

5 Trends in informal care

The importance and complexity of informal care is increasingly being recognised in a growing body of empirical and theoretical literature (e.g. Howe et al. 1997; Gibson et al. 1996; Madden et al. 1996; Sitsky 1994). Meanwhile, Australia's service system has been successful in providing services to complement informal care, to sustain the efforts and choices of carers. Of people living in a household in 1993, reporting handicap and receiving assistance, 91.9% received some assistance from family and friends and 39.8% received formal services, with 31.7% receiving both informal assistance and formal services (AIHW 1997a: reporting on the 1993 ABS disability survey). (See Chapter 16 and AIHW 1999a for analyses of the 1998 ABS disability survey data.)

The survey data also show that for 82% of people with a severe or profound handicap, the main provider of assistance with self-care activities was an informal carer, usually resident in the same household. In 1993 there were 383,100 co-resident principal carers of people with a severe or profound handicap. Home maintenance was the activity for which formal services were most likely to be the main source of assistance but, even in this area, only 14% of people used formal services as their main source of assistance (Madden et al. 1996).

According to the survey there were 152,300 non-co-resident principal carers in 1993 and a majority of them (61%) were sons or daughters of the care recipient (Gibson et al. 1996).

Using the 1993 ABS survey figures for all carers, there were 17.5% of Australia's 6.5 million households involved in caregiving and, of those, 4.8% were involved in more intense, primary caregiving (Howe et al. 1997).

A study of data from the Victorian Carers' Program found that secondary carers (carers other than the principal carer) need to be taken into account to describe the full involvement of families in caring across the community. The identification of secondary carers demonstrates that principal carers carry out their roles within a more extensive network of family and social exchanges (Howe et al. 1997).

The monetary value of the contribution of informal care was estimated at about \$16.6 billion in 1995–1996. The estimate was based on the services 'provided by members of households for the consumption of others in the household or people in other households, without any form of monetary payment. These services included work done at home caring for people who are sick or with a disability, caring for other people's children, caring for one's own sick children and other welfare services' (AIHW 1997a: 18; AIHW 1997b: 11).

This section reviews the impact of demographic trends and other social and economic factors on informal care, particularly focusing on the combined effects of population ageing and trends in de-institutionalisation among people with a disability.

5.1 Impact of population growth and population ageing on informal care

On purely demographic grounds, and without considering other factors, there are four primary impacts of population growth and population ageing on future availability of informal care. Some of these influences are countervailing.

First, there could be an increase in the number of potential carers for older people in the next decade, since the number of people aged 45–64 is projected to be substantially higher than that of those aged 65 and over during the period (Table 2.3 and Figure 2.1). The 1998 ABS disability survey data show that 43.2% of primary carers were aged 45 to 64 years, as compared with 35.0% aged 15 to 44 years and 21.0% aged 65 years and over (ABS 1999).

Second, the life expectancies of males and females are increasing and the rate of increase is faster for males than for females. This implies that married couples may survive longer together and the proportion of people being cared for by a spouse may increase. However, it is also possible that both husband and wife may require care simultaneously (McDonald 1997). Analysis of the ABS 1993 disability survey found that there were 82,900 spouse carers aged 65 years and over (Madden et al. 1996).

Third, population ageing will be particularly strong in the working-age population during the next decade due to the ageing of the baby-boom cohort. This will result in an increase in the number of people with severe or profound core activity restrictions among people aged under 65 years. The increase in the number of people with a profound or severe core activity restrictions among both the working-age population and the population aged 65 and over may further increase the need for carers.

Fourth, the ageing of carers, already an urgent current issue, is likely to become more critical. Analysis of the 1993 ABS disability survey found that an estimated 7,700 co-resident principal carers of people with severe or profound handicap were parents aged 65 years and over.² While population sampling survey estimates might be subject to high standard errors, it appears that about 65% of parents aged 65 and over had been caring for their children for 25 years or more, and 45% of them for 30 years or more. These findings highlight the urgent need to address the shortfall in long-term accommodation arrangements for the recipients of their care (Madden et al. 1996).

Ageing parents caring for their child with a severe or profound handicap appear to have a different history from people taking on the caring role as a spouse in later life. People who have been caring for a family member with a disability for 25 or 30 years experience special anxieties as they age. 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 is becoming more difficult and wish to see alternative arrangements put in place for the future care of the person involved (Madden et al. 1996).

Analysis of the ABS 1993 disability survey also found that about 38% of all co-resident principal carers had a disability, and about 6% had a severe or profound handicap (Gibson et al. 1996).

