

Disability and ageing

Australian population patterns and implications

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Disability and ageing

Australian population patterns and implications

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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.

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Abbreviations

ABI	Acquired brain injury
ABS	Australian Bureau of Statistics
ADD	New South Wales Ageing and Disability Department
AIHW	Australian Institute of Health and Welfare
BDQ	Brief Disability Questionnaire
CSDA	Commonwealth/State Disability Agreement
DSC	Western Australian Disability Services Commission
DSP	Disability Support Pension
EPAC	Economic Planning Advisory Council
GDP	Gross Domestic Product
HACC	Home and Community Care Program
ICD	International Classification of Diseases
ICIDH	International Classification of Impairment, Disabilities, and Handicaps
IDSC	South Australian Intellectual Disability Services Council
MCS	Mental component summary measure of SF12
MDS	Minimum Data Set
NDA	National Disability Administrators
OECD	Organisation of Economic Co-operation and Development
PCS	Physical component summary measure of SF-12
RSE	Relative standard error
SF-12	A 12-item short form health survey instrument
SMHWB	National Survey of Mental Health and Wellbeing of Adults
WHO	World Health Organization

1 Introduction

1.1 Project brief

The Australian Institute of Health and Welfare (AIHW) was commissioned by the National Disability Administrators (NDA) to conduct a study of disability and ageing. This project is designed to provide information to assist disability support service providers and senior policy makers faced with such questions as:

- 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?

Stages, methods and resulting products of the project are set out below.

Stage 1: Literature review

A review of studies of disability and ageing was undertaken, searching specifically for information on:

- underlying explanations of age-related disability rates and trends, including:
 - trends in life expectancy of people with disability, including possible cohort analysis of specific disability groups;
 - explanatory analyses of age-related disability rates, with investigation of the possible statistical separation of 'age' and 'disability' effects; and
- patterns and relationships of caring among older carers, and for older people with disability, including the assessment of social and population factors affecting the availability of informal care.

This review embraced not only published literature, but also studies now being conducted in Australian policy departments and universities (Chapters 1 to 10).

Stage 2: Australian population implications

Data from the four Australian Bureau of Statistics (ABS) disability surveys and other surveys or administrative data of national significance were reviewed and analysed for what they might yield on questions (a) to (h) above, and for their possible confirmation of key findings from the literature review (Chapters 11 to 16).

Stage 3: Support service implications

This stage of the project drew together the results of the two preceding stages, to provide information to address the study questions and to examine implications for support services. Analyses of service use patterns and implications for future service use were prepared, and scenarios of future service provision and use, and availability of informal care, were discussed (Chapters 17, 18 and 19).

1.2 Background and outline of the report

What is ageing?

The process of ageing is complex and influenced by a variety of factors. Thus, the study of ageing can involve many aspects. Population groups may differ in terms of the factors that affect both individual and population ageing. For a particular cohort these factors may vary over time in terms of the nature of their impact and their relative importance (e.g. Binstock & George 1990; Manton 1990; McPherson 1990; Borowski et al. 1997; Gibson 1998).

In this report a distinction is drawn between the ageing of an individual and the ageing of a population. Population ageing is viewed from a demographic perspective and individual ageing from a social perspective, with a particular focus on people with a disability.

The report examines these two aspects and looks at how changes in the ageing process interact with other factors to affect prevalence of disability and demand for disability services.

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. This is mainly attributable to lower fertility and an increase in the absolute number of older people, with the latter largely a result of lower mortality among older people and a large birth cohort ageing (e.g. when the baby-boom generation enters old age). While substantial immigration may reduce the extent of population ageing, it cannot 'keep the population young' (McDonald & Kippen 1999). Significant fluctuations in cohort size resulting from substantial changes in the basic demographic components will affect the ageing process. The time of onset, the speed and scale of the population ageing process have great social and economic impact on both individuals and society.

Individual ageing refers to the structural, sensory, motor, behavioural and cognitive changes in a person over time, in particular relating to how these factors influence opportunities and lifestyle at various stages of the life of the person (McPherson 1990: 4). Although ageing is inevitable, universal and irreversible, it is a multi-dimensional, dynamic process. It involves an interaction of biological, psychological, social and cultural factors, which may result in different rates and types of ageing for a particular individual or cohort (McPherson 1990).

Individual ageing has been conceptualised using three broad dimensions to examine the biological, psychological and social changes that result from increasing chronological age.

There has been a widening from an earlier focus on the medical and biological aspects of ageing to a broader view encompassing these three dimensions (e.g. Hayslip & Panek 1989; McPherson 1990).

Chronological ageing is only an approximate measure of the development or changes within an individual. There are substantial variations in the rate of physical, emotional, social and psychological development between individuals. Biological ageing takes into account individual differences. Biological ageing mainly reflects the relationship between biological maturation or deterioration and changes in an individual's ability to adapt and perform specific physical, cognitive and social tasks (McPherson 1990).

Psychological ageing involves the reaction of the individual to biological, cognitive, sensory, motor, emotional and behavioural changes and to external environmental factors affecting these changes (McPherson 1990).

Ageing is not only a biological and psychological process but also a social process. Social ageing refers to patterns of interaction between the ageing individual and the social system within which they live (McPherson 1990).

To study people with a disability who are ageing, we should consider not only their chronological age, but also these three dimensions of individual ageing, in particular, those elements that relate specifically to their disability.

Outline of the report

Chapters 1 to 10 of the report focus mainly on literature review. The first part (Chapters 1 to 5) of the literature review presents an overview of the ageing of the Australian population and its impact on prevalence of disability, expenditure and services for people ageing with a disability. The combined effects of population ageing and de-institutionalisation on informal care are reviewed. The second part (Chapters 6 to 10) reviews the ageing trends of people with a disability, particularly those with an early onset disability, and outlines their special needs for support. Emerging issues related to service needs for ageing people with a disability and service development and planning are also discussed.

Chapters 11 to 17 assess the key findings of the literature review in the context of Australian population data analysis. Data from the ABS disability surveys, other population surveys of national significance and service administrative data are reviewed. Analysis of the most recent population survey data, in particular the 1998 ABS disability survey data, forms an important part of these chapters.

Chapter 18 summarises the main themes and findings of previous chapters to examine the impact of ageing on support service provision, government expenditure and informal assistance for people with a disability. Chapter 19 discusses service implications associated with the changes in the needs for support services and scenarios of future trends in service use. The chapter draws out the most salient information on ageing and disability for disability administrators to consider when planning the evolution of services.

2 Population ageing in Australia

2.1 Some demographic features of Australia's population

Before discussion of the general trends in population growth and ageing, it is worth highlighting some important demographic features of Australia's population.

Changes in population age structure are determined by the demographic factors of fertility, mortality and migration. Australia's level of fertility has declined since 1971 and has been below replacement level since 1976. This decline has contributed substantially to population ageing by increasing the proportion of older people in the total Australian population (Borowski & Hugo 1997; Young 1990).

In the meantime, the Australian population experienced a decline in mortality and an increase in life expectancy among older people during the 1970s and 1980s. The low level of fertility and the decline in mortality rate among older people have resulted in a higher proportion of older people in the total population.

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'. This 'baby boom' was mainly due to changes in marriage patterns and the timing of births—a higher proportion of women married and had children—rather than any increase in average family size. Hence, the baby boom increased the proportion of children in the population during that period, but it was not a reversal of the trend towards the small family (Clare & Tulpule 1994; Rowland 1991).

It has been suggested that, to a large extent, it is the ageing of the baby-boom generation rather than increased life expectancy that is driving the projected changes in the age profile of the Australian population (Clare & Tulpule 1994).

Immigration played an important role in population growth after World War II. New immigrants and their children accounted for over half of the population growth, even during the peak of the baby boom. Immigration played a particularly important role in the 1970s and 1980s. In the 1980s Australia had the highest rate of population growth of any Western population, mainly attributed to its high level of immigration (Young 1990). The drop in natural population increase was largely offset by a rise in net immigration (Clare & Tulpule 1994).

Although immigration was an important component of population growth in Australia, it had little impact on the pace of population ageing either in the short term or in the long term. While a higher level of immigration can compensate for a lower level of fertility in terms of total population size, it may not necessarily counteract the severe undercutting of the age pyramid at the youngest ages or the increased proportion of the population at the oldest ages (Young 1990).

Only a huge increase in the annual immigrant intake (net gains of over 280,000) would have any significant effect on the pace of population ageing in Australia (Centre for International Economics 1988 cited in Borowski & Hugo 1997). The problem is that immigrants will also get older. To keep the population 'young'—to maintain the proportion of the population aged 65 and over at its present level of 12.2%—we would need an increasingly large number of immigrants, rising to 4 million per annum by 2048 (McDonald & Kippen 1999).

The current proportion of Australians aged 65 years and over (12% in 1997) puts Australia in a transitional position between the demographically 'young' populations of South-East Asia and Africa (where the proportions of the population aged 65 years and over are about 4% to 5%) and the 'old' populations of Northern Europe (with about 15% of their populations aged 65 years and over) (Kinsella & Taeuber 1993 cited in Borowski & Hugo 1997). In comparison with the Western European countries, Australia has a smaller proportion of the 65-plus population aged 80 years and older (Borowski & Hugo 1997).

Australia's population is 'younger' than that of many developed countries because Australia was much slower in reaching the point where its population structure began ageing markedly (Clare & Tulpule 1994). However, the aged population of Western European countries is now growing very slowly and many of these countries expect a decline in their older population. In contrast, the Australian aged population has itself been ageing comparatively quickly over the last decade and will continue to do so over the next few decades (Borowski & Hugo 1997; Gibson & Goss 1999).

Interstate migration is the most volatile component of population change in the States and Territories. Over recent years, the overall interstate migration patterns indicate a northward stream on the east coast and a smaller stream to the west coast. Both streams originate in the south-east, resulting in large net gains for Queensland and small net gains for Western Australia, but net losses for all other States and Territories (Wettenhall 1995; ABS 1998a: 36).

Over the past two decades there has been considerable variation between the States and Territories in terms of the proportion of the population aged 65 years or over. The greatest change has occurred in South Australia, which has overtaken the three mainland eastern states and now has the highest proportion of people aged 65 years and over. This was partly due to a relatively larger immigration of young adults in the 1950s to South Australia, and partly due to a decline in fertility and significant out-migration of young adults in the 1970s (Borowski & Hugo 1997: 37).

Throughout Australia the older population tends to be concentrated in major urban areas (10,000 residents or more). Between the 1981 and 1991 censuses, the number of people aged 65 years and over in metropolitan areas increased by an annual rate of 2.9%, more than twice the rate for the total population in large cities (Borowski & Hugo 1997: 37).

The distribution of the older population outside major urban centres shows a number of patterns (Borowski & Hugo 1997):

- There are concentrations in non-metropolitan coastal resort areas. This is particularly evident along the northern and southern coast of New South Wales and in south-eastern Queensland. This is largely driven by retirement migration towards attractive environments and climate.
- There is a growth of retirement communities in attractive environments near the large cities, as retired people move away from areas within commuting distance of their workplace.
- Many country towns have an above-average concentration of older people. This is usually a result of older people retiring from farm properties into nearby towns and out-migration of younger people.

Within large metropolitan cities, older people tend to shift from the inner to the middle suburbs. The most rapid rate of growth of the older population tends to be even further out in the outer suburbs (Borowski & Hugo 1997).

2.2 Projected growth in population

The Australian population is projected by ABS to grow from 18.5 million in 1997 to between 22.1 and 23.1 million in 2021, and between 23.5 million and 26.4 million in the year 2051. Although the growth rates are projected to vary around an average annual growth rate between 1.0% and 1.1% during 1997–2001, there is a clear long-term trend of decline in growth rates from 1.2% in 1996–97 to between 0.0% and 0.3% by 2051 (ABS 1998a).

There are considerable differences in projected population growth among the States and Territories. The most rapidly growing States are the Northern Territory, Queensland and Western Australia. Queensland is projected to replace Victoria as the second most populous State between 2022 and 2048. The population of the Australian Capital Territory is projected to overtake that of Tasmania between 2037 and 2043. Tasmania is the only State or Territory where the population is projected to decline over the projection period under each of the ABS projection series (ABS 1998a: 2).

2.3 Trends in population ageing

Two measures are usually used to measure population ageing. The first measure is the median age of the population. A population is considered 'young' if it has a median age of less than 20 years, and 'old' if it has a median age of 30 or over (Shryock & Siegel 1976).

The second measure is the proportion of the population beyond the age of 60 or 65 years (the threshold age used for this measure varies). The United Nations classifies a nation as 'aged' if 10% or more of the population are aged over 60 or 65 years, as 'mature' if between 7% and 9% are over 60 or 65, and as 'youthful' if between 4% and 6% are over 60 or 65 years of age (McPherson 1990).

ABS projections show that the ageing of the Australian population will continue, as the inevitable result of low levels of fertility over a long period and 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).

Changes in overseas migration would have little effect on the median age of the Australian population. With net overseas migration of 70,000 per year by 1999, the median age in 2051 would be between 44 and 46 years. With no net gain of overseas migration, the median age in 2051 would be between 47 and 49 years (ABS 1998a: 8).

The ageing of the Australian population is largely attributable to the projected decline in the population aged 0–14 years and the rapid increase in the population aged 65 years and over, both in terms of numbers and as a proportion of the total population. The proportion of people aged 0–14 years was 21.2% in 1997 and is projected to be between 16.0% and 17.3% in 2021 and between 14.1% and 15.8% by 2051 (ABS 1998a). The proportion of people aged 65 years and over will increase rapidly from 12.1% (2.2 million people) in 1997 to 17.6% (4.0 million people) in 2021 and between 23.7% (6.0 million people) and 25.6% (6.3 million people) in 2051 (Table 2.1). The proportion of people aged 85 years and over is projected to increase considerably, from 1.2% (216,100 people) in 1997 to between 4.4% (1.1 million people) and 4.8% (1.2 million people) in 2051 (ABS 1998a: 12).

Table 2.1: Projected changes in median age, proportion of population aged under 15 years and aged 65 years or over, Australia 1997–2051^(a)

Year	Median age (years)			Proportion pop aged 65+ (%)			Proportion pop aged under 15 (%)		
	Series 1	Series 2	Series 3	Series 1	Series 2	Series 3	Series 1	Series 2	Series 3
1997	34.3	34.3	34.3	12.1	12.1	12.1	21.2	21.2	21.2
1998	34.6	34.6	34.6	12.2	12.2	12.2	20.9	20.9	20.9
1999	34.9	34.9	35.0	12.2	12.2	12.2	20.7	20.7	20.7
2000	35.2	35.2	35.2	12.3	12.3	12.3	20.5	20.5	20.5
2001	35.4	35.5	35.5	12.3	12.4	12.4	20.3	20.3	20.2
2006	36.7	36.8	37.0	12.9	12.9	13.0	19.3	19.3	18.9
2011	38.1	38.3	38.6	13.9	14.0	14.2	18.4	18.3	17.4
2016	39.2	39.4	40.0	15.8	16.0	16.2	17.7	17.6	16.5
2021	40.1	40.4	41.1	17.6	17.9	18.2	17.3	17.1	16.0
2026	41.1	41.3	42.2	19.4	19.8	20.3	17.0	16.8	15.7
2031	41.9	42.2	43.3	20.8	21.3	21.9	16.7	16.5	15.4
2036	42.6	42.9	44.3	21.9	22.4	23.3	16.3	16.2	15.0
2041	43.1	43.5	45.2	22.8	23.3	24.3	16.1	15.9	14.6
2046	43.5	43.9	45.8	23.2	23.7	24.9	15.9	15.7	14.3
2051	43.7	44.1	46.2	23.7	24.2	25.6	15.8	15.6	14.1

(a) The three ABS projection series reported in this table differ in terms of the assumptions about future fertility and migration on which they are based.

Source: ABS 1998a: Table 4.6.

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 fluctuation in the size of some significant age cohorts, in particular the post–World War II baby-boom generation.

Table 2.2 shows that in the 1980s the highest growth rates were in the age groups 75–84 years and 85 years plus. This rapid growth partly reflected the large numbers of people born during the post–First World War period who were moving into the oldest age groups, post-war immigrants who arrived in Australia in the 1950s as young adults and the increased survival of older Australians (Borowski & Hugo 1997).

During the 1980s the growth rates of the working-age population aged 50–54 and 55–59 years were low or negative, reflecting the passage of people born in the low-fertility years of the 1930s into these age groups (Tables 2.2 and 2.3).

The population projections show that 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 greatest growth among the working-age population will be in the population aged 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 will be higher than the number aged 65 years and over throughout the projection period, although the difference in number will reduce steadily over the period (ABS 1998a; Tables A2.2 and A2.3; Figure 2.1).

Table 2.2: Estimated and projected percentage changes in selected age groups, Australia, 1981–2051

Age	1981–86	1986–91	1991–96	1996–2001	2001–06	2006–11	2011–21 ^(c)	2021–31 ^(c)	2031–41 ^(c)	2041–51 ^(c)
45–49	14.5	22.2	(a)25.7	5.1	8.4	0.9	1.3	1.7	2.7	-2.5
50–54	(b)-4.9	14.9	19.8	(a)26.9	5.1	8.5	1.5	-2.1	6.7	-0.7
55–59	2.0	(b)-3.9	14.0	21.1	(a)26.9	5.3	9.7	1.6	2.0	3.0
60–64	17.3	2.4	(b)-3.6	13.5	21.3	(a)26.9	14.6	2.0	-1.7	7.0
65–69	6.3	17.8	3.1	(b)-2.8	14.1	21.6	34.2	10.3	2.2	2.5
70–74	17.9	7.9	18.1	3.9	(b)-1.8	14.7	(a)55.2	15.8	3.0	-0.9
75–79	24.5	18.5	10.1	20.7	5.1	(b)-1.0	41.4	36.2	11.8	3.6
80–84	20.1	24.2	22.9	12.9	22.2	6.2	16.4	(a)59.1	19.1	5.6
85+	26.0	19.3	30.9	26.7	18.0	22.0	19.7	39.0	50.3	23.3
Total 45–64	6.6	9.3	15.2	15.9	14.0	9.0	6.4	0.8	2.4	1.6
Total 50–64	3.9	4.4	10.5	21.3	16.4	12.4	8.3	0.5	2.3	3.0
Total 65+	15.6	16.0	12.9	8.3	9.5	13.1	36.2	25.6	12.8	5.8
Total 70+	21.0	15.1	18.1	13.3	7.7	9.5	37.1	32.6	16.7	6.9
Total 75+	23.5	20.3	18.1	19.6	13.2	6.9	27.4	43.5	24.0	10.3

(a) This shift mainly reflects the passage of the large cohort of the post-World War II baby-boom generation.

(b) This shift mainly reflects the passage of the people born in the low-fertility years of the 1930s.

(c) 10-year period has been applied.

Source: Calculated on the basis of ABS estimated resident population and population projections Series II; ABS 1998a.

Table 2.3: Estimated and projected population ('000) in selected age groups, Australia, 1981–2051

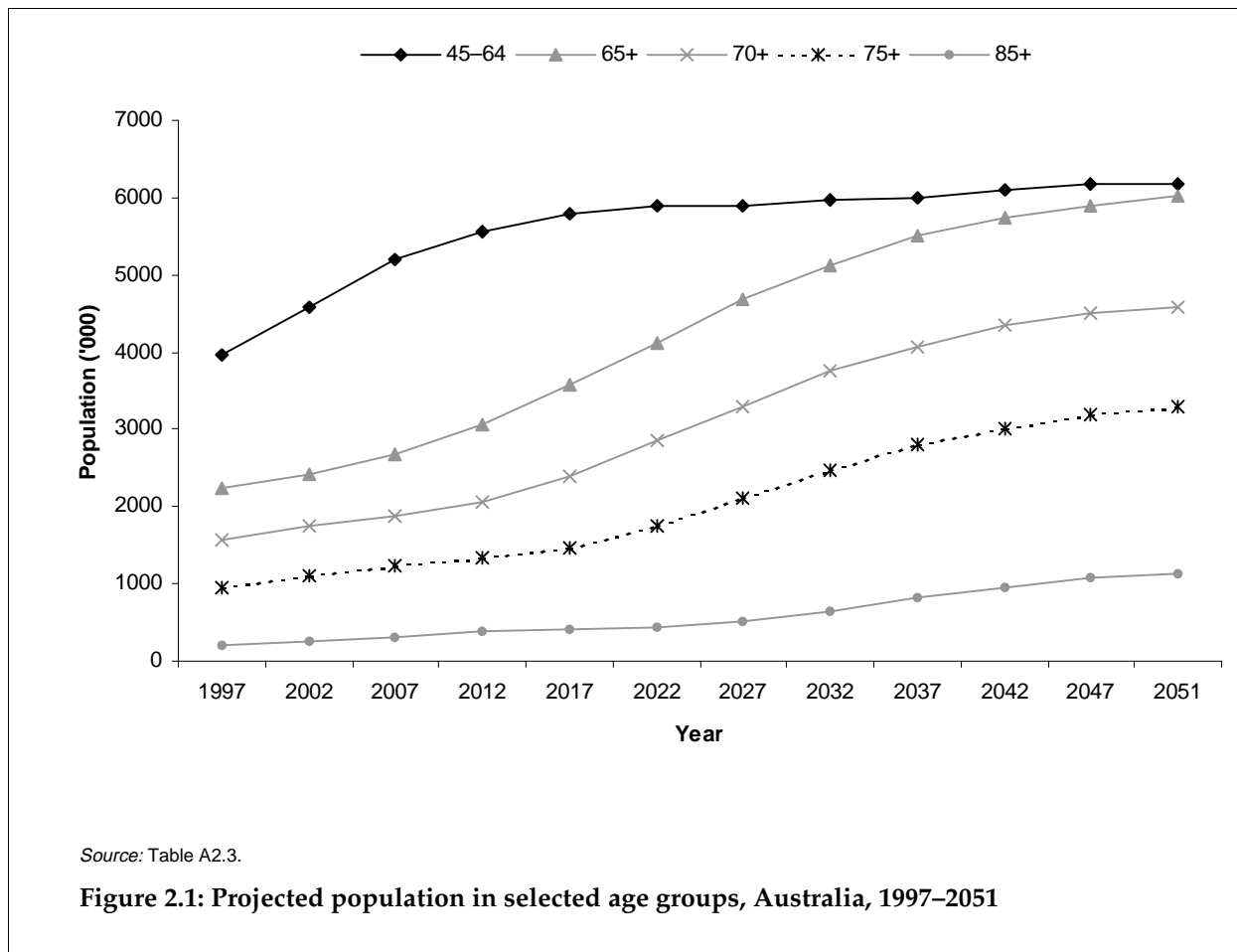
Age	1981	1986	1991	1996	2001	2006	2011	2021 ^(c)	2031 ^(c)	2041 ^(c)	2051 ^(c)
45–49	735.7	842.3	1,029.1	(a)1,293.9	1,360.5	1,475.3	1,488.4	1,507.5	1,532.7	1,574.8	1,535.2
50–54	774.6	(b)736.9	846.9	1,014.9	(a)1,287.5	1,353.7	1,468.8	1,491.5	1,459.7	1,557.2	1,546.7
55–59	740.6	755.5	(b)726.0	827.4	1,002.1	(a)1,271.3	1,338.6	1,468.7	1,492.3	1,521.4	1,566.6
60–64	613.1	719.4	736.9	(b)710.5	806.4	978.3	(a)1,241.9	1,423.4	1,452.1	1,427.1	1,527.1
65–69	536.2	570.2	671.4	692.2	(b)673.0	768.1	934.1	1,253.9	1,383.4	1,414.0	1,449.9
70–74	401.5	473.2	510.8	603.1	626.5	(b)615.2	705.5	(a)1,094.6	1,267.4	1,305.4	1,293.0
75–79	260.6	324.4	384.5	423.4	510.9	536.9	(b)531.7	751.8	1,024.0	1,145.2	1,186.6
80–84	154.1	185.0	229.8	282.5	318.7	389.4	413.4	481.1	(a)765.5	912.0	962.9
85+	102.6	129.3	154.2	201.9	255.6	301.7	368.1	440.5	612.2	920.4	1,134.8
Total 45–64	2,864.0	3,054.1	3,338.9	3,846.8	4,456.5	5,078.6	5,537.7	5,891.1	5,936.8	6,080.5	6,175.6
Total 50–64	2,128.3	2,211.8	2,309.8	2,552.8	3,096.0	3,603.3	4,049.3	4,383.6	4,404.1	4,505.7	4,640.4
Total 65+	1,455.0	1,682.1	1,950.7	2,203.1	2,384.7	2,611.3	2,952.8	4,021.9	5,052.5	5,697.0	6,027.2
Total 70+	918.8	1,112.0	1,279.3	1,510.9	1,711.7	1,843.2	2,018.7	2,768.0	3,669.1	4,283.0	4,577.3
Total 75+	517.3	638.8	768.6	907.7	1,085.2	1,228.0	1,313.2	1,673.4	2,401.7	2,977.6	3,284.3

(a) This shift mainly reflects the passage of the large cohort of the post-World War II baby-boom generation.

(b) This shift mainly reflects the passage of the people born in the low-fertility years of the 1930s.

(c) 10-year period has been applied.

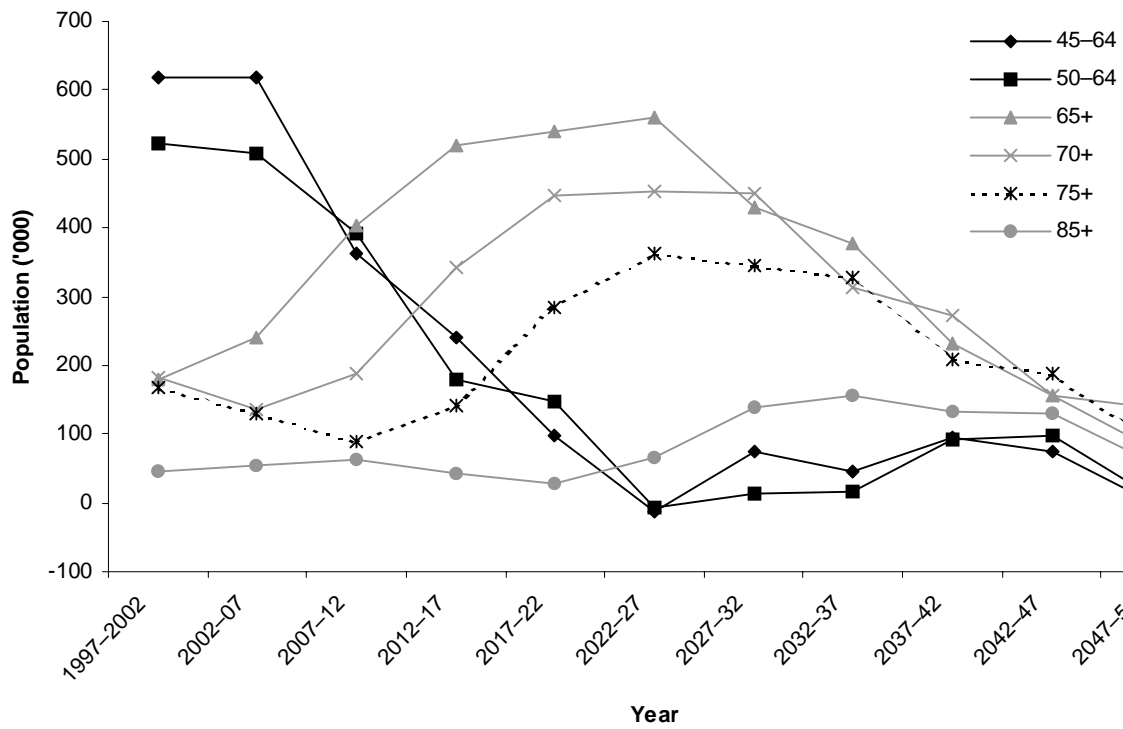
Source: Calculated on the basis of ABS estimated resident population and population projections Series II; ABS 1998a.



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. Thereafter, the population aged 65 years and over will grow faster (Figure 2.2; Table A2.2). This shift mainly reflects the passage of the post–World War II baby-boom generation. This generation is progressively moving up the age pyramid causing rapid growth in the number of older people (Tables 2.2 and 2.3; Figure 2.2).

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

The ageing of the aged population is very significant because of its size. Between 1997 and 2051, the number of people aged 75 years 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. People aged 85 or over as proportion of total people aged 65 or over is projected to increased from 9.6% in 1997 to about 18.8% in 2051 (ABS 1998a: 12).



Source: Table A2.2.

Figure 2.2: Projected increase in the population in selected age groups, Australia, 1997-2051

3 Population ageing, morbidity and disability

3.1 Mortality, morbidity and disability

Changes in mortality and morbidity can influence the prevalence of disability. Morbidity is defined as the level and type of sickness within a population. Morbidity indicators are commonly expressed in terms of the incidence and/or prevalence of specific diseases and other health-related events (e.g. injuries). Morbidity is an important predictor of disability. In conjunction with other factors (such as socioeconomic status) it can help predict or explain the prevalence and demographic pattern of disability in a community (Chamie 1995; Pol & Thomas 1992; United Nations 1988). Nevertheless, the relationships among mortality, morbidity and disability are complex.

The rapid decline in mortality and the increase in life expectancy in this century have chiefly been a result of the substitution of degenerative causes of death, such as heart disease and cancer, for deaths that were previously caused by infectious and parasitic diseases. This shift in disease pattern has been referred to as the epidemiological transition (Olshansky & Ault 1986).

Olshansky and Ault (1986) suggested that the United States has entered a new stage in the epidemiological transition—the era of delayed degenerative diseases. The general characteristics of the new stage include:

- the rapid decline in death rates and thus relatively rapid improvement in survival are concentrated mainly in advanced age groups; and
- the age distribution of deaths from degenerative causes is shifted progressively toward older ages.

This new stage of epidemiological transition is likely to have great impact on population ageing—increasing the size and proportion of the population in advanced age groups, and the health and vitality of older people (Olshansky & Ault 1986).

There is no dispute about the increase in size and proportion of the older population; the main debate focuses on the impact of greater longevity on trends in morbidity and disability. There is no clear resolution on this issue and contradictory evidence is presented in the international literature regarding recent and projected changes in levels and patterns of morbidity and disability. There are two schools of opinion on this issue, separated by differences in approach to measurement and underlying assumptions used.

Some authors suggest that improvements in health and medical care have delayed the onset of illness and resulted in a compression of morbidity into a short age range closer to the biological limit of life. The prevalence of disability could decrease as morbidity is compressed into the shorter span between the increasing age at onset of disability and the 'fixed' occurrence of death (e.g. Fries 1980, 1989).

In contrast, it is argued that the 'compression of morbidity is not near at hand' and that decline in mortality and increased longevity have resulted in more survivors who are frail

and suffer from chronic conditions; thus an increase in disability is observed. The longer life span has prolonged the period of life during which people perform their daily activities less efficiently as a result of increased exposure to non-fatal debilitating conditions such as arthritis (e.g. Verbrugge 1984, 1989; Hugo 1998).

Nevertheless, international studies generally suggest that increases in disability prevalence began in the late 1960s and 1970s when mortality rates at older ages began to decline significantly, but that these increases were confined to the less severe end of the disability spectrum. There is no evidence of expansion of morbidity based on measures of prevalence of more severe disability (Mathers 1998).

Recently emerging evidence from Europe and North America suggests that disability prevalence rates among older people may be starting to decline and we may actually be starting to see compression of morbidity in low-mortality populations (Mathers 1998). A number of recent studies have reported some evidence of a declining prevalence of disability among the older population in some countries in the Organisation for Economic Co-operation and Development (OECD) such as the United States (e.g. Manton et al. 1995). However, findings across data sets in the US suggest that there has been fluctuation rather than a clear ongoing trend in the prevalence of disability. Further evidence is needed before drawing conclusions on a trend of decline in disability prevalence among older population (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 women (Parker et al. 1997).

In Australia, the number of people reporting long-term health conditions increased from 6.2 million (45% of the total population) in the 1977–78 National Health Survey to 11.2 million (66% of the total population) in the 1989–90 survey and 13.5 million (75% of the total population) in the 1995 survey (ABS 1979, 1991, 1996; AIHW 1998a). Although there are some differences in the way conditions were identified and classified in the three surveys, it is clear that reported long-term morbidity in Australia has increased over the past two decades.

In the meantime, the Australian population experienced a decline in mortality and an increase in life expectancy (Table 3.1). However, the gain in life expectancy at birth in the 1980s mainly came from reduction of mortality in the 50–69 age group for males and in the age groups of 50–69 and 70 and over for females (Jain 1992). Mathers (1995) suggested that in Australia the extension of life expectancy has been accompanied by an increase in years lived with disability, although this is usually ‘mild or moderate’ disability; years lived with severe disability do not appear to have increased.

A study looking at trends in old age morbidity and disability in Britain concluded that the proportion of older people with severe disabilities in the population was remarkably stable over time (1980 to 1994–95) (Jarvis & Tinker 1999).

In Australia, a comparison of the four consecutive national disability surveys showed that the age-standardised rate of severe or profound core activity restrictions for people aged 65 and over increased from 16.2% in 1981 to 17.9% in 1988, declined marginally to 17.1% in 1993, and increased to 19.6% in 1998 (AIHW 1999a: 168). The increase was mainly in the 75-plus group, in particular very old people (Chapters 12 and 13). There is no sign of a clear declining trend in disability prevalence among older Australians, and this is particularly true for severe or profound core activity restrictions.

Comparative analysis of the three ABS disability surveys (1981, 1988, 1993) suggested that the age-standardised prevalence rates of severe or profound ‘handicap’, as defined by the

Table 3.1: Mortality and life expectancy, Australia, 1986–1996^(a)

	Units	1986	1987	1988	1989	1990	1991	1992	1993	1994	1995	1996
Life Expectancy												
Male life expectancy at birth	years	72.8	73.0	73.1	73.3	73.9	74.4	74.5	75.0	75.0	75.0	75.2
Female life expectancy at birth	years	79.1	79.5	79.5	79.6	80.1	80.4	80.4	80.9	80.9	80.8	81.1
Male life expectancy at 65 years	years	14.6	14.7	14.8	14.7	15.2	15.4	15.7	15.7	15.7	15.7	15.8
Female life expectancy at 65 years	years	18.5	18.6	18.7	18.7	19.0	19.1	19.2	19.5	19.7	19.5	19.6
Mortality												
Total number of deaths	'000	115.0	117.3	119.9	124.2	120.1	119.1	123.7	121.6	126.7	125.1	128.7
Crude death rate (per 1,000 population)	no.	7.2	7.2	7.2	7.4	7.0	6.9	7.1	6.9	7.1	6.9	7.0
Age standardised death rate (per 1,000 population)	no.	7.6	7.6	7.5	7.6	7.2	6.9	6.9	6.6	6.7	6.5	6.4
Infant mortality rate (per 1,000 live births)	no.	8.8	8.7	8.7	8.0	8.2	7.1	7.0	6.1	5.9	5.7	5.8
Perinatal mortality rate (per 1,000 live births and fetal deaths combined)	no.	11.5	10.6	10.7	9.9	10.3	9.6	9.4	8.2	8.0	8.1	8.5

(a) Reference periods: Data on health status are for the calendar year.

Source: Adapted from ABS 1998b: 48.

ABS, remained fairly steady between 1981 and 1993, while rates for disability increased and rates for less severe handicap varied (Wen et al. 1995). Preliminary estimates from the 1998 ABS disability survey indicate an increase in the proportions of people with a disability and specific restrictions (handicap), including severe or profound restrictions (ABS 1999). (Further analyses and discussions about the increases are presented in Chapters 12, 13 and 18.)

Possible factors contributing to the increase in reported disability and handicap prevalence levels, particularly at the less severe end of the spectrum, have been discussed (Otis & Howe 1991; Mathers 1991, 1996). Apart from the factors related to rising levels of long-term morbidity, other proposed explanations include changes in community perceptions of disability and handicap, and changes in strategies of medical prevention and intervention. Various factors affecting overall prevalence of disability in a population can be summarised as follows:

- changes in population age structures;
- changes in incidence of specific types of condition and disability;
- changes in age at onset of specific conditions and disabilities;
- changes in the diagnosis of disabling conditions;
- changes in the prevention and treatment of specific diseases (effects differ depending on nature of diseases, i.e. chronic non-fatal disease or highly fatal diseases);
- changes in mortality and life expectancy of the general population and among people with particular diseases, conditions or disabilities;
- changes in perception and awareness of disability and health;

- changes in social attitudes and economic incentives concerning sickness and disability;
- changes in personal behaviours and exposure to violence and environments that cause disease, injury or disability; and
- improvements in interviewing methods and survey design which may increase self-reported illness and disability.

There is little national data about the effects of trends in injury and its consequences on disability. However, mortality due to a number of significant external causes, such as transport and road injuries, has decreased in recent years (Abraham et al. 1995; Alessandri et al. 1996; Bordeaux & Harrison 1996). This could potentially result in increased disability prevalence, if people are surviving and living with disability rather than dying as a result of their injuries. Between 1979 and 1994, the overall number of injury deaths among children aged under 15 years declined by 51.3% while the decline has been smaller for people aged over 15 years (Moller & Kreisfeld 1997). Between 1988 and 1997, the age-standardised death rate due to all external causes of injury and poisoning fell by 21%, from 52 external caused deaths per 100,000 population in 1988 to 41 per 100,000 in 1997 (Bordeaux 1999).

The Australian Spinal Cord Injury Register has over 6,000 cases registered in its fourth year of operation, including about 4,000 cases carried over from a register that operated from 1986 to 1991. The age-adjusted incidence rate of persisting cases (people discharged from six Australian spinal units with a neurological deficit such as tetraplegia and paraplegia) was 1.52 per 100,000 in 1997–1998, as compared with 1.32 per 100,000 in 1996–1997. The number of persisting cases in 1997–1998 was higher than the average yearly figure for the combined years 1988–1990, 1995–1996 and 1996–1997 (O'Connor & Cripps 1998).

Perinatal data on the incidence of congenital malformations may also shed light on factors affecting trends in disability prevalence. The reported overall incidence of congenital malformations was higher in the late 1980s and the 1990s than that in the early 1980s, though the trend varied for different malformations (Abraham et al. 1995; Lancaster & Pedisich 1995; Lancaster et al. 1997; Hurst et al. 1999). The increase in the incidence of congenital malformations may partly reflect improved ascertainment due to new birth defect registers in some States and Territories (Abraham et al. 1995). Perinatal deaths due to congenital malformations declined from 35.9 per 10,000 births in 1973 to 15.6 per 10,000 births in 1996 (Hurst et al. 1999). Infant deaths due to congenital malformations also declined from 28.8 per 10,000 live births in 1980 to 14.8 per 10,000 live births in 1996 (Hurst et al. 1999) (also see Section 7.4).

For a person with a long-term or permanent disability, the duration of disability depends on age at onset of disability and longevity. There has been no specific study conducted on changes in age at onset of disability in Australia. It may be useful to examine the trends in age at onset of disability using the ABS disability survey data. However, since the disability surveys are cross-sectional rather than longitudinal, the analysis may be limited to generating some broad indicators. Chapters 14 and 15 contain analyses on pattern of age at onset of disability and needs for services and assistance of people with an early onset disability.

Looking at changes in age at onset of disability, it may be useful to examine not only changes relating to disability at aggregated levels—population with a disability in general—but also changes relating to particular disability groups, such as intellectual or physical disability.

3.2 Population ageing and prevalence of people with a disability

Changes in prevalence between 1981 and 1993

A demographic decomposition study was carried out as part of a comparative analysis of the three consecutive ABS disability surveys (1981, 1988, 1993) to clarify two factors, population ageing and changing age-specific prevalence rates (which underlies the trends in reported overall prevalence of disability and handicap (Wen et al. 1995)).

The analysis demonstrated that the overall age-standardised prevalence rates of severe handicap were quite stable during the 1980s and early 1990s, remaining at a level of slightly over 4% for the population overall, about 2.5% for people aged 15 to 64 and around 17% to 18% for people aged 65 and over. In contrast, the age-standardised prevalence of disability and overall handicap increased substantially between 1981 and 1988, although they levelled out between 1988 and 1993 (Wen et al. 1995).

The analysis showed that the influence of changing prevalence rates within specific age groups was equal to or greater than that of population ageing in the early 1980s. However, the influence of changing prevalence rates within specific age groups diminished and actually fell below zero during the late 1980s and early 1990s. In contrast, the influence of the changing age structure was evident throughout the 12-year period. The influence of the ageing population was greater between 1988 and 1993, particularly affecting reported overall prevalence rates of severe handicap (Wen et al. 1995).

Decomposition analysis thus confirms that age structure is the dominant factor in changing reported prevalence rates of severe handicap. Between 1981 and 1993 increases in reported prevalence rates of severe handicap were largely accounted for by the ageing of the population rather than by changes in age-specific prevalence rates (Wen et al. 1995).

Changes in prevalence between 1993 and 1998

The summary of findings from the 1998 disability survey indicates an increase in the proportions of people with a disability and specific restrictions (equivalent to handicap in previous surveys), in particular severe or profound activity restrictions, between 1993 and 1998 (ABS 1999). A preliminary comparison of the four disability surveys (1981, 1988, 1993 and 1998) showed that the overall age-standardised rate of severe or profound core activity restrictions has increased from 4.0% in 1993 to 5.5% in 1998, while the rate was relatively stable between 1981 and 1993 (ABS 1999).

In the comparison of the surveys, as far as possible, only screening questions common to all four surveys were used and prevalence rates were age standardised to the March 1998 population (ABS 1999). Nevertheless, there were a number of other changes in the 1998 survey design and interviewing methods (ABS 1993, 1999):

- 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 handicap category of the previous two surveys was divided into profound handicap and severe handicap, but the severe handicap category was not applied to the establishment component (equivalent to the cared accommodation component in the 1998 survey).

It is difficult to control for these changes in a comparative analysis and to quantify their contribution to changes in estimated prevalence between 1993 and 1998.

It appears that the increase in age-adjusted rates of severe or profound restrictions may be mainly a result of changes in survey method and the attempt to increase case identification, rather than an increasing underlying prevalence. However, further investigation and analysis are needed to understand the increase in the severe or profound rates of core activity restrictions between 1993 and 1998, and other patterns of change between the two surveys (see Chapters 12, 13 and 18).

4 Implications of population ageing

The implications of population ageing for social expenditures have been the subject of ongoing discussion in Australia over the last two decades, particularly in the 1990s, with the greatest focus on health and aged care costs.

Recently, there have been growing concerns about the extent to which existing disability support services can accommodate an increasing number of older people with disability, and about the cost implications for these services and possible implications for other related services.

This section reviews studies that examine the implications of population ageing for government health and welfare expenditures in general, and disability and aged care in particular. Potential impacts of population ageing on demand for disability and aged care services are also discussed.

4.1 Impact on government health and welfare expenditures

There are 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. Two major reports with a pessimistic view of the impact of ageing on social expenditures have attracted wide attention and provoked considerable debate. A report published by the Economic Planning and Advisory Council in 1994 focused on the long-term economic and social implications of population ageing in Australia (Clare & Tulpule 1994). Although the projections published in the report did not suggest that Australia would be unable to cope with the costs of an ageing population, the report produced some conclusions which some found alarming:

- Welfare expenditure would rise from 6.9% of Gross Domestic Product (GDP) in 1990 to 9.3% of projected GDP by 2051.
- Health expenditure would rise from 8.4% of GDP in 1990 to 11.1% of projected GDP in 2051. Such an increase would represent a large shift in health resources from the young and working age to older people (health care expenditure on older people could increase from about 33% of total health care expenditure in 1990 to 50% by 2051).

In 1996, a report to the Commonwealth Government by the National Commission of Audit found that:

- A radical and lasting change to the age structure of Australia's population would occur over the next 50 years, with aged dependency ratios (the ratio of people aged 65 years and over to those aged 18–64 years) increasing dramatically from the current level of 19% to 39% by 2041.
- Health and aged care costs would increase from a current level of 8.4% of GDP to about 14.5% of GDP by 2030.

The report recommended 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' (National Commission of Audit 1996:121).

Although there is no disagreement that the Australian population is ageing, and that health and welfare expenditure per person is increasing, the two reports, particularly the later one, were questioned or criticised on their basic approaches and the assumptions behind their projections:

- The studies adopted a rather narrow approach to the whole issue by emphasising the budgetary consequences of ageing. The 'burden of ageing' view is narrow and the ageing of the population has consequences that are far beyond the confines of the government budget (Saunders 1996).
- The models used in the 1996 report assume a direct relationship between demand for services (as defined by number of aged people in a population) and the level of service provision—in reality the relationship is more complex (Gibson & Goss 1999). To conduct a credible projection of future demand for health services and health expenditure, a range of issues should be taken into account (Madden & Goss 1998).
- Analyses of the level and pace of population ageing have found no consistent relationship between demographic trends and levels of health expenditure as a proportion of GDP in Australia. The lack of correlation between the patterns of fluctuation of health expenditure as a proportion of GDP and demographic trends is also observed in other OECD countries. Factors other than population ageing are the major influences on the level of health outlays (Howe 1997).
- Projections are based on assumptions of a relatively high rate of growth in health expenditure per person and a relatively low rate of growth in GDP. These assumptions are questioned (Gibson & Goss 1999). The projected outcome of the National Commission of Audit is at odds with Australian experience over the past 20 years and with the contemporary experience of other OECD countries with much older populations (Howe 1997).
- Australia's relatively young population age structure gives scope for a shift in 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 expenditures on younger and older age groups as the population ages (Howe 1997).
- It is believed that the Australian health system coped fairly well with rapid population ageing in the recent past; and that the controls put in place in health and welfare expenditure to contain costs have resulted in a manageable increase in government expenditure; and that 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).

Regarding the relationship between population ageing and costs of health care, it has also been questioned whether higher levels of health expenditure are associated with improved outcomes. Rather than speculating about the potentially increasing proportion of GDP that might be spent on health care for older people, an alternative approach might be to model the kinds of options that could optimise health status across the population within a given level of expenditure (Howe 1997).

4.2 Impact on government expenditures in aged care and disability services

A number of reports contain research concerning the past or future trends in government expenditures on aged care and disability services.

