

18 Implications for support services

This chapter draws together the main themes and findings of the previous chapters to examine implications for support service provision, government expenditure and the availability of informal assistance for people with a disability. In doing so, the chapter addresses the following research questions raised in the project brief:

- (a) What is the most relevant, reliable information about population ageing?
- (b) What are the ageing trends of people with a disability?
- (c) At what ages are what types of assistance needed?
- (d) What implications for disability support services arise from the overall ageing of the population?
- (e) Can we usefully distinguish between disability clients and aged care clients, with respect to their need for services? When is a person's requirement for assistance a result of ageing rather than the onset of disability at an earlier age, and does any such distinction have implications for the nature of services provided?
- (f) What are trends in informal care? How might these trends interact with population factors to affect demand for disability services into the future?
- (g) What projections can reliably be made about the population with disability over 10-, 20- and 30-year time frames?
- (h) What inferences can be made about future needs for support services over these time frames?

The Summary of the report uses those research questions as section headings.

18.1 Population ageing in Australia

Population ageing is a result of the interaction of three basic demographic components: fertility, mortality and migration. Population ageing is indicated by an increase in the proportion of older people (mainly attributable to lower fertility) and an increase in the absolute number of older people (largely a result of lower mortality among older people and a large birth cohort ageing, e.g. when the post-World War II baby-boom generation enter old age). The time, speed and scale of the population ageing process have considerable social and economic impacts on both individuals and society.

ABS 1998 population projections indicate that the ageing of the Australian population will continue, as the inevitable result of low levels of fertility over a long period and a decline in mortality rates. Median age is projected to increase from 34.3 years in 1997 to between 40.1 and 41.1 years in 2021 and between 43.7 and 46.2 years in 2051 (Table 2.1).

There are several important aspects of population ageing in Australia: the projected ageing of the aged population itself; the rapid pace of ageing of the working-age population; and the progression up the age pyramid of some significant age cohorts, in particular the post-World War II baby-boom generation.

Increase in the proportion of people aged 65 or more

The proportion of people aged 65 years and over is projected to increase rapidly from 12% (2.2 million people) in 1997 to 18% (4.0 million people) in 2021, and to between 24% (6.0 million people) and 26% (6.3 million people) in 2051 (Table 2.1).

The growth of the population aged 65 years and over is projected to reach record rates—to increase by 36.2%—as the peak of the post–World War II baby-boom generation reaches retirement age between 2011 and 2021 (Tables 2.2 and 2.3; Figure 2.2).

Ageing of the aged population

Between 1997 and 2051, the number of people aged 75 and over is projected to increase by around 3.5 times, and 5.3 times for people aged 85 and over (Table A2.3). The number of people aged 85 and over is projected to increase from 216,100 in 1997 to between 1.1 million and 1.2 million people in 2051. The number of people aged 85 or over as a proportion of total people aged 65 or over is projected to increase from 9.6% in 1997 to about 18.8% in 2051 (ABS 1998a: 12).

Ageing of the working-age population

The working-age population in Australia (aged 15–64 years) will also be ageing in the coming decades. During the next two decades the working-age population is projected to account for a higher proportion of the total population than at any time since World War II (Young 1990; ABS 1998a). The age structure of the working-age population is projected to change substantially over the projection period, with the greatest growth occurring in the age group 45–64 years—from 4.0 million in 1997 to between 6.1 million and 6.5 million in 2051. The number of people aged 45–64 years is projected to be higher than the number aged 65 years or over throughout the projection period, although the difference in size of the two groups will reduce steadily over the period (ABS 1998a; Tables 2.2 and 2.3; Figure 2.1).

The bulge of the baby-boom generation

Australia experienced a significant rise in birth rate between 1946 and 1961. People born during this period are often referred to as the post–World War II ‘baby-boom generation’. From 1997, the first of the baby-boomers have been passing age 50 and entering the age groups with significantly higher risk of disability. Between 1997 and 2006, the population aged 50–64 years is projected to increase at a markedly higher rate than the population aged 65 years and over. Between 2006 and 2011, the population aged 60–64 is projected to increase at the highest rate (26.9%) of all age groups. Thereafter, the population aged 65 years and over will grow faster (Table 2.2 and Figure 2.2). This shift mainly reflects the passage of the baby-boom generation.

18.2 Impact of population ageing on disability prevalence

Measures of disability prevalence

This report has examined changes in disability prevalence using a number of measures:

- overall prevalence rates, age- and sex-standardised prevalence rates and age- and sex-specific prevalence rates;
- number of people with a disability in the general population and in particular population age groups; and
- number of people with a disability as identified by the social welfare system (e.g. number of recipients of Disability Support Pension).

It is important to be aware that the above measures do not always show the same trend or the same magnitude of change in disability prevalence.

The age-standardised prevalence rate is an important measure for monitoring changes in underlying prevalence by controlling for the changes in population age structure, since disability is highly age-related.

Variation in overall prevalence rate and the number of people with disability in a population can be attributable to changes either in population age structure or underlying age-specific rates, or both. Hence, population ageing could result in an increase in the overall prevalence rate and the number of people with disability in the population, even though underlying age-specific prevalence rates might remain constant or decline slightly.

Changes in disability rates (or numbers) in the context of the social welfare system are more complicated, since there may be related changes in policies, programs, social attitudes and economic incentives concerning sickness and disability, as well as changes in the prevalence of disability in the population.

At any given time, the prevalence of disability is determined by the combined effect of various factors, such as past and recent incidence, remission rates for diseases, rehabilitation rates, age at onset of disability and survival rates of people with disability and of the general population. Some of these factors are countervailing. For example, a higher survival rate of people with long-term disability could increase the prevalence while a higher rate of recovery from disabling conditions may lead to lower prevalence. Various factors that affect the overall prevalence of disability, including social factors, are summarised in Chapter 3.

