

Summary

This study of disability and ageing in Australia was commissioned by the National Disability Administrators. The study is designed to provide information to assist disability support service providers and senior policy makers faced with questions about the likely impacts of population ageing on disability prevalence, support services and availability of informal assistance.

This summary draws together the main findings of the study to address the research questions of the project brief.

Report outline

Chapters 1 to 10 focus mainly on literature review. Chapters 1 to 5 present an overview of population ageing and its impact on disability prevalence, expenditure and services for people ageing with a disability. The combined effects of population ageing and de-institutionalisation on informal care are reviewed. Chapters 6 to 10 consider the ageing trends of people with a disability, particularly those with an early onset disability, and outline their special needs for support. Emerging issues related to service needs, and new initiatives in service planning and models, are also discussed.

Chapters 11 to 17 assess information from disability surveys, other population surveys of national significance, and service administrative data. The analysis in these chapters concentrates particularly on data from the most recent Australian Bureau of Statistics disability survey (in 1998).

Chapter 18 summarises the main findings of previous chapters and examines the impact of ageing on support service provision, government expenditure and informal assistance for people with a disability. Chapter 19 draws out the most salient information for disability administrators to consider when planning the evolution of services.

What is the most relevant, reliable information about population ageing?

The Australian population will continue to age, as the inevitable result of declining mortality rates and low levels of fertility over a long period. Population projections indicate a clear long-term trend of decline in growth rate: from 1.2% in 1996–97 to between 0.0% and 0.3% by 2051 (Chapter 2).

The bulge of the post–World War II baby-boom generation is currently affecting the structure of the under-65 population. Between 1997 and 2006, the 50–64 age group is projected to increase at a markedly higher rate than the 65-plus age group. Between 2006 and 2011, the 60–64 age group is expected to increase at a higher rate (26.9%) than any other age group.

Record rates of increase in the population aged 65 and over are likely between 2011 and 2021 as the peak of the baby-boom generation reaches retirement age. The proportion of the population in this age group is projected to increase from 12% (2.2 million people) in 1997 to 18% (4.0 million) in 2021, and between 24% and 26% (6.0–6.3 million) in 2051.

Two particular aspects of population ageing are likely to impact on disability prevalence and the need for services:

- *The rapid pace of ageing of the working-age population:* the greatest growth will be in the 45–64 age group—from 4 million in 1997 to over 6 million in 2051.
- *The ageing of the aged population:* the 85-plus age group is projected to increase as a proportion of the population aged 65 and over, from 9.6% in 1997 to about 18.8% in 2051.

What are the ageing trends of people with a disability?

In 1998, 954,900 people, 5.5% of the population, had a severe or profound core activity restriction, meaning that they sometimes or always needed personal assistance or supervision with a core activity (self-care, mobility or verbal communication).

As a result of general population ageing, the population with a disability is also ageing (Chapters 11, 13 and 14). Among people aged under 65 with a severe or profound core activity restriction, the proportion aged 45–54 increased from 19% in 1981 to 22% in 1998. In the 65-plus age group, the proportion aged 75 and over increased from 66% to 73% during the same period. This ageing trend is likely to continue as the baby-boom generation moves into older age groups.

Survival to older ages is now a reality for some people with an early onset disability. Of people with a severe or profound core activity restriction, 11% (30,200) of those aged 45–64 and 4% (13,000) of those aged 65 or over reported an early onset disability (i.e. acquired before age 18).

What implications for disability support services arise from the overall ageing of the population?

Population ageing and prevalence of severe or profound core activity restriction

Population change has contributed strongly to the growth in the number of people with a severe or profound core activity restriction, particularly during the most recent period (Chapter 12).

The overall effects of population change can be broken into two major components:

- change in total population size; and
- differential growth among age groups, resulting in population ageing.

Population ageing tends to result in increased disability prevalence because the risk of disability is greater in older age groups.

The number of people with a severe or profound core activity restriction in 1998 (954,900) was more than twice that in 1981 (452,900). Population change (both increase in size and population ageing) contributed about 45% of this increase.