5.2 Other factors affecting changes in informal care

Population factors are not operating alone. Rather, they interact with other social and economic factors to affect the demand for services and informal care for people with a disability. Hence, it is necessary to review other social and economic changes, especially changes in patterns of family formation, living arrangements and labour force participation. Some of these changes could potentially diminish the pool of family carers and the commitment within families to provide care (Schofield & Bloch 1998; McDonald 1997).

² Co-resident principal carers included spouses, parents, sons/daughters and friends of the care recipients.

Family formation patterns and family support structures are now markedly different from those of the 1950s and 1960s (AIHW 1997b; ABS 1998; Caldwell 1999; Glezer 1992 cited in Clare & Tulpule 1994). Declines in the marriage rates and increases in divorce rates, as well as increases in rates of singleness, reduce the potential for spouse care. For males in particular, divorce may severely reduce the level of contact with their children and, where this occurs, there may also be a reduction in the level of contact between grandchildren and their paternal grandparents (McDonald 1997; Harrison et al. 1990 cited in McDonald 1997).

Changes in the geographic location of older people and the ageing of country town populations (see Chapter 2) also affect older people's informal assistance network. Many younger people are moving away from country towns. This reduces the potential informal care that older people can expect to receive. A survey of older people living in a country town found that less than one-third of the respondents received any assistance from their children (Dempsey 1990: 67).

Some of the main social trends in family formation, living arrangements and labour force participation in Australia can be summarised as follows:

Family formation

- Average age at first marriage has been increasing and the marriage rate has been in decline. Between 1986 and 1996, median age at first marriage rose from 25.6 years to 27.6 years for males, and from 23.5 years to 25.7 years for females. During the same period, the marriage rate³ declined from 47.6 per 1,000 unmarried males to 34.7 per 1,000 (Table 5.1).
- There has been a decline in fertility and an increase in the age of mothers at first birth. The total fertility rate per woman declined from 1.87 in 1987 to 1.80 in 1996. During the same period, the median age of mothers at first birth within registered marriages increased from 26.5 years to 28.7 years (Table 5.1).
- There has been a rise in births outside marriage. Of all births, births outside marriage accounted for 27.4% in 1996, an increase of 10.6 percentage points as compared with the rate of 16.8% in 1986 (Table 5.1).
- There has been an increase in marital dissolution, which stabilised in the 1980s but increased slightly in the 1990s. The divorce rate increased from 10.7 per 1,000 married males in 1986 to 12.9 per 1,000 married males in 1996 (Table 5.1).

Living arrangements and employment

- The proportion of people living alone increased from 8.3% of people aged 15 and over in 1987 to 10.5% in 1997 (Table 5.2).
- The average family size became smaller, from 3.3 persons in 1987 to 3.1 persons in 1997 (Table 5.2).
- There has been an increase in one-parent families with dependents. This is particularly true for female one-parent families with dependents, which represented 7.0% of all families in 1988 and 9.1% in 1997 (Table 5.2).
- Single parents with dependents have become less likely to be employed. Of all single-parent families with dependents, the proportion employed dropped from 50.2% in 1989 to 46.5% in 1997 (Table 5.2).

³ The number of registered marriages per 1,000 not-married males aged 15 and over.

- Female labour force participation rates have risen from 48.7% in 1987 to 53.9% in 1997 (ABS 1998b).

Table 5.1: Australian social trends—family formation, 1986–1996^(a)

Family formation	Units	1986	1987	1988	1989	1990	1991	1992	1993	1994	1995	1996
Marriage rate												
(per 1,000 not-married males)	no.	47.6	45.8	45.5	44.6	43.5	41.7	41.1	39.8	38.2	36.7	34.7
Median age of men at												
first marriage	years	25.6	25.9	26.1	26.3	26.4	26.7	26.9	27.0	27.2	27.3	27.6
Median age of women at												
first marriage	years	23.5	23.8	24.0	24.2	24.3	24.5	24.7	24.8	25.1	25.3	25.7
Divorce rate												
(per 1,000 married males)	no.	10.7	10.6	10.8	10.8	10.9	11.6	11.5	12.1	12.0	12.3	12.9
Total fertility rate (per woman)	no.	1.87	1.85	1.84	1.84	1.90	1.85	1.89	1.87	1.85	1.82	1.80
Median age of mothers at first birth												
within registered marriage	years	26.5	26.8	27.1	27.3	27.6	27.8	28.0	28.3	28.5	28.6	28.7
Births to mothers aged 35 and over												
(of all births)	%	7.9	8.5	9.0	9.6	10.0	10.7	11.4	11.9	12.9	13.7	14.6
Births outside of marriage												
(of all births)	%	16.8	18.0	19.0	20.2	21.9	23.0	24.0	24.9	25.6	26.6	27.4

(a) Reference periods: Data on family formation are for the calendar year.