Population ageing and disability prevalence

Comparative analyses of the four ABS disability surveys (Chapter 12) reveal that:

- Between 1981 and 1998, the age-standardised disability prevalence rate increased from 14.6% to 18.8%, and the rate for all specific restrictions increased from 10.7% to 16.1%. The rate for severe or profound core activity restrictions increased from 4.3% in 1993 to 5.5% in 1998, though the rate was relatively stable between 1981 and 1993.
- The total number of people with a disability increased by 80% between 1981 and 1998. The number of people with all specific restrictions and with severe or profound core activity restriction in 1998 was more than twice that in 1981.

- Growth in the reported number of people with a severe or profound core activity restriction during the period 1993–1998 (43%) was almost four times that between 1988 and 1993 (11%).

Population growth has a major impact on disability prevalence. For the purpose of looking at effects on disability prevalence, population growth can be broken down into two components: (i) change in population size, and (ii) change in population age structure, that is, population ageing.

- During the 17-year period 1981–1998, population growth contributed about 50% of the increase in the number of people with a disability, and 45% of the increase in the number of people with severe or profound core activity restriction.
- Over the entire 17 years, increase in population size contributed more than population ageing to the increase in the number of people with a disability. However, the impact of population ageing was more evident during the most recent 10 years (1988–1998). Over that period, the effect of population ageing on the increase in disability prevalence was 1.3 times the magnitude of the effect of increasing population size, 1.5 times for all specific restrictions and 2.6 times for severe or profound core activity restriction.

The analyses suggest that population ageing has had a strong impact on the prevalence of severe or profound core activity restrictions, and that effect has been particularly evident among people aged 65 years and over in the last decade.

Some recent international studies have reported evidence of a declining prevalence of disability among the older population in some OECD countries such as the United States (e.g. Manton et al. 1995). However, findings across data sets in the United States suggest that there has been fluctuation rather than a clear ongoing trend in the prevalence of disability (Crimmins et al. 1997). Data collected between 1989 and 1994 on people aged over 65 years in England and Wales showed a greatly increased prevalence of disability in the very old population, particularly among women (Parker et al. 1997). Further evidence is needed before drawing conclusions about a trend of decline in disability prevalence among the older population (Chapter 3).

Changes in prevalence between 1993 and 1998

The 1998 ABS Survey of Disability, Ageing and Carers indicated an increase in the proportion of people with a severe or profound core activity restriction, in particular among people aged under 65, between 1993 and 1998. Although population factors, in particular population ageing, could explain a significant part of the increase, some change remains to be explained.

As discussed previously, other factors contribute to the changes in reported disability prevalence. Factors that affect the real underlying prevalence of disability include changes in the level and pattern of morbidity and changes in medical prevention and intervention strategies. In addition, there are factors that can lead to changes in reported prevalence, even when real underlying prevalence rates remain unchanged. These include changes in community perceptions and awareness of disability, changes in social attitudes and economic incentives concerning sickness and disability.

Changes in survey design and interview methods are likely to explain some changes in prevalence estimates between 1993 and 1998. Some, but not all, of these methodological changes can be controlled for in comparative analyses. It is difficult to fully quantify their contribution to changes in estimated prevalence between 1993 and 1998 (ABS 1993, 1999;

AIHW 1999a). Some changes in the 1998 survey that could have affected estimated prevalence are as follows:

- The use of computer-assisted recording of responses allowed interviews to flow more smoothly, which may have affected the way people responded to survey questions.
- Questions about difficulty with tasks and need for assistance were re-ordered, to improve interview flow; this may have affected responses concerning core activities, which were used to identify severe or profound core activity restrictions.
- The SF-12 health status instrument (which included questions on activity) was used before questions about activity restrictions were asked.
- Both the profound and severe core activity restriction categories were applied to the cared accommodation component. In 1993 the severe and profound categories were combined for people living in establishments.

In 1993 there was a substantial group of older people who reported needing help with daily activities, but who were not captured by the disability screening questions. This was seen as a problem. In 1998 there were far fewer people in this category, suggesting successful 'fine tuning' of the survey instrument (AIHW staff discussion with ABS staff 2000).

On the basis of information and analyses to date, it appears that the increase in age-standardised prevalence rates for severe or profound restrictions between 1993 and 1998 may be mainly a result of changes in survey methodology rather than a significant increase in underlying prevalence. The ABS is preparing to publish a report examining reasons for the increase in the number of people with a severe or profound core activity restriction between the 1993 and 1998 disability surveys.

Nevertheless, the marked increase in the prevalence of disability among males aged 5–14 merits further investigation. Between 1981 and 1998, age-standardised rates of severe or profound core activity restriction for males aged 5–14 years increased by 2.9 percentage points, from 2.0% to 4.9%. Most of this increase occurred between 1993 and 1998 (2.2 percentage points). This increase is more than two times the average increase for males aged 15–64 years in the period 1993–1998 (Chapter 12). Does this trend for young males reflect an increase in the underlying prevalence of early onset disability? If so, what are the implications for disability prevention and early intervention? Further study is needed to investigate whether the increase might be a result of increased labelling and recognition of particular disabilities in young males—for example, specific learning disabilities, attention deficit disorder and autism (AIHW 1999a). Another possible explanation is increased survival rates for babies and children with disabilities, due to improved medical technologies (Chapter 7).

Ageing trends of people with a disability

Comparative analyses of data from the four ABS disability surveys (Chapter 13) show that the population with a disability has aged over the period 1981 to 1998. This is particularly true for the population with severe or profound core activity restriction.