During the most recent 10 years (1988–1998) population ageing has contributed much more than growth in population size to the increase in the number of people with a severe or profound core activity restriction.

Implications for planning broad level resource allocation

Potential ageing of CSDA service users

Between 2000 and 2006, the number of people with a severe or profound core activity restriction in the age group 45–64 is estimated to increase by 19.3%, or 59,500 people. How many of these people will need disability support services? The current age distribution of service users under the Commonwealth/State Disability Agreement (CSDA) has a peak at

age 20–39 years. Time series data suggest that, over time, this age distribution may change, with people in late adulthood making up an increasingly large proportion of service users (Chapter 17).

‘Service transition’ or ‘ageing in place’

Because of their changing needs, or changes in their eligibility for certain services, it may be appropriate or necessary for people ageing with a disability to transfer between service types—for instance, from employment support to day activity services, or from specialist disability to generic aged care services. This transition is most likely to affect people with an early onset disability in their later working-age years.

How will it be decided whether a person ageing with a disability should make the transition from disability services to aged care services? In 1998, there were an estimated 274,000 people aged 45–64 with a severe or profound core activity restriction living in households. On the snapshot day of the 1999 CSDA Minimum Data Set (MDS) collection, about 15.8% of service consumers (11,563 people) were aged 50 years or over and 6.1% (4,491 people) were aged 60 years or over (Chapter 6). These people could be candidates for transition to aged care services in the near future or, alternatively, arrangements for ageing in place may be needed.

Expenditure on service provision

Over the past two decades, there has been an increase in health and welfare expenditure on older people. Nevertheless, controls have been put in place in health and aged care systems in order to maintain care at affordable levels. Australia’s relatively young population age structure provides scope for a shift in government expenditure towards older people in the future (Chapter 4).

Issues concerning the age dependency ratio

Arguably, the ratio of the population aged 65 years and over to the population of working age (15–64 years) may not be the best indicator of the ‘burden’ of population ageing. The working-age population includes people with a disability whose labour force participation may be limited, as well as unemployed people who may receive income support and other welfare services. Also, the majority of people aged 65 to 80 do not need long-term aged care services and many people aged 65 or over continue to participate in paid or voluntary work.

Ageing, need for assistance and providers of assistance

This section addresses the project brief questions:

- At what ages are what types of assistance needed?
- 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?

Differences in need for services and assistance

Differences in level of need for assistance may be related to a number of factors, in particular age, type of disabling condition and age at onset of disability (Chapters 14, 15, 18 and 19).

Among people with a severe or profound core activity restriction living in households in 1998, there were broad age differences in the levels and profiles of need:

- Of the 636,000 people aged under 65 with a severe or profound core activity restriction, 41.6% needed assistance with more than one core activity, including 8.8% who needed help with all three core activities (self-care, mobility and communication).
- Of the 325,600 people aged 65 or over with a severe or profound core activity restriction, 37.6% needed help with more than one core activity, including 5.2% who needed help with all three.
- 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.

These differences may partially be explained by differences between the two age groups in the proportion of people with early onset disability and dominant types of main disabling condition.

Many disabling conditions have strong associations with particular age groups. For people aged under 65 the two largest main condition groups were physical/other (71%) and intellectual (16%). For people aged 65 or over, the two largest main condition groups were physical/other (83%) and vision (10%). Most people with an intellectual main condition (99.6%), acquired brain injury (84.6%) or psychiatric main condition (75.8%) were aged under 65. In contrast, some 82% of people with vision-related main conditions were aged 65 or over (Chapter 15).

Some variations in need for assistance were associated with differences in type of main condition. For example, people with an intellectual or acquired brain injury as their main condition tended to report higher levels of need.

In 1998, 42% of people aged under 65 with a severe or profound core activity restriction had acquired their disability before age 18, compared with just 4% of people aged 65 or over. Although data on age at onset were not collected for people living in cared accommodation, it appears 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. At age 45–64 almost 40% of people with a severe or profound core activity restriction and an intellectual main condition were living in institutions—a much higher proportion than for other main condition groups.

