due to population growth in the older age groups and the higher prevalence of severe or profound disability at older ages. In addition, many parents caring for adult children with a disability are facing physical difficulties and anxieties associated with their capacity to continue to provide care in old age. Future levels of provision of unpaid care will be inextricably linked to the levels of workforce participation, retirement income, physical health and wellbeing of older people and their carers, and the potential for people with disabilities to remain in an appropriate living arrangement as they age. The Framework for an Australian Ageing Research Agenda aims to build capacity for further high-quality and coordinated research and analysis of these complex interrelationships (AIHW & DoHA 2003).

Increasingly, carers are being recognised as clients in their own right by programs designed primarily to deliver services to care recipients. Carer interventions extend beyond the provision of respite to services that aim to build on carers' understanding of chronic diseases and symptomatology, and on their capacity to seek assistance from formal services. The AIHW continues to undertake data development work to better measure the situation and circumstances of carers and the services that assist them. In 1999, the AIHW and the National Disability Administrators began a process to review and redevelop the Commonwealth-State/Territory Disability Agreement minimum data set and related data collections (CSTDA MDS). New data items on primary carers have been incorporated into this MDS from 2003 and assessment of carer stress and strain features in state and territory service delivery guidelines.

In order for Australians to meet one another's welfare needs, the contribution of informal caring will need to be fully appreciated. Establishing a strong evidence base regarding the needs and circumstances of carers and care recipients, and achieving greater understanding and promotion of best practice in the delivery of service and assistance to carers, will support the sustainability of this vital component of Australian society.

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