Of people aged 65 or over, the proportion aged 75 or over increased from 45% to 53% for people with a disability and 66% to 73% for people with a severe or profound core activity restriction (Chapter 13). The proportion of people with a severe or profound core activity restriction who were aged 65 or more was substantially higher for females than for males, though these sex differences declined between 1981 and 1998. This might be due to the fact

that, while the life expectancies of both males and females are increasing, the rate of increase in recent years has been faster for males than for females (McDonald 1997).

The working-age population with a severe or profound core activity restriction has also aged. Among people reporting a severe or profound core activity restriction, the proportion aged 45–54 increased significantly between 1981 and 1998. During the next decade, the progressive upward movement of the baby-boom generation in the population age pyramid could continue to cause an increase in the number of people with severe or profound core activity restrictions in the 55 to 64 year age group. It is also likely to cause significant ageing of the older population with severe or profound core activity restrictions from the second decade of the twenty-first century.

Ageing of people with an early onset disability

Survival to older ages is now a reality for some people with an early onset disability (e.g. Eyman & Borthwick-Duffy 1994), due partly to advances in medical technology. There is also empirical evidence indicating that people with an early onset disability resulting from certain diseases or conditions show earlier declines in function. A number of United States studies have suggested that functional decline for people with a developmental disability begins during the individual's mid-40s to mid-50s (e.g. Janicki et al. 1985). There are also suggestions that people with severe physical disabilities, such as those resulting from spinal cord injury and brain injury, begin ageing earlier than the general population, and that some health conditions worsen with increased duration of disability (e.g. Gething & Fethney 1998).

Signs of premature ageing have consistently been reported in people with Down syndrome and intellectual disability resulting from other chromosomal causes (e.g. Suttie 1995). There is considerable documentation of earlier onset and higher incidence of Alzheimer's disease in people with Down syndrome (e.g. Bigby 1998), and of dementia among people with other types of intellectual disability (Cooper 1997).

Analysis of the 1998 disability survey data indicates that, of people with a severe or profound core activity restriction aged between 45 and 64, 30,200 (11%) had an early onset disability. Of this group, 65% had a main condition in the group 'physical other', 13% had a psychiatric main condition and 11% had an intellectual main condition.

Early onset was very common among people with an intellectual main condition aged 45–64 with a severe or profound core activity restriction—67% had an early onset disability. Rates of early onset were much lower in other main condition groups, particularly physical/other and psychiatric.

Of people aged 65 or over with a severe or profound core activity restriction, 13,000 (4%) reported an early onset disability, and nearly 70% of these had a main condition in the group physical/other. Over 30% (154,800) of people aged 65 or over with a severe or profound core activity restriction lived in cared accommodation, and the ABS survey did not provide information about age at onset for these people. In particular, of the 4,800 people aged 65 or over with a severe or profound core activity restriction and an intellectual main condition, over 90% lived in cared accommodation.

18.3 Impact of population ageing on government health and welfare expenditure

The implications of population ageing for government expenditure have been the subject of ongoing discussion in Australia over the last two decades, particularly in the 1990s, with the main focus on health and aged care costs. Although there is no disagreement that the Australian population is ageing, and that health and welfare expenditure per person is increasing, there are two main schools of thought concerning the impact of population ageing on future trends in government expenditure (Chapter 4):

- Some reports express concerns that the accelerated ageing of the Australian population and the rapid growth in the 1980s and the early 1990s in government expenditure on older people may be not sustainable. It has been suggested that, to address the emerging social and budgetary pressures of population ageing, urgent action is needed to 'moderate community expectations of government assistance, increase incentives for self reliance in older age and more equitably share the cost of age related services funded by the government'(see e.g. National Commission of Audit 1996:121).
- Other reports have pointed out that, although over the past two decades the ageing of the Australian population has put pressure on government health and welfare expenditure, the Australian health and welfare systems have coped well with rapid population ageing in the recent past. To provide a reasonably high quality of health services for future generations of older Australians is not beyond our national resources (Choi 1998; Gibson & Goss 1999; Goss 1998; Howe 1997).

A study of demographic influences on changes in social security spending over the past three decades (1965–1997) showed that expenditure on the Age Pension increased from 1.65% of GDP to 2.45% of GDP and expenditure on the Disability Support Pension (DSP) increased from 0.32% of GDP to 0.99% of GDP (Whiteford & Jackson 1998).

Population ageing has contributed substantially to the growth in numbers of Age Pension recipients, primarily for females. Approximately two-thirds of the growth between the late 1980s and 1997 could be attributed to population ageing. Between 1971 and 1997, the number of recipients of the Aged Pension increased from just over one million to just over two million (Whiteford & Jackson 1998).

The highest incidence of receiving the DSP is in the age group 50–64 years, the upper end of the working-age population. Prior to 1997, changes in the age structure of the working-age population had little impact on growth in the number of DSP recipients, since people aged 50–64 years as a proportion of the total working-age population (15–64 years) remained fairly constant at about 22% between 1971 and 1997. However, in the late 1990s, the first baby boomers have begun to pass age 50 and are entering the highest disability incidence age group (50–64). The increasing age of this baby-boomer cohort, reflected in the ageing of the working-age population, may cause further growth in the number of DSP recipients (Whiteford & Jackson 1998; Jackson 1999).

Over the past 20 years, although health expenditure generally grew at a rate higher than GDP, there has been sufficient growth in GDP that the proportions of the GDP and of all government outlays allocated to health have not increased greatly. Government health and welfare expenditure on older people as a proportion of GDP has also remained stable (Choi 1998).

During the past two decades, many changes have been made to the health and aged care systems to maintain care at an affordable level. The controls put in place to contain health and welfare expenditure have resulted in a manageable increase in government expenditure.