Differences in main providers of assistance

Most people with a severe or profound core activity restriction living in households were assisted by co-resident informal carers. Compared with people aged 65 or over, those aged under 65 were (Chapter 15):

- more likely to rely on an informal co-resident as the main source of assistance with most daily activities;
- less likely to rely on an informal non-co-resident to assist with mobility, housework, property maintenance, paperwork and transport; and
- less likely to receive formal services in the areas of self-care, health care, housework, property maintenance and meal preparation.

These differences in patterns of main sources of assistance may have implications for the nature of the 'service transition'.

Understanding the 'grey areas' in services for ageing people with a disability

While there are similarities between the current disability and aged care service systems in broad service philosophies and policy directions, the two systems differ in their program focus, service types, main target groups and trained personnel. In particular:

- Aged care services are geared to the needs of frail older people and older people with a disability, while disability services generally focus on people aged under 65.
- Aged care services focus more on health needs, broad personal care and self-maintenance, while disability support services emphasise non-health needs and address a broader range of life domains, including employment.

People ageing with a disability may encounter 'grey areas' in service provision in the border territory between the disability and aged care service systems. There are four categories of people with special needs who are approaching potential service 'grey areas'. These categories are not necessarily mutually exclusive but may be of use in identifying particular issues for service planning:

- People ageing with an early onset disability often have fewer basic living skills and so need higher levels of assistance in some areas. The services they require may be different from those needed by their younger counterparts. In 1998, there were 274,000 people aged 45–64 with a severe or profound core activity restriction living in households; of those, 30,200 acquired a disability before age 18.
- People ageing with a disability acquired during adulthood usually have basic living skills. Their need for assistance generally arises from increasing physical frailty and diminishing levels of functional skills.
- Some people ageing with an intellectual disability may acquire dementia relatively early in life, at around age 50. They may become frail and need health and medical care more than help with other activities. These people might be more appropriately assisted by aged care services, because of their early ageing and deteriorating health.
- People retiring from Commonwealth-funded employment services may need replacement services. This may put pressure on some areas of the CSDA program. Similarly, those in CSDA-funded accommodation may require more flexible 'retirement' services, enabling them to 'age in place' or to make a smooth transition to appropriate residential aged care.

People with a disability are not a homogenous group, and it is not possible to identify a single factor (e.g. age, age at onset, disabling condition) that could reliably be used as a proxy indicator of need. This confirms the wisdom of trends towards individual assessment, and the importance of different service programs working across traditional divides to accommodate individual needs and circumstances (Chapters 7, 8, 15 and 19).

What are trends in informal care? How might these trends interact with population factors to affect demand for disability services into the future?

Trends in informal care are affected by demographic change and other social and economic factors, in particular population ageing and trends in de-institutionalisation.

Demographic impact on informal care

There are four main ways in which population growth and population ageing are likely to affect the future availability of informal care. Some of these effects are countervailing.

- As the age group 45–64 is projected to be substantially larger than the 65-plus age group over the next decade, there could be an increase in the number of potential carers for older people with a disability. In 1998, 43.2% of primary carers were aged 45 to 64 years, compared with 35.0% aged 15 to 44 years and 21.0% aged 65 years and over.
- Life expectancies are increasing at a faster rate for males than for females. Married couples may therefore 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. In 1998, there were 192,100 spouse primary carers, accounting for 42.9% of primary carers aged 15 years and over.
- Population ageing will be particularly marked in the working-age population over the next decade. This may cause an increase in the number of people with severe or profound core activity restrictions aged under 65 years, further increasing the need for carers.
- The ageing of carers is likely to continue to be of concern. In 1998, 96,700 primary carers were aged 65 years and over, of whom 60,400 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.

Other factors affecting changes in informal care

Various factors interact to affect the demand for and availability of informal care for people with a disability. In particular, changes in patterns of family formation, living arrangements and labour force participation could potentially diminish the pool of family carers and the commitment within families to provide care (Chapter 5).