A paper examining the level and patterns of government health and welfare expenditure on older Australians showed that, in the past 20 years, the ageing of the Australian population has put pressure on expenditure on the older population (Choi 1998). During this period, changes have been made in many aspects of the health and aged care systems to maintain care at an affordable level and also to introduce control over costs. The paper also found that the growth of the economy in this period 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: 12).

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 the number 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 Age 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, from 1997 on, the first of the baby boomers, born in 1945, have just passed age 50 and are entering the highest incidence age group (50–64). The increasing age of this baby-boomer cohort and the related ageing of the working-age population, are likely to cause further growth of DSP (Table 4.1; Whiteford & Jackson 1998; Jackson 1999).

If the current growth rate continues, the number of new DSP recipients would reach 140,000 per annum within a decade, and nearly 180,000 per annum by the year 2011 (Walsh 1997). The total number of recipients would increase from about 500,000 recipients in early 1996 to 935,000 by 2006. This trend reflects the combined effect of high grant rate for people aged 50 years and over and the bulge of the baby-boom population cohort, which is now entering this age group (Walsh 1997).

Walsh and De Ravin (1995) discussed future trends in demand for long-term care and projected costs. They attempted to re-open the debate about funding and delivery of long-term care by suggesting that 'free' access to long-term care services in future will need to be limited, either through increased personal financial contribution by care recipients or by introducing optional or compulsory 'pre-funding' (Walsh & De Ravin 1995: 5).

Long-term care was defined as care provided to people with a severe or profound handicap (as defined in the ABS 1993 disability survey) of any age. The paper estimated that the total cost of long-term care currently accounted for about 0.75% (or \$3.0 billion) of Australian GDP and could well increase to 1% of GDP by the middle of next century. The current level of 0.75% of GDP could remain stable with the projected trends of population ageing only if:

- residential care is successfully maintained in line with the target planning ratios;
- Home and Community Care Program (HACC) utilisation is maintained at about 33% of people with profound or severe handicap in the community; and
- GDP per capita growth is maintained at 1% per annum in real terms (Walsh & De Ravin 1995: 50).

According to the paper, the Australian private insurance industry already provided \$0.7 billion through accident compensation schemes to fund long-term care (although it is estimated that only about one-third of this amount is actually spent on long-term care). The paper stated that 'the Australian insurance industry believes government policy, taxation arrangements and legislation need to be changed to facilitate private sector involvement in the funding process, and hence ultimately assist the strains on consolidated revenue which will inevitably emerge next century' (Walsh & De Ravin 1995: 51).

Table 4.1: Disability Support Pension customers, June 1977 to June 1999

Year	Males		Females		Persons
	Number	Per cent	Number	Per cent	Number
1977					203,029
1978					205,011
1979					219,911
1980	158,327	69.1	70,892	30.9	229,219
1981	153,889	69.3	68,062	30.7	221,951
1982	151,146	69.8	65,503	30.2	216,649
1983	155,672	70.7	64,617	29.3	220,289
1984	173,063	71.9	67,511	28.1	240,574
1985	188,713	72.8	70,449	27.2	259,162
1986	200,898	73.4	72,912	26.6	273,810
1987	213,290	73.8	75,760	26.2	289,050
1988	219,168	73.8	77,745	26.2	296,913
1989	227,285	73.8	80,510	26.2	307,795
1990	233,251	73.6	83,462	26.4	316,713
1991	244,699	73.2	89,535	26.8	334,234
1992	273,697	72.3	104,861	27.7	378,558
1993	291,471	71.7	115,101	28.3	406,572
1994	309,123	70.9	127,111	29.1	436,234
1995	324,672	69.9	139,758	30.1	464,430
1996	340,256	68.2	158,979	31.8	499,235
1997	352,607	66.8	174,907	33.2	527,514
1998	361,539	65.3	191,797	34.7	553,336
1999	373,340	64.6	204,342	35.4	577,682

Source: Department of Family and Community Services unpublished data.

4.3 Impact on demand for disability support services

The AIHW estimated the projected growth in demand for disability support services in Australia, based on the projected growth in the target group—people with severe or profound handicap. The projections were based on the ABS population projections from 1995 to 2051 (AIHW 1997a).

The projected demographic trends, particularly population ageing, resulted in a substantial projected increase in the number of people with a profound or severe handicap between 1997 and 2003:

- The increase in the age group 5–64 years was estimated to be 9.9% (39,100 people).
- The growth in the working age population (age 15–64) with severe or profound handicap was estimated at 11.3% (37,200 people).
- Overall, the total number of Australians with a severe or profound handicap was projected to increase by 13.7% (109,200 people). The overall growth was mainly attributable to the rapid increase in the age groups of 45–64 years (19.5% increase or 32,600 people) and 65 years and over (17.3% increase or 70,200 people) (AIHW 1997a).

The high projected rates of increase in the number of people with a severe or profound handicap aged 45 years and over was likely to result in the ageing of the client population of disability support services. The high growth in the population aged 45–64 years would put pressure on disability services, either to provide services to increasingly older clients, or to make transitional arrangements between disability services and suitable aged care services (AIHW 1997a).

The 1997 AIHW projections of numbers of people with a severe or profound handicap relied on the assumption that the age–sex-specific prevalence rates of severe or profound handicap would remain constant (See Section 3.2).

4.4 Impact on residential aged care services

Under the policy directions of the Aged Care Reform Strategy, there has, since 1985, been a shift in policy emphasis from residential care towards home-based care in the aged care field (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). Nevertheless, this shift has been largely carried out by way of a de-institutionalisation of program structures rather than a de-institutionalisation of people. This 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 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.

Gibson and Liu (1995) examined the impact of population ageing on future use and supply of residential aged care services. Their paper presented projections of hostel and nursing home use from 1993 to 2021, based on 1993 patterns of actual use, and compared them with projected levels of supply. The study found that there may be a general under-supply of residential aged care from the turn of the century, including a likely under-supply of nursing home-type care for high-dependency aged people, particularly in the period from 2006 and 2016 (Gibson & Liu 1995).

The study also pointed out that the use of the standard planning ratio—the number of beds or places available per thousand persons aged 70 and over—to describe the level of supply over time has shortcomings. The ratio was determined on the basis of 1983 data and is not sensitive to the changing internal age structure of population 70 and over, in particular the increasing proportion of the population aged 80 years and over.¹ People aged 80 years and over are at greater risk of admission to residential care (Gibson & Liu 1995).

Liu (1998) has used refined life table models to estimate the probability of the first nursing home admission over a lifetime and the probability of nursing home use in the remaining lifetime at particular ages. The analysis of 1994–1995 nursing home data indicated that a much larger number of older people than has often been recognised are at risk of nursing home admission at some point in their lives. The results suggested that the chance of entering a nursing home after turning age 65 is actually one in three, although only 3% of people aged 65 years and over were resident in a nursing home on any one day in 1994–1995 (Liu 1998). Nevertheless, the estimated probabilities do not necessarily represent ‘need’ or ‘demand’, but rather nursing home usage patterns, as constrained by levels of provision (Liu 1998).

The new residential aged care system introduced in October 1997 has merged nursing homes and hostels into a single residential care system. The analysis of statistical data on the new system shows a continuing trend to higher dependency levels among residents. At the end of June 1999, almost half (49%) of residential aged care facility residents were aged 85 years and over, and 61% of residents were in high-care categories (AIHW 2000a).

4.5 Issues concerning the age dependency ratio

The age dependency ratio, commonly defined as the ratio of persons aged 65 years and over to the population of working age (15–64 years), has been widely used as a crude measure of the ‘burden’ of population ageing. In practice, the age groups used to define the ratio vary. For instance, a World Bank report defines the ratio as people over 60 years to people between 20 and 59 years, while the 1996 Australian National Commission of Audit report defines the ratio as people aged 65 years and over to those aged between 18 and 64 years (World Bank 1994; National Commission of Audit 1996).

The age dependency ratio must be used with caution. It has been criticised as potentially misleading for purposes of planning and policy. Old age is not synonymous with economic dependency and the ratio ignores unpaid productive activities, unpaid volunteer work and unpaid care. A true economic dependency ratio must take into consideration differences in

¹ The residential care policy aim of 40 nursing home beds per thousand persons aged 70 and over was first publicly announced in the report of the Nursing Homes and Hostels Review (Department of Community Services 1986: 25 and 44). The calculation and interpretations of the ratio were drawn from data collected and analysed by Rhys Hearn and Hearn (1986) and Howe and Preston (1985) which used mainly 1983 nursing home data (Gibson & Liu 1995: 62).

employment and other economic activity, by age and gender (Johnson 1996; Schulz et al. 1991).

Some refinements of the dependency ratio have been suggested. For example, a total dependency ratio has been proposed to include children and people with a disability as components of dependent population (e.g. Schulz et al. 1991; Borowski & Hugo 1997; Easterlin 1991). Another refinement—the labour force dependency ratio—is suggested, comparing the number of children, older persons and other people not in paid work with the number of paid workers able to provide financial support for them (e.g. Young 1994).

For disability and aged care service planning, the ageing of the working-age and older populations, and increases in the number of people with disability, particularly with severe or profound handicap, are major concerns. The dependency ratio and its modified versions cannot be used directly as measures for this analytical purpose.

It has been pointed out that the proportion of people aged 65 plus is a poor measure of the likely need for a long-term aged care services. The vast majority of people aged 65 to 80 has no need for such services. The proportion of people aged 80 and over is a more useful indicator of demand with respect to population ageing, as it is among this group that service use is highest (Gibson & Goss 1999).

A 'severe and profound handicap' dependency ratio has been used to examine need for long-term care in Australia. This is calculated as the ratio of number of people with severe or profound handicap to the number of people in the working-age population (Walsh & De Ravin 1995). However, that ratio uses the entire working-age population as the denominator. The working-age population may include unemployed people and people with a disability, or a severe or profound handicap. Again, the ratio focuses on economic concerns and there are other issues that need to be addressed.

5 Trends in informal care

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

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

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

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

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

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

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

5.1 Impact of population growth and population ageing on informal care

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

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

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

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

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

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

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

5.2 Other factors affecting changes in informal care

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

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

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

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

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

Family formation

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

Living arrangements and employment

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

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

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

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

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

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

Source: Adapted from ABS 1998b: 26.

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

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

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

Source: Adapted from ABS 1998b: 26.

5.3 Trends in community living among people with a disability

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

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

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

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

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

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

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

5.4 Impact of caring role on informal carers

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

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

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

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

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

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

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

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

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

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

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

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

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

5.5 Support needs for carers

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

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

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

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

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

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

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

6 Ageing clients of disability and aged care services and their service usage pattern

6.1 Disability services

While there are studies on trends in population ageing in Australia, few studies have analysed ageing trends in populations with disability. Chapters 13 to 15 of this report will examine the changes in age structure of the population with a disability and the potential impact of these changes on disability service planning. This chapter looks at patterns of service usage among clients in different age groups.

Many disability support services are provided or funded by Australian governments under the Commonwealth/State Disability Agreement (CSDA). Under the Agreement, the Commonwealth takes administrative responsibility for employment services, with the States and Territories taking responsibility for accommodation and other support services. Both levels of government retain some responsibility for advocacy, information, print disability and research. The services are generally directed at people aged less than 65 years, although the CSDA places no age-based restrictions on access to them.

Tables 6.1 to 6.3 present data on services received from the 1999 CSDA Minimum Data Set (MDS) collection. These data are counts of the number of times people have received services on the snapshot day, rather than counts of individual consumers. A person may have received services from more than one provider on the snapshot day, and would therefore be counted more than once. The data show that about 15.8% (or 11,563 people) of CSDA service recipients on the snapshot day in 1999 were aged 50 years or over, 9.8% (or 7,173 people) were aged 55 years or over and 6.1% (or 4,491 people) were aged 60 years or over (Table 6.1).

Of service recipients aged 45–64 years, 62.6% reported their primary disability type as intellectual and 14.5% as physical. Among those recipients aged 65 years and over, 31.5% reported intellectual and 28.4% reported vision as their primary disability type (Table 6.2).

Information about the living arrangements of service recipients showed that the proportion of recipients living 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. The proportion of recipients living with their families declined from 50.9% for those aged under 45 years to less than 25% for those aged 45–64 years and 65 years or more (Table 6.3).

Preliminary analysis of the Victorian component of the 1998 CSDA MDS found that, of all service attendances on the snapshot day, 13% were for people aged 60 years or over. The proportion of older service recipients was greatest for community access services, with 60% of recipients of Independent Living Training Services being aged 60 years and over; 69% of all recipients of this service category attended specialist agencies catering for people with disabilities associated with ageing, such as arthritis, visual and hearing impairments (Stevenson 1999).

Table 6.1: CSDA services received on the snapshot day: primary disability type of recipients, by age, 1999

Disability type	<45 years	45–64 years	65+ years	Total	Total 50+	Total 55+	Total 60+	Total
	%	%	%	%	%	%	%	Number ^(a)
Developmental	96.9	2.7	0.5	100.0	2.4	1.5	0.7	1,721
Intellectual	78.3	19.7	2.1	100.0	13.1	7.1	3.8	46,217
Learning	96.8	2.7	0.5	100.0	1.6	0.9	0.8	742
Autism	97.7	2.1	0.1	100.0	0.9	0.3	0.1	2,297
Physical	70.2	23.1	6.7	100.0	21.6	14.9	9.9	9,105
Acquired brain injury	68.4	28.2	3.4	100.0	21.5	13.1	6.6	2,365
Deafblind	69.3	9.4	21.3	100.0	25.4	24.2	21.3	244
Vision	32.7	15.0	52.2	100.0	62.8	58.5	55.4	1,650
Hearing	72.0	15.1	12.9	100.0	23.6	20.6	17.0	839
Speech	97.5	1.8	0.6	100.0	1.5	1.2	1.2	326
Psychiatric	68.6	28.4	3.0	100.0	19.9	11.3	5.6	5,377
Neurological	61.0	29.4	9.6	100.0	29.0	19.3	13.2	1,914
Not stated	83.0	15.5	1.5	100.0	12.9	8.1	4.4	271
Total	76.0	19.9	4.2	100.0	15.8	9.8	6.1	73,068

(a) The total excludes recipients whose age was not stated.

Source: AIHW analysis of the 1999 CSDA MDS collection. For detailed background information see AIHW 2000b.

Table 6.2: CSDA services received on the snapshot day: distribution of primary disability type of recipients, by age, 1999

Disability type	<45 years		45–64 years		65+ years		Total ^(a)
	Number	%	Number	%	Number	%	
Developmental	1,667	3.0	46	0.3	8	0.3	1,721
Intellectual	36,174	65.2	9,089	62.6	954	31.5	46,217
Learning	718	1.3	20	0.1	4	0.1	742
Autism	2,245	4.0	49	0.3	3	0.1	2,297
Physical	6,392	11.5	2,104	14.5	609	20.1	9,105
Acquired brain injury	1,617	2.9	667	4.6	81	2.7	2,365
Deafblind	169	0.3	23	0.2	52	1.7	244
Vision	540	1.0	248	1.7	862	28.4	1,650
Hearing	604	1.1	127	0.9	108	3.6	839
Speech	318	0.6	6	0.0	2	0.1	326
Psychiatric	3,686	6.6	1,529	10.5	162	5.3	5,377
Neurological	1,167	2.1	563	3.9	184	6.1	1,914
Not stated	225	0.4	42	0.3	4	0.1	271
Total	55,522	100.0	14,513	100.0	3,033	100.0	73,068

(a) The total excludes recipients whose age was not stated.

Source: AIHW analysis of the 1999 CSDA MDS collection. For detailed background information see AIHW 2000b.

Table 6.3: CSDA services received on the snapshot day: living arrangements of recipients, by age, 1999

Living arrangement	<45 years		45–64 years		65+ years	
	Number	%	Number	%	Number	%
Lives alone	4,614	8.3	2,126	14.6	753	24.8
With family	28,261	50.9	3,452	23.8	750	24.7
Disability community accom	14,234	25.6	4,855	33.5	626	20.6
Other community accom	2,167	3.9	794	5.5	82	2.7
Nursing home	211	0.4	269	1.9	222	7.3
Hospital	215	0.4	143	1.0	58	1.9
Other institution	4,711	8.5	2,471	17.0	469	15.5
No usual residence	63	0.1	10	0.1	2	0.1
Not known	934	1.7	366	2.5	65	2.1
Not stated	112	0.2	27	0.2	6	0.2
Total	55,522	100.0	14,513	100.0	3,033	100.0

Source: AIHW analysis of the 1999 CSDA MDS collection. For detailed background information see AIHW 2000b.

Table 6.4 presents data on the number of consumers in each age group who accessed different service types on the snapshot day. Counts of consumers are different from counts of service recipients—a statistical record linkage key is used to identify instances in which the same person accesses more than one service on the snapshot day, thus enabling an estimate of the number of individual consumers.

Accommodation support was the service category accessed by the greatest number of consumers on the snapshot day. Two-thirds of consumers of accommodation support services were aged under 45, 27.6% were aged between 45 and 64 and 4.4% were aged 65 or over. The proportion of consumers aged under 45 was highest for respite services (85.9%), and lowest for accommodation support services (67.9%), while the proportion of consumers in the age group 45–64 was highest for accommodation support services (27.6%), and lowest for respite services (10.1%). The proportion of consumers aged 65 or over was highest for community access services (7.5%).

There are people with early onset disability who are not known to disability service providers and administrators or, although known, may not have been in receipt of services for a long period. These people may need and request services as they begin to age. For instance, a preliminary analysis of new case referrals and re-referrals to Irrabeena (Western Australia) of persons aged 45 or older indicated a 40% increase in numbers in this age group between 1985–87 and 1988–1990. The percentage of new cases and re-referrals accepted (active clients) also increased from 60% to 71% (Re 1991: 29).

Table 6.4: Consumers of CSDA services, by service type by age, 1999^(a)

Service type	<45 years		45–64 years		65+ years		Total ^(b)
	Number	%	Number	%	Number	%	
Accommodation support	14,050	67.9	5,714	27.6	915	4.4	20,679
Community support	12,377	82.2	1,929	12.8	753	5.0	15,059
Community access	10,549	72.6	2,894	19.9	1,092	7.5	14,535
Respite	2,557	85.9	300	10.1	121	4.1	2,978
Employment	14,130	80.0	3,422	19.4	102	0.6	17,654
Total	46,661	75.7	12,178	19.8	2,798	4.5	61,637

(a) Numbers of consumers are estimates, made as closely as allowed by using a statistical linkage key (AIHW *Disability Data Briefing* Number 17, March 2000).

(b) The total excludes consumers whose age was not stated.

Source: AIHW analysis of the 1997 CSDA MDS collection. For detailed background information see AIHW 2000b.

6.2 Aged care services

The Home and Community Care Program (HACC) is jointly funded by the Commonwealth and State and Territory governments. Under the program, services are provided to older people and to younger people with disabilities. Services include home nursing, delivered meals, home help, home maintenance, transport and shopping assistance, paramedical services and home- and centre-based respite care (AIHW 1999a: 185).

HACC services can supplement informal care for people living at home, and may help to maintain the caring relationship for as long as possible. In a report on the service needs of people with a disability who are ageing, Gatter (1996) stated that significant increases in demand for HACC services should be anticipated, to meet the needs of both people with disabilities who are ageing, and their ageing carers.

The average age of HACC clients increased slightly from 71.2 years in 1990 to 72.4 years in 1997 and the median age increased from 76.0 years to 77.0 years. During the same period, the proportion of HACC clients aged 80 years and over increased from 36.9% to 42.1%, while the proportion of clients aged 65–79 years decreased from 42.3% to 38.2% (Department of Health and Aged Care 1998: 62).⁵

In the 1997–98 HACC user characteristics survey data collection, 8% of clients surveyed were aged under 45 years, and 11% were aged between 45 and 64 years. Table 6.5 shows the percentage of clients who needed assistance in particular areas. In all areas except housekeeping, the proportion of clients needing assistance was highest for the under-45 age group, followed by the 45–64 age group. This indicates that, on average, younger clients needed support in a greater number of areas of activity. This, in turn, may suggest that people aged under 65 who access HACC services tend to have relatively severe disabilities. The rank order of areas in which assistance was most commonly needed was very similar for the three age groups, with housekeeping and personal care being the areas in which assistance was most commonly needed.

⁵ As these statistics were derived from the HACC Service User Characteristics Survey data, the estimated proportions are subject to sampling errors.

Table 6.5: HACC clients: areas in which assistance needed, by age (per cent), Australia, 1997–98

Area in which assistance needed	Age		
	<45	45–64	65+
Mobility	48.9	39.6	33.5
Personal care	61.5	41.2	37.9
Housekeeping	81.0	75.8	81.9
Communication	43.9	20.8	11.1
Behaviour	43.4	23.5	18.1
Continence	37.1	19.9	16.4
Total number	6,391	8,575	60,407

Source: 1997–98 HACC user characteristics survey data collection.

Table 6.6 shows the percentage of clients in each age group who received particular types of services from HACC agencies. For people aged under 45 years, home-based respite, home help and transport services were the most commonly used services. For people aged between 45 and 64, home help, transport and home nursing services were most commonly used. People aged 65 and over had a similar pattern of service use to people aged between 45 and 64, but with higher usage of home help and home delivered meals services. In comparison with the two older age groups, people aged under 45 had a lower usage of home help, home nursing, home-delivered meals, and home maintenance/modification services, and higher usage of personal care and home-based respite.

It is interesting that the generally higher levels of need for assistance among clients aged under 45 are not reflected in higher levels of service usage in that age group. Some of these people may receive disability support services from non-HACC providers.

It is difficult to draw direct comparisons between the patterns of service use for CSDA service recipients and HACC service recipients because of the different service type classifications used. However, the HACC and CSDA data indicate a high rate of utilisation of respite services among people aged under 45, in comparison with older age groups.

Table 6.6: HACC clients: services received from HACC agency, by age (per cent), Australia, 1997–98^(a)

Service type	Age		
	<45	45–64	65+
Home help	24.2	33.4	38.6
Personal care	12.8	9.8	9.1
Home nursing	13.4	20.0	19.2
Paramedical services	8.1	11.1	8.9
Home-based respite	27.0	6.0	4.5
Centre day care	10.3	13.3	12.9
Home-delivered meals	2.6	7.6	12.9
Meals delivered to centres	2.9	3.7	3.9
Home maintenance/modification	4.8	9.4	10.7
Transport services	18.1	20.7	19.6
Other services	24.9	19.0	14.5
Total number	6,203	8,309	59,773

(a) The Northern Territory did not provide data on service type.

Source: 1997–98 HACC user characteristics survey data collection.

7 Individual ageing of people with an early onset of disability

This section focuses on individual ageing of people with a disability and reviews the literature on several important issues:

- How does the nature and timing of individual ageing differ between the population at large and people with an early onset disability?
- What are the differences in mortality and life expectancy between the population in general and people with an early onset disability?
- What, if any, is the main difference between the ageing population in general and ageing people with an early onset disability in terms of age-related health conditions, including major illnesses and diseases?
- What are the trends in prevalence of congenital malformations relating to early onset disability?

7.1 Early start of individual ageing

Theories of aspects of biological ageing may be divided into three broad categories: genetic, non-genetic and physiological (Section 1.2). Genetic theories are based on the belief that genetic factors are associated with particular congenital disorders that affect the rate of ageing in certain individuals. These genetically based congenital disorders include progeria such as Cockayne's syndrome (premature ageing in very young children), Werner's syndrome (which refers to the onset of ageing in late adolescent years) and the premature ageing of persons with Down syndrome (Aiken 1989; Bullock 1992; Cristofalo 1988 and Perlmutter & Hall 1985, cited in Suttie 1995:11).

Non-genetic theories generally state that ageing occurs as a result of changes to cells rather than as part of genetic development. A common conception is that body parts simply wear out over time.

Physiological theories of ageing mainly relate to illness and disease in particular body organs and systems.

While the three broad categories of theories view the ageing process from different perspectives, it is generally agreed that biological ageing is characterised by increased risk of death with age, an increase in incidence of disease and progressive deterioration of the body, and changes in the ability of the body to adapt to environmental variations (Suttie 1995: 12).

It has been suggested that to identify the onset of ageing, three factors relating to life change should be assessed in addition to chronological age (Janicki et al. 1985: 291). These factors are:

- Increasing physical frailty and decreasing physical reserves mainly attributable to chronological age rather than trauma or illness;

- Diminishing levels of functional skills, particularly in areas of self-care, personal hygiene and other basic activities of daily living attributable to chronological age rather than to trauma or illness; and
- For less mentally impaired individuals, the self-perception of ageing and desire to seek age-appropriate or normative roles and activities.

A number of US studies have suggested that the beginning of ageing for people with a developmental disability occurs during the individual's mid- to late 40s or early to mid-50s. The criteria used to define 'ageing' status in these studies often include chronological age, clinical observations of changing functional status and the individuals' own expectations of changes in normative aged-related activities (Dickerson et al. 1979; Segal 1977; Seltzer et al. 1982; Thomae & Fryers 1982, cited in Janicki et al. 1985).

There is empirical evidence indicating that people with intellectual disability resulting from certain conditions do age earlier. Signs of premature ageing have consistently been reported in people with Down syndrome and intellectual disability resulting from other chromosomal causes (e.g. Janicki et al. 1985; Suttie 1995; Williams & Chad 1998). For people with intellectual disability associated with certain chromosomal disorders or conditions such as Down syndrome, ageing may begin in their 30s, 40s or 50s (Bigby 1998; Janicki et al. 1985).

There is considerable documentation of earlier onset and higher incidence of Alzheimer's disease in people with Down syndrome (e.g. Bigby 1998; Gatter 1996). There are also suggestions that people with severe physical disabilities such as spinal cord injury and brain injury begin ageing earlier than the general population, and that a range of health conditions worsen with increased duration of disability (Fethney 1998; Gething & Fethney 1998; Menter et al. 1993 cited in Gething et al. 1999; Crewe 1990).

International studies have found that dementia occurs at much higher rates among adult and older people with intellectual disability (not related to Down syndrome) than among the general population. Some people with an intellectual disability may acquire dementia relatively early in life, at age around 50 (Cooper 1997).

A review of published research indicates that a very significant number of people with spinal cord injury do begin to experience various problems as they age. Fatigue is the single most common problem, followed by a number of other physical problems such as bones that break easily and skin that breaks down more readily than normal. These developments are considered to be more related to duration of disability than to chronological age. People who were injured in their teens often begin to experience problems in their 30s and 40s, much earlier than their peers without disabilities (Trieschmann 1987, cited in Crewe 1990).

Significant proportions of ageing people with polio have been found to experience a range of changes in functioning, such as unaccustomed fatigue, breathing problems, weakness in previously unaffected muscles and pain. These changes are called 'post-polio syndrome' and the most common explanation is that there has been premature ageing caused by over-work in the motor neurones that survived the polio virus (Trieschmann 1987, cited in Crewe 1990). The decrease in energy and strength that results from these changes requires these people to reprioritise and even drastically reduce their activities (Crewe 1990).

A recent Australian survey of adults with cerebral palsy, known to agencies, reported that a majority of respondents considered that their physical condition was deteriorating, although cerebral palsy is not considered a progressive disorder. The survey results echoed findings of similar studies conducted in the United States and United Kingdom, that individuals with cerebral palsy experience negative changes in walking, digestion, bowel and bladder control, respiration, communication and swallowing. Depression, frustration, fatigue and anger were common among the people surveyed. In some cases, depression and anxiety

about ageing resulted in reduced social contact and affected independence and social interaction (Balandin & Morgan 1997).

Studies in the US and Canada showed that adults or ageing people with developmental or intellectual disability who had been living in long-term residential care had a lower level of functional ability and a higher rate of age-related decline than those living in the general community (Anderson 1989; Badry et al. 1989).

7.2 Decline in mortality and increase in life expectancy

There is evidence to show that survival into older age is now a reality for some people with an intellectual disability, including some people with more severe disabilities (Eyman & Borthwick-Duffy 1994). However, international studies indicate that the mortality rate for people with an intellectual disability is greater than for the general population, especially for people living in institutions (Haveman et al. 1989; Haveman & Maaskant 1989). There are still large numbers of non-ambulatory individuals with severe or profound mental retardation whose life expectancies are very limited.

Until the 1950s, most studies showed that the majority of children with Down syndrome died before the age of 10 years, while in later studies at least half of them survived beyond the age of 30 years (Haveman & Maaskant 1989). A more recent birth cohort study of life expectancy for adults with Down syndrome was based on 1,610 affected individuals identified from over 1.5 million consecutive live births in British Columbia from 1908 to 1981. The study predicted that about 44.4% and 13.6% of live-born infants with Down syndrome would survive to age 60 and 68 years, respectively, as compared with 86.4% and 78.4% of the general population (Baird & Sadovnick 1988).

A 1990 United Kingdom study of trends in incidence and survival in Down syndrome also found that the number of young adults with Down syndrome was increasing, partly due to improvements in survival for those with congenital heart disease and decline in deaths from infection, and partly because of an increase of incidence in the 1960s (McGrother & Marshall 1990).

Studies conducted in the United States in the 1980s found that although the proportion of persons with mental retardation who live into old age was still lower than that for the population in general, the growth rate of this age group was higher than for other age groups with developmental disabilities (Anderson 1989:289).

With the exception of people with Down syndrome and certain other genetic conditions, and people with more severe disabilities, life expectancy and mortality rates for people with mental retardation in the United States are approaching those for the general population (Carter & Jancar 1983; Janicki 1986). A large proportion of adults with developmental disabilities now in their middle years are expected to survive into old age (Walz et al. 1986, cited in Anderson 1989: 290).

These changes are due to a number of factors, among which developments in medical technology, improvements in health care and social service programs and trends in community living are particularly important.

Over one-third of infants born with Down syndrome have congenital heart defects that are now repairable as a result of advances in medical technology. This may imply a potential further increase in the number of ageing clients with intellectual disability. However, some

people with Down syndrome who have benefited from early surgical treatment have not yet reached old age, so effects over time have not been fully documented (Suttie 1995).

7.3 Health conditions and major illnesses and diseases related to ageing: relationship to disability

Among ageing people with an early onset disability, those with Down syndrome are more likely to have hearing and vision impairments, hypothyroidism, musculoskeletal problems and congenital heart disease. The prevalence of dementia of the Alzheimer type is particularly high in people with Down syndrome. It has been reported that neuropathological features of Alzheimer's disease are presented in all post-mortems of people with Down syndrome over 40 years of age, while clinical features may only be noted in a smaller percentage prior to death (Barcikowska et al. 1989 cited in Suttie 1995: 53).

It has been suggested that, excluding people with Down syndrome, people ageing with an intellectual disability do not differ significantly from the general ageing population in terms of the incidence of major illnesses and diseases attributable to biological ageing (e.g. heart disease, arthritis and higher blood pressure) (Suttie 1995).

However, a study of adults with intellectual disability aged 20–50 years in Sydney showed that these people have increased cardiovascular risk factors, more chronic diseases, and experience higher rates of morbidity and mortality compared with the general population. They also find it difficult to access health services because of low income and problems with communication and mobility (Beange et al. 1995).

Among the people reporting intellectual disability as their primary disabling condition in the 1993 ABS disability survey, 44% also reported associated physical impairments or disabilities and more than a quarter also reported speech problems. A high proportion (22%) of people reported associated psychiatric disabilities (Wen 1997).

A number of factors need to be considered when interpreting study findings (Suttie 1995). Firstly, there is a possibility of under-reporting of diseases and illness among people with intellectual disability because of their poor communication skills or possible insensitivity to pain and illnesses (Anderson 1993).

Secondly, for many types of illness and disease, comparisons between ageing people with intellectual disability and the general ageing population are not available.

Finally, studies have found considerable variations in factors affecting health status. For instance, people with intellectual disability may be exposed to additional risk factors such as non-mobility. Long-term institutional placement may affect health status through poor self-care. Additional complicating medical conditions could also affect health conditions (Eyman & Borthwick-Duffy 1994; Suttie 1995). Hence, further study is needed to properly understand differences in health status between people ageing with intellectual disability and the general ageing population.

It has also been pointed out that the variations in the health and functional status of the older population cannot be explained simply using the dichotomy of acute or lethal and chronic degenerative diseases. Nor can these variations necessarily be explained using the simple distinction between 'age-dependent' diseases (i.e. those diseases viewed as arising as a result of ageing processes) and 'age-related' diseases (diseases related to particular ages). This distinction may reflect more about our current level of knowledge of disease mechanisms than about disease processes. It is particularly difficult to apply this distinction to chronic and degenerative diseases. For instance, Alzheimer's disease, a disease process

usually characterised as 'age dependent', appears to have some genetic determinants and may be treatable and preventable (Manton 1990).

7.4 Trends in incidence and prevalence of congenital malformations

A review of epidemiological studies found that Down syndrome is the most common genetic cause of severe intellectual disability (IQ <50). Chromosomal etiologies (the majority of which are Down syndrome) were estimated to account for 20% to 40% of all cases of severe intellectual disability (Alberman 1978; McGrother & Marshall 1990; McLaren & Bryson 1987).⁶ Therefore, changes in incidence and the prevalence of these conditions have direct implications for services.⁷

A study that looks at present estimates and future projections of the UK population with Down syndrome estimated an overall prevalence rate of 6.7 per 10,000, or 30,000 affected individuals. Results, based on a study population of over 7 million, gave no indication of a sizable reduction in the future Down syndrome population. Recent reductions in prevalence among the youngest age groups are likely to be explained by changes in the maternal age distribution for general population births together with a reduction in numbers of all births (Steele & Stratford 1995).

Prenatal diagnosis is another important factor affecting the incidence and prevalence of Down syndrome and other congenital malformations that may have resulted in early onset of disability. In 1992, Australian rates of several important congenital malformations, including Down syndrome and spina bifida, ranked in the top half of rates for developed countries (de Looper & Bhatia 1998: 35).

In Australia, incidence rates for Down syndrome in births remained relatively stable at around 12.8 per 10,000 births during the period 1987 to 1996, ranging between a high of 14.0 per 10,000 births in 1993 and a low of 11.9 per 10,000 births in 1987. The number of babies with Down syndrome surviving beyond the neonatal period (within 28 days of birth) increased from 249 in 1987 to 304 in 1990 and dropped to 246 in 1996. The reported number of induced abortions performed after prenatal diagnosis of trisomy 21 increased substantially during this period, reaching a peak of 130 in 1994. In the years 1987–1996, induced abortions accounted for 21.1% of all recorded notifications of Down syndrome, increasing from under 15% in 1987 to over 20% in the 1990s (Hurst et al. 1999: 82).

Incidence of spina bifida in Australia declined gradually from 7.1 per 10,000 births in 1987 to 3.0 per 10,000 births in 1994, increased to 3.5 in 1995, and then dropped again to 3.0 in 1996. Among 1,279 infants with spina bifida and for whom short-term outcome was known, 22.0% were stillborn and 19.8% of those born alive died during the neonatal period (Hurst et al. 1999: 38).

The 1998 ABS disability survey, unlike previous surveys, enables information on disabling condition to be related to responses to the survey screening questions (a series of questions

⁶ The higher estimates tend to come from studies that included non-survivors from the relevant populations (McLaren & Bryson 1987).

⁷ An AHIW report critically reviewed the definitions and estimates of prevalence of intellectual disability with special reference to Australia and provided refined estimates of prevalence from national population surveys. The report also presented a preliminary analysis of patterns of intellectual disability in Australia (Wen 1997).

about specific impairments, activity limitations or restrictions). This additional information may allow analysis of the associations between a disability and a particular impairment or disease. However, the difficulties of attributing disability to particular impairments and diseases using cross-sectional survey data must be appreciated when interpreting the data. Also, the time between onset of illness and development of disability may vary depending on the nature of the disease and other factors (Campbell et al. 1994).

8 Needs of ageing people with a disability

Assessing needs—both those common to all ageing people and those unique to people ageing with disability—is crucial for service planning in order to identify service target groups, develop new services and modify current services.

8.1 Needs common to the general ageing population

Most people, at least until very late in their life, do not experience losses of functional ability that seriously affect their social, physical or cognitive behaviour (McPherson 1990). However, people with a disability may have experienced losses of functional ability at different stages of their lives, depending on the nature and time of onset of their specific disabilities. 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 requirement for health, social, psychological and various other support services, including accommodation, recreation and leisure, mobility, finance, advocacy and family support. Some of the typical needs that result from biological, psychological and social ageing are outlined below.

Biological ageing

As a result of biological ageing, assistance may be required in the following areas (Janicki et al. 1985; Suttie 1995: 16–17):

- Signs of ageing—assistance with grooming and personal care such as podiatry, hairdressing and skin care.
- Sensory deficits (e.g. vision, hearing)—access to regular assessments, medical services, augmentative devices (e.g. glasses, hearing aids), adapted environments (e.g. placement of furnishings) and large-print materials.
- Fitness, muscle tone and strength—need for continued opportunities for exercise and recreation, and rehabilitation services.
- Mobility—ambulatory aids (e.g. sticks, wheel chairs), assistance with learning to use aids, adapted environments (e.g. handrails, ramps and bathroom grip rails), safety monitors, transportation and rehabilitation services.
- Diet—adequate diet and nutrition assistance, Meals-on-Wheels or access to nutrition sites.
- Physical illness and disease—access to health care and monitoring services, medical assistance including dental services, education about the signs of impending illness and disease.

- Dementia—medical services, increasing levels of supervision and support to carers.
- Other mental disorders (e.g. depression)—access to health care and monitoring services, awareness of causes of stress and stress-reduction strategies.

Psychological ageing

Needs for assistance as a result of psychological ageing may include (Suttie 1995: 33–34):

- Personality development (e.g. some people may have personality problems as they age)—opportunities for reminiscence and life review.
- Motivation (e.g. decline due to lack of stimulation, the value put on the perceived usefulness of the task)—stimulation in personally valued experiences, a variety of activity options and opportunities for new experiences.
- Changes in cognition and intelligence—need for continued practice to maintain/learn skills and interest areas.
- Personal control and choice—opportunities to have input into decisions affecting the individual and a range of options.

Social ageing

Needs for assistance as a result of social ageing may arise in the following areas (Suttie 1995: 23–24):

- Transition from work to retirement (changes in financial status, social roles, social network)—pre-retirement planning/advice, opportunities for part-time or voluntary work, assistance in leisure time preparation.
- Social network and role changes—opportunities for social contacts and inter-generation contacts, continuing links with the community and valued role at home and in the community.
- Social effects of biological ageing (e.g. increased loss of social contacts due to mobility difficulties, health problems and sensory losses)—transportation and mobility assistance to maintain community contact and support in facilitating contacts.

8.2 Special situations of older people with an early onset disability

The above section reviewed some common needs of an ageing population. People with an early onset disability may age more rapidly and thus have higher support needs at an earlier age than older people generally (see Chapter 7). For people with an early onset disability, support needs vary depending on the nature of the disability and stage of the ageing process. For example, an older person who has been blind since birth or early childhood will have needs that are quite different from one who has an intellectual disability. Therefore, only limited comparisons can be made between people ageing with an early onset disability and people who acquire disability as they age.

In many respects, differences between people living in institutions and people living in the community do not relate specifically to health care needs, but rather to factors such as independent living skills (Anderson 1989) and—probably more importantly—the availability of informal carers.

Some important differences between ageing people with an early onset disability and older people with late onset disability are identified in the literature (e.g. Anderson 1989; Ashman & Suttie 1995; Bigby 1992; Gatter 1996; Suttie 1995). Special situations of ageing people with an early onset disability may include:

- They are more likely to have low levels of functional ability, which is often the main reason they require care, particularly residential care.
- They are less likely to use community services and facilities or participate in community activities without assistance.
- They are more likely to have low levels of education, particularly those with an intellectual or learning disability.
- Many of them have never been married and hence have no spouse or children. It is these family members who provide most informal support to older people with a late onset disability. Those relying on informal support from aged parents or carers are at risk of losing their support.
- They are more likely to live in residential care and less likely to live alone or live with their families.
- They are less likely to have good social networks outside the family or their place of residence.
- They may be particularly disadvantaged due to lack of good communication skills. Many have difficulty expressing their needs or may require assistance to identify their needs.
- They have low participation rates in both formal and informal day activities and leisure programs, partly due to factors such as lack of good communication skills and informal support networks, partly because few opportunities or choices are available.
- The effects of long-term placement in residential care (including some group homes) may have reduced their capacity to engage in community activities.
- They are more likely to have participated in supported employment. For those who have been in supported employment, this may have not only provided occupation throughout their adult life, but also have been the main source of their lifelong social relationships.
- They are more likely to be dependent on pensions and not have any retirement income.
- They are much less likely to be home owners.

Thus, while most older people share common problems, people with lifelong disability are likely to have some additional disadvantages.

8.3 Special needs of older people with an early onset disability

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 (e.g. Gething et al. 1999; Gatter 1996; Bigby 1992):

- 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.

8.4 Factors contributing to restricted access to services

Apart from the special characteristics and needs of ageing people with an early onset disability reviewed in earlier sections, there are other factors that prevent these people from adequately accessing supports and services (e.g. Williams & Chad 1998). These factors can be summarised as follows:

- Many people with a lifelong disability heavily rely on others to provide adequate and appropriate support. This can indirectly cause unintentional exclusion from community-based services and activities.
- Individuals with inappropriate or intrusive behaviours are not welcomed in general community-based services and activities.
- Ageing people with a lifelong disability are often perceived as being incompatible with present client groups.
- Some services are not designed to provide a five-day structured program and full-time access is not an option.
- The location of services may make them inaccessible to some people with a lifelong disability.
- Personal financial constraints may limit access to services.
- The resources required to meet the emerging needs of older people with an early onset disability are diverse and complex.
- People ageing with disability may be excluded from specific services by restrictive program restrictions/requirements due to limited funding sources.

- Some people have difficulty in accessing appropriate services because of the regional division of administrative responsibilities.
- There is a lack of trained staff aides to support older adults with intellectual disability.

9 Existing services models: some issues

This chapter reviews the literature relating to current service models in Australia and highlights some of the issues relating to ageing people with a disability.

9.1 General issues concerning the need for appropriate services

A large number of reports and special studies have indicated that the existing Australian service models and boundaries between different programs cannot accommodate the emerging needs of people with a disability who are ageing. In Australia, disability and age-related service organisations currently appear to be providing services to two distinct populations, with little crossover or linkage (Buys & Rushworth 1997). Older adults with an early onset disability are falling between disability services and generic aged care services. They may be perceived as 'old' and unsuitable by disability services but quite 'young' and/or unsuitable by the aged care services that focus on the needs of the frail aged (Bigby 1998).

Functional abilities, not age, should be the factor in determining the suitability of services and supports, according to Williams (1999). Thus, it is important to develop effective collaboration and cooperation between services within the disability service system and between the disability system and aged care and other generic service systems to meet the needs of older people with an early onset disability. However, the complexities surrounding service provision, particularly in relation to the interface between the aged care system and the disability services system, have resulted in difficulties in service planning and provision (e.g. Gatter 1996; Williams & Chad 1998; Bigby 1999).

It appears to be widely agreed 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 moderate or mild intellectual disability (Bigby 1992). This option is to meet the needs common to ageing people generally, corresponding to their biological, psychological and social ageing. 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.

Since older people with an early onset disability are not a homogeneous group, service provision must be flexible to meet individual needs and circumstances and to accommodate individual differences in life experience, the ageing process, independent skill levels, health status, and particular interests and choices (Bigby 1992).

The existing problems of meeting the emerging needs of ageing clients with a disability are, to a large extent, related to the structures of service programs and the models of service delivery in use. For example, some ageing clients may not necessarily need new or additional services, but rather changes in the method of service delivery. People ageing with an early onset disability may need the same services but at an earlier age than the general ageing population. Day services may need to be restructured from full-day to part-day activities, or day activity arrangements should be more flexible to provide opportunities for socialisation (e.g. Janicki et al. 1985; Gatter 1996; Ruggi 1998).

Even though some service agencies have been providing services to older adults with intellectual disabilities living in the community, further information is needed to assess whether these services are appropriate and adequate to meet the needs of those people (Buys & Rushworth 1997).

In developing services that meet the needs of older people with an early onset disability it is necessary to consider:

- The decreased functional abilities and increased frailty of the target population.
- The decline in the development and retention of skills.
- The reduced appropriateness of some components of existing services suitable for younger people with disabilities (e.g. Janicki et al. 1985; Bigby 1992;).

A number of reports have raised the issue of defining a target group for the purpose of developing and planning services in response to the emerging needs of people with a disability who are ageing (e.g. Gatter 1996; Re 1991; Ruggi 1998). It is necessary to develop an integrated-service planning approach focusing on the needs of specific population target groups rather than the requirements of the existing funding programs. Broadening the planning process beyond a focus on program funding would enable greater collaboration across different programs and encourage joint planning efforts (NSW Health Services Research Group 1997).

The New South Wales Ageing and Disability Department and Health Department have jointly developed the Community Care Assessment Framework (response from New South Wales Ageing and Disability Department 1999). This framework assists in establishing a collaborative inter-agency process for comprehensive assessment of people who need complex, multiple or high levels of support. The framework applies a client-based approach, taking into account a person's overall needs. This new initiative has the potential to assist in resolving the issues arising for older people with an early onset disability whose needs cannot be met due to current program boundaries (see Section 10.1).

There is evidence that the number of workers with disabilities approaching retirement is growing. The issues surrounding the transition from work to retirement for people with disability are being examined in a study commissioned by the Commonwealth government. The study investigates the nature and extent of retirement issues for people with disability in Commonwealth-funded employment services and identifies strategies that may facilitate the transition from work to retirement for this group of people (Department of Family and Community Services 1999).

The study examines both mainstream and specialist options for retirement support services, and identifies client needs and best practice models. The study particularly considers:

- Who makes the retirement decision?
- If there is a tool to evaluate retirement suitability, how is it to be used and by whom?

- What are the best mainstream and specialist service options?
- Commonwealth and State government boundary difficulties (Williams 1999).