The growth of the economy over the past two decades has allowed more funds to be made available for government services, and some of these additional funds have been allocated to health and welfare services for older Australians (Choi 1998).

In comparison with some European developed countries, Australia's relatively young population age structure gives scope for a shift in government expenditure towards older people in the future. The current level of expenditure in Australia could accommodate a population as old as Sweden's by making marginal shifts between health expenditure on younger and older age groups as the population ages (Howe 1997).

There is room for improvement to ensure that increased levels of government expenditure are associated with improved outcomes. It will be necessary to develop approaches that will optimise health status across the population within a given level of expenditure (Howe 1997).

It has been suggested that 'free' access to long-term care services in future may be limited, either through increased personal financial contribution by care recipients or by introducing optional or compulsory 'pre-funding'; and that changes in policy and legislation and taxation arrangements are needed to facilitate private sector involvement in the funding process for long-term care (Walsh & De Ravin 1995).

It should be emphasised that the consequences of population ageing should not be seen only in terms of the narrow, budgetary implications (Saunders 1996). Old age is not synonymous with economic burden or dependency. Many older people participate in unpaid productive activities, unpaid volunteer work and unpaid care for children, people who are sick or who have a disability.

18.4 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. Gibson et al. 1996; Howe et al. 1997; Madden et al. 1996; Sitsky 1994). In 1998 there were 1,895,100 people with specific restrictions who needed assistance with a range of activities. Of these, 1,648,800 (87%) received informal help (AIHW 1999a: 250). Meanwhile, Australia's service system has been successful in providing services to complement informal care, to sustain the efforts and choices of carers. Trends in informal care are affected by demographic changes and other social and economic factors, in particular the combined effects of population ageing and trends in de-institutionalisation among people with a disability.

Demographic impact 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 people aged 65 and over during the period (Table 2.3 and Figure 2.1). The 1998 ABS disability survey data show that 43.0% of primary carers were aged 45 to 64 years, as compared with 35.0% aged 15 to 44 years and 21.4% 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 1998 disability survey found that caring for a spouse was the most common caring relationship among all adult primary carers. In 1998, there were 192,100 spouse primary carers, accounting for 42.9% of primary carers aged 15 years and over (Chapter 16).

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 profound or severe core activity restrictions among both the working-age population and the population aged 65 and over will further increase the need for carers.

Fourth, the ageing of carers is likely to continue to be an issue of concern. Analysis of the 1998 ABS disability survey found that in 1998, 96,700 primary carers were aged 65 years and over; of those, 60,400 (62.5%) were females. Of those primary carers aged 65 years and over and living with the care recipient, 8,900 were parents and 72,400 were spouses (Chapter 16).

Ageing parents caring for their son or daughter with a severe or profound core activity restriction 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. Since people with an early onset disability are living longer, ageing carers often find that the caring role becomes more difficult with time, and wish to see alternative arrangements put in place for the future care of the person involved (Madden et al. 1996).

Other factors affecting changes in informal care

Demographic factors interact with other social and economic factors to affect the demand for services and informal care for people with a disability. These social and economic factors particularly relate to 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 providing care (Schofield & Bloch 1998; McDonald 1997).

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 1993 cited in Clare & Tulpule 1994). Declines in marriage rates and increases in divorce rates reduce the potential for spouse care.

Changes in the geographic location of older people and the ageing of country town populations (Chapter 2) also affect older people's informal assistance network. Many younger people are moving away from country towns, reducing 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).

Trends in de-institutionalisation among people with a disability

A review of information in the fields of aged care, disability services and mental health indicates that there is a continuing shift from residential care to community care, although

there is some variation between the fields in terms of how this shift is occurring (Madden et al. 1999). This trend has implications for the level formal services and informal assistance required to meet the needs of ageing people, people with disabilities and carers living in the community.

Disability services

There has been a trend towards de-institutionalisation among people with a disability who need ongoing assistance over the years 1981, 1988 and 1993 (AIHW 1997a; Wen & Madden 1998a). The trend is particularly marked for people aged under 30 years. Between 1981 and 1993, there was a large increase in the number of people aged under 65 years with a severe or profound core activity restriction living with their relatives (Chapter 5). Between 1981 and 1993 nearly 40% of the increase in the number of people with a severe or profound core activity restriction aged under 65 years living in the community was associated with population growth (Wen & Madden 1998b).

The 1998 ABS disability survey data indicate that the trend towards community living has continued. The proportion of people aged 5–64 with severe or profound core activity restrictions living in cared accommodation has steadily decreased from 9.9% in 1981 to 2.6% in 1998. Since 1993, there has been an increase of 250,000 people aged 5–64 years with severe or profound core activity restrictions living in households, and a decrease in the number living in cared accommodation (although some of the changes between 1993 and 1998 may be due to changes in survey methodology) (AIHW 1999a: 256).

While major efforts to close institutions and accommodate people in the community have had a significant effect on the institutional population, the trend in de-institutionalisation is due largely to potential new service users remaining in community-based living arrangements, mainly with their relatives. It is also possible that many 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).

Aged care services

Under the policy directions of the Aged Care Reform Strategy, there has been a shift in the emphasis of care from residential towards home-based care in the aged care field since 1985 (Gibson et al. 1997; Gibson 1998). Over the past ten years, the overall level of residential care has declined from 99 to 92 beds per thousand persons aged 70 years and over. This reduction has occurred during a time of rapid ageing of the aged population in Australia (Gibson 1998). The shift from residential to home-based care is characterised by several important features (Gibson 1998):

- The level of institutionalisation has substantially declined as a result of natural attrition rather than discharge of individual clients. In other words, the de-institutionalisation is largely due to non-admission rather than to discharge.
- Within the residential care sector, there is a shift from 'high intensity' nursing home beds towards 'lower intensity' hostel places.
- There is an expansion of home-based care, not only in terms of the number and range of services but also the intensity of provision.
- An enhancement of respite care provisions has resulted in an emerging interface between home and residential care.