Family formation patterns and family support structures are now markedly different from those of the 1950s and 1960s. Declines in marriage rates and increases in divorce rates reduce the potential for spouse care. The geographic location of family members also affects carer availability. In particular, the movement of young people away from country towns impacts on informal assistance networks for older people in country areas.

Trends in de-institutionalisation 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 (Madden et al. 1999).

The proportion of people with severe or profound core activity restrictions living in cared accommodation has steadily decreased from 9.9% in 1981 to 2.6% in 1998. This trend has been particularly marked for people aged under 30 years. Since 1993, there has been an increase of 250,000 people aged 5–64 years with severe or profound core activity restrictions living in the community, and a decrease in the number living in cared accommodation.

While there have been significant efforts to close institutions and accommodate people in the community, and these initiatives have had a significant effect on the institutional population, this is not the primary factor in the increase in community living. Rather, the trend is due largely to potential new service users remaining in community-based living arrangements, mainly with their relatives.

In the aged care field, the shift from residential to home-based care is largely due to service recipients remaining in home-based care, facilitated by increased availability of higher intensity, non-residential care and enhancement of respite care services.

Support needs of carers

The combined effects of trends in de-institutionalisation and population ageing highlight the importance of support for carers. Support resources play a significant role in reducing the stress of caregiving and helping to maintain the stability of community living and caring arrangements. Assisting families in the transition to non-parental care is also an important issue for service planning and provision.

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.

Of all primary carers, 39.4% had a disability and 9.3% had a severe or profound core activity restriction. 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 friends and 22.3% said that their relationship with the main care recipient had become strained as a result of the caring role. About 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 (9.2%) who needed assistance did not get it, and 160,000 (35.7%) said that they did not have a fall-back carer. There were 59,100 (13.2%) who reported that they had used respite care services; 35,500 had used such services in the three months before the survey—19,800 of these 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.

Because of countervailing trends, it is not possible to draw any firm conclusions about the likely future availability of informal care. However, there is a clear need to ensure that carers receive the support they need, as they provide such a huge proportion of the support for people with a disability (Chapters 5 and 18).

What projections can reliably be made about the population with a disability?

The prevalence of disability is determined by the combined effect of various factors. Population factors, in particular population ageing, are likely to account for a significant proportion of the future increase in the population with a disability.

Changes in mortality and morbidity impact on the prevalence of disability. There is currently debate about the likely impact of greater longevity on trends in disability prevalence. Some argue that later onset of morbidity means that disability will be compressed into a shorter period at the end of the life span, resulting in lower prevalence in the population. Others argue that increased longevity is accompanied by a longer period of disability in the later years of life, causing disability prevalence to increase. As yet there has been no clear resolution of this issue and there is contradictory evidence in the international literature regarding recent and projected change in levels and patterns of morbidity and disability. In Australia, there is no sign of a clear declining trend in disability prevalence among the older population (Chapters 3, 12, 13 and 18).

In addition to factors that affect the real underlying prevalence of disability, there are factors that can lead to changes in reported prevalence, even when real underlying prevalence rates

remain unchanged. These factors include changes in community perceptions and awareness of disability, changes in social attitudes and economic incentives concerning the reporting of sickness and disability, and changes in survey methodology. These factors are likely to have most impact on the reported prevalence of mild disability, and less impact on reported prevalence of more severe disability.

Need for assistance with core activities is one of the critical indicators of need for CSDA services. In Australia, the age-standardised prevalence rate of severe or profound core activity restriction was relatively stable between 1981 and 1993, but increased between 1993 and 1998 from 4.3% to 5.5%. It is likely that this increase primarily reflects changes in survey methodology, rather than a significant increase in underlying prevalence (Chapter 18).