There are particular issues related to the interface between services for older people with psychiatric disability and aged care services. A scoping study on older people and mental health explored 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). A report on the second stage of the study concluded that it is very difficult to obtain data on the target group from current national data collections. Therefore, it is difficult to draw conclusions about the adequacy and appropriateness of services for older people with mental health problems. However, the report identified the national hospital morbidity database and the Aged Care Assessment Team data set as the most promising potential sources of data to gain information about service target groups (AIHW 1999b).

Caring is a matter of mutuality and partnership between governments, community and informal carers (McDonald 1997). Currently there is an absence of clear policy regarding the intersection of formal and informal support systems, so that decisions and rules become ad hoc, local and inconsistent, and often result from informal negotiations between older people and formal and informal providers of support (McDonald 1997).

9.2 Service gaps and needs for new services

A survey was conducted among 162 community-based organisations that assist older adults or people with intellectual disability in Brisbane, Queensland, regarding the types of programs offered to older adults with intellectual disability.⁸ The results showed that only 36% of the organisations had provided assistance to at least one older adult with intellectual disability in the past 12 months. Agencies assisting people with disabilities were more likely to have provided services to this group than organisations assisting the general older population. None of the agencies surveyed reported that they provided specialised programs or services to older adults with intellectual disabilities (Buys & Rushworth 1997).

A study on services for older people with an intellectual disability in Victoria found that older people with intellectual disability living in the community were less likely to be registered with Intellectual Disability Services than their younger counterparts. Those who were registered had a low level of contact with regional services and attended few registered residential or non-residential services (Bigby 1992). Further investigations would be needed to examine whether this is a general pattern across the jurisdictions. This pattern may not indicate a lower need or demand for services among older people with intellectual disability. Rather, it could reflect that their special needs cannot be accommodated within the existing service framework.

A recent survey of adults with cerebral palsy in Australia reported that, although many respondents noted increased depression, fatigue, frustration, anxiety and anger as they aged, only 16% had seen a psychologist in the past year and 11% had seen a rehabilitation specialist. Some respondents also commented that generic services are difficult to access. Hence, ageing people with cerebral palsy may benefit from more accessible specialist counselling services (Balandin & Morgan 1997).

⁸ For the purpose of the study, older adults with an intellectual disability were defined as persons with an intellectual disability over the age of 60 years (Buys & Rushworth 1997).

Because of the relatively low numbers and wide dispersal of older people with an early onset disability living in the community, it may not generally be feasible to establish separate programs just for this client group. However, separate programs may be viable and necessary where and when concentrations of older people occur (Bigby 1992). It may be necessary to 'cluster' groups of older clients with early onset disability (ideally based on similarities of need) in order to achieve economies of scale (Ruggi 1998).

Studies that report on service structures and patterns of service use and provision in the United States may provide lessons and insights for Australia. One such study reported that there were three service sectors in Massachusetts that were used by older people with intellectual disability: an age-integrated mental retardation service sector, which caters mainly for younger adults and some older clients; an age-specialised sector for older people with mental retardation; and a generic ageing service sector. (Seltzer 1988: 181).

The study found that nearly 62% of the services used by older people (aged 55 and older) with mental retardation were age-integrated mental retardation services, 33.9% were generic ageing services, and only 4.8% were age-specialised mental retardation services (Seltzer 1988).

Analysis of different usage patterns across the three sectors indicated that if the services used by older clients with mental retardation were grouped into broad program types, the age-integrated services sector contained the highest proportion of support services. The generic ageing service sector contained the highest proportion of residential programs, and the age-specialised sector contained the highest proportion of day programs (Seltzer 1988).

This usage pattern can be explained by a number of factors. Firstly, the age-integrated sector is the most fully elaborated sector of the three and is better equipped to provide support services, such as respite care and therapeutic services, to older people with mental retardation. Secondly, residential services were dominant in the generic ageing sector with its focus on nursing home care. Finally, the emphasis on day programs in the age-specialised service sector reflected the service responses of this sector to the retirement needs of older people with mental retardation (Seltzer 1988).

On the basis of responses from a client survey, the study also identified 66 strengths of age-integrated services as against 65 weaknesses; 84 strengths of generic ageing programs as against 45 weaknesses. The greatest number (94) of strengths were identified for programs in the age-specialised mental retardation sector, while 66 weaknesses were also pointed out (Seltzer 1988).

Some Australian studies have compiled these strengths and weaknesses in table form (see Table 9.1) and proposed that the Massachusetts service structure may be adapted as an integrated framework for service delivery to people with a disability who are ageing (Queensland Department of Family Services and Aboriginal and Islander Affairs 1994; Parsons 1993; Gatter 1996).

It is important to note that although 62% of the people with mental retardation used generic ageing services, many of them also used services provided within the disability system (either age-integrated or age-specialised). The 5% of people who used age-specialised mental retardation services was considered low, especially in light of the respondents' reviews of the strengths of these services. However, as suggested by the author, it is possible that the age-specialised mental retardation services will evolve rapidly, given the expected increase in the size of the potential population and the favourable attitudes of clients toward these services (Seltzer 1988).

Table 9.1: A proposed integrated framework for service delivery to people ageing with a disability

	Strengths	Weaknesses
<p>Age-integrated disability services e.g.:</p> <ul style="list-style-type: none"> Group homes with residents whose ages vary widely; Supported employment programs; Alternatives to work programs with Participants whose ages vary widely; Leisure/recreation programs with participants whose ages vary widely. 	<ul style="list-style-type: none"> Situations and programs that stimulate and challenge, and encourage clients to continue developing; Higher quality of social experiences Than in other settings and larger variety of peer groups; Appropriate for people who do not see themselves as 'old'; Age is not a central issue in normalisation. 	<ul style="list-style-type: none"> Programs are not always appropriate And age-related peer groups not always available; Activities often too intense and difficult, and not sensitive to clients' health needs; Generally designed to meet group, not individual needs; Absence of retirement option and people have little opportunity to disengage from social activities.
<p>Age-specialised disability services e.g.:</p> <ul style="list-style-type: none"> Post-retirement leisure programs for People with a disability who are ageing; Group homes specially designed to accommodate the needs of people with a disability who are ageing; Respite programs designed to meet the needs of an aged carer caring for an ageing person with a disability who has retired. 	<ul style="list-style-type: none"> Potential to facilitate retirement option and less pressure on skill development; Potential to be more flexible and Individualised; Designed to meet participants' ages and levels of ability concurrently; Able to foster relationships between clients of similar ages, encourage development of friendships; Staff trained and experienced in both age and disability fields. 	<ul style="list-style-type: none"> Potential to isolate, stigmatise and segregate clients because of age and disability; Clients may be separated from past friends and service settings; Expectation of clients may be lower than realistic; Programs may be less stimulating with fewer options.
<p>Generic aged services e.g.:</p> <ul style="list-style-type: none"> HACC Day Care Centres; Meals on Wheels; Senior Citizens Centres; Home Help Services. 	<ul style="list-style-type: none"> Age-appropriate situations and services; Generally flexible and community integrated; Normalising and beneficial to relationships with age peers. 	<ul style="list-style-type: none"> Some staff and non-disabled clients not receptive; Staff lack specialist expertise; Services not always appropriate.
<p>Generic aged services 'topped up' with specialist disability services resources, services (e.g. training and consultancy advice) and funds</p> <ul style="list-style-type: none"> A new concept. 	<ul style="list-style-type: none"> As for above, plus; Allows for development of specialist expertise in staff; Allows for generic service to be modified; People with a disability who are ageing do not have to compete with mainstream demands for places. 	<ul style="list-style-type: none"> Some staff and non disabled clients may still not be receptive People with a disability may feel isolated from the rest of the service.

Source: Seltzer 1988; Gatter 1996; Queensland Department of Family Services and Aboriginal and Islander Affairs 1994.

9.3 Need for service responses in some key service areas

Modification in some key service areas may be required in response to the emerging needs of people ageing with disability. Service areas include accommodation and housing supports, day activities, advocacy, family support and case management relating to accessing multiple services.

Accommodation support services

Many people ageing with a disability want to remain living at home, but the question is: will the support be there to enable them to do so? A study of the needs of members in the Paraplegic and Quadriplegic Association of New South Wales aged 50 and over showed that 60% of them reported that their support needs had changed over the last five years (Williams 1999). The report also found that respondents had great difficulty in identifying appropriate accommodation options with which they have no experience. Hence, 24% of respondents preferred nursing home accommodation simply because that was the one they were familiar with and which they thought would provide adequate support. The respondents also indicated that share housing accommodation was not a preferred option, though supported housing, where privacy was maintained, was seen as desirable (Williams 1999).

At present, group home residents with an early onset disability are expected to be away from their home during week days, either at work or at day or recreational programs. Current funding for group homes usually does not allow for a staff member to be on duty during the day. This will create an increasingly untenable situation in those homes which have an ageing resident (Gatter 1996).

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 needs should be enhanced (Gatter 1996).

The use of flexible program times, part-time placements and 'phasing down' of attendance hours for day programs has a direct impact on the clients' accommodation situation. Older parents or family carers require respite from caring for their dependant adult with a disability (Ruggi 1998).

It was suggested that accommodation services may be supplemented by the provision of day activity and leisure programs either through assisting residential staff to develop a program or facilitating direct provision by specialist services (Bigby 1992).

Age-specific group homes (or cluster homes) for older people with a disability have been suggested for consideration in future service planning. If 'ageing in place' is a policy priority, then the choice of people for new group homes and assessment of new residents for existing group homes should consider not only social compatibility but also age compatibility (Gatter 1996).

The design of group homes aims to meet the accommodation needs of people participating in outside activities during the working week. However, the ageing trends in people with a disability may have implications for future housing design and existing accommodation may need to be modified. As ageing people with a disability become frailer, they need to spend more time at home and engage in more home-based activities. This means more space

may be required for low-level indoor recreation and craft activities, and more consideration may need to be given to the design of gardens and outdoor living areas (Gatter 1996).

Age-appropriate day activity and leisure service programs

Although it is generally agreed that there is a high need for participation in generic activity or leisure programs by people ageing with an early onset disability, they are more likely to require assistance to choose, locate, negotiate access and travel to community-based day programs. Programs for older people should have a reduced emphasis on formal vocational training and skill acquisition and more emphasis on retention of skills and the constructive use of leisure. Activities arranged should be age appropriate though this should not necessarily preclude age-integrated activities (Bigby 1992).

The main areas that should be developed or emphasised to improve day activity programs for this target group are summarised as:

- flexible arrangement;
- individualised planning for participants;
- recognition of the need for: skill maintenance and development, social interaction, maintaining friendships, fostering or maintaining informal support and advocacy networks, enjoyable and stimulating activities and participation in valued social roles;
- skill development of staff in service networks; and
- the development of a policy framework for disability services that recognises and incorporates the above principles (e.g. Bigby 1992; Ruggi 1998).

9.4 Differences and similarities of the current disability and aged care service systems

In order to be able to proceed with an analysis of needs, it is useful to summarise briefly some of the common features of the aged care and disability service systems, and some of the differences.

A recent review of the development of aged care and disability services reported that both service systems have adopted similar service philosophies, policy directions and service delivery mechanisms (Bigby 1999):

- Both aged care and disability services have undergone substantial changes in strategic direction and have followed similar broad policy directions, moving away from institutionalisation and emphasising home- or community-based care and services.
- Similar services have been developing in the two service systems, moving towards the concept of managed care for people with more complex needs and emphasising tailored care packages to meet individual needs.
- Both systems have recognised the importance of informal carers and family support and have developed services to support informal caring roles.
- Both systems are moving away from submission-based models of funding towards more pro-active need-based planning models. More active funding management techniques are being used in the two systems, such as unit cost funding.

Some similarities of the two systems also highlight limitations in existing service provision. One such similarity is limited resources. Resource limitation may motivate administrators of disability services to encourage their ageing clients to access or transfer to aged care services. Likewise, administrators in aged care services may resist such access or transfer without a transfer of resources (Bigby 1999).

Both systems place an emphasis on 'supported independence' and reliance on informal carers. Ageing people with an early onset disability are less likely to have co-resident informal carers, or may be reliant on the care of ageing parents. The needs for supported accommodation may occur at earlier ages for ageing people with an early onset disability, not because of their own ageing but because of the loss of their informal support network (e.g. the death of their parents).

The limitations of the aged care service system in meeting the needs of older people with an early onset disability are largely associated with the differences between the aged care and disability service sectors (Bigby 1999):

- The aged care system has some services that may be used by older people with a lifelong disability. For example, programs targeted at frail older people who have dementia may also be appropriate for younger people with an early onset of dementia. However, because of the focus of the aged care system on the health needs of frail older people, it is unlikely to address the wider range of needs of most people ageing with an early onset disability.
- The existing types of residential aged care facilities may not meet the needs of ageing people with an early onset disability who are younger and perhaps more physically able than most frail older people. Large congregate care arrangements are much less acceptable in the disability service sector than in the aged care sector.
- HACC services mainly target people living in the community. It is less clear whether these services may be accessed by people with disability living in supported accommodation.
- Although various day and leisure activities exist for older people in the general community, few programs offer the structure, supervision or continuity required by many people with an early onset of disability.
- There is a lack of effective mechanisms in the services to package the existing retirement activities in the aged care system into coherent programs suited to ageing people with a lifelong disability.

10 Emerging planning and service models

There are new initiatives in service planning and models emerging in the States and Territories to meet the needs of people ageing with a disability and set up to address a number of issues raised in the literature. This section summarises some main new initiatives based on the responses from jurisdictions in response to the AIHW's request for information to inform the project.

10.1 New South Wales

In New South Wales, the Ageing and Disability Department (ADD) is currently implementing a new approach to service planning and future resource allocation which is based on population groups rather than funding programs. The model considers two separate population groups: older people with disabilities and their carers, and younger people with disabilities and their carers. The Population Group Planning (PGP) 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 (NSW Health Services Research Group 1997; response from ADD 1999).

Another initiative in New South Wales is the Community Care Assessment Framework that has been developed jointly by ADD and NSW Health Department. The framework is currently being implemented by all HACC services in New South Wales. The same framework or a complementary model will be introduced for the Disability Services Program at a later stage (response from ADD 1999).

The framework aims to establish a collaborative inter-agency process for comprehensive assessment of people who need complex, multiple or high levels of support. This is to ensure that people with complex needs undergo a single comprehensive assessment with a qualified assessor to reduce time wasting, duplication and overly intrusive assessments. The framework considers individual service needs through a streamlined assessment process, to produce an individual care plan and improved coordination between the health, HACC, disability and aged care sectors. A central component of the framework is CIARR (Client Information and Referral Record) which is a tool for recording client information and, with the permission of the client, making referrals to other service providers (Gething et al. 1999).

Because this framework is a client-based approach that takes into account a person's total needs, it may assist in resolving the issues arising for older people with a disability whose needs cannot be met due to current program boundaries (response from ADD 1999; Gething et al. 1999).

In New South Wales there is a *Memorandum of understanding on joint planning for older people, people with disabilities and their respective carers*. The partners in the Memorandum of understanding are ADD, NSW Health, and the Commonwealth Departments of Health and Aged Care, and Family and Community Services. These departments are working together on joint planning (Response from ADD 1999).

10.2 Victoria

In Victoria, a number of projects related to the issues of ageing and disability are being planned and/or carried out (response from Victorian Department of Human Services 1999):

- *'Day services for ageing clients'*: In response to one of the Department of Human Services' primary goals—to 'improve and maintain high quality services and facilities for clients'—growth funds have been allocated under the 1998–1999 Victorian State Budget to promote the development of new day service options for older people with disabilities. The project was initiated to develop a set of guiding principles to be applied to these funds.
- *'Accommodation options for older people'*: This project is currently being developed to map out the range of accommodation options available to people with a disability who are ageing.
- *'Scoping and mapping the needs of people with high medical/clinical needs'*: This project is currently being conducted to gather information on special needs of clients with high medical and/or clinical needs. One of the components of this project relates to older clients with high medical/clinical needs.
- *Help for carers resource kit*: This project targets older carers of people with a disability and provides them with important information about their planning for the future of their family, in particular the family member with a disability (response from Victorian Department of Human Services 2000).

10.3 Western Australia

In December 1998 the Disability Services Commission (DSC) held a one-day conference on disability and ageing. The DSC initiated this conference in recognition of the need to plan for the projected significant increase in the number of people with a disability who are ageing.

The Disability and Ageing 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. Examples of initiatives that are currently being undertaken are contained in the Conference Proceedings which are now available and can be accessed through the DSC's homepage (www.dsc.wa.gov.au).

The DSC 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 and their families and carers.

In July 1998 the DSC 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 the intellectually disabled residents of the hostel were mostly over the age of 55, were becoming increasingly frail, and had health needs that were becoming more significant than their needs associated with their intellectual handicap. The people concerned had lived together in the hostel for many years.

Transferring management of the hostel to Baptist Homes enabled these residents to 'age in place' and secured entry to the disability field in Western Australia for a recognised provider of high-quality aged care services.

10.4 South Australia

In South Australia, the Intellectual Disability Services Council (IDSC) Accommodation Services is currently proposing the development of specialised aged care services to meet the needs of people with an intellectual disability who are ageing (response from South Australia IDSC 1999).

Aiming to assist people with an intellectual disability in understanding the ageing process, and to assist generic aged care service providers in meeting the needs of people with an intellectual disability, IDSC Aged Care Services will be set up. 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 an intellectual disability (response from South Australia IDSC 1999).

10.5 Tasmania

It has been reported that in Tasmania there are community-based day activity services designed specifically for ageing people with a disability (Gatter 1996: 19).

Because the number of people in Tasmania is relatively small, there is the opportunity to implement 'boutique' services. Because of the limited number of specialised services available, people are tending to access generic services. This may require staff in generic services to perform functions for which they are not qualified, such as administer medication. Therefore, it is vital that ongoing training and accreditation of staff be an important priority (Williams 1999: 5).

10.6 Australian Capital Territory

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. This involves agreed protocols, regular meetings, joint projects and integrated planning (Williams 1999: 7).

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 this approach is more consumer-centred, helps to improve referral and transfer processes between services, and encourages creative and flexible arrangements (Williams 1999: 7).

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 funded by different sources (Williams 1999: 7).

11 Overview of relevant data sources

This chapter provides an overview of nationally significant data sources relevant to the ageing and disability project. The chapter begins with a review of the ABS population surveys and other data relating to disability, followed by a discussion of data relating to services provided for people with a disability. Data gaps and limitations are examined.

11.1 ABS population surveys of relevance to disability

The ABS national disability surveys

The ABS disability surveys provide cross-sectional data collected at four points in time (1981, 1988, 1993 and 1998) over a period of 17 years. The ABS disability surveys are an important source of national population data on disability, covering both rural and urban areas in all States and Territories. Data are gathered from both household and cared accommodation (establishment) samples.

In the 1998 Survey of Disability, Ageing and Carers, the household sample included about 15,300 private dwellings and 400 non-private dwelling units, while the cared accommodation sample included approximately 800 establishments. The effective sample resulted in about 37,000 persons for the household component and 5,700 persons for the cared accommodation component (ABS 1999: 52–53).

The operational definitions of disability used in the surveys were adapted from the definition of disability of the International Classification of Impairments, Disabilities, and Handicaps (ICIDH) (WHO 1980). The survey definitions are relatively broad, aiming to ensure that all people with a disability are identified by the survey. Unlike administrative agency records, the surveys rely on respondents' self-reported information.

In the 1998 disability survey a person is considered to have a disability if he/she has a limitation, restriction or impairment, which has lasted, or is likely to last, for at least six months and restricts everyday activities (ABS 1999: 67). A 'specific restriction' is defined as a restriction in core activities (self-care, mobility and communication), schooling or employment (ABS 1999: 72). This corresponds with the concept of 'handicap' used in the previous surveys. 'Handicap' was identified where a person had a limitation in performing certain tasks associated with daily living in the areas of self-care, mobility and verbal communication, schooling or employment, due to their disability (ABS 1993).

In the 1981 and 1988 surveys, three levels of severity of handicap (mild, moderate and severe) were determined on the basis of the person's ability to perform tasks relevant to self-care, mobility and verbal communication and the amount of assistance they required. In the 1993 survey the severe handicap category was further divided into severe handicap and profound handicap (ABS 1993).

Similarly, in the 1998 survey four levels of core activity restriction are determined, based on whether a person needs help with, has difficulty with, or uses aids or equipment for any of the core activities. A person's overall level of core activity restriction is determined by the highest level of restriction they experienced in any of the core activity areas. Profound core activity restriction refers to a person who is unable to do, or always needs help with, a core activity. Severe core activity restriction refers to a person who sometimes needs help with a core activity, or has difficulty understanding or being understood by family or friends, or, who can communicate more easily using sign language or other non-spoken forms of communication (ABS 1999: 66).

In the survey, respondents were also asked to indicate their long-term condition. A long-term condition is defined in the survey as a disease or disorder that has lasted or is likely to last for at least six months; or a disease, disorder or event (e.g. stroke, poisoning, accident, etc.) that produces an impairment or restriction that has lasted or is likely to last for at least six months. A main condition is a long-term condition identified by a person as the one causing the most problems. Where only one long-term condition is reported, it is recorded as the main condition (ABS 1999: 69).

The 1998 disability survey has also included questions on self-perceived health for people with a disability and primary carers. A 12-item short form (SF-12) health survey instrument was used in the survey questionnaire. People interviewed were asked to rate their own health on a five-point scale and were asked questions about the extent to which they were limited by their health in the four weeks prior to the interview (AIHW 1999a; Ware et al. 1996).

The ABS National Health Surveys

The National Health Surveys obtain information about the health status of Australians, their use of health services and facilities, and health-related aspects of their lifestyle such as smoking, alcohol consumption and exercise (ABS 1979, 1991 and 1997). These surveys have been used as a major source for the analysis of health and health service use differentials in Australia.

Information most relevant to disability in the National Health Surveys comes from the data item about long-term conditions. In the Surveys, long-term conditions are defined as medical conditions (illness, injury or disability) that have lasted or are expected to last six months or more.

Unlike the disability surveys, the long-term conditions recorded in the National Health Surveys are not necessarily associated with disabilities. According to the survey data coding rules, long-term conditions are coded as medical conditions using ICD-9 codes. Only impairments or disorders that cannot be classified using ICD-9 medical condition or injury categories are coded using a 'residual' category—'disability not elsewhere classified' (e.g. incomplete use of arms or fingers) (ABS 1996, 1997). As with many sources of health data, there is a limited amount of information on the disabilities in terms of consequences of the conditions and impairments reported.

The National Health Surveys cover only people in households and exclude people in hospitals, nursing homes and other institutions. This may contribute to an underestimation of the prevalence of long-term conditions in the general population.

Nevertheless, morbidity data on long-term conditions collected from the Surveys can assist in explaining the prevalence, demographic pattern and cause of disability in Australia, and looking at trends over time.

The National Survey of Mental Health and Wellbeing of Adults

The National Survey of Mental Health and Wellbeing of Adults (SMHWB) was conducted in 1997 as an initiative of the National Mental Health Strategy. The purpose of the survey was to collect information from adults aged 18 years and over about the prevalence of a range of major mental disorders, the severity of disability associated with these disorders, and health service usage and needs for assistance as a result of mental disorders (ABS 1998e).

The SMHWB used a number of different measures of disability and health outcome: the Brief Disability Questionnaire (BDQ), the Short Form 12 (SF-12) and Days Out of Role. The BDQ is a standard questionnaire that contains eight questions emphasising physical aspects of disability (Ormel et al. 1994). Respondents were asked whether they had limitations in a number of activities such as running or sports, carrying groceries, climbing stairs, bending, lifting, walking long distances and bathing or using the toilet. They were also asked whether they had cut down or stopped activities, had decreased motivation or personal efficiency, or experienced deterioration in their social relations. The Medical Outcome Study method of scoring (scale of 0–16) was used as a measurement for the BDQ, with a high score indicating that respondents have been limited in their activities due to health problems (ABS 1998e: 50).

The SF-12 is a commonly used international instrument consisting of 12 questions that provide a generic measure of health status. The SF-12 contains eight concepts: physical functioning, role limitations due to physical health problems, bodily pain, general health, vitality (energy/fatigue), social functioning, role limitations due to emotional problems, and mental health (psychological distress and psychological wellbeing) (ABS 1998e: 52). The SF-12 has two measures: the physical component summary (PCS) and the mental component summary (MCS).

Days Out of Role measures the number of days, in the four weeks prior to interview, when respondents were unable to carry out usual activities fully (ABS 1998e).

Some caveats should be noted when the SMHWB information about disability is used:

- The BDQ differs from the measures of disability used in the ABS disability surveys in terms of the conceptual framework and definition of disability used. Although the BDQ measures activity limitations, the scope of activity in the ABS disability surveys is much broader than that of the BDQ. The eight items of the BDQ mainly focus on physical functioning, although the ABS disability survey screening questions are also somewhat focused on physical abilities of daily living.
- The empirical basis of the two SF-12 summary measures (PCS, MCS) is not necessarily appropriate for the Australian population. The two measures were developed on the basis of physical and mental health data relating to the US population (ABS 1998e: 52).
- All three disability measures (BDQ, SF-12 and Days Out of Role) focus on disability present during the four weeks prior to the interview, while the ABS disability surveys focus on disability that has lasted, or is likely last, for at least six months.
- Information about dementia-related disorders was not collected by the SMHWB, although it contributes significantly to mental health problems and disorders among older people (AIHW 1999b).
- The exclusion of people living in any type of institution from the SMHWB means that a significant group of people with mental disorders was not captured.

The ABS national time use surveys

The ABS time use surveys conducted in 1992 and 1997 examine how people allocate their time to different activities. The surveys provide information about time spent on activities such as personal care, employment, education, community participation (including voluntary work), leisure activities, travel, fitness and health activities, together with people's use of technology and their outsourcing of domestic tasks. These surveys also contain information about time spent on caring for people with disability and children. The data were collected partly by interview and partly using self-completion diaries. First, information was collected from an adult member of the selected household for all persons aged 15 years and over in the household. A diary was then left for each of these persons to record their activities over two specified days (ABS 1998c, 1998d).

An ABS 'disability module' was used in the surveys to collect basic information about disability status. The module used, which is not the same as BDQ in the mental health survey, consisted of a series of questions about health conditions associated with disability. These questions were based on the screening questions used in the ABS disability surveys. The disability module has been used in a number of ABS household surveys not primarily designed to collect disability information but rather to identify respondents with a disability.

Data from the time use surveys could be used to monitor overall outcomes for people with a disability, in particular their level and pattern of participation in a range of activities. The surveys could also be used to compare aspects of the lives of people with a disability and people in the broader community (AIHW 1997b, 1999a).

Nevertheless, caution should be exercised in interpreting time use survey data about disability status for a number of reasons:

- While there is a disability module on the survey form, far fewer questions on disability are asked in the time use surveys than in the disability surveys.
- Information about disability status obtained from the two surveys are not directly comparable.
- The sample size (over 4,500 households or 8,600 persons) is markedly smaller than that of the disability surveys.
- The time use surveys cover only people living in private dwellings, while the disability surveys also collect information about people living in institutions and cared accommodation (ABS 1998c, 1998d).

11.2 Administrative data relating to services provided for people with a disability

The following national administrative data sources contain information about services provided for people with disability, and are relevant to this project:

- CSDA MDS and associated collections of disability administrations in all jurisdictions;
- various databases of the Department of Family and Community Services;
- residential aged care data collections;
- HACC service provision data collection; and
- HACC user characteristics data collection.

The CSDA MDS collections are under the guidance of the National Disability Administrators. The purpose of the CSDA MDS collection is to facilitate the annual collation of reliable, consistent and nationally comparable data from CSDA-funded services. The information is used for disability service planning and national program evaluation. The data are collected using two forms: a service form and a consumer form. The collections are 'snapshot' day collections, which ask for data about services on a specific day during the year. The most recent snapshot day was specified for May 2000, although the specific day varies depending on the State or Territory funding department. The first full pilot test of the CSDA MDS collection was conducted in late 1994 and the first annual collection was conducted in the second half of 1995. Data items include not only demographic characteristics but also disability group, need for support or assistance, main source of income and living arrangement. Some of the data items for consumers were designed to relate to the ABS population census and disability survey data (Black & Madden 1995; Black & Maples 1998; AIHW 1999c).

In the 1998 collection of the CSDA MDS, a linkage key was pilot tested to statistically record use of multiple services by individuals on the 'snapshot' day. The aim was to overcome the problem of double-counting clients who receive services from more than one outlet, enabling estimation of the number of individual consumers on the snapshot day, as opposed to the number of services received. All States participated in the linkage key trial in the 1999 CSDA MDS collection (AIHW *Disability Data Briefing* Number 17, March 2000).

The databases of the Department of Family and Community Services include information on recipients of disability-related pensions and benefits, such as the Disability Support Pension, Carer Pension and Child Disability Allowance. Data on recipients include demographic characteristics, impairments and medical conditions. The databases provide useful information for assessing the implications of population ageing on the number of recipients of the Disability Support Pension and the number of people likely to require disability support services. The CSDA MDS 1997 collection showed that 86% of adult clients (aged 16 years or over) of CSDA-funded services are recipients of the Disability Support Pension.

The residential aged care data collections include information about all residents admitted to a residential care facility. The residential aged care structural reform policy introduced in October 1997 has merged nursing homes and hostels into a single residential care system. As a result, the two previous data collection systems (the Nursing Home Payment System and the Commonwealth Hostel Information Payment System) were replaced by a single system—the System of Payment for Aged Residential Care (SPARC) (AIHW 1999a).

The HACC service provision data collection obtains information from HACC-funded service outlets on recipient profiles and the amount of service provided. The information is collected twice a year (May and November) from all HACC-funded service outlets by State Governments and provided to the Commonwealth Government for coordination and monitoring. The data have been used to compare a region's share of the service target population (people with a profound, severe or moderate handicap) with its share of HACC services (Department of Health and Aged Care 1998).

The HACC user characteristics data collection provides data used to monitor access of the HACC target group and special needs groups to HACC-funded services. The collection obtains client information by surveying a 10–20% sample of HACC recipients from all services participating in the HACC service provision data collection (a higher proportion of recipients is selected in the Northern Territory and the Australian Capital Territory). Service providers complete client survey forms using their client records. States are responsible for collecting data and providing it to the Commonwealth for national coordination and

monitoring. Over 28,000 survey forms were completed in 1989–90 and 41,600 in 1993–1994 (Department of Health and Aged Care 1998).

There are several limitations that need to be taken into account in the analysis of the HACC data. There are duplicate records for clients who receive services from more than one outlet; forms with any data missing are not included in the collection; sampling methods, service type definitions and data quality vary between jurisdictions. The current data cannot provide definitive answers to such questions as:

- How many people receive HACC services at any given time or over a set time period?
- How much HACC service is provided in a particular region?
- What combinations of service types might one client use over a specific period?

A new HACC MDS, developed by the AIHW for Commonwealth and State/Territory HACC officials in 1998, and pilot tested nationally in 1999, is scheduled for full implementation from 1 January 2001. The HACC MDS collection is a client-centred data collection that will replace the previous HACC Service Provision, HACC User Characteristics and Community Options data collections. It is designed to answer the sort of questions listed above (Ryan et al. 1998: 1).

11.3 Data limitations and key data sources for analysis

This chapter has reviewed some significant national data sources currently available. Other data sources relating to disability prevalence and disability groups have been reviewed in a number of AIHW reports (e.g. Madden et al. 1996; Wen 1997; Mathers et al. 1999; Fortune & Wen 1999; Wen & Fortune 1999). These data sources include special studies providing health or epidemiological information of possible relevance to disability, registration data and hospital morbidity data.

One of the major limitations of the data currently available is the difficulty in making comparisons between population and administrative data sources, and between different administrative collections. The underlying purposes of surveys and data collections are diverse, and thus the data collection methods vary.

For this project, therefore, a key population data source and a key administrative data source were identified and relied on. Other data sources were used as supplementary information. The key data sources chosen are those most recent and readily available and most relevant to the current project.

Of the national population surveys, only the ABS disability surveys are designed specifically to generate a comprehensive national overview of levels and patterns of disability in Australia. The surveys contain useful information on people with a disability and their needs for assistance. The survey definition of severe or profound core activity restrictions is based on the need for frequent or continual personal support in three areas of activity (self-care, mobility and communication). This corresponds quite closely to the 'target population' of CSDA services (AIHW 1997b). The information collected by the survey is also relevant to the analysis of aged care services. Therefore, the ABS disability surveys will be used in this project as the key population data source for conducting analyses and producing estimates at the national level.

The CSDA MDS collections are used in this project as the key administrative data source for information about disability service provision and usage, since this project focuses on CSDA

services. The Department of Family and Community Services databases provide information on recipients of income support programs and service programs. HACC service data and residential aged care data provide supplementary information on services used by people with a disability, especially as they age.

12 Population ageing and prevalence of disability

This chapter examines the impact of population ageing on prevalence of disability, focusing particularly on changes in prevalence of severe or profound core activity restriction. Changes in the number of people with a disability in a population may be attributable to a combination of two factors: change in underlying age-specific prevalence rates and population change. Population change can be broken into two components: changes in overall population size and disproportionate growth among different age groups. Population ageing is indicated by an increasing proportion of older people in the population, as a result of higher proportional growth in older age groups.

The chapter begins with an overview of the changes in age-standardised rates of disability prevalence over a period of nearly two decades, indicated by the four ABS disability surveys (1981, 1988, 1993 and 1998), followed by a comparative analysis of changes in estimated numbers of people with disability. A demographic decomposition method is then used to estimate the impact of population change and, in particular, population ageing on the number of people with disability.

12.1 Data sources for comparisons of the four surveys

Data in this chapter are from the four ABS disability surveys—generally from unpublished data tables. In order to conduct a comparative analysis, prevalence data for the four disability surveys were re-derived using, as far as possible, only criteria common to all four surveys. However, there remain some variations between the surveys. In particular, changes in the 1998 survey design and interviewing methods are difficult to control for, and it is difficult to assess their impact on reported disability prevalence (AIHW 1999a).

12.2 Comparison of age-standardised prevalence estimates

Prevalence of disability is highly age-related. Change in population age structure is one of the most important factors affecting the prevalence of disability. Hence, to assess changes in the underlying prevalence rate of disability, it is important to begin with controlling for the impacts of population change.

To examine changes over the 17-year period 1981–1998, estimated rates of disability and activity restrictions have been standardised using the estimated resident population at March 1998. The estimates from the previous three surveys were adjusted to show the prevalence rates that would have been expected in the 1981, 1988 and 1993 populations, if those populations had the same age and sex structure as the 1998 population.

The age-standardised estimates indicate that, between 1981 and 1998, disability prevalence increased from 14.6% to 18.8%, and the prevalence of specific restrictions⁹ increased from 10.7% to 16.1%. The prevalence rate of severe and profound core activity restrictions was relatively stable between 1981 and 1993, but increased from 4.3% in 1993 to 5.5% in 1998 (Table 12.1).

The age-standardised prevalence rate allows meaningful comparison of underlying prevalence rates between the four surveys by controlling for changes in population age structure. However, it is worth noting that the age-standardised rate does not reflect actual prevalence. The rate is used only for comparison of relative prevalence over time or between different population groups (e.g. between States and Territories). Unstandardised rates should be used for estimating need or demand for disability services. Therefore, the next section looks at changes in the reported number of people with disability, especially with severe or profound core activity restriction.

⁹ In the 1998 disability survey, a specific restriction is defined as a restriction in core activities (self-care, mobility and communication), schooling or employment (ABS 1999: 72). This corresponds with the concept of 'handicap' used in the previous surveys. 'Handicap' was identified as a limitation in performing certain tasks associated with daily living in the areas of self-care, mobility and verbal communication, schooling or employment, due to disability (ABS 1993).

Table 12.1: Comparison of age-standardised prevalence rates of disability for 1981, 1988, 1993 and 1998, Australia^(a)

Year/sex	Severe/profound core activity restriction ^(b)					Specific restrictions ^(b)					Total with disability				
	5-14	15-64	65+	Total 5-64	All ages	5-14	15-64	65+	Total 5-64	All ages	0-14	15-64	65+	Total 0-64	All ages
Males															
1981	2.0	2.1	11.6	2.1	3.2	5.0	8.9	29.4	8.1	10.6	6.2	13.5	42.0	11.8	15.0
1988	2.5	2.1	12.7	2.2	3.4	7.2	11.5	43.6	10.7	14.5	7.0	14.2	53.4	12.5	16.8
1993	2.7	2.3	12.4	2.4	3.5	7.3	11.4	44.3	10.7	14.6	7.6	15.3	56.9	13.4	18.1
1998	4.9	3.3	14.8	3.6	4.9	10.6	13.3	45.0	12.8	16.6	9.8	17.2	57.3	15.4	19.9
Females															
1981	1.2	2.2	19.7	2.1	4.6	3.0	7.4	35.6	6.6	10.9	4.2	11.2	43.6	9.6	14.2
1988	1.9	2.5	21.9	2.4	5.3	5.1	10.2	46.2	9.3	14.7	5.1	12.2	52.2	10.5	16.2
1993	1.8	2.4	20.8	2.3	5.0	4.5	9.8	44.9	8.9	14.1	5.1	12.5	51.2	10.8	16.3
1998	2.4	3.4	23.3	3.2	6.1	5.7	11.4	45.9	10.0	15.6	5.5	14.2	52.5	12.1	17.6
Persons															
1981	1.6	2.2	16.2	2.1	3.9	4.0	8.1	32.9	7.4	10.7	5.2	12.4	42.9	10.7	14.6
1988	2.2	2.3	17.9	2.3	4.3	6.2	10.9	45.1	10.0	14.6	6.1	13.2	52.7	11.5	16.5
1993	2.3	2.4	17.1	2.3	4.3	5.9	10.6	44.6	9.8	14.3	6.4	13.9	53.7	12.1	17.2
1998	3.7	3.3	19.6	3.4	5.5	8.2	12.4	45.5	11.7	16.1	7.7	15.7	54.6	13.8	18.8

(a) Disability data were re-derived using criteria common to the four surveys. Rates are age-standardised to the estimated resident population for March, 1998.

(b) Only people aged 5 years and over are included. The estimates of overall prevalence rates of severe or profound core activity restriction and specific restrictions in 1981, 1988, and 1993 are slightly different from the rates published by the ABS (1999: Table 7). The age standardised estimates for the 1981, 1988 and 1993 surveys were slightly higher than the ABS rates, by 0.3% for severe or profound core activity restriction and by 0.7% for specific restrictions. Information on severity of core activity restriction among children aged under 5 years was collected in the 1998 survey but not in the previous surveys. For comparative purposes and because of this project's focus on ageing, information on activity restrictions among children under 5 is not included in the data presented here, and people aged under 5 years have been excluded from the total population used as the denominator to calculate the prevalence rates. The difference between estimates in this table and the rates published by the ABS may be due to inclusion of the population aged under 5 years in the denominator for ABS rates.

Source: AIHW analysis of the ABS 1998 Survey of Disability, Ageing and Carers unpublished data tables.

12.3 Changes in reported number of people with disability

The total number of people with a disability increased by 80% over the 17-year period 1981–1998. Much of this was associated with the increase in the size of the population, especially the older population. The numbers of people with specific restrictions and with a severe or profound core activity restriction in 1998 were more than twice the numbers in 1981. The increases in all three disability categories were higher over the most recent 5-year period (1993–1998) than in the previous 5-year period (1988–1993). Between 1993 and 1998, the number of people with a severe or profound core activity restriction increased by 43%; this was almost four times the rate of increase (11%) during the 1988–1993 period (Tables 12.2, A12.1 and Figure 12.1).

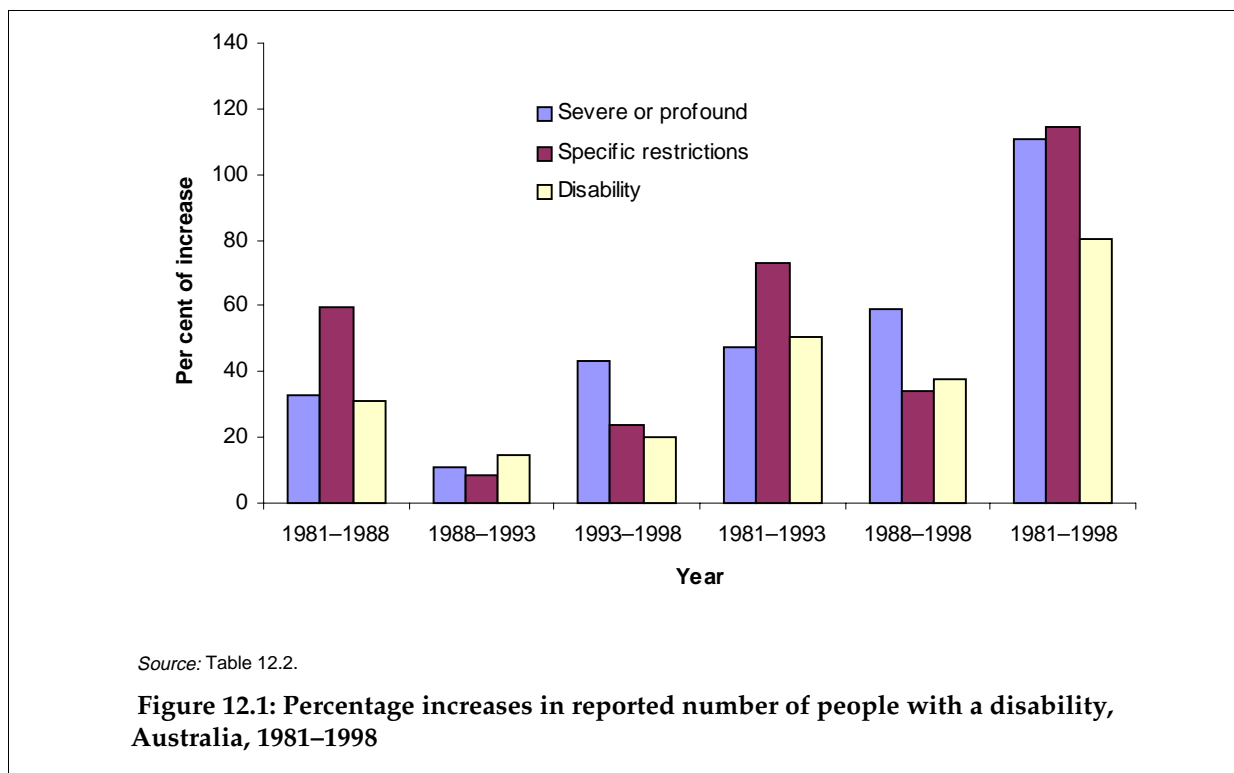
Table 12.2: Increases in disability prevalence, Australia, 1981, 1988, 1993 and 1998^(a)

Period	Age	Percentage increase in reported number of people		
		Severe or profound core activity restriction ^(b)	Specific restrictions ^(b)	Total with disability
1981–1988	Under 65	24.0	52.1	20.4
	65+	42.2	74.2	54.9
	Total	32.6	59.7	30.9
1988–1993	Under 65	10.8	4.9	13.4
	65+	11.3	14.1	17.4
	Total	11.1	8.4	14.8
1981–1993	Under 65	37.4	59.6	36.5
	65+	58.4	98.8	82.0
	Total	47.3	73.1	50.4
1993–1998	Under 65	54.8	29.1	23.0
	65+	31.7	15.8	14.7
	Total	43.2	23.9	20.0
1988–1998	Under 65	71.6	35.5	39.5
	65+	46.7	32.2	34.7
	Total	59.0	34.2	37.8
1981–1998	Under 65	112.8	106.1	67.9
	65+	108.6	130.3	108.8
	Total	110.9	114.4	80.4

(a) Disability data were re-derived using criteria common to the four surveys.

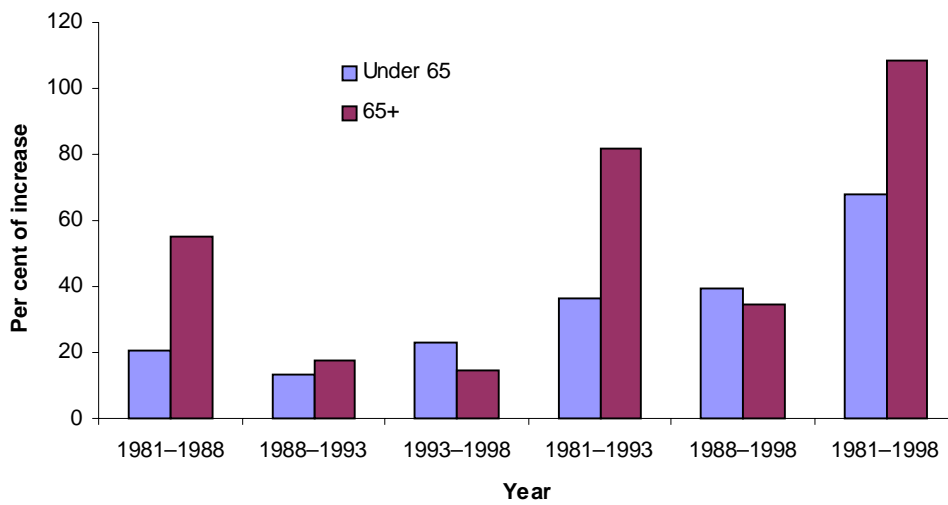
(b) Only people aged 5 years and over are included.

Source: AIHW analysis of the ABS 1998 Survey of Disability, Ageing and Carers unpublished data.