Support needs for carers

The caring role can be physically, mentally, emotionally and economically demanding. 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). 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.

Support resources play a significant role in reducing the 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 (Bigby 1994, 1996).

Analysis of the 1998 ABS disability survey data has found that, in 1998, 450,900 Australians, or 2.4% of the total population, were primary carers of people with a disability. There were 161,300 primary carers who spent, on average, 40 hours or more per week in providing care and, of these, 22,700 had been caring for at least 25 years.

Primary carers had high rates of disability. Of all primary carers, 177,500, or 39.4%, had a disability and 41,900 (9.3%) had a severe or profound core activity restriction. While these high overall rates of disability may be due in part to the older age structure of the carer population, age-specific rates of disability were significantly higher for primary carers than for the total population in the age groups 0–29, 30–44 and 45–64.

Many primary carers reported that the caring role impacted on their relationships with others, their financial situation and workforce status, and their health and well-being. Nearly a quarter said that they had lost or were losing touch with existing friends and 22.3% said that their relationship with the main care recipient had become strained as a result of the caring role. Nearly 30% of primary carers reported difficulty meeting living costs, and 10% had been diagnosed with a stress related illness.

Nearly half of primary carers aged 15 years and over received support in providing care. However, 41,300 primary carers (9.2%) who needed assistance did not get it, and 160,000 primary carers (35.7%) said that they did not have a fall-back carer. Of primary carers aged 15 years or over, 59,100 (13.2%) reported that they had used respite care services; 35,500 had used such services in the three months prior to the survey and, of those, 19,800 wanted more respite care. A vast majority of primary carers (388,900, or 86.8%) had never used respite care services, though 43,800 of those said that they needed such services.

18.5 Ageing, need for assistance and providers of assistance

Findings from the literature

Most people, at least until very late in their lives, do not experience losses of functional ability that seriously affect their social, physical or cognitive behaviour (McPherson 1990). However, some people experience losses of functional ability at different stages of their lives, depending on the nature and time of onset of their specific disabling conditions. Older people differ in terms of the rate and degree of biological and psychological change that they experience. The range of life circumstances and individual characteristics among older people with a disability is similar to that found among older people generally (Ashman & Suttie 1995).

There are needs common to all older people, related to their biological, psychological and social ageing. Older people tend to have a greater need for health, social, psychological and other support services, including accommodation, recreation and leisure, mobility, finance, advocacy and family support. However, ageing people with an early onset disability, in particular intellectual disability, are reported to need a different range of psychological and social supports, although their physical support needs may be quite similar to those of the general ageing population. The nature of services required by older people with an early onset disability may also differ from those required by their younger counterparts.

The literature indicates that the special needs of older people with an early onset disability are as follows (Chapter 8):

- They have a high need for formal support services, particularly accommodation support services, since they often do not have good informal support networks and may lack independent living skills.
- They have a high need for age-appropriate day activity and leisure programs. Separate specialist activity programs may be required in addition to, or instead of, community-based services designed for older people generally.
- Appropriate activity services may be required for people with an early onset disability who have previously worked in either supported employment or open employment.
- They have a high need for assistance in choosing, locating, negotiating access and travelling to community-based programs, and may also require short-term or ongoing assistance in order to participate in chosen activities.
- They have a high need for assistance in expanding their social networks beyond their families and parents' peer group.
- They may need special assistance in personal financial planning. The extra costs incurred by people with lifelong disability can mean that they face old age with few financial resources.
- The impact of disability changes throughout the life span and needs for support tend to increase with ageing. Therefore, reassessment of needs should be available to ageing people with a lifelong disability and they should be involved in initiating reassessments as required.

Findings based on population data

The analysis of the ABS population survey data in this report has examined the impact of ageing—both population ageing and ageing of people with a disability—on the level and profile of need for services and assistance, main sources of assistance, and changes between 1993 and 1998. The analysis focused on people with a severe or profound core activity restriction living in households and used a number of variables relating to need for services and assistance:

- need for assistance with any of ten daily activities (self-care, mobility, communication, health care, housework, property maintenance, paperwork, meal preparation, transport and guidance);
- need for assistance with any of three core activities (self-care, mobility and communication);
- need for assistance in more than one core activity;
- number of tasks for which assistance is needed with personal activities (core activities plus health care) and personal guidance; and
- frequency of need for assistance with particular activities.

Level and profile of need for assistance

Population ageing has had a strong impact on the prevalence of severe or profound core activity restrictions (Chapter 12) and thus on need for services and assistance (Chapter 15).

In 1998 there were 961,600 people with a severe or profound core activity restriction living in households, most of whom needed assistance with at least one of ten daily activities. There were 386,700 people who needed help with more than one core activity, including 73,000 needing assistance with all three core activities (self-care, mobility and communication).

Age differentials in need for assistance

The analysis indicated that there were differences in the level and profile of need for assistance between people aged under 65 and those aged 65 or more:

- Of people aged under 65, 633,400 needed assistance with at least one of the ten activities; of those, 264,300 needed assistance with more than one core activity, including 56,000 needing help with all the three core activities.
- Among people aged 65 or over, 324,600 needed assistance with at least one of the ten activities; of those, 122,400 needed help with more than one core activity, including 17,000 needing help with all three core activities.
- The proportions needing assistance with self-care, communication and personal guidance were substantially higher for people aged under 65 than for people aged 65 or over. For all other activity types, higher proportions of people aged 65 or over reported need for assistance.
- For people aged under 65 with a severe or profound core activity restriction, the activities with which need for assistance was most commonly reported were mobility (70.9%), self-care (56.8%) and health care (50.6%). Of children aged under 15, 71.6% needed guidance, 63.3% needed assistance with communication and 59.3% needed help with self-care.