Nevertheless, the marked increase in disability prevalence among males aged 5–14 merits further investigation. Between 1993 and 1998, prevalence of severe or profound core activity restriction for males aged 5–14 increased from 2.7% to 4.9%, more than twice the average increase for males aged 15–64. Does this trend reflect an increase in the underlying prevalence of early onset disability? It may be a result of increased recognition of particular disabilities (e.g. specific learning disabilities, attention deficit disorder and autism) or increased survival rates for babies and children with disabilities, due to improved medical technologies (Chapters 7 and 12).

Because of the various uncertainties outlined above, long-term projections of disability prevalence would not be reliable. However, short-term (2000–2006) projections can provide broad indicators to aid in planning support services.

Growth estimates of severe or profound core activity restriction

Between 2000 and 2006 there is likely to be significant growth in the number of people with a severe or profound core activity restriction. Estimates of the number of people with a severe or profound core activity restriction, based on 1998 age- and sex-specific prevalence rates, indicate that (Chapter 17):

- The total number will increase by 11.6%, from 1,189,500 to 1,327,100 people. This will mainly be due to the rapid increase in the age groups 45–64 (19.3%, or 59,500 people) and 65 and over (15%, or 76,300 people).
- The number aged 0–64 will increase by 9.0%, from 681,600 to 742,900.
- The number aged 15–64 will increase by 12.0%, from 536,200 to 600,500.
- The number aged 0–14 will decrease by 2%, from 145,300 to 142,400.

What inferences can be made about future needs for support services?

Levels of future demand for support services will be affected by the interaction of a number of factors, including population ageing, disability prevalence, life expectancies of people with a disability, patterns of informal care and service provision policies. While information currently available does not provide a solid basis for forward projections, it can be used to give trend indications.

Between 1993 and 1996, the overall growth rate of recipients of CSDA-funded services was 8.4%, or 2.7% per year (Chapter 17). The general shape of the age-specific growth rate of service recipients followed a similar but ‘accelerated’ pattern to that of the population with a severe or profound core activity restriction, in particular for the age groups of 35 years and over. There is evidence that the age distribution has been changing: in 1996 there was a sharp peak in the 20–29 year age group, while by 1999 the peak was not so sharp and had moved towards the 30–39 year age group. If the age distribution of service users continues

this pattern of change, the service usage rate for the age group 45–64 could increase. Between 2000 and 2006, the number of people with a severe or profound core activity restriction is estimated to increase by 11.6% and the highest increase (19.3%) is in the population aged 45–64.

General implications for service planning

The importance of individual needs and circumstances

People with a disability are not a homogenous group. Their needs for assistance are affected by various factors, including age, age at onset of disability and disability type, none of which can be used as a simple indicator of need. Individual needs should be the primary factor in determining what support services are appropriate.

Confirmation of the need for flexible service types and provision

People with an early onset disability may need the same services as the general ageing population, but at an earlier age. Their support requirements may also need to be reassessed as they age. Day services may need to be restructured from full to part day, with more flexible arrangements for people ageing with a disability. In-home accommodation support and respite may be provided via flexible support packages, allowing people to modify their balance between these two service types.

Carer support

On the basis of available data it is not possible to draw any firm conclusions about the likely future levels of carer availability. However, there is a clear need to provide a range of flexible services to support the role of carers, who provide most of the support for people with disabilities. It is carers (mainly relatives) who have enabled much of the increase in community living to occur—between 1993 and 1998 there was an increase of 257,500 people aged 5–64 years with severe or profound core activity restrictions living in the community, mainly with relatives. Support resources play a significant role in assisting carers and reducing the stress of caring, particularly among ageing carers.

Disability and aged care services ‘links’

There may be scope for improving the linkage between different sectors and spheres of government. The need for flexible services spans broad program areas. It may be helpful to clarify the roles of disability and aged care services with respect to the needs of people ageing with a disability. What needs does each program aim to meet? What criteria will be used to decide who moves from CSDA accommodation support services to generic aged care? Who will ‘retire’ from Commonwealth employment services to CSDA day activity or generic aged care day activity services? When do the benefits of ageing in place take precedence over other factors, including cost? A broad framework for planning individual services, spanning and possibly mixing aged care and disability service programs, could be useful, along with clear criteria for decision making.