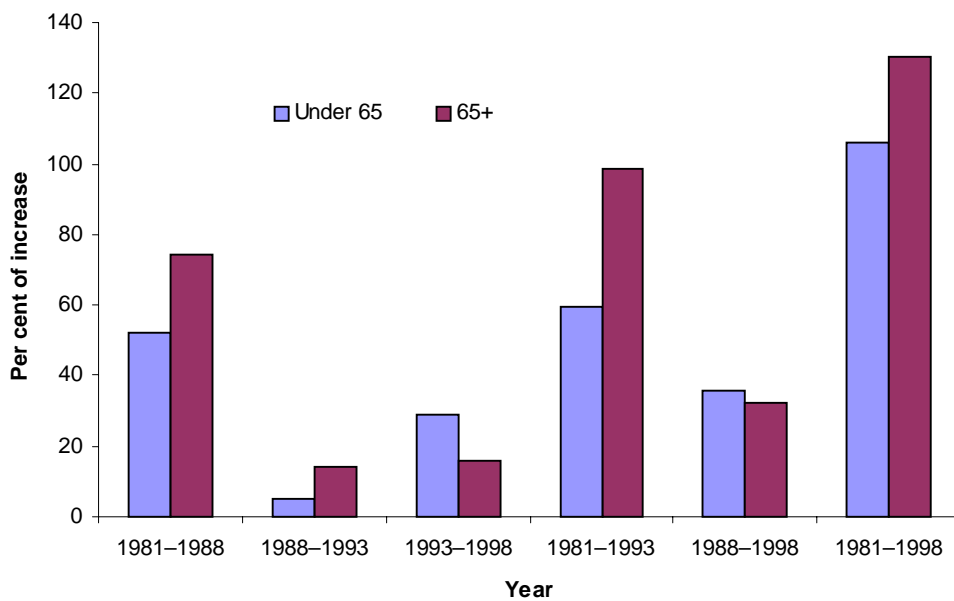
The rates of increase for people aged under 65 years were different from those for people aged 65 years and over. Overall, in the 17-year period 1981-1998, the number of people with a disability and all specific restrictions increased at a higher rate in the age group 65 years and over than in younger age groups. The rate of increase of severe or profound core activity restrictions, however, was slightly higher for people aged under 65 than for those aged 65 and over (Table 12.2, Figures 12.2, 12.3 and 12.4).

There were striking contrasts between the most recent 5-year period and earlier periods. For the periods between 1981, 1988 and 1993, the number of people with disability increased at consistently higher rates for those aged 65 years and over than for those aged under 65, in all three disability categories. However, the reverse pattern occurred between 1993 and 1998—bigger increases for people aged under 65 than for those aged 65 and over. This reverse pattern was particularly evident for severe or profound core activity restriction. This was largely attributable to a marked increase (55%) in the number of people with a severe or profound core activity restriction among those aged under 65 years between 1993 and 1998 (Table 12.2, Figures 12.2, 12.3 and 12.4).



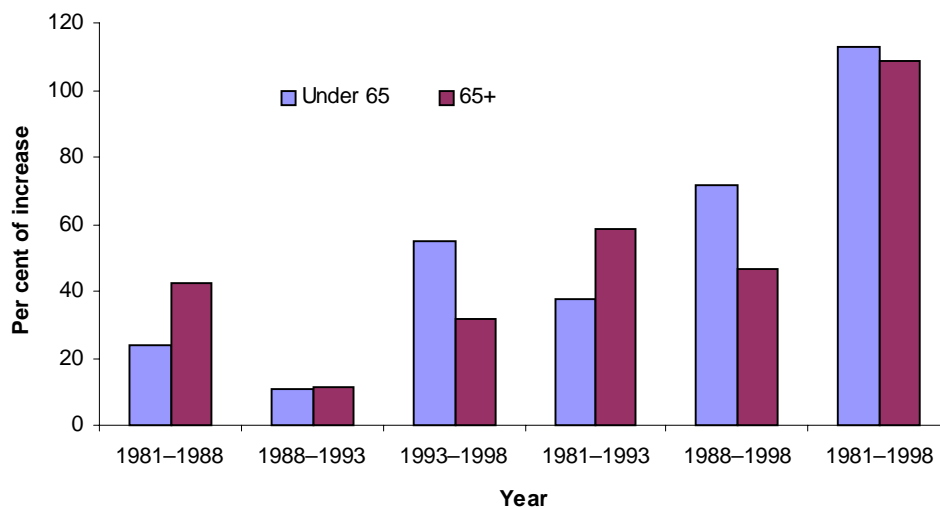
Source: Table 12.2.

Figure 12.2: Percentage increases in reported number of people with a disability by age, Australia, 1981-1998



Source: Table 12.2.

Figure 12.3: Percentage increases in reported number of people with specific restrictions by age, Australia, 1981-1998



Source: Table 12.2.

Figure 12.4: Percentage increases in reported number of people with a severe or profound core activity restriction by age, Australia, 1981-1998

12.4 Effects of population change on disability prevalence

The preceding two sections have discussed the trends in prevalence of disability, by controlling for population growth and ageing to estimate changes in underlying prevalence and by looking at the changes in reported numbers without controlling for population effects.

This section begins with an overview of population change. It then uses a demographic decomposition method to quantify the overall effect of population change on disability prevalence and to separate the overall effect into two components: change in population size and disproportionate growth among age groups (population ageing).

Population growth and changes in population age structure

Table 12.3 shows that, in contrast to a general population growth rate of 27% between 1981 and 1998, growth rates for the population aged between 35 and 54 years ranged from 48% to 76%, with the peak of 76% in the age group 45-49. This reflects the passage of the post-World War II baby-boom generation.

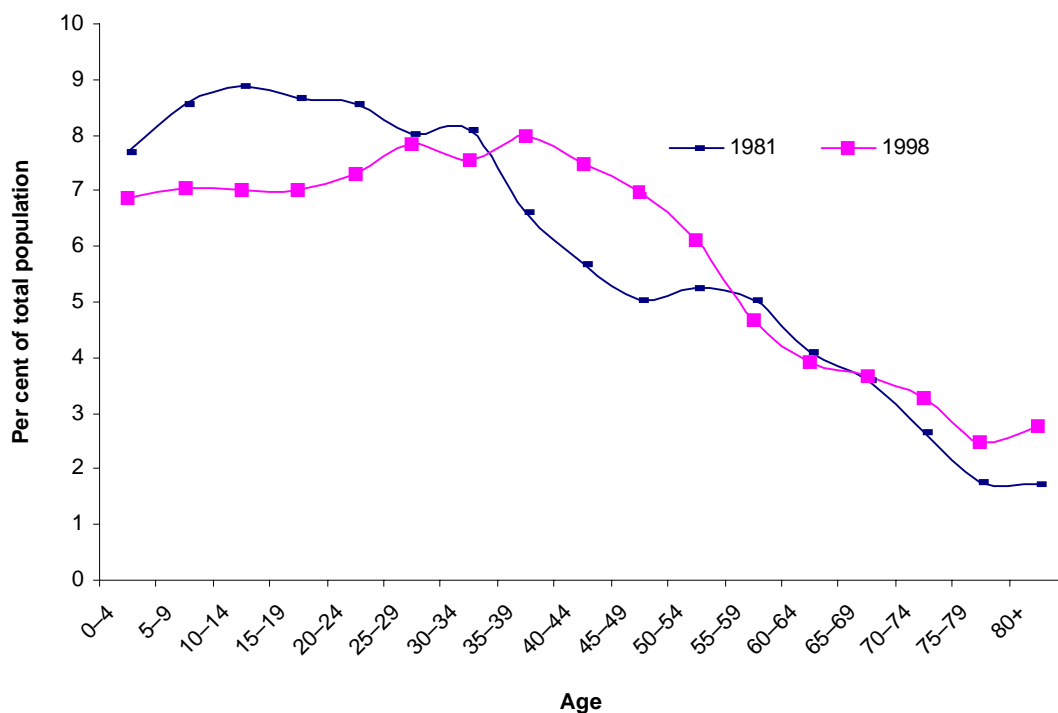
Growth rates for the population aged 70 years and over were even higher, ranging from 56% for the 70-74 age group to 102% for the 80 years and over age group. This was partly due to the increased survival rate of older Australians, as well as the large numbers of people born during the post-First World War period, and post-World War II immigrants who arrived in Australia in the 1950s as young adults, moving into the oldest age groups (see Chapter 2).

The disproportionate growth in certain age groups has resulted in changes in population age structure, resulting in a general pattern of population ageing between 1981 and 1998. The proportion of the population aged under 25 years has declined, while the proportion of the population aged between 35 and 54 years has increased substantially. There has also been a significant increase in the proportion aged 65 years and over (Figure 12.5 and Table 12.3). The next section will quantify the impact of these demographic changes on the prevalence of disability.

Table 12.3: Changes in population size and age structure, Australia, 1981–1993

Age	Population age structure (% of total population)				Population growth (%)
	1981	1988	1993	1998	1981–1998
0–4	7.7	7.5	7.3	6.9	13.6
5–9	8.6	7.4	7.2	7.1	4.6
10–14	8.9	7.6	7.1	7.0	0.2
15–19	8.7	8.4	7.4	7.0	2.5
20–24	8.6	7.9	8.2	7.3	8.2
25–29	8.0	8.4	7.8	7.9	24.2
30–34	8.1	8.0	8.3	7.6	18.8
35–39	6.6	7.7	7.7	8.0	53.2
40–44	5.7	7.0	7.4	7.5	66.6
45–49	5.0	5.4	6.5	7.0	75.6
50–54	5.3	4.7	5.0	6.1	47.8
55–59	5.0	4.5	4.3	4.7	17.6
60–64	4.1	4.5	4.1	3.9	21.5
65–69	3.6	3.8	3.9	3.7	29.4
70–74	2.7	2.9	3.1	3.3	56.1
75–79	1.8	2.1	2.2	2.5	79.2
80+	1.7	2.1	2.4	2.8	102.3
Total	100.0	100.0	100.0	100.0	27.0

Source: AIHW analysis of the ABS 1998 Survey of Disability, Ageing and Carers unpublished data tables.



Source: Table 12.3.

Figure 12.5: Comparison of population age structures, Australia, 1981 and 1998

Demographic decomposition

The demographic decomposition method enables us not only to estimate the overall impacts of population change but also to separate effects attributable to changes in total population size and those due to differential growth among age groups (population ageing) (Otis & Howe 1991).

The first stage of the method assesses the overall effect of population change on the number of people with a disability and specific activity restrictions.

The second stage separately examines the effects of the two components—change in population size and change in age structure. This allows us to determine the proportion of the increase due to population ageing. Population ageing is the effect of differential growth among age groups resulting, in Australia, in relatively higher growth in older age groups with higher age-specific prevalence of disability.

The effect of growth in total population size can be estimated by subtracting the impact of population ageing from the overall effects of population change.

The demographic decomposition method is explained in detail below.

Calculating total change

Step 1: Data from the four ABS surveys are used to calculate absolute increases in the reported number of people with a disability, specific restrictions and severe or profound core activity restrictions in the periods 1993–1998, 1988–1998 and 1981–1998.

Calculating the overall effects of population change

Step 2: Age-sex-specific prevalence rates for 1981, 1988 and 1993 are applied to the estimated resident population for March 1998, to estimate the expected numbers of people with a disability, specific restrictions and severe or profound core activity restrictions for 1981, 1988 and 1993, respectively, i.e. the numbers that would have been expected in 1981, 1988 and 1993 had the population size, age and sex structure in those years been the same as in 1998. This step produces estimates based on 'constant' prevalence rates.

Step 3: The actual numbers reported in 1981, 1988 and 1993 are then subtracted from the expected numbers, to give the change in numbers attributable to the overall effects of population change.

Step 4: The results of Step 3 (i.e. change due to population effects) are divided by the results of Step 1 (i.e. total change) to estimate the proportion of the change that can be explained by the overall effects of population change.

Calculating the effects of different components of population change

Step 5: The age and sex distribution of each of the 1981, 1988 and 1993 populations is applied to the total 1998 population. This gives three projected 1998 populations with the same age and sex composition as the 1981, 1988 and 1993 populations, respectively.

Step 6: The age–sex-specific prevalence rates of 1981, 1988 and 1993 are applied to the three projected 1998 populations, respectively, to estimate the expected numbers of people with a disability, specific restrictions and severe or profound restrictions. This step assumes not only constant prevalence rates (as for Step 2) but also constant population age and sex distributions of the 1981, 1988 and 1993 populations. Only total population size is changed, to that of the 1998 population.

Step 7: These results are then subtracted from the results of Step 2 to estimate changes in expected numbers due to disproportionate growth among age groups.

Step 8: The resulting numbers of Step 7 (i.e. changes due to population age and sex structure) are divided by the results of Step 1 (i.e. total change) to estimate the proportion of the change that can be explained by changes in population age and sex structure.

Step 9: The proportion of change due to the effects of change in total population size alone is calculated by subtracting the results of Step 8 (i.e. proportion of change due to changes in age and sex structure) from the results of Step 4 (i.e. proportion of change due to overall population change).

Data limitations

There are some specific limitations of the ABS unpublished data tables that affect analyses using the decomposition method:

- The available age-specific data use 10-year age groups for people aged under 55 years, 5-year age groups for people aged between 55 and 74 years, and one open-ended age group of 75 years and over. In the analysis, the impact of population ageing (disproportionate growth between age cohorts) may be underestimated for the older

working age population and for the population aged 75 years and over, due to the broad age groupings.

- The number of people with moderate core activity restriction increased from 278,100 in 1981 to 551,800 in 1988, dropped to 377,000 in 1993, and then jumped to 506,700 in 1998. This pattern is unlikely to reflect real changes in prevalence. Given that our focus is on severe or profound core activity restrictions, moderate and mild core activity restrictions are not presented as separate categories in the following comparative data tables (e.g. Table 12.4).

Results of the decomposition

The demographic decomposition analysis shows that, over the 17 years 1981–1998, the overall effects of population growth accounted for 50% of the increase in the number of people with a disability and 45% of the increase in severe or profound core activity restrictions (Table 12.4). This impact was more evident during the most recent 10 years (1988–1998). Between 1988 and 1998, the effects of population growth were almost equal to, or greater than, the effects of population growth over the entire 17 years (1981–1998), despite the fact that the impact of population change usually increases when a longer period is considered. Between 1988 and 1998, 56% of the increase in disability, 64% of the increase in specific restrictions and 43% of the increase in severe or profound core activity restrictions were due to population growth, as compared with 50%, 38% and 45% of the increases over the entire 17-year period (Figure 12.6 and Table 12.4).

As expected, the effects of population growth on the numbers of people with severe or profound core activity restriction differed markedly between people aged under 65 years and people aged 65 years and over (26% versus 67% during 1981–1998), and these differences also increased over the most recent 10 years (23% versus 73% during 1988–1998) (Figure 12.7 and Table 12.4).

Insight into the impact of differential growth among age groups (population ageing) on the number of people with a disability is provided by the separation of the two components of population change (change in overall population size, and change in population age- and sex-structure). Figures 12.8, 12.9, 12.10 and Table 12.4 show the disaggregated effects of disproportionate growth between age groups versus changes in population size. Over the entire 17-year period, increased population size appears to have contributed more to the increase in disability prevalence than have changes in population age structure (33.5% as against 16.6%). Nevertheless, the contributions of the two components were similar when only more severe disabilities were considered (24.4% versus 20.5%), suggesting that population ageing has had a strong impact on the prevalence of severe or profound core activity restriction.

When the most recent 10-year period is considered, as a striking contrast, the effects of population ageing were 1.3 times the effects of increase in population size for disability generally (32% versus 24%), 1.5 times for all specific restrictions (39% versus 26%) and 2.6 times for severe or profound core activity restrictions (31% versus 12%) (Table 12.4; Figures 12.8, 12.9 and 12.10).

Among people aged 65 years and over, over the 17-year period (1981–1998) population ageing accounted for 34% of the increase in disability (Table 12.4 and Figure 12.11). Again, the pattern for the most recent 10-year period (1988–1998) is markedly different—population ageing contributed 84% of the increase in disability between 1988 and 1998 for this age group. The contribution of population ageing to increases in all specific restrictions was 94% (1988–1998) versus 30% (1981–1998), and for severe or profound care activity restrictions,

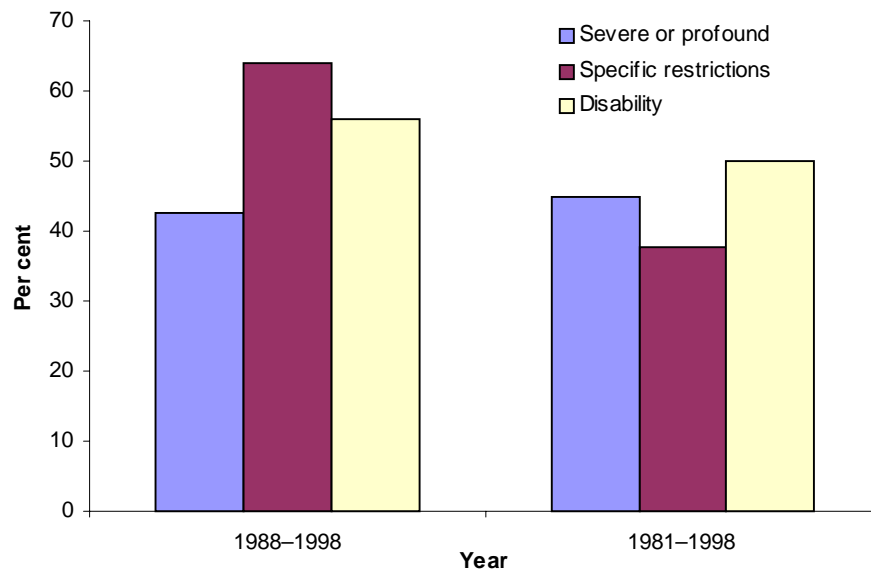
75% (1988–1998) versus 42% (1981–1998). This reflects an increasing effect of population ageing during the more recent period (Table 12.4).

Table 12.4: Effects of population growth on disability prevalence, Australia, 1981–1998^(a)

Period	Age	Severe or profound core activity restriction	Specific restrictions	Total with disability
% changes due to overall population growth				
1993–1998	Under 65	14.1	28.5	34.1
	65+	47.8	85.0	87.1
	Total	26.6	43.3	48.6
1988–1998	Under 65	22.7	46.7	40.6
	65+	72.5	95.9	86.7
	Total	42.6	64.1	56.0
1981–1998	Under 65	26.1	28.9	44.0
	65+	66.7	51.0	58.8
	Total	44.8	37.6	50.1
Decomposition of population effects—% changes due to:				
1988–1998	<i>Differential growth between age groups</i>			
	Under 65	1.9	8.1	5.8
	65+	74.7	94.3	84.1
	Total	31.0	38.6	31.9
	<i>Growth in population size alone</i>			
	Under 65	20.8	38.6	34.8
	65+	–2.2	1.6	2.6
	Total	11.7	25.5	24.1
	1981–1998	<i>Differential growth between age groups</i>		
Under 65		2.2	3.5	4.4
65+		41.8	30.3	34.0
Total		20.5	14.0	16.6
<i>Growth in population size alone</i>				
Under 65		23.9	25.4	39.6
65+		24.9	20.7	24.8
Total		24.4	23.6	33.5

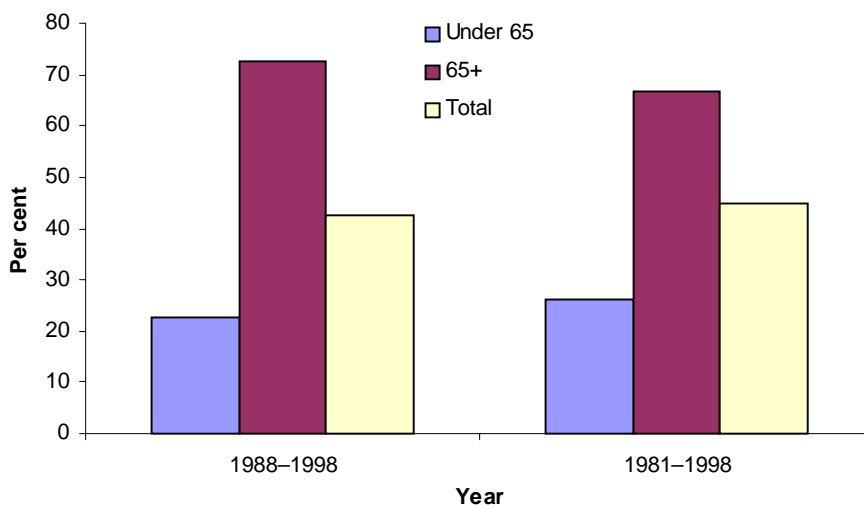
(a) This table summarises the results of demographic decomposition. Detailed illustrations of the method and calculation are in the previous section.

Source: AIHW analysis of the ABS 1998 Survey of Disability, Ageing and Carers unpublished data tables.



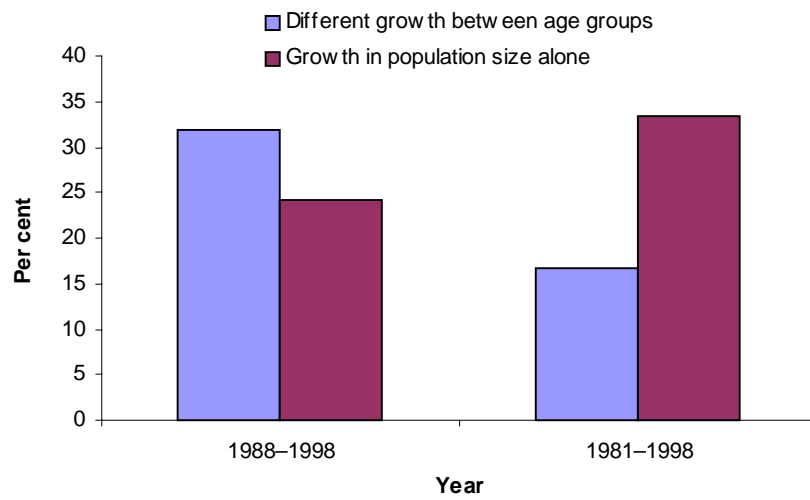
Source: Table 12.4.

Figure 12.6: Changes in prevalence of disability due to population growth, Australia, 1981-1998



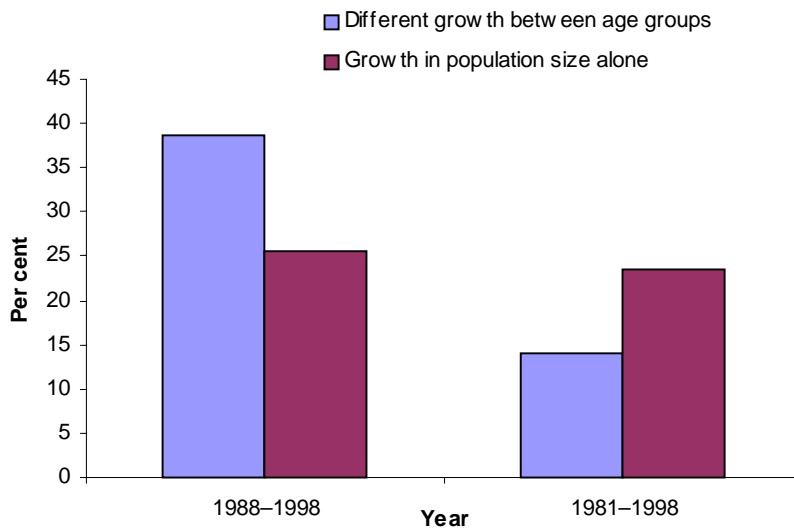
Source: Table 12.4.

Figure 12.7: Changes in prevalence of severe or profound core activity restriction due to population growth, by age, Australia, 1981-1998



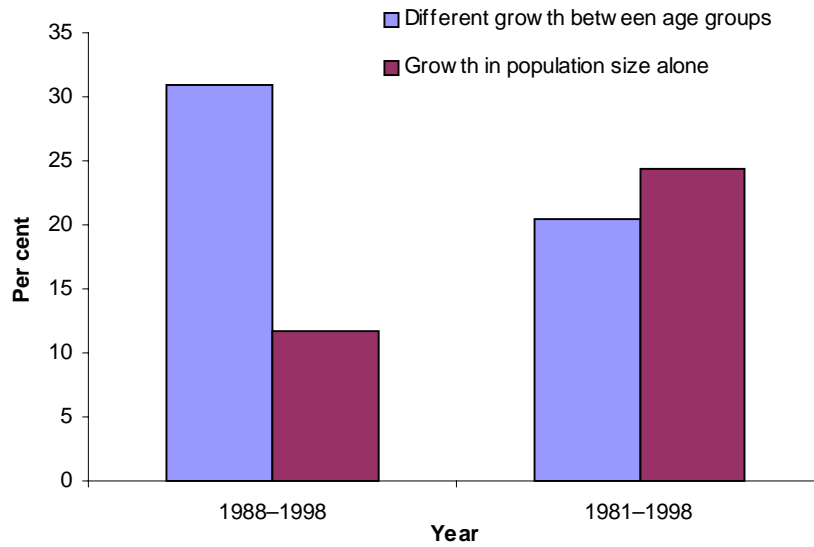
Source: Table 12.4.

Figure 12.8: Decomposition of population effects on prevalence of disability, Australia, 1981-1998



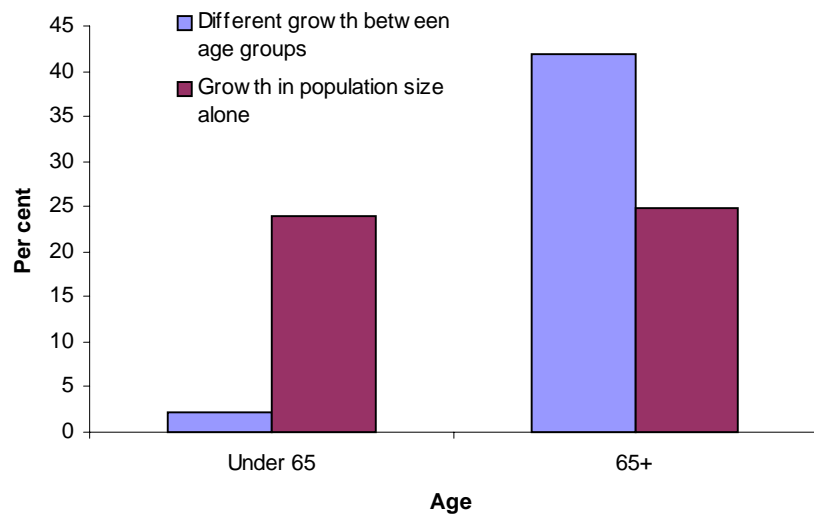
Source: Table 12.4

Figure 12.9: Decomposition of population effects on prevalence of specific restrictions, Australia, 1981-1998



Source: Table 12.4.

Figure 12.10: Decomposition of population effects on prevalence of severe or profound core activity restrictions, Australia, 1981-1998



Source: Table 12.4.

Figure 12.11: Decomposition of population effects on prevalence of severe or profound core activity restrictions, by age, Australia, 1981-1998

12.5 Summary

The comparative analyses of the four ABS disability surveys in this chapter reveal the following trends in population change and their impact on prevalence of disability:

- The comparison of age-standardised estimates showed that between 1981 and 1998 the 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.
- Between 1981 and 1998, the total number of people with a disability increased by 80%, from 1,942,200 in 1981 to 3,503,700 in 1998. 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) (Table A12.1).
- Growth in the 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%).
- 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 restriction, and that effect has been particularly evident among people aged 65 years and over in the last decade.

The 1998 ABS disability survey indicated an substantial increase in the number of people with a severe or profound core activity restriction 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. Detailed discussions are presented in Chapters 13 and 18.

13 Ageing of people with a disability

This chapter examines the impact of population ageing on changes in the age structure of the population with a disability, in particular with severe or profound core activity restrictions. The data used in this chapter are the same as those used in Chapter 12, and include the four ABS disability surveys.

Comparative analyses of data from the four surveys showed that the trend in ageing of people with a disability has three main features:

- a general increase in the proportion of people aged 65 years and over among people with a disability for the 17-year period (1981–1998);
- a recent increase (between 1993–1998) in the proportion of people with a disability aged under 65 years; and
- ageing of the older population with a disability.

These features are associated with several important demographic trends and their impacts on disability prevalence, as discussed in the literature review and the previous chapter. The demographic trends include the ageing of the aged population itself, the rapid pace of ageing of the working-age population, and the passage of some significant age cohorts. The following sections will discuss these features in detail.

13.1 Increase in the proportion of people aged 65 years and over among people with a disability

In line with the ageing of the general population, people with a disability are also ageing. During the 17-year period 1981–1998, the general trend indicated that among all people with a disability or all people with specific restrictions, there was an increase in the proportion of people aged 65 years and over and a decline in the proportion aged under 65 years. Of total people with a disability, the proportion of those aged 65 years and over increased from 30.6% in 1981 to 35.4% in 1998. During the same period, among all people with specific restrictions the proportion of people aged 65 years and over increased from 34.4% to 37.0% (Tables 13.1 and A12.1).

For all people with severe or profound core activity restriction, there was a general increase in the proportion of those aged 65 years and over from 47.1% in 1981 to 50.6% in 1993. However, between 1993 and 1998 this proportion declined from 50.6% to 46.6% (Tables 13.1 and A12.1). This was largely due to a marked increase in the number of people with a severe or profound core activity restriction aged under 65 years between 1993 and 1998 (Table A12.1; Figure 13.1) (detailed discussion about this increase is presented in later sections).

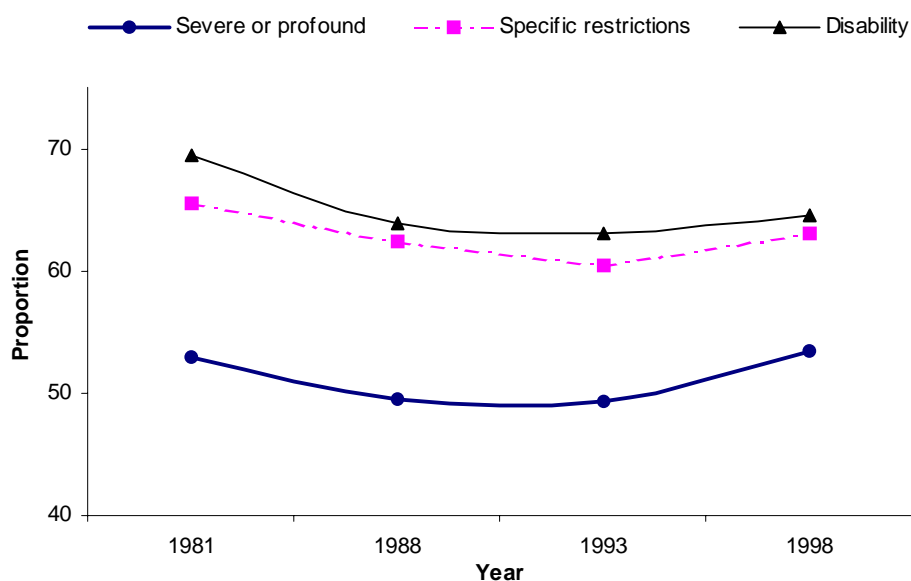
Table 13.1: Age and sex composition of people with a disability (%), Australia, 1981, 1988, 1993 and 1998^(a)

Age/sex	Severe or profound core activity restriction ^(b)				Specific restrictions ^(b)				Total with a disability			
	1981	1988	1993	1998	1981	1988	1993	1998	1981	1988	1993	1998
Males												
Under 15	13.6	13.3	13.0	15.8	9.8	8.8	8.3	10.0	11.9	10.1	9.7	10.7
15–64	52.1	47.5	48.6	49.0	64.0	59.8	58.0	58.6	63.4	59.1	57.9	58.5
65+	34.4	39.2	38.4	35.2	26.2	31.4	33.6	31.3	24.6	30.8	32.4	30.8
<i>Total</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>
<i>Under 65</i>	<i>65.6</i>	<i>60.8</i>	<i>61.6</i>	<i>64.8</i>	<i>73.8</i>	<i>68.6</i>	<i>66.4</i>	<i>68.7</i>	<i>75.4</i>	<i>69.2</i>	<i>67.6</i>	<i>69.2</i>
Females												
Under 15	5.7	6.1	5.8	5.7	5.5	5.8	4.9	5.3	8.2	7.3	6.8	6.3
15–64	38.3	36.1	35.0	38.8	52.0	50.6	49.5	51.8	54.9	50.9	51.2	53.1
65+	56.0	57.8	59.2	55.4	42.6	43.6	45.6	42.9	36.9	41.8	42.1	40.6
<i>Total</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>
<i>Under 65</i>	<i>44.0</i>	<i>42.2</i>	<i>40.8</i>	<i>44.6</i>	<i>57.4</i>	<i>56.4</i>	<i>54.4</i>	<i>57.1</i>	<i>63.1</i>	<i>58.2</i>	<i>57.9</i>	<i>59.4</i>
Persons												
Under 15	9.0	8.9	8.8	10.1	7.6	7.2	6.7	7.7	10.1	8.7	8.3	8.6
15–64	44.0	40.6	40.6	43.3	57.9	55.2	53.8	55.3	59.3	55.1	54.7	56.0
65+	47.1	50.5	50.6	46.6	34.4	37.6	39.6	37.0	30.6	36.2	37.0	35.4
<i>Total</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>
<i>Under 65</i>	<i>52.9</i>	<i>49.5</i>	<i>49.4</i>	<i>53.4</i>	<i>65.6</i>	<i>62.4</i>	<i>60.4</i>	<i>63.0</i>	<i>69.4</i>	<i>63.8</i>	<i>63.0</i>	<i>64.6</i>

(a) Disability data were re-derived using criteria common to the four surveys.

(b) Only people aged 5 years and over are included.

Source: Tables 13.3, 13.4 and 13.5; AIHW analysis of the ABS 1998 Survey of Disability, Ageing and Carers unpublished data tables.



Source: Table 13.1.

Figure 13.1: Proportion of people with a disability aged under 65 years, Australia, 1981–1998

13.2 Ageing of aged people with a disability

In the population with a disability aged 65 or more, large increases occurred in the proportion of people aged 75 or over between 1981 and 1998. The proportion increased from 45% to 53% for people with a disability and from 66% to 73% for people with a severe or profound core activity restriction (Table 13.2). These increases were associated with high growth rates in the population aged 70 and over, and particularly in the population aged 75 and over (Chapter 2).

Severity of disability is strongly related to age for people aged 65 and over. In 1998, about 73% of people with a severe or profound core activity restriction were aged 75 or over, compared with 53% for all people with a disability (Table 13.2).

For females with a disability, and with severe or profound core activity restrictions, there were substantially higher proportions aged 65-plus than for males, though these sex differences declined over the 17-year period (Table 13.1). 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 (McDonald 1997).

Table 13.2: People with a disability aged 65 years and over: proportion in selected age groups, by sex, Australia, 1981–1998^(a)

	1981	1988	1993	1998
Severe or profound core activity restriction				
Male				
Total 70+ (%)	76.2	76.4	81.5	83.8
Total 75+ (%)	55.2	53.0	61.4	65.2
Total number 65+ ('000)	64.4	92.3	105.2	147.4
Females				
Total 70+ (%)	85.9	87.7	88.2	90.4
Total 75+ (%)	70.0	72.2	70.6	76.4
Total number 65+ ('000)	148.8	211.0	232.4	297.4
Persons				
Total 70+ (%)	83.0	84.3	86.1	88.2
Total 75+ (%)	65.5	66.4	67.7	72.7
Total number 65+ ('000)	213.2	303.3	337.6	444.8
Specific restrictions				
Male				
Total 70+ (%)	68.5	68.0	73.7	76.8
Total 75+ (%)	40.7	41.6	45.6	50.5
Total number 65+ ('000)	170.4	324.0	382.9	447.3
Females				
Total 70+ (%)	78.4	79.7	81.4	83.8
Total 75+ (%)	57.4	57.4	57.9	63.1
Total number 65+ ('000)	278.9	458.6	510.3	587.2
Persons				
Total 70+ (%)	74.7	74.8	78.1	80.8
Total 75+ (%)	51.1	50.9	52.6	57.7
Total number 65+ ('000)	449.3	782.5	893.1	1,034.5
Total with disability				
Male				
Total 70+ (%)	65.4	65.7	70.7	73.5
Total 75+ (%)	37.0	38.7	41.6	45.9
Total number 65+ ('000)	246.5	399.2	494.8	569.2
Females				
Total 70+ (%)	74.5	77.5	78.7	81.3
Total 75+ (%)	51.3	54.0	53.7	59.2
Total number 65+ ('000)	347.5	521.2	586.1	671.0
Persons				
Total 70+ (%)	70.7	72.4	75.0	77.7
Total 75+ (%)	45.3	47.4	48.2	53.1
Total number 65+ ('000)	594.1	920.4	1,081.0	1,240.2

(a) Disability data were re-derived using criteria common to the four surveys.

Source: AIHW analysis of the ABS 1998 Survey of Disability, Ageing and Carers unpublished data tables.

13.3 Recent increase in the proportions of people with a disability aged under 65 years

In contrast to the trends in the period 1981–1993, between 1993 and 1998 the proportion of people with a disability aged under 65 years increased by 1.6 percentage points for all disability, 2.6 percentage points for all specific restrictions and 4.0 percentage points for severe or profound core activity restrictions (Figure 13.1 and Table 13.1). This is mainly attributable to the large increase (54.8%) in the number of people aged under 65 with a severe or profound core activity restriction over the 5-year period (Table 13.3).

A closer examination of the age and sex patterns found that the increases occurred mainly in the age group of 45–54 years for both males and females, and among males aged 5–14 years (Tables 13.3, 13.4 and 13.5). The number of males aged 5–14 years with a severe or profound core activity restriction as a proportion of all males aged under 65 with a severe or profound core activity restriction increased from 21.2% to 24.4% between 1993 and 1998 (Table 13.3).

The significant increases in the proportion of people with a disability in the age range 45–54 years reflect the bulge of the baby-boom generation who are now entering age groups associated with high risk of disability (Table 13.6). Between 1981 and 1998 the population growth rates for people aged between 35 and 54 years ranged from 48% to 76%, with a peak in the age group 40–49 (Chapter 12: Table 12.3).

The decline in the proportion of people with a disability aged 55–64 years between 1981 and 1998 was associated with low growth rates of the working-age population aged 50–54 and 55–59 during the 1980s, reflecting the passage of people born in the low-fertility years of the 1930s (Table 13.5; Chapter 2: Tables 2.2 and 2.3).

Table 13.3: People with a severe or profound core activity restriction aged under 65 years^(a), age and sex composition (%), Australia, 1981, 1988, 1993 and 1998^(b)

Age/sex	1981	1988	1993	1998
Males				
5-14	20.7	21.9	21.2	24.4
15-24	8.9	8.8	10.1	8.9
25-34	12.5	12.3	13.4	11.3
35-44	12.7	17.0	17.7	12.6
45-54	18.2	16.8	17.2	20.4
55-59	14.1	10.2	11.2	12.8
60-64	13.0	13.1	9.2	9.7
<i>Total</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>
Total 35-64	57.9	57.0	55.3	55.5
Total 45-64	45.3	40.1	37.6	42.9
Total 55-64	27.1	23.3	20.4	22.5
<i>Total number under 65 ('000)</i>	<i>123.0</i>	<i>143.2</i>	<i>169.1</i>	<i>270.9</i>
Females				
5-14	13.0	14.5	14.2	12.9
15-24	10.6	9.6	11.7	8.6
25-34	11.3	14.0	14.7	11.3
35-44	16.0	20.2	18.2	19.3
45-54	20.7	18.1	20.6	24.5
55-59	13.9	10.9	11.0	11.9
60-64	14.5	12.7	9.6	11.6
<i>Total</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>
Total 35-64	65.1	61.9	59.4	67.2
Total 45-64	49.1	41.7	41.2	48.0
Total 55-64	28.4	23.7	20.6	23.5
<i>Total number under 65 ('000)</i>	<i>116.7</i>	<i>154.0</i>	<i>160.4</i>	<i>239.2</i>
Persons				
5-14	16.9	18.1	17.8	19.0
15-24	9.8	9.2	10.9	8.7
25-34	11.9	13.2	14.0	11.3
35-44	14.3	18.6	18.0	15.7
45-54	19.4	17.5	18.8	22.3
55-59	14.0	10.6	11.1	12.4
60-64	13.7	12.9	9.4	10.6
<i>Total</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>
Total 35-64	61.4	59.6	57.3	61.0
Total 45-64	47.2	40.9	39.3	45.3
Total 55-64	27.7	23.5	20.5	23.0
<i>Total number under 65 ('000)</i>	<i>239.7</i>	<i>297.2</i>	<i>329.4</i>	<i>510.1</i>

(a) Only people aged 5 years and over are included.

(b) Disability data were re-derived using criteria common to the four surveys.

Source: Tables A13.1, A13.2 and A13.3; AIHW analysis of the ABS 1998 Survey of Disability, Ageing and Carers unpublished data tables.

Table 13.4: People with specific restrictions aged under 65 years^(a), age and sex composition (%), Australia, 1981, 1988, 1993 and 1998^(b)

Age/sex	1981	1988	1993	1998
Males				
5-14	13.3	12.8	12.6	14.6
15-24	8.3	9.1	9.3	11.0
25-34	11.7	12.6	12.5	11.9
35-44	13.4	16.3	17.0	16.3
45-54	19.0	17.3	20.6	21.1
55-59	17.3	13.0	12.3	11.9
60-64	16.9	19.0	15.8	13.2
<i>Total</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>
Total 35-64	66.7	65.6	65.7	62.6
Total 45-64	53.2	49.3	48.7	46.3
Total 55-64	34.2	32.1	28.1	25.2
<i>Total number under 65 ('000)</i>	<i>478.9</i>	<i>707.2</i>	<i>755.5</i>	<i>980.3</i>
Females				
5-14	9.5	10.2	9.1	9.3
15-24	10.7	9.6	10.5	9.7
25-34	13.7	13.4	14.3	12.0
35-44	14.6	19.2	18.9	19.5
45-54	21.8	20.3	22.2	24.6
55-59	14.8	11.8	12.8	13.0
60-64	14.9	15.4	12.3	11.9
<i>Total</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>
Total 35-64	66.1	66.7	66.1	69.0
Total 45-64	51.5	47.5	47.2	49.5
Total 55-64	29.7	27.2	25.1	24.9
<i>Total number under 65 ('000)</i>	<i>376.2</i>	<i>593.4</i>	<i>609.0</i>	<i>781.6</i>
Persons				
5-14	11.6	11.6	11.0	12.2
15-24	9.3	9.3	9.8	10.4
25-34	12.6	13.0	13.3	11.9
35-44	14.0	17.6	17.8	17.7
45-54	20.3	18.6	21.3	22.7
55-59	16.2	12.5	12.5	12.4
60-64	16.0	17.4	14.2	12.6
<i>Total</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>
Total 35-64	66.4	66.1	65.9	65.4
Total 45-64	52.5	48.5	48.1	47.7
Total 55-64	32.2	29.8	26.7	25.0
<i>Total number under 65 ('000)</i>	<i>855.0</i>	<i>1,300.6</i>	<i>1,364.6</i>	<i>1,761.9</i>

(a) Only people aged 5 years and over are included.

(b) Disability data were re-derived using criteria common to the four surveys.

Source: Tables A13.1, A13.2 and A13.3; AIHW analysis of the ABS 1998 Survey of Disability, Ageing and Carers unpublished data tables.

Table 13.5: People with a disability aged under 65 years, age and sex composition (%), Australia, 1981, 1988, 1993 and 1998^(a)

Age/sex	1981	1988	1993	1998
Males				
0-4	3.1	2.8	2.9	2.4
5-14	12.8	11.9	11.5	13.0
15-24	9.8	9.8	9.1	9.7
25-34	13.1	12.8	13.1	12.0
35-44	14.1	16.5	17.1	17.1
45-54	18.5	16.6	20.5	21.5
55-59	14.9	12.1	11.4	11.9
60-64	13.7	17.4	14.4	12.3
<i>Total</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>
Total 35-64	61.2	62.7	63.4	62.8
Total 45-64	47.1	46.2	46.3	45.7
Total 55-64	28.6	29.5	25.8	24.2
<i>Total number under 65 ('000)</i>	<i>754.2</i>	<i>896.3</i>	<i>1,032.6</i>	<i>1,280.2</i>
Females				
0-4	2.7	2.2	2.9	1.6
5-14	10.2	10.4	8.7	9.0
15-24	12.0	10.7	11.1	9.6
25-34	15.1	13.7	14.8	12.9
35-44	15.0	18.8	18.9	19.4
45-54	19.5	19.0	20.0	24.0
55-59	12.8	11.0	11.7	12.6
60-64	12.6	14.2	11.7	10.8
<i>Total</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>
Total 35-64	59.9	63.1	62.3	66.9
Total 45-64	44.9	44.3	43.4	47.4
Total 55-64	25.5	25.2	23.4	23.4
<i>Total number under 65 ('000)</i>	<i>593.9</i>	<i>726.4</i>	<i>807.0</i>	<i>983.2</i>
Persons				
0-4	2.9	2.5	2.9	2.1
5-14	11.6	11.2	10.3	11.3
15-24	10.8	10.2	10.0	9.6
25-34	14.0	13.2	13.9	12.4
35-44	14.5	17.6	17.9	18.1
45-54	18.9	17.7	20.3	22.6
55-59	14.0	11.6	11.5	12.2
60-64	13.2	16.0	13.2	11.7
<i>Total</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>
Total 35-64	60.6	62.9	63.0	64.6
Total 45-64	46.1	45.3	45.0	46.5
Total 55-64	27.2	27.6	24.7	23.9
<i>Total number under 65 ('000)</i>	<i>1,348.1</i>	<i>1,622.7</i>	<i>1,839.6</i>	<i>2,263.5</i>

(a) Disability data were re-derived using criteria common to the four surveys.

Source: Tables A13.1, A13.2 and A13.3; AIHW analysis of the ABS 1998 Survey of Disability, Ageing and Carers unpublished data tables.