- For people aged 65 and over with a severe or profound core activity restriction, the activities with which need for assistance was most commonly reported were mobility (84.0%), property maintenance (76.8%) and transport (71.3%).

Differences in need for assistance by age and main disabling condition

When both age and main disabling condition were taken into account, the analysis showed that some of the variations in level and profile of need for assistance were related to differences in main condition. Of all people aged under 65 with a severe or profound core activity restriction living in households, the two largest main condition groups were physical/other (453,500 people or 71.3%) and intellectual (102,400 people or 16.1%). People aged under 65:

- with an intellectual main condition most commonly needed assistance in the areas of guidance (85.9%), communication (71.6%), mobility (59.7%), self-care (57.2%) and health care (57.2%). Nearly 60% of people in this condition group needed assistance with more than one core activity, and 30% needed help with all three core activities.
- with a psychiatric main condition most commonly needed assistance with guidance (85.7%), mobility (83.6%) and transport (57.5%). About 28% of people in this condition group needed help with more than one core activity.
- with a vision-related main condition most commonly needed assistance with mobility (89.6%) and transport (82.8%).
- with a hearing-related main condition most commonly needed assistance with communication (63.2%) and guidance (53.7%). In the other activity areas, the proportions of people reporting need for assistance were relatively low.
- in the acquired brain injury main condition group most commonly needed assistance with mobility (92.7%), transport (82.4%), health care (71.5%) and paperwork (71.0%).
- in the physical/other main condition group, people most commonly reported need for assistance with mobility (72.7%), self-care (61.5%) and property maintenance (58.8%). About 40% of people in this group needed assistance with more than one core activity, and 4.6% needed help with all three core activities.
- in all main condition groups except hearing, a high proportion of people reported needing help with mobility.
- in the intellectual and the acquired brain injury main condition groups reported greater number of areas in which a high proportion of people needed assistance than did people in other groups.

Of all people aged 65 or over with a severe or profound core activity restriction living in households, the two largest main condition groups were physical/other (268,900 people or 82.6%) and vision (28,900 people or 8.9%). In each group about 37% of people reported needing assistance with more than one core activity. Nearly 5% of people with a physical/other main condition needed help with all three core activities. People aged 65 or over:

- with psychiatric and vision-related main conditions most commonly reported need for assistance with mobility and transport.
- with a hearing-related main condition most commonly reported need for assistance with mobility.

Of all people with a physical/other main condition, a higher proportion of people aged 65 or over than those aged under 65 reported need for assistance with personal activities of

mobility and health care and non-personal activities (e.g. housework and transport). In contrast, a higher proportion of people aged under 65 than those aged 65 or over reported need for assistance with self-care and guidance.

Over 90% of those aged 65 or over with an intellectual main condition were living in cared accommodation. Nearly 80% of people aged 65 or over with a psychiatric main condition were living in cared accommodation, a large proportion of whom may have had dementia-related conditions.

Main provider of assistance

In 1998, over 80% of people with a severe or profound core activity restriction reported an informal carer as their main source of assistance with self-care, mobility and communication activities. Substantial numbers of people reported no main provider of assistance with mobility (46,700), self-care (40,700), property maintenance (31,000), health care (28,400) and transport (22,200).

Health care, property maintenance and housework were the activities for which people were most likely to rely on formal services as their main source of assistance. Government organisations played a greater role than private sector organisations as the main formal service providers for the core activities of mobility and communication. Private organisations, in particular private profit-making organisations, were more likely to be the main provider of formal services with health care and property maintenance.

There were differences between people aged under 65 and those aged 65 or over:

- People aged under 65 were more likely than those aged 65 or over to rely on an informal co-resident carer as their main source of assistance with all activities except communication.
- People aged 65 or over were more likely to rely on an informal non-co-resident carer to assist with mobility, housework, property maintenance, paperwork and transport.
- People aged 65 or over were more likely to receive assistance from a formal provider than were those aged under 65 in the activities of self-care, health care, housework, property maintenance and meal preparation.
- Some 13% of people aged under 65 used a formal provider as their main source of assistance with communication while no people aged 65 or more did so.

Changes in the need for assistance 1993–1998

- Overall, the number of people reporting need for assistance increased substantially for all activities, with the largest increases in the areas of mobility (192,500), health care (184,800) and self-care (154,100).
- For all activities, percentage increases in the number of people needing assistance were markedly higher for people aged under 65 than for people aged 65 and over, although the growth rate of the population aged 65 or over (10.2%) was nearly twice as high as that for the population aged under 65 (5.8%).
- Percentage increases in the number of people needing assistance were particularly high in the age group 45–64. This reflects the impact of the baby-boom generation entering the older working-age groups.
- There was a large increase in need for assistance with communication among people aged 5–14 years.

Changes in main provider of assistance 1993–1998

- The number of people who reported that their main source of assistance was an informal co-resident care increased markedly for all types of activity, with increases of 100,000 or more in the activities of mobility, self-care, health care and transport.
- There was also an increase in the number of people who reported an informal non-co-resident carer as their main source of assistance, particularly with mobility, transport and housework.
- Increases in the number of people relying on formal services as their main assistance provider were greatest for the activities of health care (57,000), property maintenance (35,100) and mobility (26,000).
- There were no substantial changes in the proportions of people reporting informal co-resident, informal non-co-resident and formal providers as their main source of assistance, suggesting there has been little change in the balance between formal and informal sources of assistance.
- The increase in the number of people reporting an informal co-resident carer as their main source of assistance was much greater for people aged under 65 than for people aged 65 or more. This was largely because of the greater increase in the number of people with a severe or profound core activity restriction among people aged under 65.