Source: Adapted from ABS 1998b: 26.

Table 5.2: Australian social trends—living arrangements, 1987–1997^(a)

Living arrangements	Units	1987	1988	1989	1990	1991	1992	1993	1994	1995	1996	1997
Persons who live alone												
(of persons aged 15 and over)	%	8.3	8.5	8.4	8.2	8.6	8.9	9.6	9.6	10.0	10.2	10.5
Average family size (persons)	no.	3.3	3.2	3.2	3.2	3.2	3.2	3.2	3.1	3.1	3.1	3.1
Couple families with dependants												
(of all families)	%	45.5	45.7	44.7	44.3	43.7	43.4	42.9	41.6	41.4	40.6	40.8
One-parent families with a male												
Parent with dependants												
(of all families)	%	n.a.	1.0	0.9	1.0	1.1	1.1	1.0	1.2	1.2	1.3	1.3
One-parent families with a female												
Parent with dependants												
(of all families)	%	n.a.	7.0	6.8	7.1	7.4	7.9	7.9	7.8	8.5	8.4	9.1
Couple-only families (of all families)	%	30.4	30.7	31.5	31.2	31.3	31.1	32.1	33.3	33.6	34.1	33.6
Couples with dependants, both												
Employed (of all couples with												
Dependants)	%	50.2	50.9	53.8	55.9	53.4	53.3	52.5	52.8	57.7	55.7	56.3
One-parent families with dependants,												
Parent employed (of all												
one-parent families with dependents)	%	n.a.	n.a.	50.2	49.0	47.0	45.7	45.3	45.9	46.9	46.8	46.5

(a) Reference periods: Data on living arrangements are at June.

Source: Adapted from ABS 1998b: 26.

5.3 Trends in community living among people with a disability

There is a continuing shift from residential care to community care in the fields of aged care, disability services and mental health, although there are some variations between the fields in terms of how this shift is occurring (Madden et al. 1999). This trend has implications for the level of formal services and informal assistance required to meet the needs of people with a disability and their carers living in the community.

A comparative analysis of three consecutive ABS disability surveys (1981, 1988, 1993) showed that de-institutionalisation (i.e. a reduction in the number of people living in institutions) has been occurring among people with a disability who need ongoing support. Between 1981 and 1993 the number of people aged 5–64 years with a severe or profound handicap living in households rose from 244,100 to 349,100, while the number living in establishments⁴ fell from 27,000 to 19,200. The trend is even more marked for people aged under 30 years—in 1981 there were, on average, 15.9 people aged under 30 years with a severe or profound handicap living in establishments for every 100 living in households,

⁴ Establishments are defined by the ABS disability survey as general hospitals, psychiatric hospitals, nursing homes, hostels, retirement villages and other ‘homes’ (ABS 1993).

whereas by 1993 this ratio had dropped to 3.1 for every 100 living in households (AIHW 1997a; Wen & Madden 1998a).

There has been a large increase in the numbers and proportions of people with severe or profound handicap aged under 65 years living with their relatives. There has also been a small but growing number living alone, or with non-relatives, many of whom may be living in supported arrangements in the community (Wen & Madden 1998a).

Between 1981 and 1993 nearly 40% of the increase in the number of people with severe or profound handicap aged under 65 years living in the community was associated with population growth (Wen & Madden 1998b) (see Chapter 16 and AIHW 1999a for analyses of the 1998 ABS disability survey data).

It is likely that trends in de-institutionalisation (in terms of decreasing numbers living in institutions) are due largely to potential new service users remaining in community-based living arrangements, while there have been significant efforts to close institutions and accommodate people in the community. The results of the analysis also indicate the possibility that individual de-institutionalisation efforts have been focused on younger people (Wen & Madden 1998a). For example, in New South Wales there has been a deliberate policy to minimise institutionalisation of children (response from New South Wales Ageing and Disability Department 1999).

5.4 Impact of caring role on informal carers

Although patterns of family formation and living arrangements are changing, there is strong evidence of continuing mutual support among family members, in various patterns and relationships (AIHW 1997a: 18). Nevertheless, there will be pressure and new challenges for both informal care and community-based services from the combined effects of ongoing trends in de-institutionalisation and population ageing.

The ageing of people with a disability who live with families places a greater strain on the traditional informal family support network. These people are at high risk of early entry to institutional support care. People with an early onset disability, such as intellectual disability, are now more likely to outlive their parents. When parents die, siblings may not be readily able to maintain the state of 'supported independence' (Bigby 1994, 1996; Buys & Rushworth 1997).