Table 13.6: Population age structure for people aged under 65 years, Australia, 1981, 1988, 1993 and 1998

Age/sex	1981	1988	1993	1998
Males				
0-4	8.6	8.5	8.4	8.0
5-14	19.6	17.1	16.5	16.2
15-24	19.1	18.3	17.8	16.5
25-34	17.6	18.1	17.9	17.4
35-44	13.7	16.5	16.9	17.3
45-54	11.5	11.5	13.2	14.9
55-59	5.5	5.1	4.8	5.3
60-64	4.3	4.9	4.5	4.4
<i>Total</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>
Total 35-64	35.1	38.0	39.4	42.0
Total 45-64	21.4	21.5	22.5	24.6
Total 55-64	9.8	10.0	9.3	9.7
<i>Total number under 65 ('000)</i>	<i>6,727.9</i>	<i>7,363.4</i>	<i>7,898.0</i>	<i>8,289.1</i>
Females				
0-4	8.4	8.3	8.2	7.7
5-14	19.1	16.6	16.1	15.8
15-24	19.1	18.4	17.5	16.1
25-34	18.1	18.7	18.4	17.8
35-44	13.5	16.6	17.3	17.8
45-54	11.3	11.2	13.0	14.9
55-59	5.7	5.0	4.9	5.3
60-64	4.8	5.1	4.7	4.5
<i>Total</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>
Total 35-64	35.2	38.0	39.8	42.6
Total 45-64	21.7	21.4	22.5	24.7
Total 55-64	10.4	10.2	9.5	9.8
<i>Total number under 65 ('000)</i>	<i>6,539.2</i>	<i>7,194.2</i>	<i>7,682.3</i>	<i>8,100.3</i>
Persons				
0-4	8.5	8.4	8.3	7.8
5-14	19.4	16.8	16.3	16.0
15-24	19.1	18.4	17.7	16.3
25-34	17.9	18.4	18.1	17.6
35-44	13.6	16.5	17.1	17.6
45-54	11.4	11.4	13.1	14.9
55-59	5.6	5.1	4.8	5.3
60-64	4.6	5.0	4.6	4.5
<i>Total</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>
Total 35-64	35.2	38.0	39.6	42.3
Total 45-64	21.5	21.4	22.5	24.7
Total 55-64	10.1	10.1	9.4	9.8
<i>Total number under 65 ('000)</i>	<i>13,267.2</i>	<i>14,557.6</i>	<i>15,580.3</i>	<i>16,389.4</i>

Source: AIHW analysis of the ABS 1998 Survey of Disability, Ageing and Carers unpublished data tables.

13.4 Discussion

Comparative analyses of data from the four surveys show that, as a result of population ageing, the population with a disability has also aged over the period 1981 to 1998. This is particularly true for the population with a severe or profound core activity restriction. The ageing of people with a disability was indicated by a general increase in the proportion of people with a disability aged 65 years and over and the ageing of the older population with a disability.

The more recent (1993–1998) increase in the proportion of people with a disability aged under 65 years, in particular the increase in the proportion with a severe or profound core activity restriction, should not be seen as a reversal of the general ageing trend among people with a disability. Further investigation is needed to understand the recent increase between 1993 and 1998. Three main trends need attention in terms of their implications for disability service planning and understanding the recent increase in severe or profound core activity restrictions among people aged under 65 years.

First, 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 restrictions for males aged 5–14 years increased by 2.9 percentage points. Most of this increase (2.2 percentage points) occurred between 1993 and 1998. This increase is more than two times the average increase for males aged 15–64 years in the period 1993–1998 (Chapter 12.2: Table 12.1). A major concern is whether this trend reflects 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 a disability, due to improved medical technologies (Chapter 7).

Second, it seems there may be an increase in the number of older working-age people with a severe or profound core activity restriction. Among people reporting a severe or profound core activity restriction the number of people aged 45–54 increased significantly between 1981 and 1998 (Table 13.3). During the next decade, the progressive upward movement of the baby-boom generation in the population age pyramid could potentially continue to increase the number of people with a severe or profound core activity restrictions in the 55 to 64 year age group. 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 (Chapter 2).

Third, the ageing of older people with a severe or profound core activity restrictions could be very significant from the second decade of this century because of the size of the baby-boom generation moving into older age groups. The growth of the population aged 65 years and over is projected to reach record rates (to increase by 36.2%) between 2011 and 2021 (Table 2.3). Between 1997 and 2051 the number of people aged 75 years and over is projected to increase by around 3.5 times, and 5.3 times for people aged 85 and over (Table A2.3).

14 People ageing with an early onset disability

This chapter presents data on age at onset of main condition for people ageing with a disability and looks at relationships between main condition and age at onset.

For the purposes of the analyses in this section, early onset disability is defined as disability where the age at onset of main condition was 17 years or less, and late onset disability is defined as disability where the age at onset of main condition was 65 years or more.

14.1 Age at onset of disability

Although no direct question about age at onset of disability was asked in the ABS disability surveys, information about age at onset of main condition was collected. The survey respondent was asked how old he/she was when it was first found that he/she had the condition.

In the 1998 survey, a person's main condition was defined as 'a long-term condition identified by a person as the one causing the most problems'. Where a person reported only one long-term condition, this was recorded as their main long-term condition. A long-term condition is defined as 'a disease or disorder that has lasted or is likely to last for at least six months; or a disease, disorder or event (e.g. stroke, poisoning, accident etc.) which produces an impairment or restriction which has lasted or is likely to last for at least six months' (ABS 1999: 69).

When interpreting data on age at onset from the ABS disability surveys, some data limitations need to be considered.

The time between onset of a condition and the development of disability may vary depending on the nature of the condition and other factors. In the analysis presented in this report, age at onset of main condition is used as a proxy for age at onset of disability. However, a person with multiple long-term conditions may have been experiencing disability caused by another condition prior to the onset of their main condition. It is possible that a person with an early onset disability who has learned to cope with that disability very well might find a recently acquired condition more disabling because they have had less time to adjust to it. In this case, the person might report the more recently acquired condition as their main condition. In the following discussion of the ABS disability data, 'age at onset of disability' means 'age at onset of main condition', treated as indicative of age at onset of disability.

Information about age at onset of main condition was only collected among people living in households. In 1998, among people with a disability living in households, 29,900 people (0.9%) reported that they did not know their age at onset of their main condition (Table 14.1). For people with a severe or profound core activity restriction, 11,300 people (1.2%) did not know their age at onset of their main condition (Table 14.2).

Because the ABS disability survey data are cross-sectional (i.e. represent a snapshot at a point in time) they cannot provide information on the overall distribution of age at onset of main condition. Longitudinal data would be more useful in this regard, as they could give a more complete picture of disability experience in the population. However, there are no

such data available in Australia. The ABS disability survey data provide information on respondents' life experience up to the date of the survey. Cross-sectional data cannot provide disability information on young people who have no disability at the time of the survey, but who may acquire a disability later in life, or people with a disability who died before the survey date. Therefore, percentage distribution patterns of age at onset do not reflect the probability of acquiring disability in particular age groups.

Despite these caveats, the information on age at onset of main condition is useful for disability service planning. It can be used to provide some indication of the proportion of people with an early onset disability, as against the proportion who acquire a disability later in life, within particular age groups. For instance, when considering clients with a disability aged between 45 and 64, it may be relevant to know what percentage have an early onset disability, as these people may have different support needs from people with a recently acquired disability. These issues will be explored further in Chapter 18 (implications for support services).

14.2 Distribution of age at onset by current age

Table 14.1 shows the distribution of age at onset by current age (i.e. age of the respondent at the time of the survey) for people with a disability living in households. Table 14.2 shows the distribution of age at onset by current age for people with a severe or profound core activity restriction living in households. In this section we focus particularly on two age groups—people aged between 45 and 64 years, and people aged 65 years and over. In the following discussion, people who did not know their age at onset of their main condition are excluded from calculations.

Table 14.1: People with a disability living in households: age at onset of disability by age ('000), Australia, 1998^(a)

Age	Age at onset								Not known	Total	Total excluding not known
	0–14	15–29	30–44	45–59	60–64	65–69	70–75	75+			
0–14	295.0								**0.7	295.7	295.0
15–29	195.1	174.3							**0.9	370.3	369.4
30–44	110.0	232.0	245.9						*7.9	595.9	587.9
45–59	74.0	130.2	316.7	296.9					*3.3	821.0	817.7
60–64	16.6	21.3	56.8	145.9	38.4				*3.5	282.5	279.0
65–69	12.6	19.6	39.2	103.1	54.8	34.0			**2.7	266.0	263.3
70–74	12.1	27.9	28.2	71.3	45.0	58.1	39.3		**2.6	284.5	282.0
75+	16.6	31.4	43.1	58.1	51.9	55.6	88.8	156.2	*8.4	510.2	501.7
Total	732.0	636.7	729.8	675.3	190.2	147.7	128.1	156.2	29.9	3,426.0	3,396.1

(a) Estimates marked with ** have an associated relative standard error (RSE) of 50% or more. Estimates marked with * have an associated RSE of between 25% and 50%. These estimates should be interpreted accordingly.

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

Table 14.2: People with a severe or profound core activity restriction living in households: age at onset of disability by age ('000), Australia, 1998^(a)

Age	Age at onset								Not known	Total	Total excluding not known
	0–14	15–29	30–44	45–59	60–64	65–69	70–75	75+			
0–14	143.6									143.6	143.6
15–29	44.3	35.2							**0.6	80.1	80.1
30–44	28.8	50.0	55.0						**2.4	136.2	133.8
45–59	19.1	37.2	84.6	72.0					**1.4	214.3	212.9
60–64	*5.4	*4.3	12.7	29.2	9.5				**0.6	61.7	61.1
65–69	*3.2	*2.8	*5.5	18.8	10.2	*8.9			**1.3	50.6	49.4
70–74	**2.2	*5.6	9.6	16.5	10.3	13.0	10.3		**1.0	68.6	67.5
75+	*6.0	*8.8	18.2	19.1	18.5	24.2	33.9	73.8	*4.0	206.4	202.4
Total	252.6	144.0	185.6	155.7	48.4	46.1	44.1	73.8	11.3	961.6	950.3

(a) Estimates marked with ** have an associated relative standard error (RSE) of 50% or more. Estimates marked with * have an associated RSE of between 25% and 50%. These estimates should be interpreted accordingly.

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

For people aged between 45 and 64 years, 11.0% of those with a severe or profound core activity restriction first experienced disability before the age of 18 years, and 48.6% between the ages of 18 and 44 years. Of all people with a disability aged between 45 and 64 years, 10.3% first experienced disability before the age of 18 years, and 45.9% between the ages of 18 and 44 years (Figure 14.1 and Table 14.3).

Among people aged 65 years and over, only 4.1% of people with a severe or profound core activity restriction and 4.8% of people with a disability first experienced disability before the age of 18 years. Some 51.4% of people with a severe or profound core activity restriction and 41.3% of all people with a disability had a late onset disability (i.e. first experienced at age 65 or over) (Figure 14.2 and Table 14.3). Clearly, it is not possible for people aged 45–64 to report an age at onset of 65 or over, and this in large part explains the different percentage distributions of age at onset between the 45–64 and the 65 or over age groups.

14.3 Age at onset of disability by main condition

This section looks at how patterns of age at onset differ with main condition groups, for people aged 45 to 64 and people aged 65 or over. Six broad main condition groups are used—intellectual, psychiatric, vision, hearing, acquired brain injury and physical/other. Table A14.1 shows which conditions fall within each of the broad groupings.

In making comparisons between main condition groups it is important to note that the proportions of people living in cared accommodation vary substantially between different main condition groups. Since the question about age at onset of main condition was not asked among people living in cared accommodation, this could affect the percentage distributions of age at onset.

Overall, 5% of people with a disability and 17% of people with a severe or profound core activity restriction were living in cared accommodation. However, the proportion living in cared accommodation was much higher in some main condition groups (e.g. psychiatric, intellectual and other mental) and lower in others (e.g. vision, hearing).

Table 14.3: People with a disability living in households: distribution of age at onset of disability by age, Australia, 1998^(a)

	Age at onset				Total ^(a)
	0–17	18–44	45–64	65+	
Age 45–64					
Severe or profound core activity restriction					
Number ('000)	30.2	133.1	110.7	—	274.1
%	11.0	48.6	40.4	—	100.0
All with disability					
Number ('000)	112.5	503.0	481.2	—	1,096.7
%	10.3	45.9	43.9	—	100.0
Age 65 or over					
Severe or profound core activity restriction					
Number ('000)	13.0	48.9	93.4	164.0	319.3
%	4.1	15.3	29.2	51.4	100.0
All with disability					
Number ('000)	49.9	180.9	384.3	432.0	1,047.0
%	4.8	17.3	36.7	41.3	100.0

(a) Estimates marked with ** have an associated relative standard error (RSE) of 50% or more. Estimates marked with * have an associated RSE of between 25% and 50%. These estimates should be interpreted accordingly.

(b) Total excludes people who did not know their age at onset of disability.

— Nil or rounded to zero.

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

For condition groups such as intellectual and other mental disorders that have higher rates of early onset and higher risk of institutionalisation for those affected (see Tables A14.2, A14.3, A14.4 and A14.5), the exclusion of people living in cared accommodation may result in an underestimation of the proportion with an early onset disability. Likewise, for conditions that are more common in older age groups and possibly associated with institutional living, the proportion of people with a late onset disability may be underestimated.

People aged between 45 and 64 years

Of people with a disability aged between 45 and 64 years, the main condition group with the highest rate of early onset was intellectual—63.3% of people aged 45–64 with an intellectual main condition reported an age at onset of under 18 years (Table 14.4). The main condition groups physical/other and psychiatric had the lowest rates of early onset (8.3% and 10.6%, respectively). The groups of vision and physical/other had relatively high rates of onset between ages 45 and 64. For the main condition groups psychiatric, hearing, and acquired brain injury, the highest rates of onset were in the age group 18–44 years.

Of people with a disability aged between 45 and 64 years who reported onset before age 18, 67.2% had a main condition in the group physical/other, and 14.3% had a hearing-related main condition. Of those who reported onset between ages 45 and 64, 85.9% had a main condition in the group physical/other, 6.2% had a psychiatric main condition and 5.5% had a hearing-related main condition (Table 14.4).

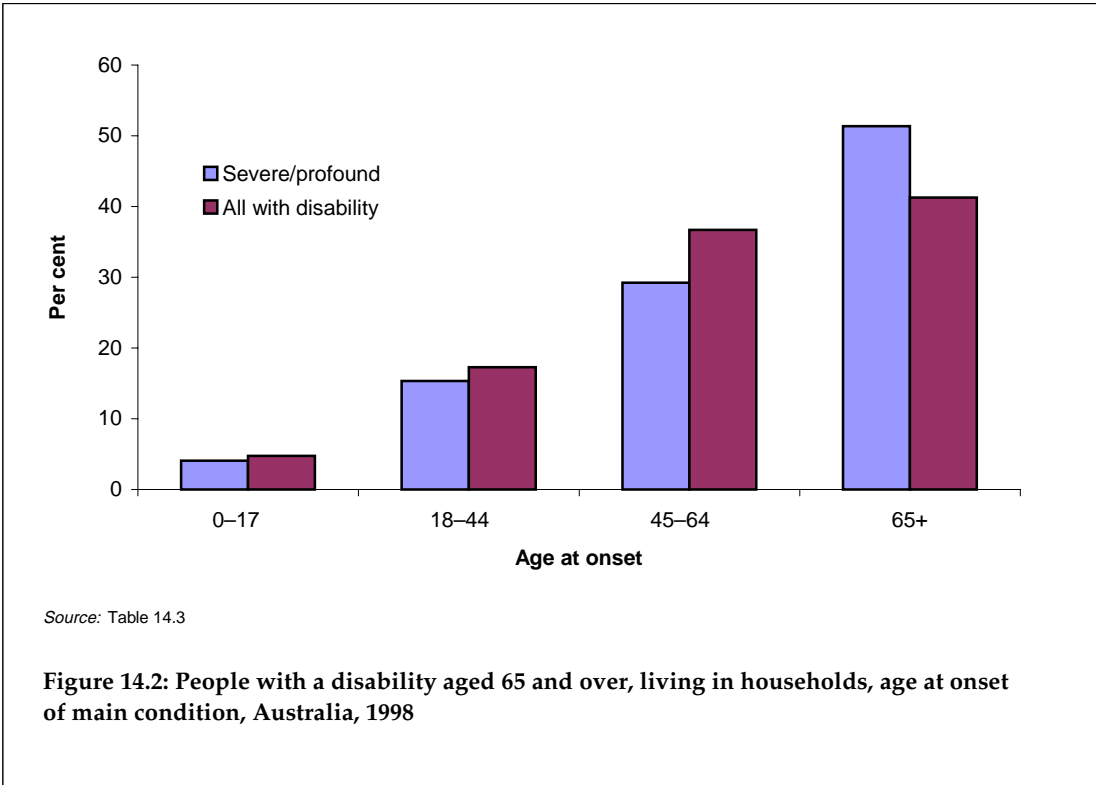
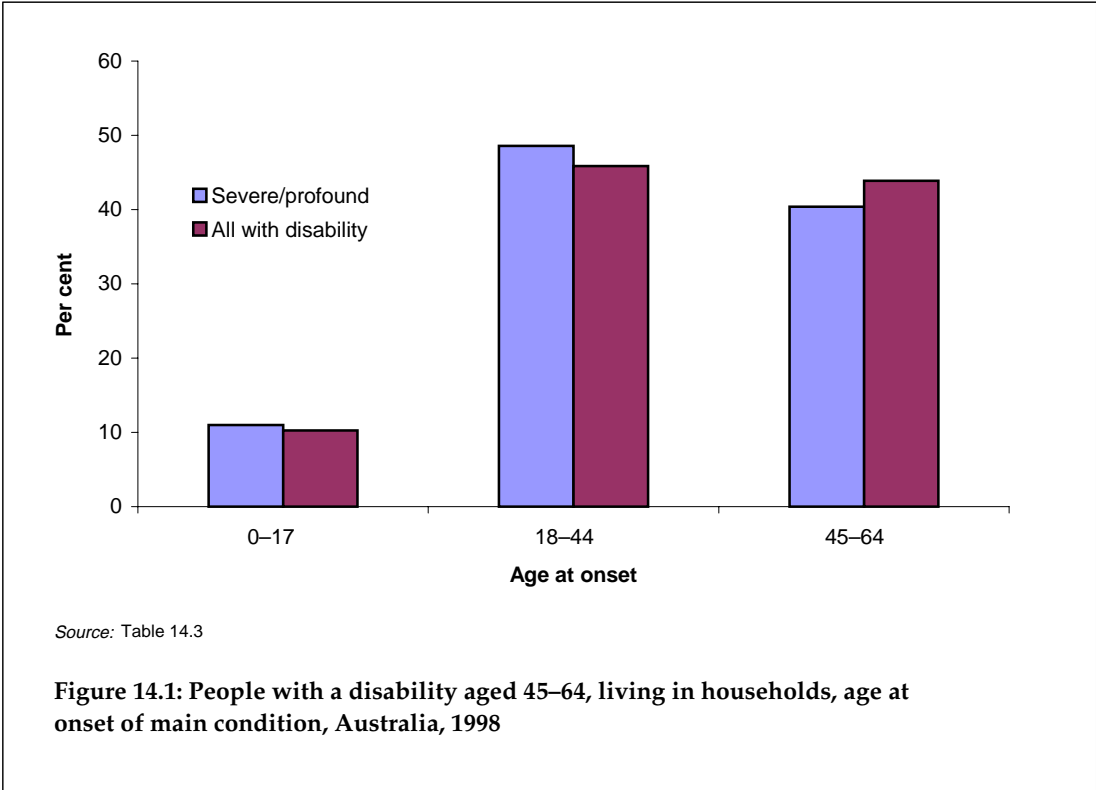


Table 14.4: People with a disability aged 45–64 living in households: distribution of age at onset of disability by main condition, by age, Australia, 1998^(a)

	Age at onset			Total ^(b)
	0–17	18–44	45–64	
	Number ('000)			
Intellectual	*7.6	*4.0	**0.4	11.9
Psychiatric	*7.9	36.7	30.0	74.7
Vision	*2.9	*4.9	*8.0	15.8
Hearing	16.1	39.3	26.5	82.1
Acquired brain injury	**2.5	*6.1	*2.8	11.4
Physical/other	75.6	412.0	413.4	907.6
Total	112.5	503.0	481.2	1,103.5
	Per cent (sum horizontally)			
Intellectual	63.3	*33.4	**3.3	100.0
Psychiatric	*10.6	49.2	40.2	100.0
Vision	*18.1	*31.1	50.8	100.0
Hearing	19.7	47.8	32.3	100.0
Acquired brain injury	*21.7	53.7	*24.6	100.0
Physical/other	8.3	45.4	45.6	100.0
Total	10.2	45.6	43.6	100.0
	Per cent (sum vertically)			
Intellectual	*6.7	*0.8	**0.1	1.1
Psychiatric	*7.0	7.3	6.2	6.8
Vision	*2.5	*1.0	*1.7	1.4
Hearing	14.3	7.8	5.5	7.5
Acquired brain injury	**2.2	*1.2	*0.6	1.0
Physical/other	67.2	81.9	85.9	82.2
Total	100.0	100.0	100.0	100.0

(a) Estimates marked with ** have an associated relative standard error (RSE) of 50% or more. Estimates marked with * have an associated RSE of between 25% and 50%. These estimates should be interpreted accordingly.

(b) Total excludes people who did not know their age at onset of disability.

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

For people aged 45–64 with a severe or profound core activity restriction, intellectual was, again, the main condition group with the highest rate of early onset (Table 14.5). In comparison with all people with a disability (Table 14.4), rates of later onset (i.e. age 45–64) were substantially lower in the psychiatric, vision and hearing groups. That is, in these groups, greater severity of activity restriction may be associated with earlier onset of disability. However, it should be noted that many of the estimates in Tables 14.4 and 14.5 are small and have very high relative standard errors, which limits the confidence with which comparisons can be made.

Table 14.5: People with a severe or profound core activity restriction aged 45–64 living in households: distribution of age at onset of disability by main condition, by age, Australia, 1998^(a)

	Age at onset			Total ^(b)
	0–17	18–44	45–64	
	Number ('000)			
Intellectual	*3.4	**1.3	**0.4	*5.1
Psychiatric	*3.8	10.2	*6.0	20.0
Vision	**0.7	**1.4	**0.3	**2.5
Hearing	**1.1	*3.0	**1.0	*5.1
Acquired brain injury	**1.6	**1.9	**0.8	*4.3
Physical/other	19.5	115.4	102.3	237.1
Total	30.2	133.1	110.7	274.1
	Per cent (sum horizontally)			
Intellectual	*66.9	**25.2	**7.8	100.0
Psychiatric	*19.1	51.0	*29.9	100.0
Vision	**30.3	**55.7	**14.1	100.0
Hearing	**21.9	*58.5	**19.6	100.0
Acquired brain injury	**37.9	*44.1	**18.0	100.0
Physical/other	8.2	48.7	43.1	100.0
Total	11.0	48.6	40.4	100.0
	Per cent (sum vertically)			
Intellectual	*11.3	**1.0	**0.4	*1.9
Psychiatric	*12.6	7.7	*5.4	7.3
Vision	**2.5	**1.0	**0.3	**0.9
Hearing	**3.7	*2.3	**0.9	*1.9
Acquired brain injury	**5.4	**1.4	**0.7	*1.6
Physical/other	64.6	86.7	92.3	86.5
Total	100.0	100.0	100.0	100.0

(a) Estimates marked with ** have an associated relative standard error (RSE) of 50% or more. Estimates marked with * have an associated RSE of between 25% and 50%. These estimates should be interpreted accordingly.

(b) Total excludes people who did not know their age at onset of disability.

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

Of people with a severe or profound core activity restriction aged between 45 and 64 years who reported onset before age 18, 64.6% had a main condition in the group physical/other, 12.6% had a psychiatric main condition and 11.3% had an intellectual main condition. This pattern is somewhat different from that for all people with a disability aged 45–64 who reported onset before age 18 (Table 14.4). Of people with a severe or profound core activity restriction aged between 45 and 64 who reported onset between ages 45 and 64, 92.3% had a main condition in the group physical/other (Table 14.5).

For people aged between 45 and 64 with a disability, 0.6% (6,800 people) reported that they did not know their age at onset of their main condition (Table A14.2). Most people who did not know their age at onset had a main condition in the group physical/other (97.3%), and the remainder had a hearing-related main condition (2.7%). For people aged 45–64 with a severe or profound core activity restriction, 0.7% (2,000 people) did not know their age at onset of their main condition (Table A14.3). All of these people had a main condition in the group physical/other.

The proportion of people living in cared accommodation also varied between main condition groups. For people aged 45–64 with a disability, 1.1% lived in cared accommodation. However, the proportion was much higher for people with an intellectual main condition (22.6%), and was also relatively high for people with acquired brain injury and psychiatric main conditions (3.4% and 3.1%, respectively) (Table A14.2). For people aged 45–64 with a severe or profound core activity restriction, 3.9% lived in cared accommodation (Table A14.3). Again, the proportion was higher for some main condition groups, particularly intellectual (39.2%) and psychiatric (8.9%). As noted above, this variation needs to be taken into account when comparing the percentage distributions of age at onset between main condition groups, as the question about age at onset of main condition was not asked of people living in cared accommodation.

People aged 65 or over

Of people with a disability aged 65 or over, only 3,000 reported an intellectual main condition (Table 14.6). The number was even lower for people with severe and profound core activity restrictions (Table 14.7). Because these estimates are so small, and correspondingly have very high relative standard errors, it is not possible to make comments about the distribution of age at onset for people aged 65 or over with an intellectual main condition.

For the main condition groups physical/other, hearing and vision, there tended to be higher rates of onset later in life (i.e. in the age groups 45–64 and 65+). For the psychiatric main condition group, there was a more even spread of onset through the adult years. The patterns for people with severe or profound core activity restrictions were similar to those for disability generally, although the estimates are smaller still, so it is difficult to make valid comparisons between main condition groups.

Of people aged 65 or over with a disability, 1.1% (13,600 people) reported that they did not know their age at onset of their main condition (Table A14.4). For people with a severe or profound core activity restriction the rate was similar—1.3% or 6,300 people (Table A14.5).

The proportion of people with a disability living in cared accommodation was much higher for people aged 65 or over than for people aged between 45 and 64. Of people aged 65 or over, 13.2% (161,900) of all people with a disability and 32.2% (154,800) of people with a severe or profound core activity restriction lived in cared accommodation (Tables A14.4 and A14.5). People who reported an intellectual or psychiatric main condition were much more likely to be living in cared accommodation than people in other main condition groups. For people aged 65 or over with a severe or profound core activity restriction, 91.5% of those with an intellectual main condition and 78.6% of those with a psychiatric main condition were living in cared accommodation.

Table 14.6: People with a disability aged 65 or over living in households: distribution of age at onset of disability by main condition, by age, Australia, 1998^(a)

	Age at onset				Total ^(b)
	0–17	18–44	45–64	65+	
	Number ('000)				
Intellectual	**0.5	**0.8	**0.5	**1.1	*3.0
Psychiatric	*3.2	*7.4	*7.4	*7.8	25.8
Vision	*4.6	*5.2	14.5	43.3	67.6
Hearing	10.4	22.0	41.2	40.5	114.2
Acquired brain injury	—	**1.0	**2.2	—	*3.2
Physical/other	31.2	144.5	318.3	339.2	833.2
Total	49.9	180.9	384.3	432.0	1,047.0
	Per cent (sum horizontally)				
Intellectual ^(c)	—	—	—	—	—
Psychiatric	*12.5	*28.5	28.7	30.3	100.0
Vision	*6.7	*7.7	21.5	64.1	100.0
Hearing	9.1	19.3	36.1	35.5	100.0
Acquired brain injury ^(c)	—	—	—	—	—
Physical/other	3.7	17.3	38.2	40.7	100.0
Total	4.8	17.3	36.7	41.3	100.0
	Per cent (sum vertically)				
Intellectual	**1.1	**0.4	**0.1	**0.3	*0.3
Psychiatric	*6.5	*4.1	*1.9	*1.8	2.5
Vision	*9.2	*2.9	3.8	10.0	6.5
Hearing	20.8	12.2	10.7	9.4	10.9
Acquired brain injury	—	**0.5	**0.6	—	*0.3
Physical/other	62.5	79.9	82.8	78.5	79.6
Total	100.0	100.0	100.0	100.0	100.0

(a) Estimates marked with ** have an associated relative standard error (RSE) of 50% or more. Estimates marked with * have an associated RSE of between 25% and 50%. These estimates should be interpreted accordingly.

(b) Total excludes people who did not know their age at onset of disability.

(c) Estimates for intellectual and acquired brain injury main condition groups were too small to allow percentage breakdown by age at onset.
— Nil or rounded to zero.

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

Table 14.7: People with a severe or profound core activity restriction aged 65 or over living in households: distribution of age at onset of disability by main condition, by age, Australia, 1998^(a)

	Age at onset				Total ^(b)
	0–17	18–44	45–64	65+	
	Number ('000)				
Intellectual	—	—	—	**0.4	**0.4
Psychiatric	**1.2	*3.1	*3.1	*6.3	13.6
Vision	**1.9	**1.3	*6.0	19.1	28.3
Hearing	**0.8	**0.7	**2.5	*6.1	10.0
Acquired brain injury	—	**0.6	**1.3	—	**1.8
Physical/other	*9.0	43.3	80.6	132.2	265.1
Total	13.0	48.9	93.4	164.0	319.3
	Per cent (sum horizontally)				
Intellectual ^(c)	—	—	—	—	—
Psychiatric	**9.1	*22.4	*22.5	46.0	100.0
Vision	**6.9	**4.6	*21.2	67.4	100.0
Hearing	**7.9	**7.1	*24.6	60.4	100.0
Acquired brain injury ^(c)	—	—	—	—	—
Physical/other	*3.4	16.4	30.4	49.9	100.0
Total	4.1	15.3	29.2	51.4	100.0
	Per cent (sum vertically)				
Intellectual	—	—	—	**0.2	**0.1
Psychiatric	**9.5	*6.2	*3.3	*3.8	4.3
Vision	**15.0	**2.6	*6.4	11.7	8.9
Hearing	**6.1	**1.4	**2.6	*3.7	3.1
Acquired brain injury	—	**1.1	**1.4	—	**0.6
Physical/other	69.4	88.6	86.3	80.6	83.0
Total	100.0	100.0	100.0	100.0	100.0

(a) Estimates marked with ** have an associated relative standard error (RSE) of 50% or more. Estimates marked with * have an associated RSE of between 25% and 50%. These estimates should be interpreted accordingly.

(b) Total excludes people who did not know their age at onset of disability.

(c) Estimates for intellectual and acquired brain injury main condition groups were too small to allow percentage breakdown by age at onset.

— Nil or rounded to zero.

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

14.4 Summary

- The 1998 ABS disability survey provides information on age at onset of main condition, which can be treated as indicative of age at onset of disability. Information about age at onset was not collected among people living in cared accommodation.
- Among people living in households, 0.9% of people with a disability and 1.2% of people with severe or profound core activity restriction did not know their age at onset of their main condition.

People aged between 45 and 64 years

- 10.3% (112,500) of all those with a disability and 11.0% (30,200) of those with a severe or profound core activity restriction had an early onset disability (before age 18);
- 45.9% (503,000) of those with a disability and 48.6% (133,100) of those with a severe or profound core activity restriction reported an age at onset of between 18 and 44 years.
- The main condition group with the highest rate of early onset was intellectual—63.3% of people with a disability and an intellectual main condition reported an age at onset of under 18 years.
- The main condition groups physical/other and psychiatric had the lowest rates of early onset (8.3% and 10.6%, respectively, for all people with a disability aged 45–64).
- Of people with a severe or profound core activity restriction who reported onset before age 18, 64.6% had a main condition in the group physical/other, 12.6% had a psychiatric main condition and 11.3% had an intellectual main condition.
- Of people with a severe or profound core activity restriction, 3.9% (11,200) lived in cared accommodation. However, the proportion was much higher for the main condition groups intellectual (39.2%) and psychiatric (8.9%). This variation needs to be taken into account when comparing the percentage distributions of age at onset between main condition groups.

People aged 65 or over

- Only 4.8% (49,900) of people with a disability and 4.1% (13,000) of people with severe or profound core activity restriction first experienced disability before the age of 18 years.
- 41.3% (432,000) of people with a disability and 51.4% (164,000) of people with a severe or profound core activity restriction had a late onset disability (age 65 or over).
- 13.2% (161,900) of all people with a disability and 32.2% (154,800) of people with a severe or profound core activity restriction lived in cared accommodation.
- People with an intellectual or psychiatric main condition were much more likely to be living in cared accommodation. For people with a severe or profound core activity restriction, 91.5% (4,400) of those with an intellectual main condition and 78.6% (55,200) of those with a psychiatric main condition were living in cared accommodation.

15 Ageing, need for assistance and providers of assistance

This chapter examines the level and profile of need for assistance and the main sources of assistance among people with a severe or profound core activity restriction living in households. Comparisons are made between people ageing with an early onset disability (before 18 years) and people who acquired their disability later in life.

Section 15.1 briefly discusses the ABS disability survey data on need for assistance. Section 15.2 presents an analysis of the level and profile of need for assistance, followed by an examination of changes between 1993 and 1998 in Section 15.3. Section 15.4 focuses on need for assistance among people ageing with a disability. The final section summarises the findings of the chapter.

15.1 ABS survey data on need for assistance

In the 1998 ABS disability survey, people with a disability and people aged 60 years or over without a disability were asked questions about their need for assistance with various tasks associated with daily activities. The tasks were grouped into ten types of activities, listed in Table 15.1. Nine of these ten activity types were included in the two previous disability surveys (1988 and 1993), while the need for guidance was added in the 1998 survey. Need for guidance refers to need for assistance with making and maintaining relationships, coping with emotions, and making decisions or thinking through problems. Self-care, mobility and communication were designated in the survey as 'core activities'. 'Personal activities' were defined as the three core activities plus health care (ABS 1999).

Survey respondents could report the need for assistance with more than one task or type of activity. Need for assistance is defined as needing help or supervision with daily activities due to disability or old age. Where a person cannot cook meals or drive, for example, because the person has never learned these skills or has not been accustomed to performing these activities, the person is not considered as having a relevant need for assistance (ABS 1999: 70).

It should be noted that, given the survey definitions of severe and profound core activity restrictions, which are based largely on need for assistance (see Section 11.1), most people identified as having severe or profound core activity restriction reported needing help with one or more activities (see middle section of Table 15.2).

15.2 Need for assistance and main provider of assistance

Activities with which assistance needed

In 1998, 958,000 people (5.1% of Australians) with a severe or profound core activity restriction living in households reported need for assistance with at least one of the ten

activities described in Table 15.1 (Table 15.2). This figure included 633,400 people aged under 65 (3.9% of the population of that age) and 324,600 people aged 65 or more (14.3% of the population of that age). Overall, need for assistance was most commonly reported with mobility (3.9% of the total population), property maintenance (3.0%), health care (2.9%),

Table 15.1: Activities and tasks of daily life addressed in the 1998 ABS disability survey

Activities	Tasks
Self-care ^(a)	Showering/bathing Dressing Eating Toileting
Mobility ^(a)	Getting into or out of bed/chair Moving about usual place of residence Moving about a place away from usual residence Ability to use public transport Walking 200 metres Walking up and down stairs without a rail Bending to pick something up off the floor
Communication ^(a)	Understanding family/friends Being understood by family/friends Understanding strangers Being understood by strangers
Health care	Foot care Taking medications/administering injections Dressing wounds Using medical machinery Manipulating muscles or limbs
Housework	Household chores such as: Washing Vacuuming Dusting
Property maintenance	Changing light bulbs, tap washers, car registration stickers Making minor home repairs Mowing lawns, watering, pruning shrubs, light weeding, planting Removing rubbish
Paperwork	Reading or writing tasks such as: Checking bills or bank statements Writing letters Filling in forms
Meal preparation	Preparing ingredients Cooking food
Transport	Going to places away from the usual place of residence
Guidance	Interacting, making and maintaining relationships Coping with emotions Making decisions, thinking through problems Managing behaviour (children aged under 15 years, people in cared accommodation)

(a) Self-care, mobility and communication were defined as core activities in the survey.

Source: ABS 1999.

self-care (2.8%) and transport (2.8%) (Table 15.2). It should be noted that some people with a severe or profound core activity restriction who reported a need for help with core activity might not have reported a need for help with other activities, such as housework or paperwork, because they do not do these activities. People who reported need for help with only non-core activities were not included in this analysis, because of the focus on the needs of people with a severe or profound core activity restriction.

There were differences in the profile of need for assistance between people aged under 65 and people aged 65 or more. The middle section of Table 15.2 shows the number of people needing assistance as a percentage of people with a severe or profound core activity restriction. The proportion needing assistance with self-care was substantially higher for people aged under 65 (56.8%) than for people aged 65 or over (47.7%). The proportions needing assistance with communication and personal guidance were also substantially higher for people aged under 65. However, for all other activity types higher proportions of people aged 65 or over reported need for assistance in comparison with those aged under 65 (Table 15.2).

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 (Table 15.2).

For people aged 65 or 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%) (Table 15.2).

The bottom section of Table 15.2 shows the number of people needing assistance as a percentage of the total population in each age group. The proportion reporting need for assistance was higher for people aged 65 or over than for people aged under 65 for all activity types, reflecting the higher prevalence of disability among people aged 65 or over.

Need for assistance with core activities

In 1998, 386,700 people with a severe or profound core activity restriction living in households reported need for assistance with more than one core activity. Of those, 73,000 needed assistance with all three core activities (self-care, mobility and communication) (Table 15.3).

Of people aged under 65 with a severe or profound core activity restriction, 264,300 (41.6%) reported need for assistance with more than one core activity, with 56,000 (8.8%) needing help with all three core activities. Among those aged 65 or over, 122,400 people (37.6%) reported need for assistance with more than one core activity, with 17,000 (5.2%) needing help with all three core activities. Nearly a quarter of children aged under 15 with a severe or profound core activity restriction needed assistance with all three core activities—this was a substantially higher proportion than in any other age group (Table 15.3).

For people needing assistance with only one core activity, communication was the most commonly reported activity for children aged under 15, and mobility was the most commonly reported in all other age groups. Among people needing assistance with two core activities, self-care and mobility was the most common combination, reported by 175,800 people aged under 65 and 97,100 people aged 65 or over (Table 15.3).

Table 15.2: People with a severe or profound core activity restriction living in households: activity type in which assistance needed, by age, Australia, 1998^{(a)(b)}

	Age group							
	0–14	15–19	20–29	30–44	45–64	Total <65	65+	All ages
	Number ('000)							
Self-care	85.2	9.7	22.6	82.5	161.2	361.2	155.2	516.4
Mobility	72.9	22.7	39.7	105.3	210.3	451.0	273.6	724.6
Communication	90.9	12.7	10.3	15.4	*9.0	138.3	28.6	166.9
Health care	72.7	14.0	20.6	68.8	145.8	321.9	216.4	538.3
Housework	n.a.	11.4	19.8	76.6	144.8	252.6	226.2	478.8
Property maintenance	n.a.	11.2	19.6	87.4	192.3	310.6	250.2	560.7
Paperwork	n.a.	17.7	19.4	40.6	52.3	129.9	110.3	240.3
Meal preparation	n.a.	*8.0	14.4	38.9	60.2	121.6	120.2	241.8
Transport	32.4	16.1	22.9	80.9	141.3	293.6	232.2	525.8
Guidance	102.8	21.8	28.8	59.6	87.7	300.7	69.6	370.4
Total need assistance^(c)	142.4	30.7	48.8	135.5	276.0	633.4	324.6	958.0
Total severe or profound	143.6	30.7	49.4	136.2	276.0	636.0	325.6	961.6
Total population	3,905.6	1,316.1	2,827.9	4,292.8	4,048.7	16,391.1	2,268.6	18,659.7
	Per cent of people with severe or profound core activity restriction of that age							
Self-care	59.3	31.6	45.7	60.6	58.4	56.8	47.7	53.7
Mobility	50.8	74.1	80.4	77.3	76.2	70.9	84.0	75.4
Communication	63.3	41.3	20.9	11.3	*3.3	21.8	8.8	17.4
Health care	50.6	45.7	41.6	50.5	52.8	50.6	66.5	56.0
Housework	n.a.	37.1	40.1	56.2	52.5	39.7	69.5	49.8
Property maintenance	n.a.	36.6	39.7	64.2	69.7	48.8	76.8	58.3
Paperwork	n.a.	57.5	39.3	29.8	19.0	20.4	33.9	25.0
Meal preparation	n.a.	26.2	29.3	28.5	21.8	19.1	36.9	25.1
Transport	22.6	52.5	46.3	59.4	51.2	46.2	71.3	54.7
Guidance	71.6	71.0	58.4	43.7	31.8	47.3	21.4	38.5
Total need assistance^(c)	99.1	100.0	98.8	99.5	100.0	99.6	99.7	99.6
	Per cent of the Australian population of that age							
Self-care	2.2	0.7	0.8	1.9	4.0	2.2	6.8	2.8
Mobility	1.9	1.7	1.4	2.5	5.2	2.8	12.1	3.9
Communication	2.3	1.0	0.4	0.4	*0.2	0.8	1.3	0.9
Health care	1.9	1.1	0.7	1.6	3.6	2.0	9.5	2.9
Housework	n.a.	0.9	0.7	1.8	3.6	1.5	10.0	2.6
Property maintenance	n.a.	0.9	0.7	2.0	4.8	1.9	11.0	3.0
Paperwork	n.a.	1.3	0.7	0.9	1.3	0.8	4.9	1.3
Meal preparation	n.a.	*0.6	0.5	0.9	1.5	0.7	5.3	1.3
Transport	0.8	1.2	0.8	1.9	3.5	1.8	10.2	2.8
Guidance	2.6	1.7	1.0	1.4	2.2	1.8	3.1	2.0
Total need assistance^(c)	3.6	2.3	1.7	3.2	6.8	3.9	14.3	5.1

(a) Estimates marked with ** have an associated relative standard error (RSE) of 50% or more. Estimates marked with * have an associated RSE of between 25% and 50%. These estimates should be interpreted accordingly.

(b) n.a.= not applicable.

(c) The total number of people needing assistance may be less than sum of the number of people needing assistance with each activity type, as people may need help with more than one activity.

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

Table 15.3: People with a severe or profound core activity restriction living in households: core activities in which assistance needed, by age, Australia, 1998^(a)

	Age group							All ages
	0–14	15–19	20–29	30–44	45–64	Total <65	65+	
	Number ('000)							
Self-care only	17.5	**1.8	*6.5	24.9	61.0	111.8	39.5	151.3
Mobility only	14.7	12.2	20.8	47.1	109.5	204.3	152.7	357.0
Communication only	37.1	*5.3	**1.4	*3.2	*2.9	49.9	*3.2	53.1
Self-care and mobility	18.5	*4.0	10.4	47.6	95.3	175.8	97.1	272.9
Self-care and communication	14.2	**0.9	**0.4	**1.6	**0.6	17.6	**1.5	19.2
Mobility and communication	*4.7	*3.5	*3.3	**2.2	*1.2	14.9	*6.8	21.7
All three activities	35.0	*3.0	*5.3	*8.4	*4.3	56.0	17.0	73.0
<i>Total with two or more activities</i>	<i>72.3</i>	<i>11.4</i>	<i>19.4</i>	<i>59.8</i>	<i>101.4</i>	<i>264.3</i>	<i>122.4</i>	<i>386.7</i>
Total population	3,905.6	1,316.1	2,827.9	4,292.8	4,048.7	16,391.1	2,268.6	18,659.7
	Per cent of people with a severe or profound core activity restriction of that age							
Self-care only	12.2	**5.9	*13.2	18.3	22.1	17.6	12.1	15.7
Mobility only	10.3	39.7	42.1	34.6	39.7	32.1	46.9	37.1
Communication only	25.8	*17.2	**2.8	*2.3	*1.1	7.8	*1.0	5.5
Self-care and mobility	12.9	*13.1	21.1	34.9	34.5	27.6	29.8	28.4
Self-care and communication	9.9	**2.9	**0.8	**1.2	**0.2	2.8	**0.5	2.0
Mobility and communication	*3.2	*11.5	*6.6	**1.6	**0.4	2.3	*2.1	2.3
All three activities	24.4	*9.7	*10.7	*6.2	*1.6	8.8	5.2	7.6
<i>Total with two or more activities</i>	<i>50.4</i>	<i>37.2</i>	<i>39.2</i>	<i>43.9</i>	<i>36.7</i>	<i>41.6</i>	<i>37.6</i>	<i>40.2</i>
Total	98.7	100.0	97.2	99.1	99.6	99.1	97.6	98.6

(a) Estimates marked with ** have an associated relative standard error (RSE) of 50% or more. Estimates marked with * have an associated RSE of between 25% and 50%. These estimates should be interpreted accordingly.

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

Main condition and need for assistance

Tables 15.4 and A15.1 present data on need for assistance by main condition group, for people with a severe or profound core activity restriction living in households. For people aged under 65, 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%).
- with a psychiatric main condition most commonly needed assistance with guidance (85.7%), mobility (83.6%) and transport (57.5%).
- 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%).

In all main condition groups except hearing, a high proportion of people reported needing help with mobility. The number of activities in which a high proportion of people needed assistance was greater in the intellectual and acquired brain injury main condition groups than in other groups.

Among people with a severe or profound core activity restriction living in households, few people with an intellectual main condition were aged 65 or more, as over 90% of people in that age group with an intellectual main condition were living in cared accommodation (see Table 15.13). The number of people aged 65 or over with an acquired brain injury was also too small to be used for valid comparisons. 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%).

People aged 65 or over with psychiatric and vision-related main conditions most commonly reported need for assistance with mobility and transport. People with a hearing-related main condition most commonly reported need for assistance with mobility. For people with a 'physical or other' main condition, need for assistance with mobility and health care was reported by a higher proportion of those aged 65 or over, while need for assistance with self-care and guidance was reported by a higher proportion of those aged under 65. In comparison with those aged under 65, a higher proportion of people aged 65 or over with a physical/other main condition tended to report need for assistance with non-personal activities (e.g. housework and transport) (Tables 15.4 and A15.1).

Tables 15.5 and A15.2 present data on need for assistance with core activities. It is important to note that small sample sizes and high relative standard errors make it difficult to draw meaningful comparisons between some main condition groups. Among people aged under 65, nearly 60% of those with an intellectual main condition needed assistance with more than one core activity, including 30% who needed help with all three core activities. In contrast, about 40% of those with a physical/other main condition needed assistance with more than one core activity, including only 4.6% who needed help with all three core activities.