Need for assistance and main source of assistance for people ageing with a disability

All people aged 45–64

Need for assistance among people ageing with a disability was examined by focusing on people aged 45–64 years with a severe or profound core activity restriction living in households. Comparisons were made both between people aged 45–64 and those aged 65 or more, and, where possible, between people aged 45–64 with an early onset disability (before 18 years) and people aged 45–64 with a disability acquired between ages 18 and 64.

In 1998, there were 276,000 people aged 45–64 years with a severe or profound core activity restriction living in households. Assistance was most often needed with activities of mobility (76.2%), self-care (58.1%) and property maintenance (69.5%). Some 78,200 people (28.5%) needed daily assistance with housework, 57,600 (21%) with self-care, 52,700 (19.2%) with mobility and 39,300 (14.3%) with health care. Nearly 100,000 people needed assistance with at least two core activities.

The proportions needing assistance with self-care and personal guidance were substantially higher for people aged 45–64 than for people aged 65 or over. However, for all other types of activity, higher proportions of people aged 65 and over reported need for help in comparison with those aged 45–64.

In 1998, 76.9% of people aged 45–64 with a severe or profound core activity restriction living in households were married or in a de facto relationship, compared with 48.7% of those aged 65 or over. People aged 45–64 with a severe or profound core activity restriction living in households were less likely to own a house outright than were those aged 65 or over.

People ageing with an early onset disability

Some of the comparative analyses of need for assistance between people aged 45–64 with an early onset disability (acquired before 18 years) and those with a disability acquired later in life suggest that people with early onset disability have higher levels of need. However,

because of the limitations of the survey data, in particular high relative standard errors associated with small estimates, it is not possible to reach firm conclusions.

Although data on age at onset were not collected for people living in cared accommodation, there are suggestions that people with an early onset disability are more likely to be living in institutions, probably due to higher levels of need for additional support at an earlier age.

Intellectual disability can be used as an indicator of early onset, as the majority of people with an intellectual disability have had their disability since childhood. In the age group 45–64 almost 40% of people with a severe or profound core activity restriction and an intellectual main condition were living in cared accommodation—a much higher proportion than for other main condition groups such as psychiatric (8.9%) and physical/other (2.2%). Among those aged 65 or more with a severe or profound core activity restriction, over 90% of those with an intellectual main condition were living in cared accommodation. People who have spent a large part of their life in cared accommodation are likely to face different issues and have different needs from those who have spent most of their life living in the community.

For people aged 45–64, the proportion who had ever married was substantially lower among those with an early onset disability than among those with a disability acquired later in life (82% versus 95%). This indicates that people with an early onset disability might be less likely to receive support from a spouse or children.

The data also show that 35.6% of people aged 45–64 with an early onset disability owned a house outright, while 38.5% were renting, boarding or living rent-free. In contrast, among those with a disability acquired between ages 18 and 64, over 45% owned a house and only about 23% were renting, boarding or living rent-free.

18.6 Service use pattern

Disability services

Many disability support services are provided or funded by Australian Governments under the Commonwealth/State Disability Agreement (CSDA). Data from the 1999 CSDA Minimum Data Set collection show that 20% of CSDA service recipients on the 'snapshot day' in 1999 were aged between 45 and 64 years, and 4% were aged 65 years or over.

The CSDA Minimum Data Set collection does not provide information about age at onset of disability. However, more than 60% of service recipients aged 45–64 years and 30% of those aged 65 or over reported their primary disability type as intellectual. This indicates that a high proportion of CSDA clients have early onset disability.

The proportion of service recipients who lived alone increased with age: 8.3% of those aged under 45, 14.6% of those aged 45–64, and 24.8% of those aged 65 and over. This suggests that older people with disabilities who are accessing services may have more limited access to informal care.

Aged care services

The Home and Community Care Program (HACC) is jointly funded by the Commonwealth and State and Territory Governments to provide services to older people and to younger people with disabilities. The HACC client population is showing signs of ageing. Between

1990 and 1997 the median age of HACC clients increased from 76 to 77 years. Over that period, the proportion of clients aged 80 years and over increased from 36.9% to 42.1%, while the proportion aged 65–79 years decreased from 42.3% to 38.2% (Department of Health and Aged Care 1998: 62).

The HACC user characteristics survey provides information on HACC clients, including services received and need for assistance in one or more of six broad areas of activity. In 1997–98, 8% of clients surveyed were aged under 45 years and 11% were aged between 45 and 64 years. In all activity areas except housekeeping, the proportion of clients who needed assistance was highest for the under-45 age group, followed by the 45–64 age group. This may suggest that people aged under 65 who access HACC services have relatively severe disabilities.