Informal carers can help only to the extent that they are functional and available. A wide variety of personal and social reasons may prevent family members from providing direct care and assistance (Buys & Rushworth 1997).

Increased labour force participation by women may affect the availability of family carers. The 1993 ABS disability survey data showed that most (67%) principal carers of all ages were women (ABS 1995: 23). The labour force participation of females in the main caring ages has increased markedly. In 1992, 65% of females aged 45–54 years were in the labour force compared with 37% in 1966. However, of females aged 45–54 years in 1992, only slightly over a third were in full-time paid employment (McDonald 1997). The increase in women's labour force participation may partly reflect the inability of many households to sustain an adequate standard of living without two incomes (Clare & Tulpule 1994).

Carers of people with a disability reported lower levels of labour force participation and income than the general population. Analysis of the ABS 1993 disability survey data shows:

- Of the estimated 383,100 co-resident principal carers, 33,000 people gave up work to take on a caring role (mainly women and mainly people aged 30 and over).

- 61,700 reported reduced income, 80,800 reported extra expenses and over 100,000 reported difficulty in meeting living expenses (Madden et al. 1996).

In 1993, 52% of all principal carers had a personal weekly income of less than \$200; 14% of principal carers were recipients of the Age Pension which was under \$200 per week at the time (ABS 1995: 32).

The 1993 ABS survey data also indicated a range of other effects on principal carers:

- 98,300 had frequently interrupted sleep which interfered with normal daily activities—73.5 % of these people were female;
- 13,800 people were not able to go out during the day, and 50,500 were not able to go out at night—again, approximately 70% of people affected were female;
- 84,400 people could not take holidays;
- 116,200 felt weary and lacked energy; this figure included an estimated 1,200 people aged under 20 years old;
- 128,000 people felt ‘worried, depressed and/or angry’, including 1,700 people aged less than 20 years.

The main effects varied with the age and sex of the carers. Overall, these effects fell most heavily on women aged 30 and over, consistent with their predominance as principal carers (Madden et al. 1996: 63).

Nevertheless, there is evidence of many positive aspects of caring. The 1993 ABS disability survey showed that 110,800 co-resident principal carers stated that their caring role had brought them closer to the care recipient, as compared with 88,200 who reported that there was a strain placed on the relationship (Madden et al. 1996: 64–65). About two-thirds of principal carers reported that their caring role had not affected their friendships with others, or that there had been only a minor change (ABS 1995: 35).

A study of data from the Victorian Carers Program found that most carers acknowledged the satisfaction, reassurance and increased confidence they gained through caregiving. Most carers also denied negative feelings about their care recipients and about the impacts of caregiving on their lives in terms of lost opportunities, social contacts and control. Some carers also acquired new skills and made new friends or broadened their interests (Schofield et al. 1998: 34).

5.5 Support needs for carers

The above section shows that the caring role can be physically, mentally, emotionally and economically demanding. The combined effects of trends in de-institutionalisation and population ageing further emphasise the importance of community-based programs to support carers and help maintain the stability of community living and caring arrangements.

According to the 1993 disability survey, just over half of principal carers did not receive any help with the caring role from family, friends or formal services (ABS 1995: 39). Support resources play a significant role in reducing the perceived stress of caregiving, particularly among ageing carers. High unmet support needs of ageing parent carers are associated with a preference for residential placement for their adult or ageing child (Heller & Factor 1993).

Assisting ageing people with an early onset disability and their families to plan for the transition from parental to non-parental care will be an important issue for service planning

and provision. Parents' reluctance to relinquish care or make concrete plans for the transition and their pivotal role in the support networks of adults with disabilities who remain at home suggest that the transition from parental care to non-parental care may be a time of crisis (Bigby 1994, 1996).

There are, therefore, needs for both support programs to assist families caring for ageing people with disability living at home and the development of residential options for those needing placements when families can no longer provide care in the home.

It has been suggested that carers should receive a separate assessment of their own needs. The assessment should consider the carer's relationship with the person with lifelong disability and the assistance the carer needs for his/her caring role. The impact of caring on the carer and the supports needed to maintain quality of life and wellbeing of both the carer and care recipient should also be taken into account (Gething et al. 1999).

More flexible working arrangements in the future are likely to assist carers in a caring role. In 1996, more than 43% of females were working on a part-time basis, while in 1970s only one-third of women did so (Jackson 1998). (See Chapters 16 and 18; AIHW 1999a for analyses of the 1998 ABS disability survey data.)