Among people aged 65 or over with a severe or profound core activity restriction, physical/other and vision were the two largest main condition groups, and in each group 37% of people reported needing help with more than one core activity. Nearly 5% of people with a physical/other main condition needed help with all three core activities, while nobody with a vision-related main condition needed help with all three core activities (Table 15.5).

Table 15.4: People with a severe or profound core activity restriction living in households: main condition by activity type in which help needed, by age, as a percentage of people with a severe or profound core activity restriction of that age in each condition group, Australia, 1998^(a)

	Main condition						All conditions
	Intellectual ^(c)	Psychiatric	Vision	Hearing	ABI ^(c)	Physical/other	
Age 0–64							
Self-care	57.2	33.5	**27.6	**12.7	*40.1	61.5	56.8
Mobility	59.7	83.6	89.6	*35.0	92.7	72.7	70.9
Communication	71.6	*10.2	—	63.2	*26.9	10.4	21.8
Health care	57.2	42.0	*34.4	*14.7	71.5	51.1	50.6
Housework	15.3	33.0	**22.5	**3.4	*42.0	47.5	39.7
Property maintenance	16.5	37.5	*42.5	*14.8	*40.8	58.8	48.8
Paperwork	30.6	40.4	*37.1	**9.2	71.0	15.1	20.4
Meal preparation	14.1	22.7	**7.8	0.0	*45.6	20.2	19.1
Transport	36.2	57.5	82.8	*21.3	82.4	46.8	46.2
Guidance	85.9	85.7	**22.8	53.7	53.4	34.5	47.3
Total need assistance^(b)	100.0	100.0	100.0	92.3	100.0	99.7	99.6
Total number ('000)	102.4	47.0	*6.4	16.7	10.0	453.5	636.0
Age 65 or over							
Self-care	—	42.9	39.1	*26.6	—	49.8	47.7
Mobility	—	89.3	95.5	74.3	—	82.9	84.0
Communication	—	44.9	**2.7	**16.0	—	7.0	8.8
Health care	—	57.1	70.0	*45.5	—	67.2	66.5
Housework	—	70.5	54.8	*33.2	—	72.5	69.5
Property maintenance	—	76.6	72.1	63.1	—	77.7	76.8
Paperwork	—	55.9	79.2	**17.8	—	28.3	33.9
Meal preparation	—	55.4	44.9	*26.4	—	35.4	36.9
Transport	—	80.0	84.2	53.1	—	70.3	71.3
Guidance	—	57.9	*14.7	*33.5	—	19.4	21.4
Total need assistance^(b)	—	100.0	100.0	94.5	—	99.8	99.7
Total number ('000)	**0.4	15.0	28.9	10.6	**1.8	268.9	325.6

(a) Estimates marked with ** have an associated relative standard error (RSE) of 50% or more. Estimates marked with * have an associated RSE of between 25% and 50%. These estimates should be interpreted accordingly.

(b) The total number of people needing assistance may be less than sum of the number of people needing assistance with each activity type, as people may need help with more than one activity.

(c) Numbers of people with an intellectual or acquired brain injury main condition aged 65 or over and living in households were too small to allow meaningful analysis of activities in which assistance was needed.

— Nil or rounded to zero.

Source: Table A15.1; AIHW analysis of ABS 1998 Survey of Disability, Ageing and Carers Confidentialised Unit Record File.

Table 15.5: People with a severe or profound core activity restriction living in households: main condition, by core activities in which help needed, by age, as a percentage of all people with a severe or profound core activity restriction of that age in each main condition group, Australia, 1998^(a)

	Main condition						Total
	Intellectual ^(b)	Psychiatric	Vision	Hearing	ABI ^(b)	Physical/other	
Age 0–64							
Self-care only	*6.9	*12.2	**10.4	**2.0	—	21.6	17.6
Mobility only	13.8	55.9	72.4	*18.3	*52.6	33.3	32.1
Communication only	21.2	**1.7	—	49.0	**7.3	4.1	7.8
Self-care and mobility	*7.7	19.1	**17.3	**4.0	**20.5	34.2	27.6
Self-care and communication	12.2	0.0	—	**1.6	—	*1.1	2.8
Mobility and communication	*7.9	*6.4	—	**7.5	—	**0.6	2.3
All three activities	30.3	**2.2	—	**5.1	**19.6	4.6	8.8
Total	100.0	97.5	100.0	87.5	100.0	99.5	99.1
<i>Two or more</i>	<i>58.2</i>	<i>27.7</i>	<i>**17.3</i>	<i>*18.3</i>	<i>*40.1</i>	<i>40.5</i>	<i>41.6</i>
Total number ('000)	102.4	47.0	6.4	16.7	10.0	453.5	636.0
Age 65 or over							
Self-care only	—	**5.1	**4.5	**3.3	—	13.7	12.1
Mobility only	—	*38.6	58.3	*45.7	—	46.2	46.9
Communication only	—	**5.6	—	**6.6	—	**0.6	*1.0
Self-care and mobility	—	**11.4	34.6	**19.2	—	30.8	29.8
Self-care and communication	—	—	—	—	—	**0.6	**0.5
Mobility and communication	—	**12.9	**2.7	**5.3	—	*1.1	*2.1
All three activities	—	*26.4	—	**4.0	—	4.7	5.2
Total	—	100.0	100.0	84.2	—	97.7	97.6
<i>Two or more</i>	—	<i>50.7</i>	<i>37.3</i>	<i>*28.6</i>	—	<i>37.2</i>	<i>37.6</i>
Total number ('000)	**0.4	15.0	28.9	10.6	**1.8	268.9	325.6

(a) Estimates marked with ** have an associated relative standard error (RSE) of 50% or more. Estimates marked with * have an associated RSE of between 25% and 50%. These estimates should be interpreted accordingly.

(b) Numbers of people with intellectual disability and acquired brain injury aged 65 or over and living in households were too small to allow meaningful analysis of activities in which assistance was needed.

— Nil or rounded to zero.

Source: Table A15.2; AIHW analysis of ABS 1998 Survey of Disability, Ageing and Carers Confidentialised Unit Record File.

Main provider of assistance

Tables 15.6 and A15.3 present information on whether assistance was received, and the main provider of assistance, for activities with which assistance was needed. Relatively large numbers of people with a severe or profound core activity restriction reported no provider of assistance with mobility (46,700, or 6.4% of people who needed assistance with mobility), self-care (40,700, or 7.9%), property maintenance (31,000, or 5.5%), health care (28,400, or 5.3%) and transport (22,200, or 4.2%).

For all activities, most people said that their main source of assistance was a carer living in the same household. Over 80% of people who needed assistance with self-care, mobility and communication were assisted by informal carers.

Table 15.6: People with a severe or profound core activity restriction living in households: main source of assistance by activity type, by age, as a percentage of all people needing assistance with a particular activity, Australia, 1998

	Type of provider				Total %	Total number ('000)
	No provider	Informal co-resident	Informal non-co-resident	Formal provider		
Age 0–64						
Self-care	7.4	84.6	4.0	4.0	100.0	361.2
Mobility	6.8	76.2	10.6	6.3	100.0	451.0
Communication	*4.3	82.1	**0.6	13.0	100.0	138.3
Health care	5.2	74.8	4.5	15.5	100.0	321.9
Housework	*3.4	82.2	7.1	7.4	100.0	252.6
Property maintenance	6.8	67.7	12.6	12.9	100.0	309.9
Paperwork	*6.7	75.4	10.9	7.0	100.0	129.9
Meal preparation	*5.0	86.2	*3.9	*4.9	100.0	121.6
Transport	*3.0	76.4	14.1	6.4	100.0	293.6
Age 65 or over						
Self-care	9.0	73.1	6.4	11.5	100.0	155.2
Mobility	5.9	54.1	31.9	8.1	100.0	273.6
Communication	*10.8	88.5	**0.7	—	100.0	28.6
Health care	5.4	42.9	7.6	44.1	100.0	216.4
Housework	*2.7	57.3	13.5	26.5	100.0	226.2
Property maintenance	4.0	45.3	20.7	30.0	100.0	249.5
Paperwork	*3.0	63.4	28.9	*4.6	100.0	110.3
Meal preparation	**1.6	71.8	*6.9	19.7	100.0	120.2
Transport	5.7	46.7	37.7	9.8	100.0	232.2
All ages						
Self-care	7.9	81.1	4.7	6.3	100.0	516.4
Mobility	6.4	67.9	18.7	7.0	100.0	724.6
Communication	*5.4	83.2	**0.6	10.8	100.0	166.9
Health care	5.3	62.0	5.8	27.0	100.0	538.3
Housework	3.1	70.4	10.1	16.4	100.0	478.8
Property maintenance	5.5	57.7	16.2	20.5	100.0	559.4
Paperwork	5.0	69.9	19.2	5.9	100.0	240.3
Meal preparation	*3.3	79.0	5.4	12.3	100.0	241.8
Transport	4.2	63.3	24.5	7.9	100.0	525.8

(a) Estimates marked with ** have an associated relative standard error (RSE) of 50% or more. Estimates marked with * have an associated RSE of between 25% and 50%. These estimates should be interpreted accordingly.
— Nil or rounded to zero.

Source: Table A15.3; AIHW analysis of ABS 1998 Survey of Disability, Ageing and Carers Confidentialised Unit Record File.

The activities for which the highest proportion of people reported a formal provider as their main source of assistance were health care (27.0%), property maintenance (20.5%) and housework (16.4%).

In comparison with people aged 65 or over, those aged under 65 were more likely to rely on an informal co-resident as their main source of assistance with all activities except communication. However, people aged 65 or over were more likely to rely on an informal non-co-resident as their main source of assistance 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 (11.5% versus 4.0%), health care (44.1% versus 15.5%), housework (26.5% versus 7.4%), property maintenance (30.0% versus 12.9%) and meal preparation (19.7% versus 4.9%). 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 (Tables 15.6 and A15.3).

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 (Table 15.7).

Table 15.7: People with a severe or profound core activity restriction living in households: main formal source of assistance by activity type, Australia, 1998^(a)

	Per cent				Number ('000)			
	Government	Private non-profit	Private profit	Total	Government	Private non-profit	Private profit	Total
Self-care	56.3	*18.3	25.4	100.0	18.2	*5.9	*8.2	32.3
Mobility	69.5	18.1	*12.5	100.0	35.3	*9.2	*6.3	50.8
Communication	77.1	**3.8	*19.1	100.0	13.9	**0.7	*3.4	18.0
Health care	37.1	*5.6	57.3	100.0	53.8	*8.2	83.2	145.2
Housework	57.7	*10.1	32.3	100.0	45.3	*7.9	25.4	78.6
Property maintenance	13.9	*4.0	82.1	100.0	16.0	*4.6	94.3	114.9
Paperwork	52.2	**13.5	*34.3	100.0	*7.4	**1.9	*4.9	14.2
Meal preparation	54.2	32.7	*13.2	100.0	16.1	9.7	*3.9	29.7
Transport	56.1	23.3	20.6	100.0	23.4	9.7	*8.6	41.7

(a) Estimates marked with ** have an associated relative standard error (RSE) of 50% or more. Estimates marked with * have an associated RSE of between 25% and 50%. These estimates should be interpreted accordingly.

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

15.3 Changes in need for assistance and main provider of assistance between 1993 and 1998

This section examines the changes in the level and profile of need for assistance and main provider of assistance with daily activities between 1993 and 1998. In order to make the comparisons, the 1998 ABS disability survey data were re-derived using the operational definition of disability used in the 1993 survey. However, there remain some differences between the two surveys in terms of the questions on need for assistance that were asked. In

the 1998 survey some activities are more precisely defined than in 1993, and some have been expanded:

- Need for assistance with transport in the 1998 survey refers specifically to the need to be driven in order to go somewhere.
- In the 1998 survey 'paperwork' activities replaced 'personal affairs' activities (managing money, such as checking bank statements, paying bills), with an increased focus on reading and writing skills required for daily living, such as writing letters and filling in forms.
- Assistance with health care activities has been extended from help with medication, dressing wounds and foot care, to include assistance with medical equipment and with manipulating or exercising muscles and limbs (ABS 1999: 56).

Changes in need for assistance

Table 15.8 shows that, between 1993 and 1998, 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), self-care (154,100) and property maintenance (149,200). 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 or 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. Between 1993 and 1998 the growth rate of the population aged 45–64 (15.4%) was higher than that of the population aged 65 or over (10.2%), and much higher than that of the population in younger age groups (Table 15.8).

For people aged under 65, in particular those aged 45–64, increases in the number of people needing assistance were particularly notable in the activities of self-care, mobility, health care, transport and property maintenance. There was a large increase in need for assistance with communication among people aged 5–14 years (Table 15.8).

Overall, in both 1993 and 1998, the three activities in which need for assistance was most commonly reported were mobility, property maintenance and transport (Table 15.8). In both years, the three activities in which need for assistance was most commonly reported for people aged under 65 were mobility, self-care and property maintenance; for people aged 65 or over, the three most commonly reported activities were mobility, property maintenance and transport.

Changes in main provider of assistance

All people aged 5 years and over

Tables 15.9 and 15.10 illustrate changes between 1993 and 1998 in the main providers of assistance reported by people aged 5 and over with a severe or profound core activity restriction.

The number of people who said that their main source of assistance was an informal co-resident carer 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

Table 15.8: People aged 5 years and over with a severe or profound core activity restriction living in households: activity type in which assistance needed, by age ('000), Australia, 1993–1998^(a)

	Age group							All ages
	5–14	15–19	20–29	30–44	45–64	Total <65	65+	
	1993							
Self-care	47.7	9.5	18.2	52.3	78.6	206.3	124.8	331.2
Mobility	43.1	14.2	36.8	72.5	113.6	280.2	214.1	494.3
Communication	26.4	*6.7	10.6	8.1	*7.1	59.0	25.9	84.9
Health care	—	*7.5	18.9	29.2	51.5	107.1	161.9	269.0
Housework	—	*7.1	17.5	45.7	78.9	149.2	188.4	337.6
Property maintenance	—	8.6	22.7	49.1	98.0	178.5	219.7	398.2
Paperwork	—	9.8	21.3	25.1	27.6	83.9	85.4	169.3
Meal preparation	—	*5.1	13.9	20.9	18.5	58.4	82.3	140.7
Transport	24.3	12.0	24.4	35.3	67.1	163.2	209.3	372.5
Total population	2,535.7	1,303.9	2,811.6	4,114.1	3,496.4	14,261.7	1,907.9	16,169.6
	1998^(b)							
Self-care	70.1	9.7	21.6	74.9	154.2	330.4	154.9	485.3
Mobility	61.4	22.3	38.7	99.4	197.0	418.8	268.1	686.9
Communication	69.9	12.7	10.3	15.4	9.0	117.3	28.6	145.8
Health care ^(c)	—	14.0	19.3	65.7	140.9	240.0	213.8	453.8
Housework	—	11.4	19.0	74.1	141.1	245.6	222.8	468.4
Property maintenance	—	11.2	18.8	83.5	185.1	298.6	248.7	547.4
Paperwork	—	17.7	19.4	40.6	51.7	129.3	110.2	239.5
Meal preparation	—	8.0	14.1	38.4	59.7	120.1	120.2	240.4
Transport	32.3	16.1	22.5	77.1	137.1	285.1	229.6	514.7
Total population	2,625.5	1,315.1	2,825.5	4,286.5	4,036.2	15,088.9	2,101.8	17,190.7
	Changes in number between 1993 and 1998^(b)							
Self-care	22.3	**0.2	*3.4	22.6	75.6	124.1	30.1	154.1
Mobility	18.3	8.1	**1.9	26.8	83.4	138.6	54.0	192.5
Communication	43.4	*6.0	**−0.3	*7.3	**1.9	58.3	2.6	60.9
Health care ^(c)	—	*6.6	**0.4	36.5	89.4	132.9	51.9	184.8
Housework	—	*4.3	**1.5	28.4	62.2	96.5	34.3	130.8
Property maintenance	—	*2.6	−3.9	34.4	87.1	120.2	29.0	149.2
Paperwork	—	*7.8	*−1.9	15.4	24.1	45.5	24.8	70.2
Meal preparation	—	*3.0	**0.2	17.5	41.2	61.8	37.9	99.7
Transport	*7.9	*4.1	**−2.0	41.8	70.0	121.9	20.3	142.2
Total population	89.7	11.3	13.9	172.5	539.8	827.2	193.9	1,021.1

(continued)

Table 15.8 (continued): People aged 5 years and over with a severe or profound core activity restriction living in households: activity type in which assistance needed, by age ('000), Australia, 1993–1998^(a)

	Age group							All ages
	5–14	15–19	20–29	30–44	45–64	Total <65	65+	
	% changes in the number of people needing assistance between 1993 and 1998^(b)							
Self-care	46.8	1.7	18.7	43.2	96.2	60.1	24.1	46.5
Mobility	42.4	57.0	5.2	37.0	73.4	49.4	25.2	38.9
Communication	164.3	88.9	–2.9	90.9	26.5	98.9	10.2	71.8
Health care ^(c)	—	88.3	2.2	125.3	173.6	124.2	32.0	68.7
Housework	—	61.4	8.4	62.1	78.9	64.7	18.2	38.7
Property maintenance	—	29.9	–17.3	70.1	88.8	67.3	13.2	37.5
Paperwork	—	79.4	–8.8	61.4	87.1	54.2	29.0	41.5
Meal preparation	—	58.0	1.1	83.5	223.0	105.8	46.1	70.8
Transport	32.6	33.9	–8.0	118.6	104.3	74.7	9.7	38.2
Total population	3.5	0.9	0.5	4.2	15.4	5.8	10.2	6.3

(a) Estimates marked with ** have an associated relative standard error (RSE) of 50% or more. Estimates marked with * have an associated RSE of between 25% and 50%. These estimates should be interpreted accordingly.

(b) For comparative purposes, 1998 data were re-derived using the 1993 operational definition of disability.

(c) 71,100 people aged 5–14 years who needed assistance with health care in 1998 were excluded to allow comparisons between 1993 and 1998 data, as data on this age group were not collected in the 1993 survey.

— Nil or rounded to zero.

Source: AIHW analysis of ABS 1998 Survey of Disability, Ageing and Carers Confidentialised Unit Record File and 1993 Survey of Disability, Ageing and Carers data.

the number of people who said that an informal non-co-resident carer was their main source of assistance, particularly with mobility, transport and housework.

Increases in the number of people who reported that their main source of assistance was a formal service provider were greatest for the activities of health care (57,000), property maintenance (35,100) and mobility (26,000). Percentage increases were greatest for the activities of meal preparation (147.9%), communication (119.6%) and mobility (106.2%) (Table 15.9).

There were substantial increases in the number of people without a main provider of assistance with self-care (19,100), health care (15,100) and property maintenance (18,100) (Table 15.9). The data suggest declines in the number of people without a main provider of assistance with mobility and housework, but because of the small sample sizes and high relative standard errors it is difficult to draw firm conclusions about these trends. For activities of communication, meal preparation and transport, there was relatively little change in the number of people who did not have a main provider of assistance, despite substantial increases in need for assistance with between 1993 and 1998 (Table 15.9). This is probably due to the large increase in the number of providers of assistance, particularly informal co-resident carers.

Table 15.10 shows that, in general, there have not been dramatic changes between 1993 and 1998 in the proportions of people reporting informal co-resident, informal non-co-resident and formal providers as their main source of assistance. This suggests there has been little change in the balance between formal and informal sources of assistance. Between 1993 and 1998 there was an apparent decrease in the proportion of people reporting no main provider of assistance with communication, largely due to an increase in the proportion reporting an informal carer and formal provider as their main source of assistance with communication (Table 15.10).

Table 15.9: People aged 5 years and over with a severe or profound core activity restriction who needed help and were living in households: activity type in which help needed by type of main provider ('000), Australia, 1993–1998^(a)

	Type of main provider				Total
	No provider	Informal co-resident	Informal non-co-resident	Formal provider	
1993					
Self-care	19.2	267.6	14.8	29.5	331.2
Mobility	48.1	330.6	91.2	24.5	494.4
Communication	12.0	64.2	*1.9	*6.7	84.9
Health care	10.7	157.4	18.5	82.4	269.0
Housework	22.1	232.4	23.6	59.6	337.6
Property maintenance	12.1	234.5	71.9	79.0	397.5
Paperwork	*3.8	127.3	29.9	8.4	169.4
Meal preparation	10.9	111.8	*4.3	12.0	138.9
Transport	23.8	220.6	92.2	35.9	372.5
1998^(b)					
Self-care	38.3	390.6	24.5	32.0	485.3
Mobility	41.8	461.0	133.6	50.4	686.9
Communication	*8.5	121.7	**1.0	14.6	145.8
Health care ^(c)	25.8	258.2	30.3	139.4	453.8
Housework	13.9	328.7	48.0	77.9	468.4
Property maintenance	30.2	312.4	90.0	114.1	546.7
Paperwork	12.0	168.0	46.0	13.6	239.5
Meal preparation	*7.9	189.7	13.1	29.7	240.4
Transport	22.2	323.8	127.0	41.7	514.7
Changes in number between 1993 and 1998^(b)					
Self-care	19.1	123.0	9.6	**2.5	154.1
Mobility	*-6.3	130.4	42.4	26.0	192.5
Communication	*-3.5	57.4	**-0.9	*8.0	60.9
Health care ^(c)	15.1	100.8	11.9	57.0	184.8
Housework	*-8.2	96.3	24.4	18.3	130.8
Property maintenance	18.1	77.8	18.1	35.1	149.3
Paperwork	*8.2	40.7	16.1	*5.2	70.2
Meal preparation	-3.0	77.9	*8.8	17.7	101.4
Transport	-1.6	103.1	34.8	*5.9	142.2

(continued)

Table 15.9 (continued): People aged 5 years and over with a severe or profound core activity restriction who needed help and were living in households: activity type in which help needed by type of main provider ('000), Australia, 1993–1998^(a)

	Type of main provider				Total
	No provider	Informal co-resident	Informal non co-resident	Formal provider	
	% changes between 1993 and 1998^(b)				
Self-care	99.5	45.9	64.8	8.4	46.5
Mobility	-13.1	39.5	46.5	106.2	38.9
Communication	-29.3	89.4	-48.0	119.6	71.8
Health care ^(c)	140.7	64.1	64.4	69.1	68.7
Housework	-37.2	41.5	103.3	30.7	38.7
Property maintenance	150.3	33.2	25.2	44.5	37.6
Paperwork	217.3	32.0	53.6	61.4	41.4
Meal preparation	-27.2	69.7	205.2	147.9	73.0
Transport	-6.9	46.7	37.8	16.4	38.2

(a) Estimates marked with ** have an associated relative standard error (RSE) of 50% or more. Estimates marked with * have an associated RSE of between 25% and 50%. These estimates should be interpreted accordingly.

(b) For comparative purposes, 1998 data were re-derived using the 1993 operational definition of disability.

(c) 71,100 people aged 5–14 years who needed assistance with health care in 1998 were excluded to allow comparisons between 1993 and 1998 data, as data on this age group were not collected in the 1993 survey.

Source: AIHW analysis of ABS 1998 Survey of Disability, Ageing and Carers Confidentialised Unit Record File and 1993 Survey of Disability, Ageing and Carers data.

People aged 5–64 versus 65 or over

Between 1993 and 1998, the increase in the number of people reporting an informal co-resident as their main source of assistance was much greater for people aged 5–64 than for people aged 65 or more. This was partly associated with the greater increase in the number of people needing assistance among those aged 5–64, resulting from the larger increase in the number of people with a severe or profound core activity restriction in this age group (Tables 15.11 and 15.12).

For people aged 5–64, the largest increases in the number reporting an informal co-resident carer as the main provider of assistance were in the activities of self-care (108,300), mobility (101,900) and transport (106,100). In contrast, among people aged 65 or over, the greatest increases were in the areas of mobility (28,600), meal preparation (20,400) and health care (15,600) (Tables 15.11 and 15.12).

Increases in the number of people relying on formal services as their main source of assistance were mainly in the areas of health care (26,400), mobility (16,500) and property maintenance (14,400) for people aged 5–64, and in the areas of health care (30,600) property maintenance (20,800) and meal preparation (16,200) for people aged 65 or over (Tables 15.11 and 15.12).

Table 15.10: People aged 5 years and over with a severe or profound core activity restriction who needed help and were living in households: activity type in which help needed by type of main provider (per cent), Australia, 1993–1998^(a)

	Type of main provider				Total
	No provider	Informal co-resident	Informal non-co-resident	Formal provider	
1993					
Self-care	5.8	80.8	4.5	8.9	100.0
Mobility	9.7	66.9	18.5	4.9	100.0
Communication	14.2	75.7	*2.3	*7.8	100.0
Health care	4.0	58.5	6.9	30.6	100.0
Housework	6.5	68.8	7.0	17.6	100.0
Property maintenance	3.0	59.0	18.1	19.9	100.0
Paperwork	2.2	75.1	17.7	5.0	100.0
Meal preparation	7.8	80.5	*3.1	8.6	100.0
Transport	6.4	59.2	24.7	9.6	100.0
1998^(b)					
Self-care	7.9	80.5	5.0	6.6	100.0
Mobility	6.1	67.1	19.5	7.3	100.0
Communication	*5.8	83.4	**0.7	10.0	100.0
Health care ^(c)	5.7	56.9	6.7	30.7	100.0
Housework	3.0	70.2	10.2	16.6	100.0
Property maintenance	5.5	57.1	16.5	20.9	100.0
Paperwork	5.0	70.1	19.2	5.7	100.0
Meal preparation	*3.3	78.9	5.4	12.3	100.0
Transport	4.3	62.9	24.7	8.1	100.0

(a) Estimates marked with ** have an associated relative standard error (RSE) of 50% or more. Estimates marked with * have an associated RSE of between 25% and 50%. These estimates should be interpreted accordingly.

(b) For comparative purposes, 1998 data were re-derived using the 1993 operational definition of disability.

(c) 71,100 people aged 5–14 years who needed assistance with health care in 1998 were excluded to allow comparisons between 1993 and 1998 data, as data on this age group were not collected in the 1993 survey.

Source: Table 15.9: AIHW analysis of ABS 1998 Survey of Disability, Ageing and Carers Confidentialised Unit Record File and 1993 Survey of Disability, Ageing and Carers data.

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

The analyses presented in this section focus on people aged between 45 and 64 years with a severe or profound core activity restriction living in households. Comparisons are made between people aged 45–64 and those aged 65 or over.

Among people aged 45–64, comparisons are made, where possible, between people with a disability acquired before age 18, between the ages 18 and 45, and between the ages 45 and 64. However, due to the high relative standard errors associated with small estimates, it is not always possible to determine whether there are differences between people with early onset disability and people who acquired a disability later in life. It is also important to note that the survey did not collect information on age at onset of disability among people living in institutions.

Table 15.11: People aged 5–64 years with a severe or profound core activity restriction who needed help and were living in households: activity type in which help needed by type of main provider, Australia, 1993–1998^(a)

	Type of main provider				Total
	No provider	Informal co-resident	Informal non-co-resident	Formal provider	
Changes in number between 1993 and 1998 ('000)^(b)					
Self-care	10.1	108.3	*5.3	**0.4	124.1
Mobility	**2.4	101.9	17.7	16.5	138.6
Communication	**−1.5	52.1	**−0.3	*8.0	58.3
Health care ^(c)	12.0	85.2	9.3	26.4	132.9
Housework	*−8.9	88.4	11.0	*5.9	96.5
Property maintenance	12.0	75.1	19.4	14.4	120.9
Paperwork	*6.3	31.5	*6.7	**0.9	45.4
Meal	**−0.8	57.4	*4.2	**1.5	62.3
Transport	*−6.2	106.1	20.3	**1.7	121.9
% changes between 1993 and 1998^(b)					
Self-care	70.5	64.0	57.7	2.8	60.1
Mobility	10.0	47.4	60.9	141.3	49.4
Communication	−21.3	117.6	−27.2	119.6	98.9
Health care ^(c)	393.6	105.0	197.6	145.5	124.2
Housework	−50.9	78.3	172.5	47.5	64.7
Property maintenance	147.8	59.7	102.7	57.6	68.0
Paperwork	264.2	47.5	88.5	11.7	54.1
Meal preparation	−12.0	125.0	684.3	34.5	107.7
Transport	−41.2	95.0	105.9	9.8	74.7

(a) Estimates marked with ** have an associated relative standard error (RSE) of 50% or more. Estimates marked with * have an associated RSE of between 25% and 50%. These estimates should be interpreted accordingly.

(b) For comparative purposes, 1998 data were re-derived using the 1993 operational definition of disability.

(c) 71,100 people aged 5–14 years who needed assistance with health care in 1998 were excluded to allow comparisons between 1993 and 1998 data, as data on this age group were not collected in the 1993 survey.

Source: Table A15.4; AIHW analysis of ABS 1998 Survey of Disability, Ageing and Carers Confidentialised Unit Record File and 1993 Survey of Disability, Ageing and Carers data.

Proportion living in residential care

Figure 15.1 and Table 15.13 show that people with an intellectual main condition were much more likely to live in residential care at younger ages than were people with other main conditions. In the age group 45–64, almost 40% of people with an intellectual main condition were living in cared accommodation. This was in striking contrast to other main condition groups, in which much smaller proportions of people aged 45–64 were living in cared accommodation. Among people aged 65 or more, over 90% of those with an intellectual main condition were living in cared accommodation, in comparison with 12.3% for vision, 22.7% for hearing and 24.6% for physical/other. Nearly 80% of people aged 65 or over with a psychiatric main condition were in residential care, a large proportion of whom may have had dementia-related conditions.

Table 15.12: People aged 65 years and over with a profound or severe core activity restriction who needed help and were living in households: activity type in which help needed by type of main provider ('000), Australia, 1993–1998^(a)

	Type of main provider				Total
	No provider	Informal co-resident	Informal non-co-resident	Formal provider	
Changes between 1993 and 1998^(b)					
Self-care	9.0	14.7	*4.3	**2.1	30.1
Mobility	*-8.7	28.6	24.7	9.4	54.0
Communication	** -2.1	*5.3	** -0.6	0.0	*2.6
Health care ^(c)	*3.1	15.6	*2.6	30.6	51.9
Housework	**0.7	*8.0	13.4	12.4	34.3
Property maintenance	*6.1	*2.8	** -1.3	20.8	28.4
Paperwork	**1.9	9.2	9.4	*4.3	24.8
Meal preparation	** -2.1	20.4	*4.6	16.2	39.1
Transport	*4.6	** -3.0	14.5	*4.2	20.3
% changes between 1993 and 1998^(b)					
Self-care	184.7	14.9	76.4	13.3	24.1
Mobility	-36.6	24.7	39.7	74.0	25.2
Communication	-40.0	26.7	-76.2	0.0	10.2
Health care ^(c)	39.9	20.5	19.0	47.6	32.0
Housework	14.5	6.7	77.6	26.2	18.2
Property maintenance	155.5	2.6	-2.5	38.5	12.9
Paperwork	137.1	15.1	41.9	500.2	29.0
Meal preparation	-53.0	31.0	126.1	215.1	48.2
Transport	52.1	-2.7	19.9	22.6	9.7

(a) Estimates marked with ** have an associated relative standard error (RSE) of 50% or more. Estimates marked with * have an associated RSE of between 25% and 50%. These estimates should be interpreted accordingly.

(b) For comparative purposes, 1998 data were re-derived using the 1993 operational definition of disability.

(c) 71,100 people aged 5–14 years who needed assistance with health care in 1998 were excluded to allow comparisons between 1993 and 1998 data, as data on this age group were not collected in the 1993 survey.

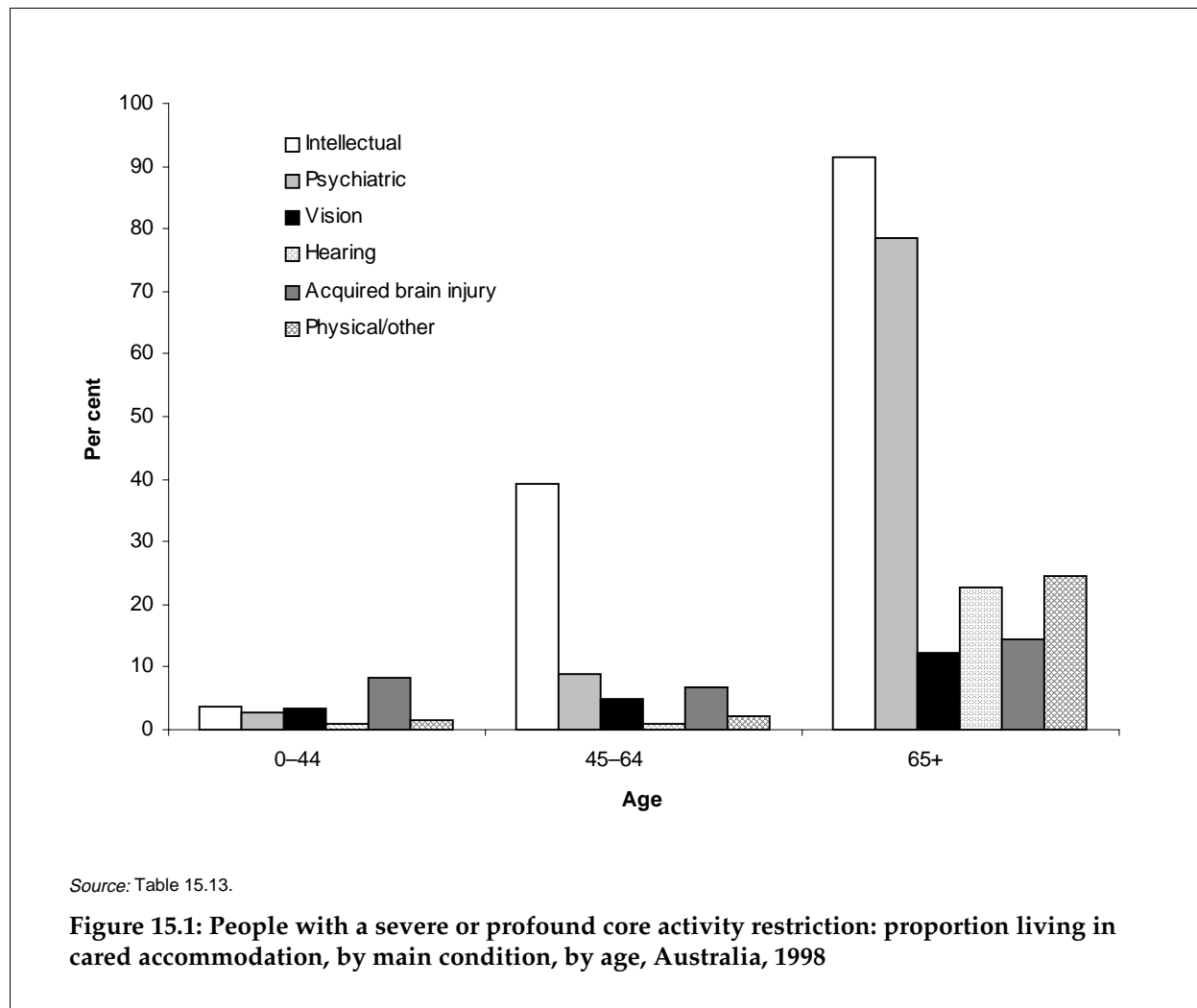
Source: Table A15.5; AIHW analysis of ABS 1998 Survey of Disability, Ageing and Carers Confidentialised Unit Record File and 1993 Survey of Disability, Ageing and Carers data.

Activities with which assistance needed

Table 15.14 shows the numbers and proportions of people needing help with various activities, by age at onset of disability. The proportions were calculated using the number of people in each 'age at onset' group as denominators.

In 1998, there were 276,000 people aged 45–64 years with a severe or profound core activity restriction living in households.¹⁰ For all people aged 45–64 years, assistance was most often needed with activities of mobility (76.2%), self-care (58.1%) and property maintenance (69.5%). 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

¹⁰ Of these, 2,000 reported that they did not know their age at onset of their main condition. These people were excluded from the analyses in this section.



other types of activity higher proportions of people aged 65 or over reported need for help in comparison with those aged 45-64 (Table 15.14).

People aged 45-64 with an early onset disability (before 18 years) were significantly more likely to report need for assistance with paperwork than were people who acquired a disability later in life. The data also suggest that, in comparison with people who acquired a disability later in life, people with an early onset disability were more likely to need help with mobility, communication, meal preparation and guidance, and were less likely to need help with housework and property maintenance. However, because of high relative standard errors it is not possible to conclusively determine whether people with early onset disability had different levels of need for assistance with these activities, in comparison with people who acquired a disability later in life.

Table 15.13: People with a severe or profound core activity restriction: main condition, by age, by accommodation type, Australia, 1998^(a)

	Main condition						Total
	Intellectual	Psychiatric	Vision	Hearing	ABI	Physical/other	
Number ('000)							
Household							
0–44	97.3	27.0	*3.9	11.6	*5.7	214.4	359.9
45–64	*5.1	20.0	**2.5	*5.1	*4.3	239.1	276.0
65+	**0.4	15.0	28.9	10.6	**1.8	268.9	325.6
Total	102.8	62.0	35.3	27.4	11.8	722.4	961.6
Cared accommodation							
0–44	*3.8	**0.7	**0.1	**0.1	**0.5	*3.6	*8.9
45–64	*3.3	**2.0	**0.1	–	**0.3	*5.5	11.2
65+	*4.4	55.2	*4.0	*3.1	**0.3	87.7	154.8
Total	11.5	57.9	*4.3	*3.3	**1.1	96.8	174.9
All							
0–44	101.1	27.8	*4.0	11.7	*6.2	218.0	368.9
45–64	*8.3	21.9	**2.6	*5.2	*4.6	244.6	287.2
65+	*4.8	70.2	32.9	13.7	**2.1	356.6	480.4
Total	114.3	119.9	39.6	30.6	12.9	819.2	1136.5
Percentage distribution							
Household							
0–44	94.7	43.6	*11.1	42.4	*48.5	29.7	37.4
45–64	*4.9	32.2	**7.0	*18.7	*36.1	33.1	28.7
65+	**0.4	24.2	82.0	38.8	**15.4	37.2	33.9
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0
Cared accommodation							
0–44	*33.4	**1.3	**3.3	**2.9	**45.0	*3.7	*5.1
45–64	*28.5	**3.4	**2.9	**1.5	**27.8	*5.6	6.4
65+	*38.1	95.4	*93.8	95.6	**27.1	90.6	88.5
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0
All							
0–44	88.5	23.2	*10.2	38.2	48.2	26.6	32.5
45–64	*7.3	18.3	**6.5	*16.9	*35.4	29.9	25.3
65+	*4.2	58.5	83.2	44.9	**16.4	43.5	42.3
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0
Per cent living in cared accommodation							
0–44	*3.8	**2.6	**3.5	**0.8	**8.2	*1.7	*2.4
45–64	*39.2	**8.9	**4.8	**0.9	**6.9	*2.2	3.9
65+	91.5	78.6	*12.3	*22.7	**14.4	24.6	32.2
Total	10.1	48.3	*10.9	*10.7	**8.7	11.8	15.4

(a) Estimates marked with ** have an associated relative standard error (RSE) of 50% or more. Estimates marked with * have an associated RSE of between 25% and 50%. These estimates should be interpreted accordingly.

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

Table 15.14: People aged 45 years and over with a severe or profound core activity restriction living in households: need for assistance by activity type, by age at onset of main condition, Australia, 1998^(a)

	Current age 45–64				Current age 65 or over				
	Age at onset of main condition				Age at onset of main condition				
	0–17	18–44	45–64	Total	0–17	18–44	45–64	65+	Total
Self-care									
Need ('000)	16.0	80.6	62.6	159.2	*3.7	21.1	51.8	75.7	152.4
Do not need ('000)	14.1	52.6	48.1	114.8	9.3	27.8	41.6	88.6	167.3
% needing help	53.2	60.5	56.5	58.1	*28.6	43.2	55.5	46.1	47.7
Mobility									
Need ('000)	24.5	98.5	85.7	208.7	12.3	43.7	72.8	140.2	269.0
Do not need ('000)	*5.7	34.7	25.0	65.3	**0.7	*5.3	20.6	23.8	50.3
% needing help	81.2	74.0	77.4	76.2	94.6	89.2	78.0	85.5	84.2
Communication									
Need ('000)	*3.4	*3.4	**2.2	*9.0	**0.6	*2.7	*6.2	18.5	28.0
Do not need ('000)	26.8	129.7	108.5	265.1	12.4	46.3	87.1	145.5	291.4
% needing help	*11.2	*2.6	**2.0	*3.3	**4.4	*5.5	*6.7	11.3	8.8
Health care									
Need ('000)	16.9	67.4	59.9	144.2	10.1	32.9	61.0	107.7	211.8
Do not need ('000)	13.3	65.8	50.8	129.8	*2.9	16.0	32.3	56.3	107.5
% needing help	56.0	50.6	54.1	52.6	77.5	67.2	65.4	65.7	66.3
Housework									
Need ('000)	13.4	67.4	62.4	143.2	9.6	30.3	66.5	116.1	222.5
Do not need ('000)	16.8	65.7	48.4	130.9	*3.4	18.7	26.9	47.9	96.8
% needing help	44.4	50.7	56.3	52.2	73.8	61.9	71.2	70.8	69.7
Property maintenance									
Need ('000)	18.7	93.4	78.3	190.4	11.3	36.1	70.7	126.8	244.9
Do not need ('000)	11.5	39.8	32.4	83.7	**1.6	12.9	22.6	37.3	74.4
% needing help	61.9	70.1	70.7	69.5	87.4	73.7	75.8	77.3	76.7
Paperwork									
Need ('000)	11.0	20.7	20.1	51.8	*4.5	9.8	26.7	67.4	108.4
Do not need ('000)	19.2	112.5	90.6	222.3	*8.5	39.1	66.6	96.6	210.9
% needing help	36.5	15.5	18.2	18.9	*34.4	20.1	28.6	41.1	34.0

(continued)

Table 15.14 (continued): People aged 45 years and over with a severe or profound core activity restriction living in households: need for assistance by activity type, by age at onset of main condition, Australia, 1998^(a)

	Current age 45–64				Current age 65 or over				
	Age at onset of main condition				Age at onset of main condition				
	0–17	18–44	45–64	Total	0–17	18–44	45–64	65+	Total
Meal preparation									
Need ('000)	*8.9	24.9	26.5	60.2	*3.8	11.5	30.5	71.0	116.7
Do not need ('000)	21.3	108.3	84.2	213.8	9.2	37.5	62.9	93.1	202.6
% needing help	29.4	18.7	23.9	22.0	*29.4	23.4	32.7	43.3	36.6
Transport									
Not applicable ('000)	—	**2.3	**1.9	*4.1	—	**1.3	*2.7	*8.0	12.0
Need ('000)	17.1	61.7	60.5	139.3	9.9	31.5	61.9	123.9	227.2
Do not need ('000)	13.1	69.2	48.4	130.7	*3.1	16.2	28.8	32.1	80.2
% needing help	56.7	46.3	54.6	50.8	76.2	64.3	66.3	75.5	71.1
Guidance									
Need ('000)	11.7	40.5	35.1	87.2	*2.7	*7.8	21.1	36.8	68.5
Do not need ('000)	18.5	92.7	75.7	186.9	10.3	41.1	72.2	127.2	250.9
% needing help	38.7	30.4	31.7	31.8	*21.0	*15.9	22.6	22.4	21.4

(a) Estimates marked with ** have an associated relative standard error (RSE) of 50% or more. Estimates marked with * have an associated RSE of between 25% and 50%. These estimates should be interpreted accordingly.
— Nil or rounded to zero.

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

Core activities and personal activities

Table 15.15 shows the number of core activities with which assistance was needed by people aged 45 or over with a severe or profound core activity restriction living in households. In 1998, 99,800 people aged 45–64 and 120,200 people aged 65 or over reported need for assistance with at least two core activities.

The proportion needing assistance with only self-care was substantially higher for people aged 45–64 than for people aged 65 or over, while the proportion needing help with only mobility was higher for people aged 65 or over than for people aged 45–64.

Focusing on personal activities, Table 15.16 provides data on the number of tasks with which assistance was needed (see Table 15.1 for a list of tasks for each activity). In comparison with people aged 65 and over, a greater proportion of people aged 45–64 reported needing help with self-care and guidance; a greater proportion of people aged 65 or more needed help with mobility and health care.

In comparison with those aged 65 and over, the proportion of people aged 45–64 needing help with two or more tasks was lower for health care (18.9% versus 27.9%) and higher for guidance (18.7% versus 8.0%).

Table 15.15: People aged 45 years and over with a severe or profound core activity restriction living in households: type of core activities in which assistance needed by current age, Australia, 1998^(a)

	Current age 45–64		Current age 65 or over	
	Number ('000)	Per cent	Number ('000)	Per cent
Self-care only	60.7	22.2	38.4	12.3
Mobility only	109.5	40.1	150.3	48.2
Communication only	*2.9	*1.1	*3.2	*1.0
Total with two or more activities	99.8	36.6	120.2	38.5
Total	272.9	100.0	312.1	100.0

(a) Estimates marked with ** have an associated relative standard error (RSE) of 50% or more. Estimates marked with * have an associated RSE of between 25% and 50%. These estimates should be interpreted accordingly.

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

Frequency of need for assistance

Table 15.17 presents data on frequency of need for assistance with different activities reported by people aged 45 or over with a severe or profound core activity restriction living in households. Housework, self-care, mobility and health care were the activities for which assistance was most frequently needed.

Of those aged 45–64, 78,200 people (28.5%) needed assistance at least once a day with housework, 57,600 (21%) with self-care, 52,700 (19.2%) with mobility and 39,300 (14.3%) with health care (Table 15.17).

Among those aged 65 or over, 102,400 people (32.1%) needed assistance at least once a day with housework, 93,200 (29.2%) with self-care, 73,300 (23.0%) with meal preparation, 64,000 (20.0%) with mobility and 53,800 (16.9%) with health care. The proportions needing daily assistance with meal preparation and self-care were higher for people aged 65 or over than for those aged 45–64 (Table 15.17).