18.7 Discussion of support service implications

Needs for appropriate services: issues raised in the literature

The literature reviewed in Chapter 9 raises a number of issues concerning the provision of appropriate services for people ageing with a disability:

- People ageing with a disability are not a homogeneous group. Therefore, service provision should be flexible to meet individual needs and circumstances and to accommodate individual differences in life experience, the ageing process, independent living skills, health status and particular interests and preferences.
- It has been suggested that, because of service boundaries, there is currently inadequate linkage between disability and age care service programs. This makes it difficult to accommodate the emerging needs of people ageing with a disability. Older adults with an early onset disability may be falling between disability services and generic aged care services (e.g. Buys & Rushworth 1997; Bigby 1998).
- Existing problems with meeting the needs of people ageing with a disability are, to a large extent, related to the structures of service programs and the models of service delivery in use. That is, new types of services may not necessarily be needed if existing service models can be used more flexibly (e.g. Janicki et al. 1985; Gatter 1996; Ruggi 1998).
- It has been suggested that a streamlined assessment process should be used to produce individual care plans based on information about a person's overall needs. Different program areas could be involved in the assessment process. This might assist in resolving issues that arise for people with complex needs that cannot be fully met due to current service boundaries (Response from NSWADD 1999; Gething et al. 1999).
- There is wide agreement that one of the principal goals of a service program for ageing people with a disability is to maintain people in the community accommodation option of their choice for as long as possible and to minimise premature admission to nursing homes (e.g. Gatter 1996; Williams & Chad 1998).
- It has been suggested that, where appropriate, generic services should be seen as the first option for older people with an early onset disability, especially for people with mild or moderate intellectual disability. Nevertheless, specialist services may be necessary to assist people in accessing generic services, or to ensure that generic services are provided in a sensitive and appropriate manner (Bigby 1992).

- Some people with an early onset disability have difficulty accessing generic services for various reasons. As well as program restrictions and funding limitations, people with disabilities are often perceived as being incompatible with present client groups of generic services; access to generic services may be particularly limited for individuals with challenging behaviours. Providers of generic services may lack the skills and resources required to meet the needs of people with certain disabilities. Some people with an early onset disability rely heavily on others to provide adequate and appropriate support to access generic services (e.g. Williams & Chad 1998).
- There is a growing number of employed people with a disability who are approaching retirement. The nature and extent of retirement issues for people with a disability in Commonwealth-funded employment services is being examined in a study commissioned by the Commonwealth Government to identify strategies that may facilitate the transition from work to retirement for this group of people.
- There are particular issues related to the interface between services for older people with psychiatric disability and aged care services. A scoping study has been conducted by AIHW to explore possibilities for further improvement of health care services to meet the needs of older Australians with mental disorders and their carers (AIHW 1998b; AIHW 1999b).
- The demand for accommodation support services by ageing parents for their adult sons and daughters with disabilities is expected to increase. Demand for respite services can also be expected to increase, especially from those families who have chosen to continue to care for their ageing relatives with a disability in the family home. The capacity of services to respond to more frequent crisis in caring should be enhanced (Gatter 1996).

Emerging planning and service models

New initiatives in service planning and models are emerging in the States and Territories to meet the needs of people ageing with a disability and to begin to address a number of issues raised in the literature. Some major initiatives are (see Chapter 10):

- In New South Wales, the Ageing and Disability Department is currently implementing a new approach to service planning and future resource allocation which is based on population groups rather than funding programs. The Population Group Planning model assists in allocating resources on the basis of service supply and demand data. The model has been designed so that data from other government departments and organisations can be included.
- Another initiative in New South Wales is the Community Care Assessment Framework that has been developed jointly by the Ageing and Disability Department and Health Department. The framework aims to establish a collaborative inter-agency process for comprehensive assessment of people who need complex, multiple or high levels of support. A streamlined assessment process is used to develop a care plan which comprehensively addresses the service needs of the individual. The framework is aimed at improving coordination between the health, HACC, disability and aged care sectors. It is currently being implemented by all HACC services in New South Wales. The same framework or a complementary model will be introduced into the Disability Services Program at a later stage.
- In Victoria, a number of projects related to the issues of ageing and disability are being planned and/or carried out: day support service options for older adults with a disability, accommodation options for older people, and scoping and mapping the needs

of people with high medical/clinical needs. The day support service options project is a national study to identify issues concerning the development and provision of day support services for older adults with a disability and their carers, community service providers and government. The project is being guided by a steering committee representing the NDA.

- In Western Australia, the Disability Services Commission held a one-day conference on disability and ageing, in recognition of the need to plan for the projected significant increase in the number of people with a disability who are ageing. The conference provided an opportunity to profile some of the work that is being undertaken by service providers across the disability and aged care sectors and to explore the potential for other partnerships across the two sectors. The Disability Services Commission plans to continue providing opportunities for the two sectors to get together and has also undertaken to develop a Disability and Ageing Plan that will provide a mechanism to strategically address the range of issues confronting people with disabilities who are ageing, their families and carers.
- In 1998, the Disability Services Commission outsourced a 12-bed hostel to the management and operation of an aged care provider, Baptist Homes. This was in response to the fact that most residents of the hostel were aged 55 or over and had an intellectual disability, were becoming increasingly frail, and had health needs that were becoming more dominant than the needs associated with their disability.
- In South Australia, the Intellectual Disability Services Council Accommodation Services is currently proposing to set up specialised aged care services. The services are expected to meet the ongoing needs of people with an intellectual disability and to provide specialist support to other agencies assisting people with intellectual disability.
- The Australian Capital Territory Government is promoting a partnership approach to service provision. It is working to put in place a framework for joint planning involving local offices of Health and Aged Care, and Family and Community Services. The Australian Capital Territory has negotiated a bilateral agreement with the Commonwealth to improve the interface between State-funded day support services and Commonwealth-funded employment and training services. The purpose is to assist people needing a flexible combination of these services and to avoid problems that may arise when people move between services.
- The Australian Capital Territory Health and Community Care Department is currently testing a model under which one provider is contracted to deliver a range of in-home support services, such as home help, personal care, food services and respite, where a client needs a mix of these services. Although there is no formal evaluation yet, informal feedback indicates that this approach is more consumer-centred, helps to improve referral and transfer processes between services, and encourages creative and flexible arrangements (Williams 1999: 7).