Provider of assistance

In comparison with people aged 65 or over, those aged 45–64 were more likely to rely on an informal co-resident as their main source of assistance with self-care, mobility, health care and property maintenance. However, people aged 65 or over were more likely to rely on an informal co-resident as their main provider of assistance with meal preparation and paperwork than were those aged 45–64 (Table 15.18).

People aged 65 or over were more likely to rely on formal services as their main provider of assistance than were those aged 45–64 with activities of health care (29.2% versus 9.7%), housework (18.6% versus 4.0%) and property maintenance (23.0% versus 8.8%) (Table 15.18).

Table 15.19 present data on the total use of formal and informal sources of assistance. People aged 65 or over were more likely than those aged 45–64 to receive assistance from one or more formal service providers with self-care (10.8% versus 6.1%), mobility (15.3% versus 6.5%), health care (40.0% versus 20.2%), housework (28.6% versus 8.1%), property maintenance (31.3% versus 14.8%), meal preparation (9.1% versus 1.7%) and transport (12.6% versus 4.7%).

The proportions of people receiving informal assistance from one or more sources were higher for people aged 45–64 than for those aged 65 or over in the areas of self-care and

health care; proportions were higher for people aged 65 or over in the areas of mobility, communication, paperwork, meal preparation and transport (Table 15.19).

Marital status and housing tenure type

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 (Tables 15.20 and A15.6). The 1998 disability survey data also indicate that, of all those aged 45–64, the proportion of people who had ever married were substantially lower among those with an early onset disability than that of people with a disability acquired later in life (82% versus 95%) (Table 15.20 and A15.6).

People aged 45–64 with a severe or profound core activity restriction were less likely to own a house outright than were those aged 65 or over (46.0% versus 60.2%). 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. Among people aged 45–64 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 (Table 15.20 and Table A15.6).

Table 15.16: People aged 45 years and over with a severe or profound core activity restriction living in households: number of tasks with which assistance needed, Australia, 1998^(a)

Number of tasks	Current age 45–64		Current age 65 or over	
	Number ('000)	Per cent	Number ('000)	Per cent
Self-care				
One	89.3	32.6	72.8	22.8
Two or more	69.9	25.5	80.4	25.2
Total need assistance	159.2	58.1	153.2	48.0
Mobility				
One	128.6	46.9	191.7	60.0
Two or more	80.2	29.3	77.3	24.2
Total need assistance	208.7	76.2	269.0	84.2
Communication				
One	**2.4	**0.9	10.4	3.3
Two or more	*5.7	*2.1	14.7	4.6
Total need assistance	*8.0	*2.9	16.8	5.3
Health care				
One	92.3	33.7	122.7	38.4
Two	51.9	18.9	89.0	27.9
Total need assistance	144.2	52.6	211.8	66.3
Guidance				
One	36.1	13.2	42.8	13.4
Two or more	51.1	18.7	25.6	8.0
Total need assistance	87.2	31.8	68.4	21.4
Total persons	274.1		319.3	

(a) Estimates marked with ** have an associated relative standard error (RSE) of 50% or more. Estimates marked with * have an associated RSE of between 25% and 50%. These estimates should be interpreted accordingly.

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

Table 15.17: People aged 45 years or over with a severe or profound core activity restriction living in households: frequency of need for assistance by activity type in which help needed, Australia, 1998^(a)

Frequency	Current age 45–64		Current age 65 or over	
	Number ('000)	Per cent	Number ('000)	Per cent
Self-care				
Less than once/week	56.5	20.6	24.3	7.6
1–6 times/week	45.1	16.5	34.8	10.9
At least once/day	57.6	21.0	93.2	29.2
Mobility				
Less than once/week	92.5	33.8	85.1	26.6
1–6 times/week	63.5	23.2	119.9	37.6
At least once/day	52.7	19.2	64.0	20.0
Communication				
Less than once/week	**1.4	**0.5	*6.6	*2.1
At least once/week	*3.9	*1.4	*8.5	*2.7
At least once/day	*3.7	*1.4	12.8	4.0
Health care				
Less than once/week	70.7	25.8	133.5	41.8
1–6 times/week	34.2	12.5	24.4	7.6
At least once/day	39.3	14.3	53.8	16.9
Housework				
Less than once/week	17.7	6.5	44.4	13.9
1–6 times/week	47.3	17.3	75.6	23.7
At least once/day	78.2	28.5	102.4	32.1
Property maintenance				
Less than once/week	95.5	34.8	135.5	42.4
1–6 times/week	75.5	27.6	85.3	26.7
At least once/day	19.4	7.1	24.1	7.5
Paperwork				
Less than once/week	19.4	7.1	31.8	10.0
1–6 times/week	16.9	6.2	52.8	16.5
At least once/day	15.5	5.7	23.8	7.5
Meal preparation				
Less than once/week	14.1	5.2	12.5	3.9
1–6 times/week	13.4	4.9	30.9	9.7
Once/day	32.7	11.9	73.3	23.0
Total persons	274.1		319.3	

(continued)

Table 15.17 (continued): People aged 45 years or over with a severe or profound core activity restriction living in households: frequency of need for assistance by activity type in which help needed, Australia, 1998^(a)

Frequency	Current age 45–64		Current age 65 or over	
	Number ('000)	Per cent	Number ('000)	Per cent
Transport				
Less than once/week	50.0	18.2	72.3	22.7
1–6 times/week	67.1	24.5	136.2	42.6
At least once/day	22.1	8.1	18.7	5.8
Guidance				
Less than once/week	34.3	12.5	22.4	7.0
1–6 times/week	27.5	10.0	20.5	6.4
At least once/day	25.4	9.3	25.6	8.0
Total persons	274.1		319.3	319.3

(a) Estimates marked with ** have an associated relative standard error (RSE) of 50% or more. Estimates marked with * have an associated RSE of between 25% and 50%. These estimates should be interpreted accordingly.

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

Table 15.18: People aged 45 years or over with a severe or profound core activity restriction living in households: main source of assistance, by activity type in which help needed, Australia, 1998^(a)

Frequency	Current age 45–64		Current age 65 or over	
	Number ('000)	Per cent	Number ('000)	Per cent
Self-care				
No provider	15.2	5.5	13.4	4.2
Informal co-resident	129.6	47.3	112.9	35.4
Informal non-co-resident	*7.3	*2.7	*8.9	*2.8
Formal provider	*7.2	*2.6	17.2	5.4
Mobility				
No provider	18.8	6.9	16.1	5.0
Informal co-resident	158.9	58.0	146.3	45.8
Informal non-co-resident	23.6	8.6	85.0	26.6
Formal provider	*7.5	*2.7	21.7	6.8
Communication				
No provider	**1.3	**0.5	*3.1	*1.0
Informal co-resident	*7.7	*2.8	24.7	7.7
Informal non-co-resident	—	—	**0.2	**0.1
Health care				
No provider	9.8	3.6	11.8	3.7
Informal co-resident	99.4	36.3	90.9	28.5
Informal non-co-resident	*8.4	*3.1	15.9	5.0
Formal provider	26.6	9.7	93.3	29.2
Housework				
No provider	*3.8	*1.4	*6.1	*1.9
Informal co-resident	117.6	42.9	127.6	40.0
Informal non-co-resident	10.9	4.0	29.3	9.2
Formal provider	10.8	4.0	59.5	18.6
Property maintenance				
No provider	13.2	4.8	9.4	2.9
Informal co-resident	124.7	45.5	111.0	34.8
Informal non-co-resident	27.7	10.1	50.4	15.8
Formal provider	24.1	8.8	73.5	23.0
Paperwork				
No provider	*3.7	*1.4	*2.7	*0.8
Informal co-resident	37.4	13.6	69.2	21.7
Informal non-co-resident	*8.0	*2.9	31.4	9.8
Formal provider	**2.6	**1.0	*5.1	*1.6
Total persons ('000)	274.1		319.3	

(continued)

Table 15.18 (continued): People aged 45 years or over with a severe or profound core activity restriction living in households: main source of assistance, by activity type in which help needed, Australia, 1998^(a)

Frequency	Current age 45–64		Current age 65 or over	
	Number ('000)	Per cent	Number ('000)	Per cent
Meal preparation				
No provider	*3.2	*1.1	**1.9	**0.6
Informal co-resident	51.1	18.6	83.9	26.3
Informal non-co-resident	*2.7	*1.0	*7.3	*2.3
Formal provider	*3.3	*1.2	23.7	7.4
Transport				
No provider	*5.1	*1.8	12.7	4.0
Informal co-resident	107.9	39.4	106.9	33.5
Informal non-co-resident	19.5	7.1	85.8	26.9
Formal provider	*6.8	*2.5	21.8	6.8
Total persons ('000)	274.1		319.3	

(a) Estimates marked with ** have an associated relative standard error (RSE) of 50% or more. Estimates marked with * have an associated RSE of between 25% and 50%. These estimates should be interpreted accordingly.
 — Nil or rounded to zero.

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

Table 15.19: People aged 45 years or over with a severe or profound core activity restriction living in households: total use of formal and informal sources of assistance, by activity type in which help needed, Australia, 1998^(a)

	Current age 45–64		Current age 65 or over	
	Number ('000)	Per cent	Number ('000)	Per cent
Self-care				
Formal	16.7	6.1	34.5	10.8
Informal	138.0	50.4	126.3	39.6
Mobility				
Formal	17.9	6.5	48.8	15.3
Informal	185.7	67.7	240.6	75.3
Communication				
Formal	—	—	**1.0	**0.3
Informal	*7.7	*2.8	24.9	7.8
Health care				
Formal	55.4	20.2	127.8	40.0
Informal	114.7	41.8	117.3	36.7
Housework				
Formal	22.2	8.1	91.2	28.6
Informal	132.8	48.5	173.2	54.3
Property maintenance				
Formal	40.6	14.8	99.9	31.3
Informal	160.0	58.4	187.5	58.7
Paperwork				
Formal	*5.2	*1.9	*8.3	*2.6
Informal	45.9	16.8	101.9	31.9
Meal preparation				
Formal	*4.7	*1.7	29.0	9.1
Informal	56.1	20.5	98.5	30.8
Transport				
Formal	12.8	4.7	40.1	12.6
Informal	129.6	47.3	200.7	62.9
Total persons ('000)	274.1		319.3	

(a) Estimates marked with ** have an associated relative standard error (RSE) of 50% or more. Estimates marked with * have an associated RSE of between 25% and 50%. These estimates should be interpreted accordingly.
— Nil or rounded to zero.

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

Table 15.20: People aged 45 years and over with a severe or profound core activity restriction living in households: marital status and housing tenure type, by age at onset of main condition (per cent), Australia, 1998^(a)

	Current age 45–64 years				Current age 65 or over		
	Age at onset of main condition				Age at onset of main condition		
	0–17	18–44	45–64	Total	0–64	65+	Total
Marital status							
Married or de facto	69.3	78.4	77.2	76.9	53.3	44.4	48.7
Separated or divorced	*11.2	14.5	11.0	12.7	*5.4	*2.9	4.1
Widowed	**1.9	**1.8	*7.0	3.9	37.7	49.2	43.6
<i>Total ever married</i>	<i>82.3</i>	<i>94.7</i>	<i>95.2</i>	<i>93.5</i>	<i>96.4</i>	<i>96.6</i>	<i>96.5</i>
Never married	*17.7	*5.3	*4.8	6.5	*3.6	*3.4	3.5
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0
Housing tenure type							
Owner without mortgage	35.6	44.0	51.4	46.0	65.5	55.1	60.2
Owner with mortgage	25.9	34.5	21.2	28.2	8.8	9.1	8.9
Renter	*25.0	17.8	18.7	19.0	13.2	11.9	12.5
Boarder	**4.9	*2.1	*2.4	*2.5	*4.9	7.4	6.2
Living rent-free	*8.6	**1.2	*3.9	*3.1	*4.4	9.8	7.2
Other	—	—	—	—	**0.7	*3.0	*1.9
Not applicable	—	**0.5	*2.4	*1.2	*2.5	*3.7	3.1
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0
Total persons ('000)	30.2	133.1	110.7	274.1	155.3	164.0	319.3

(a) Estimates marked with ** have an associated relative standard error (RSE) of 50% or more. Estimates marked with * have an associated RSE of between 25% and 50%. These estimates should be interpreted accordingly.
— Nil or rounded to zero.

Source: Table A15.6; AIHW analysis of ABS 1998 Survey of Disability, Ageing and Carers Confidentialised Unit Record File.

15.5 Summary of findings

This chapter examines the level and profile of need for services and assistance, main sources of assistance, and changes between 1993 and 1998, focusing on people with a severe or profound core activity restriction living in households. The main statistical findings are summarised in this section.

Level and profile of need for assistance

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

There were differences in the levels and profiles of need for assistance between people aged under 65 and those aged 65 or more:

- Of the 636,000 people aged under 65 with a severe or profound core activity restriction, 264,300 (41.6%) needed assistance with more than one core activity, including 56,000 (8.8%) who needed help with all three core activities.
- Of the 325,600 people aged 65 or over with a severe or profound core activity restriction, 122,400 (37.6%) needed help with more than one core activity, including 17,000 (5.2%) who needed 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.

Differences in need for assistance by main condition

Some of the variation in level and profile of need for assistance was associated with differences in main condition. For 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 with guidance (85.9%), communication (71.6%), mobility (59.7%), self-care (57.2%) and health care (57.2%). Nearly 60% of people in this group needed assistance with more than one core activity, including 30% who needed help with all three core activities.

People aged under 65 with a physical/other main condition 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, including 4.6% needing help with all three core activities.

Among those aged under 65, the number of areas in which a high proportion of people needed assistance was greater in the intellectual and acquired brain injury main condition groups than in other groups. A high proportion of people reported needing help with mobility in all main condition groups except hearing.

For 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.

Of all people with a 'physical or other' main condition, a higher proportion of those aged 65 or over than those aged under 65 reported need for assistance with personal activities of mobility and health care, and with non-personal activities (e.g. housework and transport). In contrast, a higher proportion of people aged under 65 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

- Informal carers were the main source of assistance with self-care, mobility and communication for more than 80% of people with a severe or profound core activity restriction.

- Health care, property maintenance and housework were the activities with 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.
- 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).
- People aged under 65 were more likely than those aged 65 or over to rely on an informal co-resident as their main source of assistance with all activities except communication, while people aged 65 or over were more likely to rely on an informal non-co-resident 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.

Changes between 1993 and 1998

Comparative analyses of need for assistance and main provider of assistance between the 1993 and 1998 surveys indicate that:

- 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 those aged 65 or over. The percentage increases were particularly high in the age group 45–64, reflecting 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.
- The number of people who reported that their main source of assistance was an informal co-resident increased markedly for all types of activity. There were also increases in the number of people relying on an informal non-co-resident or a formal provider as their main source of assistance.
- 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. This suggests 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 as their main source of assistance was much greater for people aged under 65 than for people aged 65 or more. This was partly because of the larger increase in the number of people with a severe or profound core activity restriction among people aged under 65.

However, there were some differences between the two surveys in terms of the questions on need for assistance that were asked, and there may have been a greater ‘capture’ of people with a disability in the 1998 survey than in the 1993 survey (see Section 18.2).

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

All people aged 45–64

In 1998, there were 276,000 people aged 45–64 years with a severe or profound core activity restriction living in households, of whom 99,800 needed assistance with at least two core activities. 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.

The proportions needing help 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 assistance in comparison with those aged 45–64.

In comparison with people aged 65 or over, people aged 45–64 were more likely to rely on an informal co-resident as their main source of assistance with self-care, mobility, health care and property maintenance, and less likely to receive formal assistance for most activities.

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 (see Table 14.5). 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%). The data also show that 35.6% of those with an early onset disability owned a house outright, while 38.5% were renting, boarding or living rent-free. In contrast, for those with a disability acquired later in life, over 45% owned a house and only about 23% were renting, boarding or living rent-free.

16 Ageing, informal care and carers

This chapter presents analyses of the ABS disability survey data related to ageing, informal care and carers. The chapter starts with a brief discussion of the relevant survey definitions and methods of collecting data on informal carers. The first section examines the profile of carers, including age and sex profiles, length of time in the caring role and a comparison of some social and economic characteristics between carer and non-carer populations. This is followed by analyses of the effect of the caring role on carers and their support needs. The trend in de-institutionalisation and its impact on informal care is then discussed.

16.1 Disability survey data on carers

In the 1998 disability survey, information was collected about informal assistance provided by carers and 'primary carers'. A carer was defined as a person, of any age, who provides any informal assistance, in terms of help or supervision, to people with disabilities or long-term conditions, or to people aged 60 years or over. The assistance has to be ongoing, or likely to be ongoing, for at least six months. Where the assistance is provided to a person in a different household, the assistance must relate to 'everyday types of activities', but no specific information on the activities is collected. Where the carer and recipient live in the same household, the assistance must be for one or more activities related to self-care, mobility, communication, health care, housework, meal preparation, paperwork, property maintenance or transport (ABS 1999: 65).

A 'primary carer' was defined as the person, of any age, who provides the most informal assistance to a person with one or more disabilities. The assistance must be ongoing, or likely to be ongoing, for at least six months and must be provided for one or more of the core activities (self-care, mobility or communication) (ABS 1999: 71).

The main differences between a carer and a primary carer are:

- a primary carer must provide 'the most' informal assistance;
- the care recipient of a primary carer must be a person with a disability (as opposed to a person aged 60 or over without a disability as defined in the survey); and
- for a primary carer, the assistance provided must relate to one or more core activities.

This chapter focuses mainly on primary carers, since they are the group of people who provide most assistance to people who have core activity restrictions.

The terms and definitions used to define the person providing most informal care to a person with a disability changed between the 1993 and 1998 surveys, as did the method for identifying carers. In the 1993 disability survey, the 'principal carer' of a person with a disability was the person, aged 15 or over, who provided the most informal care in the areas of self-care, mobility or verbal communication (ABS 1993).

In the 1998 survey, both co-resident and non-co-resident primary carers were identified by a responsible adult in the household, and carer status was then confirmed by the carer in person. In 1993, non-co-resident principal carers were identified in this way, but co-resident principal carers were identified by the recipient of care. As a result of this change, the

number of co-resident primary carers identified in the 1998 survey was estimated at only about 60% of what might have been expected if the 1993 method had been used. In comparison with the 1993 survey data, a higher proportion of primary carers identified in the 1998 survey had care recipients with high-frequency care needs (ABS 1999: 56–57).

16.2 Ageing and profile of informal carers

Age and sex

According to the 1998 disability survey, over 2.3 million people, or 12.6% of the total Australian population, were carers who provided informal assistance to people who needed assistance because of disability or ageing. Of those carers, 450,900 people, or 2.4% of the total population, were primary carers (Tables 16.1 and A16.1).

Females were more likely to be in a caring role than males, and this was particularly true for primary carers. There were 317,300 females, or 3.4% of the total female population, who were primary carers, in contrast to 133,500 males, or 1.4% of the total male population (Table 16.1). Of all people providing care, 56% were females, and 70% of primary carers were females.

The age group in which people were most likely to be involved in a caring role differed for men and women. The peak for women was in the 45–64 age group—24.0% of women in this age group were in a caring role, and 6.6% were a primary carer. The peak for men was in the 65+ age group—22.6% of men in this age group were in a caring role, and 3.8% were a primary carer (Figures 16.1 and 16.2; Table A16.2). The age group 45–64 years accounted for 43% of all primary carers—46% of female primary carers and 42% of male primary carers (Table 16.1).

The impact of population ageing was also reflected in informal care and the carer population. In 1998, there were 96,400 primary carers aged 65 years and over, of whom 62.5% were females (Table A16.1). Primary carers in younger age groups were also noticeable—in 1998, 31,300 primary carers were aged under 30 years. An intensive caring role may have a particular impact on younger carers, in terms of education and career development in an increasingly competitive environment.

Relationship to care recipient

Caring for a spouse is the most common care relationship among adult primary carers. The 1998 disability survey showed that 192,100 primary carers were spouses of their recipients, accounting for 42.9% of primary carers aged 15 years and over. Spouse carers made up about 41.3% of primary carers aged 45–64 years and 75.5% of those aged 65 years and over. The vast majority of son or daughter primary carers were aged under 65 years and 53.9% of them were not living with their parents (Table 16.2).

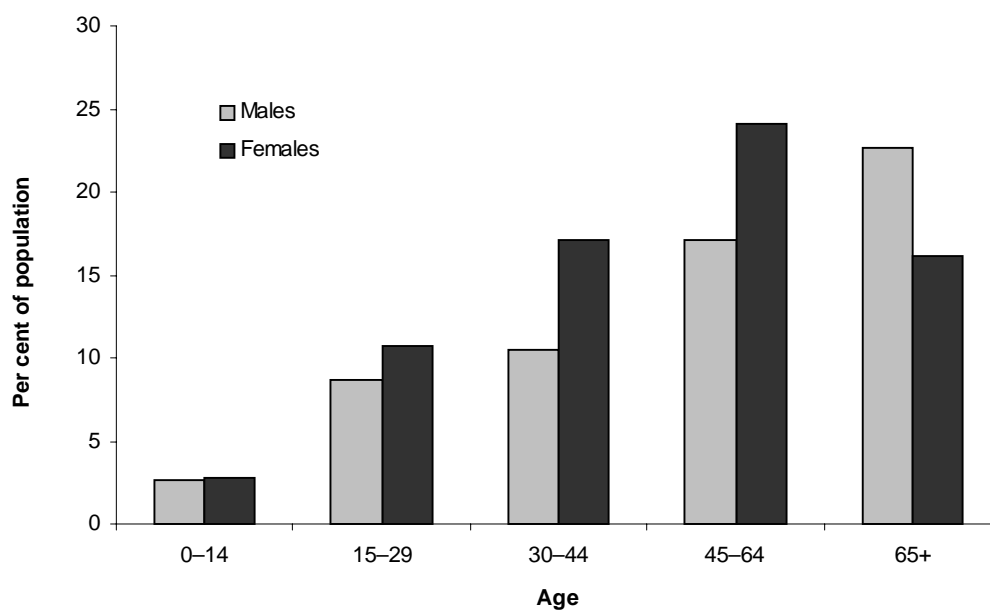
In 1998, 9,700 parent primary carers and 73,000 spouse primary carers were aged 65 years or over. Most ageing parent carers (8,800) were mothers who were living with the son or daughter they cared for (Table 16.2). Ageing parents caring for their son or daughter with a severe or profound core activity restriction often have a different history from people taking on the caring role as a spouse or other relative in later life, because of the long duration of the caring relationship (Madden et al. 1996).

Table 16.1: People living in households: carer status by age by sex (per cent), Australia, 1998^(a)

	Age groups					Total			Total number ('000)	Per cent of population
	0-14	15-29	30-44	45-64	65+		0-64	15-64		
Males										
Primary carer	**0.9	*4.6	21.2	46.3	27.1	100	72.9	72.0	133.5	1.4
Carer, not primary	5.8	19.8	22.0	32.5	20.0	100	80.0	74.2	888.4	9.6
Total carer	5.2	17.8	21.9	34.3	20.9	100	79.1	73.9	1,021.9	11.1
Not a carer	23.7	23.5	23.3	20.6	8.9	100	91.1	67.4	8,198.6	88.9
<i>Total</i>	<i>21.7</i>	<i>22.8</i>	<i>23.1</i>	<i>22.1</i>	<i>10.2</i>	<i>100</i>	<i>89.8</i>	<i>68.1</i>	<i>9,220.5</i>	<i>100.0</i>
Females										
Primary carer	**0.5	7.1	31.9	41.6	19.0	100	81.0	80.5	317.3	3.4
Carer, not primary	5.1	19.8	27.1	35.2	12.8	100	87.2	82.1	988.4	10.7
Total carer	4.0	16.7	28.2	36.8	14.3	100	85.7	81.7	1,305.8	14.1
Not a carer	23.3	22.9	22.5	19.1	12.2	100	87.8	64.4	7,943.7	85.9
<i>Total</i>	<i>20.6</i>	<i>22.0</i>	<i>23.3</i>	<i>21.6</i>	<i>12.5</i>	<i>100</i>	<i>87.5</i>	<i>66.9</i>	<i>9,249.5</i>	<i>100.0</i>
Persons										
Primary carer	*0.6	6.3	28.7	43.0	21.4	100	78.6	78.0	450.9	2.4
Carer, not primary	5.5	19.8	24.7	33.9	16.2	100	83.8	78.4	1,876.8	10.2
Total carer	4.5	17.2	25.4	35.7	17.2	100	82.8	78.3	2,327.7	12.6
Not a carer	23.5	23.2	22.9	19.9	10.5	100	89.5	65.9	16,142.3	87.4
Total	21.1	22.4	23.2	21.9	11.4	100	88.6	67.5	18,469.9	100.0

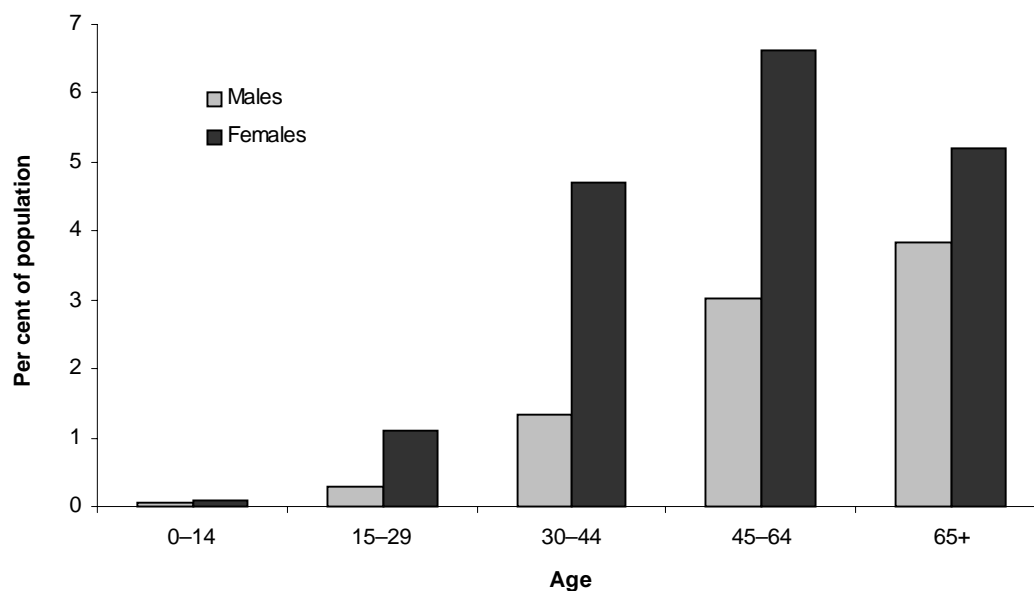
(a) Estimates marked with ** have an associated relative standard error (RSE) of 50% or more. Estimates marked with * have an associated RSE of between 25% and 50%. These estimates should be interpreted accordingly.

Source: Table A16.1; AIHW analysis of 1998 ABS Survey of Disability, Ageing and Carers Confidentialised Unit Record File.



Source: Table A16.2.

Figure 16.1: Carers living in households, by sex and age, as a percentage of the population of that sex and age, Australia, 1998



Source: Table A16.2.

Figure 16.2: Primary carers living in households, by sex and age, as a percentage of the population of that sex and age, Australia, 1998

Table 16.2: Primary carers aged 15 years and over: relationship to main recipient of care, by sex and age of primary carer ('000), Australia, 1998^(a)

	Males	Females	Living with main recipient	Not living with main recipient	Total	%
15–44 years						
Partner	14.9	24.3	38.9	n.p.	39.2	24.9
Child	10.5	31.9	20.0	22.4	42.4	26.9
Parent	*4.0	52.1	55.3	n.p.	56.0	35.5
Other	*4.7	15.3	*6.6	13.4	20.1	12.7
Total	34.2	123.6	120.8	36.9	157.7	100.0
45–64 years						
Partner	36.2	43.8	80.0	—	80.0	41.3
Child	16.3	49.5	29.9	35.9	65.8	34.0
Parent	*5.8	22.9	26.1	**2.6	28.7	14.8
Other	*3.6	15.5	*7.9	11.2	19.1	9.9
Total	61.9	131.6	143.9	49.6	193.5	100.0
65 years and over						
Partner	34.7	38.2	72.4	n.p.	73.0	75.5
Child	—	*3.5	n.p.	**2.0	*3.5	*3.6
Parent	n.p.	*8.8	*8.9	n.p.	9.7	10.0
Other	n.p.	9.9	*4.7	*5.8	10.5	10.9
Total	36.3	60.4	87.4	*9.3	96.7	100.0
All ages						
Partner	85.9	106.2	191.2	**0.9	192.1	42.9
Child	26.8	84.9	51.5	60.2	111.7	24.9
Parent	10.7	83.7	90.2	*4.2	94.4	21.1
Other	*8.9	40.8	19.3	30.4	49.7	11.1
Total	132.3	315.6	352.2	95.8	447.9	100.0

(a) Estimates marked with ** have an associated relative standard error (RSE) of 50% or more. Estimates marked with * have an associated RSE of between 25% and 50%. These estimates should be interpreted accordingly.
n.p. Not available for publication but included in totals where applicable.
— Nil or rounded to zero.

Source: ABS 1999: Table 32.

Of all primary carers, 39.4% (177,500) had a disability and 9.3% (41,900) had a severe or profound core activity restriction (Table 16.3). Of non-primary carers, 30.9% (59,800) had a disability and 7.3% (137,200) had a severe or profound core activity restriction. These high rates of disability among carers are likely to be due in part to the older age structure of the carer population. However, 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.

Table 16.3: People living in households: carer status by disability status by age, Australia, 1998^(a)

	Age groups				Total
	0–29	30–44	45–64	65+	
Primary carers					
% with disability	29.1	28.5	40.3	55.5	39.4
% with severe or profound core activity restrictions	*8.8	*5.1	9.9	13.8	9.3
Total number ('000)	31.3	129.4	193.7	96.4	450.9
Carers, not primary					
% with disability	15.5	22.5	35.6	57.8	30.9
% with severe or profound core activity restrictions	3.9	6.0	8.2	12.8	7.3
Total number ('000)	474.1	462.8	636.4	303.5	1,876.8
Total population					
% with disability	8.3	13.9	27.3	50.5	18.5
% with severe or profound core activity restrictions	2.8	3.2	6.8	15.5	5.2
Total number ('000)	8,045.4	4,286.5	4,036.2	2,101.8	18,469.9

(a) Estimates marked with ** have an associated relative standard error (RSE) of 50% or more. Estimates marked with * have an associated RSE of between 25% and 50%. These estimates should be interpreted accordingly.

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

Length of time in the caring role

In 1998, 178,300 primary carers (39.8%) had been in their caring role for at least 10 years. Of those, 59,600 (13.3% of primary carers) had been in their caring role for at least 25 years.

161,300 primary carers (36.0%) spent, on average, 40 hours or more per week providing care. Of these, 22,700 had been caring for at least 25 years (Table 16.4).

Labor force status, income and housing tenure type

Tables 16.5 and A16.3 provide a comparison of some socioeconomic characteristics between primary carers, non-primary carers, and those not involved in care-giving. In 1998, nearly 50% of primary carers aged between 15 and 64 years were not in the labour force, compared to 23% of people who were not in a caring role. Primary carers were much less likely to work full-time (21.6%) than non-carers (51.1%).

Corresponding to the lower labour force participation rate of primary carers, only a third of them reported wages or salary as their principal source of cash income, in contrast to 58.6% of people who were not carers. Nearly half of primary carers relied on a Government pension or allowance as their principal source of income, as compared with 20% of those who were not in a caring role (Tables 16.5 and A16.3).

The data on total cash income indicate that primary carers were more likely to be in lower income quintiles. Income quintiles are calculated by dividing the income distribution for survey respondents into five equal parts. The first quintile contains the 20% of respondents with the lowest incomes and the fifth quintile contains the 20% of respondents with the highest incomes. About 45% of primary carers were in the first or second quintiles,

Table 16.4: Primary carers aged 15 years and over: time spent on caring, Australia, 1998^(a)

Years in caring role	Average weekly hours				Total
	<20 hours	20–39 hours	40 hours+	Not stated	
	Number ('000)				
<2	11.6	*5.1	9.3	**1.5	27.6
2–4	53.8	16.9	35.7	*7.2	113.7
5–9	52.2	20.3	51.4	*4.5	128.5
10–24	51.1	20.7	42.2	*4.7	118.7
25+	26.3	*7.2	22.7	*3.3	59.6
Total	195.0	70.3	161.3	21.3	447.9
	Per cent (sum vertically)				
<2	5.9	*7.3	5.8	**7.0	6.2
2–4	27.6	24.0	22.1	33.8	25.4
5–9	26.8	28.9	31.9	*21.1	28.7
10–24	26.2	29.4	26.2	*22.1	26.5
25+	13.5	*10.2	14.1	*15.5	13.3
Total	100.0	100.0	100.0	100.0	100.0
	Per cent (sum horizontally)				
<2	42.0	*18.5	33.7	**5.4	100.0
2–4	47.3	14.9	31.4	*6.3	100.0
5–9	40.6	15.8	40.0	*3.5	100.0
10–24	43.0	17.4	35.6	*4.0	100.0
25+	44.1	*12.1	38.1	*5.5	100.0
Total	43.5	15.7	36.0	4.8	100.0

(a) Estimates marked with ** have an associated relative standard error (RSE) of 50% or more. Estimates marked with * have an associated RSE of between 25% and 50%. These estimates should be interpreted accordingly.

Source: ABS 1999: Table 33.

concentrated mainly in the second quintile, while only about 32% of the non-carer population was in these quintiles—that is, primary carers were over-represented in lower income brackets (Tables 16.5 and A16.3).

Primary carers were more likely to own their home outright than those who were not carers (Table 16.5), probably reflecting the different age distributions of the primary carer and non-carer populations. Of all primary carers, 43% were aged 45–64, in comparison with 20% of non-carers (Table 16.1). In the population as a whole, older people, in particular couples in late adult or older age groups, were the group most likely to own their home without a mortgage (AIHW analysis of 1998 Survey of Disability, Ageing and Carers Confidentialised Unit Record File).

Table 16.5: People aged 15–64 years living in households, carer status, by income, labour force status and tenure type (per cent), Australia, 1998^(a)

	Carer status				Total
	Primary carer	Carer (not primary)	Total carer	Not a carer	
Labour force status					
Employed full-time workers	21.6	41.4	37.6	51.1	49.1
Employed part-time workers	23.0	21.3	21.6	20.0	20.2
Total employed	44.6	62.7	59.2	71.1	69.3
Unemployed	6.0	7.7	7.4	6.1	6.3
Not in the labour force	49.4	29.6	33.4	22.9	24.4
<i>Total</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>
Principal source of cash income					
Wages or salary	33.2	49.7	46.5	58.6	56.8
Own business or partnership income	6.1	7.7	7.4	8.3	8.2
Other private income ^(b)	5.5	5.2	5.3	3.9	4.1
Government pension or allowance	49.2	29.7	33.4	20.3	22.2
Not stated ^(c)	5.9	7.8	7.4	8.9	8.7
<i>Total</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>
Total cash income					
First income quintile ^(d)	18.6	19.2	19.1	20.2	20.0
Second income quintile	26.1	19.0	20.4	12.2	13.4
Third income quintile	24.7	18.4	19.7	16.5	17.0
Fourth income quintile	15.7	21.0	20.0	22.1	21.8
Fifth income quintile	9.9	15.6	14.5	20.9	20.0
Income not known ^(e)	5.0	6.7	6.4	8.1	7.8
<i>Total</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>
Tenure type					
Owner without mortgage	35.2	29.8	30.8	22.9	24.1
Owner with mortgage	34.3	34.8	34.7	37.3	36.9
Public renter	9.6	4.4	5.4	3.2	3.6
Private renter	13.9	13.4	13.5	22.0	20.8
Boarder	*1.7	8.2	7.0	6.1	6.2
Living rent-free	4.3	7.8	7.1	6.9	6.9
Other ^(f)	**0.3	0.8	0.7	0.4	0.4
Not applicable	**0.7	0.8	0.8	1.2	1.3
<i>Total</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>

(a) Estimates marked with ** have an associated relative standard error (RSE) of 50% or more. Estimates marked with * have an associated RSE of between 25% and 50%. These estimates should be interpreted accordingly.

(b) Include child support or maintenance, workers compensation, profit or loss from rental property, dividends or interest, superannuation or annuity.

(c) Includes people who report no source of income and main source of income not known.

(d) Includes people with nil income, and no source of income.

(e) Includes refusals.

(f) Includes life tenure schemes and rent/buy or shared equity schemes.

Source: AIHW analysis of 1998 ABS Survey of Disability, Ageing and Carers Confidentialised Unit Record File; Table A16.3.

16.3 Need for and receipt of assistance

Receipt of government pension or benefit

In 1998, 308,200 primary carers aged 15 years and over (69%) were recipients of a government pension or benefit. The most common type of government pension or benefit was a Family Payment or Parenting Allowance, received by 104,600 primary carers (23%), followed by the Age Pension, received by 67,800 primary carers (15%) (Table 16.6). The number of primary carers receiving the Age Pension accounted for about 70% of primary carers aged 65 years and over, meaning that a majority of ageing primary carers were recipients of the Age Pension.

Receipt of support in providing care

The 1998 disability survey shows that about half of all primary carers aged 15 years or more did not receive any assistance in providing care (Table 16.7). While 41.5% of primary carers reported that they did not need any assistance, there were 41,300 (9.2%) who needed assistance but did not receive any, and 70,300 (15.7%) who received assistance but said that they needed further assistance. Some 150,200 primary carers (33.5%) received assistance and did not need further help. Primary carers living in non-capital city regions were less likely to receive assistance than those living in capital cities.

Over 250,000 primary carers (56.2%) reported that a fall-back carer was available. However, there were 160,000 primary carers (35.7%) who did not have a fall-back carer and 36,300 (8.1%) who did not know if a fall-back carer was available (Table 16.7).

In 1998, 59,100 primary carers aged 15 years or over (13.2%) reported that they had used respite care services, such as in-home respite care and day care (Table 16.7). Among the primary carers who had used respite care services, 35,500 had used such services in the last three months and, of those, 15,700 stated that they did not need further services or preferred to provide care without such services. However, 19,800 primary carers who had used respite services in the last three months needed further respite services.

Most primary carers (86.8% or 388,900 people) had never received respite care services. Although the majority of them (345,100) stated that they did not need or want such services, 43,800 primary carers reported that they needed respite services but had never received them (Table 16.7).

16.4 Effects of the caring role on carers

The 1998 survey asked various questions of primary carers regarding the effect of the caring role on their relationships with others, their financial situation and workforce status, and their health and well-being. Table 16.8 shows the effect of the caring role on relationships with friends, the main care recipient, the carer's spouse or partner, and other co-resident family members. Of all primary carers, 55% said that their friendships remained unaffected. However, nearly a quarter said that they had lost or were losing touch with existing friends as a result of the caring role. Regarding their relationship with their main care recipient, 32.7% of primary carers said that they had been brought closer together, while 22.3% said that the relationship had become strained.

Table 16.6: Primary carers aged 15 years and over: receipt of government pension/benefit, Australia, 1998^(a)

	Number ('000)	Per cent
Type of government pension/benefit received		
Age Pension	67.8	15.1
Newstart Allowance/Youth Training Allowance	11.5	2.6
Service Pension ^(b)	17.8	4.0
Disability Support Pension ^(c)	20.7	4.6
Sole Parents Pension	23.8	5.3
Wife Pension/Partner's Allowance	28.0	6.3
Carer Payment	47.8	10.7
Domicillary Allowance/Child Disability Allowance	60.0	13.4
War Widows or Disability Pension ^(b)	9.5	2.1
Family Payment or Parenting Allowance	104.6	23.4
Other benefit ^(d)	33.3	7.4
<i>All receiving government pension/benefit^(d)</i>	<i>308.2</i>	<i>68.8</i>
Does not receive pension/benefit	139.7	31.2
Total^(e)	447.9	100.0

(a) Estimates marked with ** have an associated relative standard error (RSE) of 50% or more. Estimates marked with * have an associated RSE of between 25% and 50%. These estimates should be interpreted accordingly.

(b) Department of Veterans' Affairs.

(c) Department of Family and Community Services (Department of Social Security at time of collection).

(d) Includes Mature Age Allowance, Disability Allowance and Widows Pension.

(e) Total may be less than the sum of the components as people may receive more than one pension or benefit.

Source: ABS 1999: Table 35.

Of all primary carers, 45.6% reported that their income was not affected by caring, while 20.6% said that their income had decreased and 25.7% reported extra expenses as a result of the caring role (Table 16.9). Nearly 30% of primary carers reported difficulty meeting living costs. Compared with other age groups, a greater proportion of primary carers aged 30–44 reported negative effects of the caring role on income, living costs and hours worked. Over 10% of primary carers (47,500) reported that they had left their job in order to commence or increase their caring role.

Over a quarter of primary carers said that interrupted sleep affected them in performing daily activities—only 50% of primary carers said that their sleep was not interrupted due to the caring role (Table 16.10). Nearly 30% of primary carers said that their physical or emotional well-being had changed, and 34% said that they frequently felt weary or lacked energy due to their caring role. Over 30% of primary carers frequently felt worried or depressed, and 17% frequently felt angry or resentful, due to their caring role. Over 10% of primary carers had been diagnosed with a stress-related illness.

Table 16.7: Primary carers aged 15 years and over: need and receipt of support in providing care, Australia, 1998^(a)

	Number ('000)			Per cent		
	Capital city	Balance of State/Territory	Total	Capital city	Balance of State/Territory	Total
Need for and receipt of assistance						
Receives assistance:						
Does not need further assistance	98.4	51.9	150.2	34.6	31.7	33.5
Needs further assistance	48.2	22.1	70.3	17.0	13.5	15.7
Does not receive assistance:						
Does not need assistance	112.1	74.1	186.1	39.5	45.2	41.5
Needs assistance	25.4	15.9	41.3	8.9	9.7	9.2
Total	284.0	163.9	447.9	100.0	100.0	100.0
Availability of a fall-back carer						
Available	161.4	90.2	251.6	56.8	55.0	56.2
Not available	98.2	61.9	160.0	34.6	37.8	35.7
Don't know if available	24.5	11.8	36.3	8.6	7.2	8.1
Total	284.0	163.9	447.9	100.0	100.0	100.0
Need for and receipt of respite care						
Received respite care in the last three months:						
Does not need further care	*7.4	*8.3	15.7	*2.6	*5.1	3.5
Needs further care	13.2	*6.5	19.8	4.6	*4.0	4.4
Received respite care, but not in the last three months:						
Does not need care	10.6	*4.6	15.2	3.7	*2.8	3.4
Needs care	*6.2	**2.1	*8.4	*2.2	**1.3	*1.9
<i>Total received respite</i>	<i>37.4</i>	<i>21.5</i>	<i>59.1</i>	<i>13.2</i>	<i>13.1</i>	<i>13.2</i>
Never received respite care:						
Does not need/want care	219.0	126.1	345.1	77.1	76.9	77.0
Needs care	27.6	16.2	43.8	9.7	9.9	9.8
<i>Total never received respite</i>	<i>246.6</i>	<i>142.3</i>	<i>388.9</i>	<i>86.8</i>	<i>86.8</i>	<i>86.8</i>
Total	284.0	163.9	447.9	100.0	100.0	100.0

(a) Estimates marked with ** have an associated relative standard error (RSE) of 50% or more. Estimates marked with * have an associated RSE of between 25% and 50%. These estimates should be interpreted accordingly.

Source: ABS 1999: Table 35.

Table 16.8: Primary carers: effects of the caring role on relationships (per cent), Australia, 1998^(a)

	Age group				Total
	0–29	30–44	45–64	65+	
Effect on friendships					
Friendships unaffected	49.4	51.8	56.3	59.8	55.3
Circle of friends increased	**5.3	*3.2	*2.3	*3.9	3.1
Circle of friends changed	*10.6	15.7	10.4	11.5	12.2
Lost or losing touch with existing friends	*16.3	25.2	27.1	20.5	24.4
NA or not stated	*18.5	*4.1	*3.8	*4.3	5.0
Effect on relationship with main care recipient					
Relationship unaffected	36.5	35.9	38.3	48.7	39.7
Brought closer together	34.8	34.9	32.3	30.0	32.7
Relationship strained	*10.3	25.6	25.4	15.7	22.3
NA or not stated	*18.5	*3.6	*3.9	*5.5	5.2
Effect on relationship with partner					
Relationship unaffected	*23.2	18.6	16.8	*9.1	16.1
Brought closer together	*8.4	*6.2	*4.1	**0.9	4.3
Lack time alone together	**3.0	11.1	7.0	**0.2	6.4
Relationship strained	**2.0	12.2	9.0	**0.4	7.6
NA or not stated	63.4	52.0	63.1	89.4	65.6
Effect on relationship with co-resident family members					
Relationship unaffected	38.4	28.5	29.7	30.9	30.2
Brought closer together	**1.0	8.8	7.0	*6.5	7.0
Less time to spend with them	**8.0	32.0	12.8	*3.9	16.1
Relationship strained	*9.3	14.6	10.4	*4.4	10.3
Relationship changed in other way	**2.3	**1.0	**0.9	**0.5	*1.0
NA or not stated	41.0	15.0	39.2	53.8	35.5
Total number ('000)	31.3	129.4	193.7	96.4	450.9

(a) Estimates marked with ** have an associated relative standard error (RSE) of 50% or more. Estimates marked with * have an associated RSE of between 25% and 50%. These estimates should be interpreted accordingly.

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

Table 16.9: Primary carers: effects of the caring role on income, living costs and work (per cent), Australia, 1998^(a)

	Age group				Total
	0–29	30–44	45–64	65+	
Effect on financial situation					
Income not affected	52.6	37.0	44.4	57.2	45.6
Income has increased	**3.2	*3.9	*1.6	**1.9	2.4
Income has decreased	**7.3	29.4	23.6	*6.8	20.6
Has extra expenses	*18.4	25.0	26.1	28.1	25.7
NA/not stated	*18.5	*4.6	*4.3	*6.1	5.7
Whether has difficulty with living costs					
Has difficulty	*18.2	36.6	31.4	17.1	28.9
Does not have difficulty	**7.5	17.1	18.0	15.8	16.5
NA/not stated	74.3	46.3	50.6	67.2	54.5
Effect on weekly hours worked					
Unchanged	33.3	35.3	28.8	*2.9	25.4
Reduced	**2.9	14.8	6.7	**0.4	7.4
Increased	**2.5	*3.3	*3.5	**0.5	2.7
NA/not stated	61.3	46.7	61.0	96.3	64.4
Reason left work					
To commence or increase care	**5.6	9.6	15.0	*4.4	10.5
Total number ('000)	31.3	129.4	193.7	96.4	450.9

(a) Estimates marked with ** have an associated relative standard error (RSE) of 50% or more. Estimates marked with * have an associated RSE of between 25% and 50%. These estimates should be interpreted accordingly.

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

16.5 Trends in de-institutionalisation

Over recent years there has been a trend towards de-institutionalisation among people with a disability who need ongoing assistance (AIHW 1997b; Wen & Madden 1998a; Madden et al. 1999). 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 (see Chapter 5).

The 1998 survey data indicate that the trend towards community living has continued (Table 16.11). The proportion of people with a severe or profound core activity restriction living in cared accommodation has steadily decreased from 9.9% in 1981 to 2.6% in 1998. Since 1993, there was an increase of 257,500 people aged 5–64 years with a severe or profound core activity restriction 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 methods). In 1998, 606,600 people aged 5–64 years with severe or profound core activity restrictions were living in households, while only 20,000 were living in cared accommodation. Most of those living in households were living with their relatives (AIHW 1999a: 256). One of the implications of this trend towards community living is that more people with disabilities are reliant on informal carers to provide the assistance they need.

Table 16.10: Primary carers: effects of the caring role on health and well-being, Australia, 1998^(a)

	Age groups				Total
	0–29	30–44	45–64	65+	
Effect on sleep					
Not interrupted	46.6	44.4	54.6	48.9	49.9
Interrupted, affects activities	*23.0	30.8	22.1	24.5	25.2
Interrupted, does not affect activities	*11.9	20.1	19.0	20.9	19.2
Interrupted, effect not stated	—	**1.1	**0.8	**0.8	*0.8
NA/not stated	*18.5	*3.6	*3.4	*4.8	4.8
Whether physical/emotional well-being has changed					
Has changed	*17.6	38.2	31.2	15.4	28.9
Has not changed	63.9	57.9	64.5	79.8	65.8
NA/not stated	*18.5	*3.9	*4.3	*4.8	5.3
Whether feels satisfied due to caring role					
Feels satisfied	25.3	25.0	27.7	33.4	27.9
Does not feel satisfied	56.2	71.1	68.0	61.9	66.8
NA/not stated	*18.5	*3.9	*4.3	*4.8	5.3
Whether frequently feels weary or lacks energy					
Feels weary/lacks energy	*18.5	39.6	36.4	28.6	34.4
Does not feel weary/lack energy	63.1	56.5	59.3	66.6	60.3
NA/not stated	*18.5	*3.9	*4.3	*4.8	5.3
Whether frequently feels angry or resentful					
Feels angry or resentful	*8.4	19.3	18.9	13.3	17.1
Does not feel angry or resentful	73.2	76.8	76.8	81.9	77.7
NA/not stated	*18.5	*3.9	*4.3	*4.8	5.3
Whether frequently feels worried or depressed					
Feels worried or depressed	26.9	36.3	32.3	24.2	31.3
Does not feel worried or depressed	54.6	59.7	63.4	71.0	63.4
NA/not stated	*18.5	*3.9	*4.3	*4.8	5.3
Whether has a stress-related illness					
Yes	*8.9	10.1	12.2	7.4	10.3
No	72.7	86.0	83.5	87.8	84.4
NA/not stated	*18.5	*3.9	*4.3	*4.8	5.3
Total number ('000)	31.3	129.4	193.7	96.4	450.9

(a) Estimates marked with ** have an associated relative standard error (RSE) of 50% or more. Estimates marked with * have an associated RSE of between 25% and 50%. These estimates should be interpreted accordingly.
 — Nil or rounded to zero.

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

Table 16.11: People aged 5–64 years and with profound or severe core activity restriction(s), by living arrangements ('000), Australia, 1981, 1988, 1993 and 1998^(a)

Living arrangements	People with severe or profound handicap				
	1981	1988	1993	1998	1998
Households	244.1	302.5	349.1	606.6	606.6
Cared accommodation ^(b)	27.0	24.2	19.2	20.0 ^(inc)	16.4 ^(exc)
Total	271.1	326.7	368.3	626.6	623.0
<i>Proportion in cared accommodation (%)</i>	<i>9.9</i>	<i>7.4</i>	<i>5.2</i>	<i>3.2</i>	<i>2.6</i>

- (a) In the 1981, 1988 and 1993 surveys, three levels of severity of handicap (severe, moderate and mild) were applied to both household and establishment components. In 1993 the severe handicap category was further divided into profound handicap and severe handicap, but the severe handicap category was not applied to the establishment component. In the 1998 survey both the profound and severe core activity restriction categories were applied to the cared accommodation component. To enable comparisons of the four surveys, the 3,600 people with severe core activity restriction in cared accommodation are first included in (inc) and then excluded from (exc) the 1998 results.
- (b) Cared accommodation (1998) and establishments (1981, 1988 and 1993) are defined by ABS as hospitals, nursing homes, hostels, retirement villages and other 'homes'.

Source: AIHW 1999a:256 (Table 7.19).

16.5 Summary

Demographics of the carer population

- In 1998, 450,900 Australians, or 2.4% of the total population, were primary carers of people with a disability. 317,300 females, or 3.4% of the total female population, were primary carers, in contrast to 133,500 males, or 1.4% of the total male population. 96,400 primary carers were aged 65 years or over; of those, 62.5% were females.
- Caring for a spouse was the most common caring relationship among adult primary carers. In 1998, there were 192,100 spouse primary carers, accounting for 42.9% of primary carers aged 15 years and over. Of those primary carers aged 65 years and over, 73,000 (75.5%) were spouses and 9,700 (10.0%) were parents of the main care recipient. Of those primary carers aged between 45 and 64 years, 80,000 (41.3%) were spouses, 65,800 (34.0%) were children and 28,700 (14.8%) were parents of the main care recipient.

Time spent caring

- 59,600 primary carers (13.3%) had been in the caring role for at least 25 years. 161,300 primary carers (36.0%) spent, on average, 40 hours or more per week in providing care; of those, 22,700 had been caring for at least 25 years.

Economic status of the carer population

- In 1998, nearly 50% of primary carers aged between 15 and 64 years were not in the labour force, compared to 23% of non-carers. Only one-third of primary carers aged between 15 and 64 years reported wages or salary as their principal source of cash income, in contrast to nearly 60% of those who were not a carer.

- 308,200 primary carers aged 15 years and over (69%) were recipients of a government pension or benefit. Half of all primary carers aged between 15 and 64 years relied on a pension or benefit as their principal source of income, as compared with 20% of those who were not in a caring role.

Assistance with caring

- Almost half of all primary carers aged 15 years and over received support in providing care. There were 41,300 primary carers (9.2%) who needed assistance but did not receive any help. More than 160,000 primary carers (35.7%) did not have a fall-back carer and 36,300 primary carers (8.1%) did not know if a fall-back carer was available.
- Primary carers living in non-capital city regions were less likely to receive assistance than those living in capital cities.
- 59,100 primary carers aged 15 years or over (13.2%) reported that they had used respite care services. 35,500 had used respite services in the three months prior to the survey, and, of those, 19,800 wanted more respite care. A vast majority of primary carers (86.8%) had never used respite care services; of these, 11% (43,800 primary carers) said that they needed such services.

Effects of the caring role

- 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.

The trend towards community living

- There is a continuing trend towards community living. In 1998, 606,600 people aged 5–64 years with a severe or profound core activity restriction were living in households, while only 20,000 were living in cared accommodation. One of the implications of this trend is that people with a disability are increasingly reliant on informal carers to provide the assistance they need.

17 Ageing and trends in service use

This chapter discusses the possible impacts of population ageing on trends in service use. Trends may be affected by the interplay of various factors discussed in this report: population growth, trends in the prevalence and severity of various disabilities, changes in life expectancy for people with various disabilities, trends in patterns of informal care, and changes in service provision. This report has clarified these factors as far as it can. For many of them, information currently available does not provide a solid basis for forward projections, but can be used to provide trend indications.

Therefore, it is not the purpose of this chapter to present projections of future trends in service use. Rather, the available information is used to provide broad indicators of trends in service use, based on a number of underlying assumptions. It is hoped that this may assist in planning broad-level resource allocation.

Section 17.1 discusses the methods, data sources, assumptions and caveats that underpin the estimates. Section 17.2 presents estimated future numbers of people with a severe or profound core activity restriction, which could be used as indicators of the size of the 'potential population' needing services. Section 17.3 discusses trends in service use.

17.1 Methods and underlying assumptions

Number of people with a severe or profound core activity restriction

The number of people with a severe or profound core activity restriction is generally accepted as a broad indicator of potential need for disability support services and is, for instance, used in the denominators for the service performance indicators presented in the CSDA MDS reports (e.g. AHIW 2000b) and the *Report on Government Services 2000* (SCRCSSP 2000).

The ABS survey definition of severe or profound core activity restriction does not directly relate to any particular category or level of impairment. Rather, it is based on the need for frequent or continual personal support in three areas of activity (self-care, mobility and communication). This corresponds quite closely to the CSDA 'target population', that is, people with a disability which results in substantially reduced capacity in at least one of three areas—self-care/management, mobility, communication—requiring ongoing or episodic support (Commonwealth of Australia 1998).

However, the survey questions about restrictions and limitations in activities are primarily focused on physical abilities, and may therefore emphasise the presence of restrictions arising from physical impairment (Madden et al. 1995). Therefore, using the number of people with a severe or profound core activity restriction may mismatch, to some extent, the number of people for whom CSDA-funded services would be appropriate. For instance, some people with an intellectual or psychiatric disability who are current recipients of

CSDA-funded services or who need support might be classified, under the ABS survey definition, as having a 'mild' or 'moderate' core activity restriction.

Three data sources are used to estimate growth in the number of people with a severe or profound core activity restriction:

- ABS 1998 Survey of Disability, Ageing and Carers, which provides the latest national information on the number of people with a severe or profound core activity restriction and their need for and receipt of assistance.
- ABS 1993 Survey of Disability, Ageing and Carers, which is used together with the 1998 survey to provide a range of estimates of the numbers of people with a severe or profound core activity restriction, taking into consideration the reported changes in prevalence rates between 1993 and 1998.
- ABS 1998 population projections data, which provide projected population sizes, and age and sex profiles between 1997 and 2051. The projections take account of possible future changes in fertility, mortality and migration and thus factor in the effects of population ageing resulting from the interaction of these components.

The estimates rely on three underlying assumptions:

- The age- and sex-specific prevalence rates of severe or profound core activity restriction in 1998 (or in 1993) remain constant over the projection period.
- The trend in population growth follows the ABS 1998 population projections.
- Other factors affecting the prevalence of severe or profound core activity restrictions remain unchanged in the future.

The population data used are the ABS 1998 population projections (1997 to 2051) Series K. This projection series assumes that the total fertility rate¹¹ declines to 1.6 births per woman in 2005–06, and then remains constant ('low assumption'). Series K also assumes an annual net overseas migration gain of 90,000 people from 1989–1999 to the end of the projection period ('high assumption') (ABS 1998a: 20). These assumptions closely reflect the recent decline in birth rate in Australia and the current level of net overseas migration (Chapter 2).¹²

It is important to be aware that any departure from these assumptions could result in different estimates. Therefore, the estimates should be interpreted in the context of the assumptions outlined above. Although estimates are presented for a period up to 2031, the discussion in this chapter focuses on the period of 2000–2006.

The 1998 disability survey indicated an increase in the prevalence of severe or profound core activity restrictions, which had been relatively stable between 1981 and 1993. On the basis of information and analyses to date, it appears that the increase in age-standardised prevalence rates of severe or profound core activity restriction between 1993 and 1998 may be mainly a result of improved survey methods which 'captured' a large number of people who were not identified as having a disability in the 1993 survey. In other words, the increase in estimated prevalence in 1998 may not reflect a substantial increase in the underlying prevalence of

¹¹ Total fertility rate is a summary measure based on age-specific fertility rates. The rate for a given year indicates the average number of children that women would have over their lifetimes if they experienced the rates of child-bearing experienced by women at each age in the given year.

¹² The other two assumptions concerning overseas migration for which ABS population projections are available are: an annual net gain of 70,000 people ('low assumption') and zero net migration gain throughout the projection period (ABS 1998a: 20).

disability and need for support (see Section 18.2 for discussion of the changes between 1993 and 1998). Hence, the estimated numbers of people with a severe or profound core activity restriction are based on 1998 prevalence rates and the rates are assumed to remain constant over the projection period. The changes in the prevalence rates between 1993 and 1998 have not been a factor in the assumptions. However, this chapter first presents growth estimates of severe or profound core activity restriction based on 1998 prevalence rates, then presents estimates based on 1993 prevalence rates to illustrate the growth that could have been expected had the 1993 prevalence rates persisted.

The method used to calculate the estimated number of people with a severe or profound core activity restriction is as follows:

Step 1: Data from the 1998 (or 1993) ABS Survey of Disability, Ageing and Carers are used to derive age- and sex-specific rates of severe or profound core activity restriction.

Step 2: These rates are applied to the projected 2000–2031 age and sex distributions of the Australian population (from the ABS Series K projections) to calculate the expected number of people with severe or profound core activity restriction, by age and sex.

Step 3: The resulting numbers for each age and sex group are summed to give an estimate of the total projected number of people with a severe or profound core activity restriction in the Australian population.

17.2 Growth estimates of severe or profound core activity restriction

This section presents the estimated future number of people with a severe or profound core activity restriction—the ‘potential population’ needing services. Growth estimates of severe or profound core activity restriction using 1998 and 1993 prevalence rates are presented, and differences between these two sets of estimates are discussed.

Growth estimates based on 1998 prevalence rates

Population trends, in particular population ageing, are expected to have a great impact on the number of people with a severe or profound core activity restriction. The growth estimates based on the 1998 age- and sex-specific prevalence rates indicate that, between 2000 and 2006, the total number of people with a severe or profound core activity restriction can be expected to increase by 11.6% (137,600 people) (Tables 17.1 and 17.2). This overall growth is mainly attributable to the rapid increase in size of the age groups 45–64 (19.3%, or 59,500 people) and 65 and over (15.0% or 76,300 people). Thus, the ageing of the working-age population and the aged population is expected to contribute strongly to the growth in number of people with a severe or profound core activity restriction.

Among people aged under 65, the total estimated increase in the number of people with a severe or profound core activity restriction between 2000 and 2006 is 9.0%, or 61,300 people. However, the rate of increase varies with age. Growth in the working age population (age 15–64) is estimated at 12.0%, or 64,300 people. The expected growth rate in the age group 45–64 is 19.3%, or 59,500 people—this is the highest growth rate of any age group. In contrast, the projected decline in the population aged under 15 will result in a 2.0% decrease in the number of people with a severe or profound core activity restriction in that age group (Tables 17.1 and 17.2).

Table 17.1: Percentage change in the estimated number of people with a severe or profound core activity restriction, by age and sex, Australia, 2000–2006 (based on 1998 prevalence rates)^{(a)(b)}

Age/sex	2000–2001	2001–2002	2002–2003	2003–2004	2004–2005	2005–2006	2000–2006
Males							
0–14	–0.1	–0.1	–0.2	–0.3	–0.6	–0.7	–2.0
15–19	0.8	0.2	0.0	0.3	0.9	0.7	3.0
20–29	–0.7	–0.4	0.1	0.4	0.5	0.8	0.7
30–44	1.2	1.0	0.6	0.3	0.0	–0.4	2.8
45–64	3.1	3.2	3.1	2.9	2.8	2.7	19.1
65+	2.8	2.7	2.5	2.4	2.9	3.2	17.7
Total 0–64	1.5	1.5	1.4	1.3	1.1	1.1	8.1
Total 15–64	2.1	2.1	2.0	1.8	1.7	1.7	11.9
<i>Total</i>	<i>1.9</i>	<i>1.9</i>	<i>1.8</i>	<i>1.6</i>	<i>1.7</i>	<i>1.8</i>	<i>11.2</i>
Females							
0–14	–0.1	–0.1	–0.2	–0.4	–0.7	–0.7	–2.2
15–19	0.7	0.4	0.1	0.2	0.7	0.8	3.0
20–29	–1.1	–0.9	–0.2	0.2	0.3	0.7	–0.9
30–44	1.0	0.8	0.4	0.3	0.1	0.0	2.6
45–64	3.1	3.1	3.0	3.0	3.0	2.9	19.4
65+	2.4	2.1	2.0	1.8	2.2	2.4	13.7
Total 0–64	1.7	1.7	1.6	1.6	1.5	1.5	10.0
Total 15–64	2.0	2.0	1.9	1.9	1.9	1.9	12.0
<i>Total</i>	<i>2.1</i>	<i>1.9</i>	<i>1.8</i>	<i>1.7</i>	<i>1.9</i>	<i>2.0</i>	<i>11.9</i>
Persons							
0–14	–0.1	–0.1	–0.2	–0.4	–0.6	–0.7	–2.0
15–19	0.8	0.3	0.1	0.3	0.8	0.8	3.0
20–29	–0.9	–0.6	0.0	0.3	0.4	0.8	–0.1
30–44	1.1	0.9	0.5	0.3	0.0	–0.2	2.7
45–64	3.1	3.2	3.1	2.9	2.9	2.8	19.3
65+	2.6	2.3	2.2	2.0	2.4	2.7	15.0
Total 0–64	1.6	1.6	1.5	1.4	1.3	1.3	9.0
Total 15–64	2.0	2.0	1.9	1.9	1.8	1.8	12.0
Total	2.0	1.9	1.8	1.7	1.8	1.9	11.6

(a) ABS 1998 population projections (Series K) as at 30 June.

(b) Estimated numbers were calculated using age- and sex-specific prevalence rates derived from the ABS 1998 Survey of Disability, Ageing and Carers.

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

Table 17.2: Estimated number of people with a severe or profound core activity restriction, by age and sex ('000), Australia, 2000–2031 (based on 1998 prevalence rates)^{(a)(b)}

Age/sex	2000	2001	2002	2003	2004	2005	2006	2011	2021	2031
Males										
0–14	98.2	98.1	98.0	97.9	97.5	96.9	96.2	92.8	91.2	92.9
15–19	17.9	18.1	18.1	18.1	18.2	18.3	18.5	18.8	17.4	17.4
20–29	26.0	25.8	25.7	25.8	25.9	26.0	26.2	27.2	27.6	25.9
30–44	66.4	67.2	67.9	68.3	68.5	68.5	68.2	68.5	71.0	73.4
45–64	147.3	151.8	156.7	161.6	166.2	170.8	175.4	192.6	208.6	214.8
65+	172.1	177.0	181.8	186.3	190.8	196.3	202.5	233.9	315.6	424.6
Total 0–64	355.7	361.0	366.5	371.6	376.2	380.5	384.5	399.9	415.8	424.4
Total 15–64	257.6	262.9	268.4	273.7	278.7	283.6	288.3	307.2	324.6	331.5
<i>Total</i>	<i>527.8</i>	<i>538.0</i>	<i>548.2</i>	<i>557.9</i>	<i>567.0</i>	<i>576.8</i>	<i>587.1</i>	<i>633.8</i>	<i>731.4</i>	<i>849.0</i>
Females										
0–14	47.2	47.1	47.1	47.0	46.8	46.5	46.1	44.4	43.6	44.5
15–19	13.9	14.0	14.0	14.0	14.1	14.2	14.3	14.5	13.4	13.4
20–29	25.5	25.2	25.0	24.9	25.0	25.1	25.3	26.3	26.6	25.0
30–44	78.1	78.9	79.5	79.8	80.1	80.1	80.1	80.3	81.8	84.6
45–64	161.2	166.1	171.3	176.4	181.7	187.1	192.5	214.0	233.2	238.0
65+	335.8	343.9	351.2	358.3	364.7	372.7	381.7	425.3	540.8	729.3
Total 0–64	325.8	331.3	336.9	342.3	347.6	353.0	358.3	379.6	398.7	405.5
Total 15–64	278.7	284.2	289.8	295.3	300.8	306.5	312.2	335.1	355.1	361.0
<i>Total</i>	<i>661.7</i>	<i>675.3</i>	<i>688.1</i>	<i>700.5</i>	<i>712.3</i>	<i>725.7</i>	<i>740.1</i>	<i>804.8</i>	<i>939.5</i>	<i>1,134.8</i>
Persons										
0–14	145.3	145.2	145.1	144.8	144.3	143.4	142.4	137.2	134.8	137.4
15–19	31.8	32.0	32.1	32.1	32.2	32.5	32.7	33.3	30.8	30.7
20–29	51.5	51.1	50.7	50.7	50.9	51.1	51.5	53.5	54.2	50.9
30–44	144.5	146.0	147.3	148.1	148.6	148.7	148.3	148.9	152.8	158.0
45–64	308.4	318.0	328.0	338.0	347.8	357.8	368.0	406.6	441.8	452.8
65+	507.9	520.9	533.0	544.6	555.5	569.0	584.3	659.2	856.4	1,153.9
Total 0–64	681.6	692.3	703.3	713.8	723.8	733.5	742.9	779.5	814.5	829.9
Total 15–64	536.2	547.1	558.2	569.0	579.5	590.1	600.5	642.3	679.7	692.5
Total	1,189.5	1,213.2	1,236.3	1,258.4	1,279.4	1,302.5	1,327.1	1,438.7	1,670.9	1,983.8

(a) ABS 1998 population projections (Series K) as at 30 June.

(b) Estimated numbers were calculated using age- and sex-specific prevalence rates derived from the ABS 1998 Survey of Disability, Ageing and Carers.

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

Growth estimates based on 1993 prevalence rates

Growth estimates based on the 1993 age- and sex-specific prevalence rates show a similar pattern to the estimates based on 1998 rates, but the estimated numbers of people are lower. Estimates based on 1993 rates suggest that, between 2000 and 2006, the total number of people with a severe or profound core activity restriction will increase by 12.6% (106,800 people). The overall growth is largely due to the rapid increase in the age groups 45–64 (19.4%, or 35,600 people) and 65 and over (15.7%, or 68,900 people). This pattern again reflects a strong impact of population ageing on the number of people with a severe or profound core activity restriction (Tables 17.3 and 17.4).

Between 2000 and 2006, the total estimated growth in the number of people aged under 65 with a severe or profound core activity restriction is 9.2%, or 38,000 people. The increase in the working age population (aged 15–64) is estimated at 11.2%, or 38,900 people. There is an expected decrease of 1.5% in the number of people with a severe or profound core activity restriction aged under 15 (Tables 17.3 and 17.4).

Differences between the estimates based on 1993 and 1998 prevalence rates

Table 17.5 compares the estimated number of people with a severe or profound core activity restriction based on 1993 and 1998 age- and sex-specific prevalence rates. In the 1993 survey, severity of core activity restriction was not determined for children aged under 5 with a disability. For comparative purposes, Table 17.5 provides two sets of estimates using 1998 rates: one for people aged 5 or over and one for people of all ages.

The growth estimates based on 1993 and 1998 prevalence rates can be thought of as representing low and high ends (respectively) of a range for the future number of people with a severe or profound core activity restriction. For people aged 5 or over, the low end of the range in 2000 is 850,900 (1993 rates) and the high end is 1,162,300 (1998 rates) (Table 17.5)—a difference of 311,400 people. In 2006, for people aged 5 or over, the difference between the low end (using 1993 rates) and the high end (using 1998 rates) is 343,700 people.

The differences between the estimates based on 1993 and 1998 rates are due to differences in age- and sex-specific prevalence rates between 1993 and 1998 (Figure 17.1). In comparison with the 1993 survey, the reported prevalence of severe or profound core activity restriction in 1998 survey was higher in several age groups, particularly the age groups 45–64 and 70–79 for males and females, and the age group 5–14 for males (see discussions in Chapters 12 and 13). The inclusion of children aged under 5 with a severe or profound core activity restriction in 1998 also contributed to the overall higher prevalence rate.

Table 17.3: Percentage change in the estimated number of people with a severe or profound core activity restriction, by age and sex, Australia, 2000–2006 (based on 1993 prevalence rates)^{(a)(b)}

Age/sex	2000–2001	2001–2002	2002–2003	2003–2004	2004–2005	2005–2006	2000–2006
Males							
5–14 ^(c)	0.1	0.1	0.0	–0.2	–0.6	–0.6	–1.2
15–19	0.8	0.2	0.0	0.3	0.9	0.7	3.0
20–29	–0.7	–0.4	0.1	0.4	0.4	0.8	0.6
30–44	0.9	0.7	0.4	0.3	0.1	–0.1	2.3
45–64	3.1	3.3	3.1	2.8	2.8	2.7	19.3
65+	3.1	3.0	2.7	2.6	3.1	3.4	19.3
Total 5–64 ^(c)	1.5	1.6	1.5	1.3	1.2	1.2	8.7
Total 15–64	1.8	1.9	1.8	1.7	1.6	1.6	11.0
<i>Total</i>	2.2	2.2	2.0	1.9	2.0	2.1	13.0
Females							
5–14 ^(c)	0.0	0.0	–0.2	–0.4	–0.6	–0.7	–1.9
15–19	0.7	0.4	0.1	0.2	0.7	0.8	3.0
20–29	–0.9	–0.7	–0.1	0.3	0.4	0.7	–0.2
30–44	1.4	1.1	0.7	0.4	–0.1	–0.5	3.0
45–64	3.0	3.3	3.1	2.9	2.9	2.9	19.5
65+	2.5	2.2	2.1	1.9	2.2	2.4	14.0
Total 5–64 ^(c)	1.7	1.8	1.6	1.5	1.4	1.3	9.7
Total 15–64	1.9	2.0	1.9	1.7	1.7	1.6	11.3
<i>Total</i>	2.1	2.0	1.9	1.7	1.9	2.0	12.2
Persons							
5–14 ^(c)	0.1	0.1	–0.1	–0.3	–0.6	–0.7	–1.5
15–19	0.8	0.3	0.1	0.3	0.8	0.8	3.0
20–29	–0.8	–0.6	0.0	0.3	0.4	0.8	0.2
30–44	1.1	0.9	0.6	0.3	0.0	–0.3	2.7
45–64	3.1	3.3	3.1	2.9	2.9	2.8	19.4
65+	2.7	2.5	2.3	2.2	2.5	2.7	15.7
Total 5–64 ^(c)	1.6	1.7	1.6	1.4	1.3	1.3	9.2
Total 15–64	1.9	2.0	1.9	1.7	1.7	1.6	11.2
Total	2.2	2.1	1.9	1.8	1.9	2.0	12.6

(a) ABS 1998 population projections (Series K) as at 30 June.

(b) Estimated numbers were calculated using age- and sex-specific prevalence rates derived from the ABS 1993 Survey of Disability, Ageing and Carers.

(c) In the 1993 survey, severity of core activity restriction was not determined for children aged 0–4 years with a disability.

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

Table 17.4: Estimated number of people with a severe or profound core activity restriction, by age and sex ('000), Australia, 2000–2031 (based on 1993 prevalence rates)^{(a)(b)}

Age/sex	2000	2001	2002	2003	2004	2005	2006	2011	2021	2031
Males										
5–14 ^(c)	38.9	38.9	39.0	38.9	38.9	38.6	38.4	36.9	35.8	36.7
15–19	8.4	8.5	8.5	8.5	8.6	8.6	8.7	8.9	8.2	8.2
20–29	20.6	20.5	20.4	20.4	20.5	20.6	20.7	21.5	21.9	20.5
30–44	49.6	50.0	50.4	50.6	50.7	50.8	50.7	51.1	52.8	54.8
45–64	85.9	88.6	91.6	94.5	97.1	99.8	102.5	112.2	121.5	125.2
65+	141.1	145.4	149.8	153.8	157.9	162.7	168.2	195.5	260.7	355.5
Total 5–64 ^(c)	203.4	206.5	209.8	212.9	215.8	218.4	221.1	230.6	240.2	245.4
Total 15–64	164.6	167.6	170.8	174.0	176.9	179.8	182.7	193.8	204.4	208.7
<i>Total</i>	<i>344.5</i>	<i>351.9</i>	<i>359.6</i>	<i>366.7</i>	<i>373.7</i>	<i>381.2</i>	<i>389.3</i>	<i>426.2</i>	<i>500.9</i>	<i>601.0</i>
Females										
5–14 ^(c)	26.4	26.4	26.4	26.3	26.2	26.1	25.9	24.8	24.2	24.8
15–19	9.0	9.1	9.1	9.1	9.1	9.2	9.3	9.4	8.7	8.7
20–29	23.8	23.6	23.4	23.4	23.5	23.6	23.8	24.7	24.9	23.4
30–44	53.3	54.0	54.6	55.0	55.2	55.2	54.9	55.0	55.9	57.9
45–64	97.1	100.0	103.3	106.5	109.6	112.8	116.1	127.8	138.8	141.8
65+	296.8	304.2	310.9	317.5	323.6	330.6	338.5	377.6	479.6	647.1
Total 5–64 ^(c)	209.6	213.1	216.8	220.4	223.6	226.8	229.9	241.7	252.6	256.6
Total 15–64	183.2	186.7	190.5	194.0	197.4	200.7	204.0	216.9	228.4	231.8
<i>Total</i>	<i>506.4</i>	<i>517.3</i>	<i>527.8</i>	<i>537.8</i>	<i>547.2</i>	<i>557.4</i>	<i>568.4</i>	<i>619.3</i>	<i>732.2</i>	<i>903.7</i>
Persons										
5–14 ^(c)	65.2	65.3	65.3	65.3	65.1	64.7	64.3	61.7	60.0	61.6
15–19	17.4	17.6	17.6	17.6	17.7	17.8	18.0	18.3	16.9	16.8
20–29	44.4	44.1	43.8	43.8	44.0	44.2	44.5	46.2	46.8	43.9
30–44	102.9	104.0	105.0	105.6	106.0	106.0	105.6	106.1	108.8	112.7
45–64	183.0	188.6	194.9	201.0	206.7	212.6	218.6	240.0	260.3	266.9
65+	437.9	449.6	460.7	471.3	481.5	493.3	506.8	573.1	740.3	1,002.7
Total 5–64 ^(c)	413.0	419.6	426.7	433.3	439.4	445.3	451.0	472.3	492.8	502.0
Total 15–64	347.8	354.3	361.3	368.0	374.3	380.6	386.7	410.6	432.8	440.5
Total	850.9	869.2	887.3	904.6	920.9	938.6	957.7	1,045.5	1,233.1	1,504.7

(a) ABS 1998 population projections (Series K) as at 30 June.

(b) Estimated numbers were calculated using age- and sex-specific prevalence rates derived from the ABS 1993 Survey of Disability, Ageing and Carers.

(c) In the 1993 survey, severity of core activity restriction was not determined for children aged 0–4 years with a disability.

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

Table 17.5: Comparison of estimated number of people with a severe or profound core activity restriction: estimates based on 1993 and 1998 prevalence rates, by age and sex, Australia, 2000–2006^{(a)(b)}

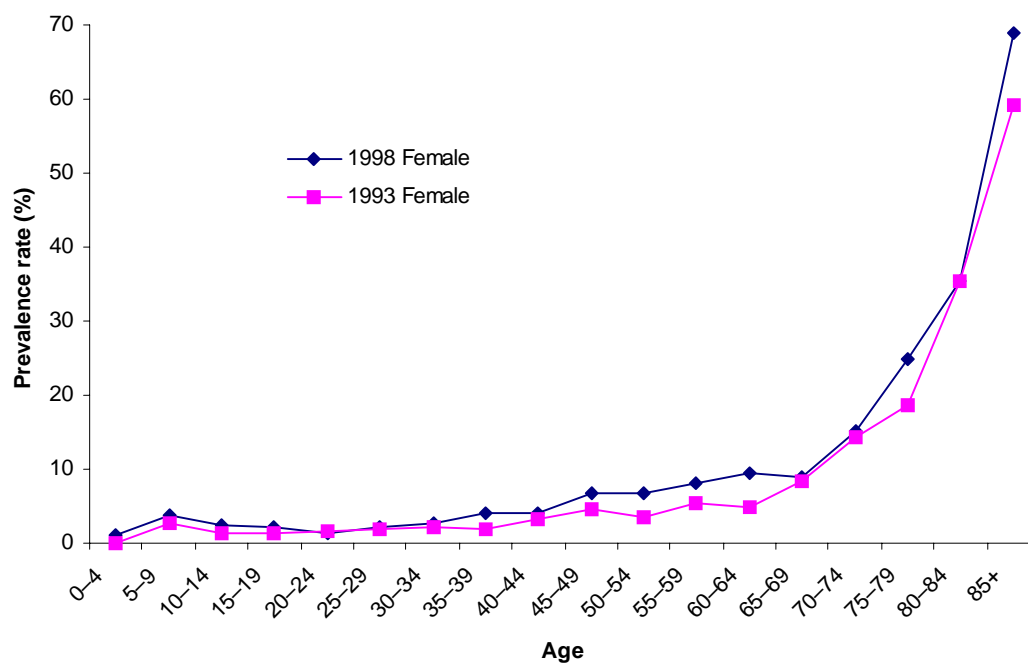
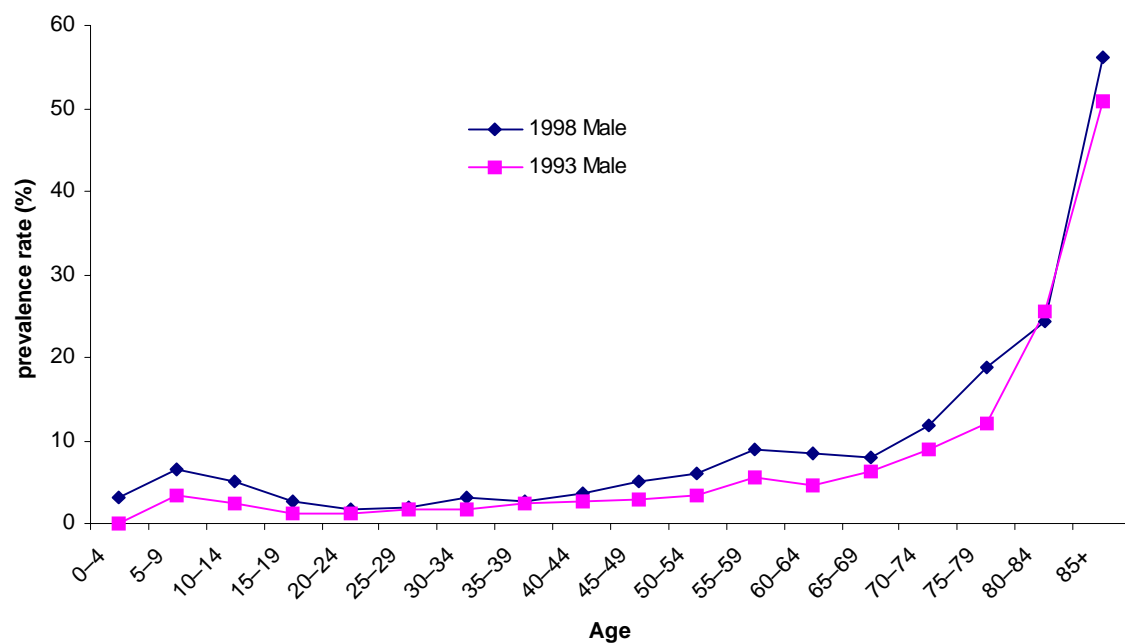
Age/sex	Number ('000)						Percentage change		
	2000			2006			2001–2006		
	1993 rates	1998 rates	1998 rates	1993 rates	1998 rates	1998 rates	1993 rates	1998 rates	1998 rates
	Aged 5+	Aged 5+	All ages	Aged 5+	Aged 5+	All ages	Aged 5+	Aged 5+	All ages
Males									
0–14 ^(c)	38.9	78.1	98.2	38.4	77.3	96.2	–1.2	–1.1	–2.0
15–19	8.4	17.9	17.9	8.7	18.5	18.5	3.0	3.0	3.0
20–29	20.6	26.0	26.0	20.7	26.2	26.2	0.6	0.7	0.7
30–44	49.6	66.4	66.4	50.7	68.2	68.2	2.3	2.8	2.8
45–64	85.9	147.3	147.3	102.5	175.4	175.4	19.3	19.1	19.1
65+	141.1	172.1	172.1	168.2	202.5	202.5	19.3	17.7	17.7
Total 0–64 ^(c)	203.4	335.7	355.7	221.1	365.6	384.5	8.7	8.9	8.1
Total 15–64	164.6	257.6	257.6	182.7	288.3	288.3	11.0	11.9	11.9
<i>Total</i>	<i>344.5</i>	<i>507.8</i>	<i>527.8</i>	<i>389.3</i>	<i>568.1</i>	<i>587.1</i>	<i>13.0</i>	<i>11.9</i>	<i>11.2</i>
Females									
0–14 ^(c)	26.4	40.0	47.2	25.9	39.4	46.1	–1.9	–1.6	–2.2
15–19	9.0	13.9	13.9	9.3	14.3	14.3	3.0	3.0	3.0
20–29	23.8	25.5	25.5	23.8	25.3	25.3	–0.2	–0.9	–0.9
30–44	53.3	78.1	78.1	54.9	80.1	80.1	3.0	2.6	2.6
45–64	97.1	161.2	161.2	116.1	192.5	192.5	19.5	19.4	19.4
65+	296.8	335.8	335.8	338.5	381.7	381.7	14.0	13.7	13.7
Total 0–64 ^(c)	209.6	318.7	325.8	229.9	351.6	358.3	9.7	10.3	10.0
Total 15–64	183.2	278.7	278.7	204.0	312.2	312.2	11.3	12.0	12.0
<i>Total</i>	<i>506.4</i>	<i>654.5</i>	<i>661.7</i>	<i>568.4</i>	<i>733.3</i>	<i>740.1</i>	<i>12.2</i>	<i>12.0</i>	<i>11.9</i>
Persons									
0–14 ^(c)	65.2	118.2	145.3	64.3	116.7	142.4	–1.5	–1.3	–2.0
15–19	17.4	31.8	31.8	18.0	32.7	32.7	3.0	3.0	3.0
20–29	44.4	51.5	51.5	44.5	51.5	51.5	0.2	–0.1	–0.1
30–44	102.9	144.5	144.5	105.6	148.3	148.3	2.7	2.7	2.7
45–64	183.0	308.4	308.4	218.6	368.0	368.0	19.4	19.3	19.3
65+	437.9	507.9	507.9	506.8	584.3	584.3	15.7	15.0	15.0
Total 0–64 ^(c)	413.0	654.4	681.6	451.0	717.1	742.9	9.2	9.6	9.0
Total 15–64	347.8	536.2	536.2	386.7	600.5	600.5	11.2	12.0	12.0
Total	850.9	1,162.3	1,189.5	957.7	1,301.4	1,327.1	12.6	12.0	11.6

(a) ABS 1998 population projections (Series K) as at 30 June.

(b) Estimated numbers were calculated using age- and sex-specific prevalence rates derived from the ABS 1993 and 1998 Survey of Disability, Ageing and Carers, respectively, to show a range of estimates.

(c) In the 1993 survey, severity of core activity restriction was not determined for children aged 0–4 years with a disability.

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



Note: In the 1993 survey, severity of core activity restriction was not determined for children aged under 5 with a disability.

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

Figure 17.1: Age- and sex-specific prevalence rates of severe or profound core activity restriction, Australia, 1993 and 1998

17.3 Trends in service use

This section discusses trends in CSDA-funded service use. The previous section has shown that the projected population trends, in particular population ageing, are expected to have a substantial impact on the growth in the number of people with a severe or profound core activity restriction—the ‘potential population’ needing services. The estimated future growth in the number of people with a severe or profound core activity restriction is affected by two aspects of population ageing in Australia: the ageing of the aged population and the rapid ageing of the working-age population. However, growth of the target population may not necessarily result in an equivalent increase in the number of consumers of CSDA-funded services. Future trends in service use will be affected by the interplay of various factors, including service provision policies and the level of available resources.

Figure 17.2 and Table 17.6 show a comparison of the age composition of consumers of CSDA-funded services and the estimated population with a severe or profound core activity restriction in 1999. Almost 73% of people with a severe or profound core activity restriction were aged 40 or over, in comparison with only 34% of consumers of CSDA-funded services. The highest proportions of consumers of CSDA-funded services were in the age groups of 20–29 (22.6%) and 30–39 (23.0%), while only 12% of people with a severe or profound core activity restriction were in these age groups. About 12% of consumers of CSDA-funded services were aged 50–64, in comparison with 19% of people with a severe or profound core activity restriction.

Table 17.6: Age distribution of people with a severe or profound core activity restriction and consumers of CSDA-funded services, Australia, 1999

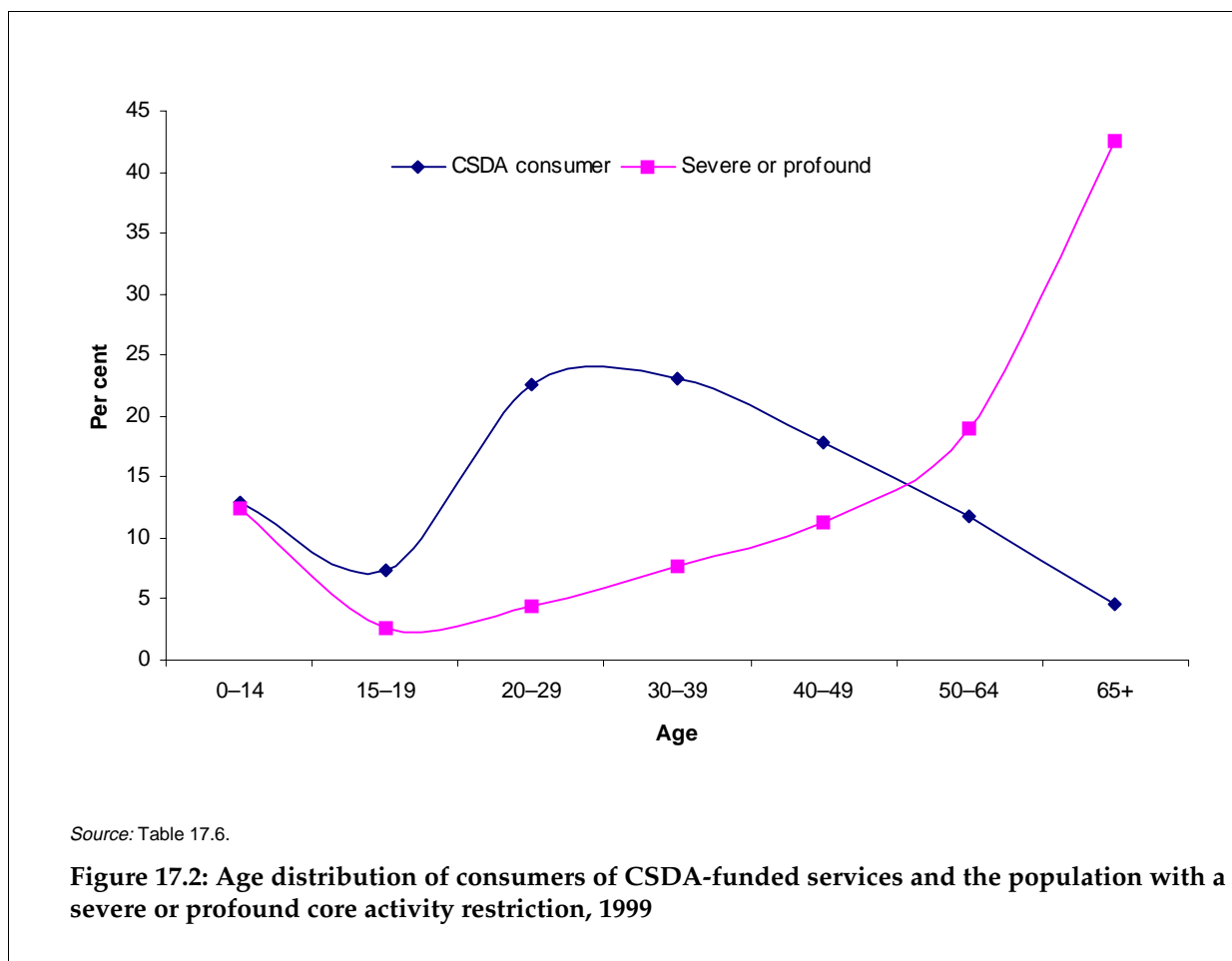
	Severe or profound ^(a)			CSDA consumers ^(b)		
	Number	% of 0–64	% of total	Number	% of 0–64	% of total
0–14	145,200	13.6	12.4	8,157	21.7	13.0
15–19	31,500	7.7	2.7	4,626	4.7	7.4
20–29	51,600	23.6	4.4	14,155	7.7	22.6
30–39	89,200	24.1	7.6	14,451	13.3	23.0
40–49	132,200	18.6	11.3	11,145	19.7	17.8
50–64	220,900	12.3	18.9	7,368	32.9	11.7
65+	495,700	—	42.5	2,850	—	4.5
0–64	670,500	100.0	57.5	59,902	100.0	95.5
15–64	525,300		45.0	51,744		82.5
All ages	1,166,200		100.0	62,752		100.0

(a) Estimated numbers of people with a severe or profound core activity restriction in 1999.

(b) Based on the number of people who received services on the ‘snapshot’ day in 1999 from providers who received at least some CSDA funding. The numbers are estimates, made using a linkage key (AIHW Disability Data Briefing Number 17, March 2000).

— Nil or rounded to zero.

Source: AIHW analysis of ABS 1998 Survey of Disability, Ageing and Carers data; AIHW analysis of 1999 CSDA MDS collection; ABS 1998a.

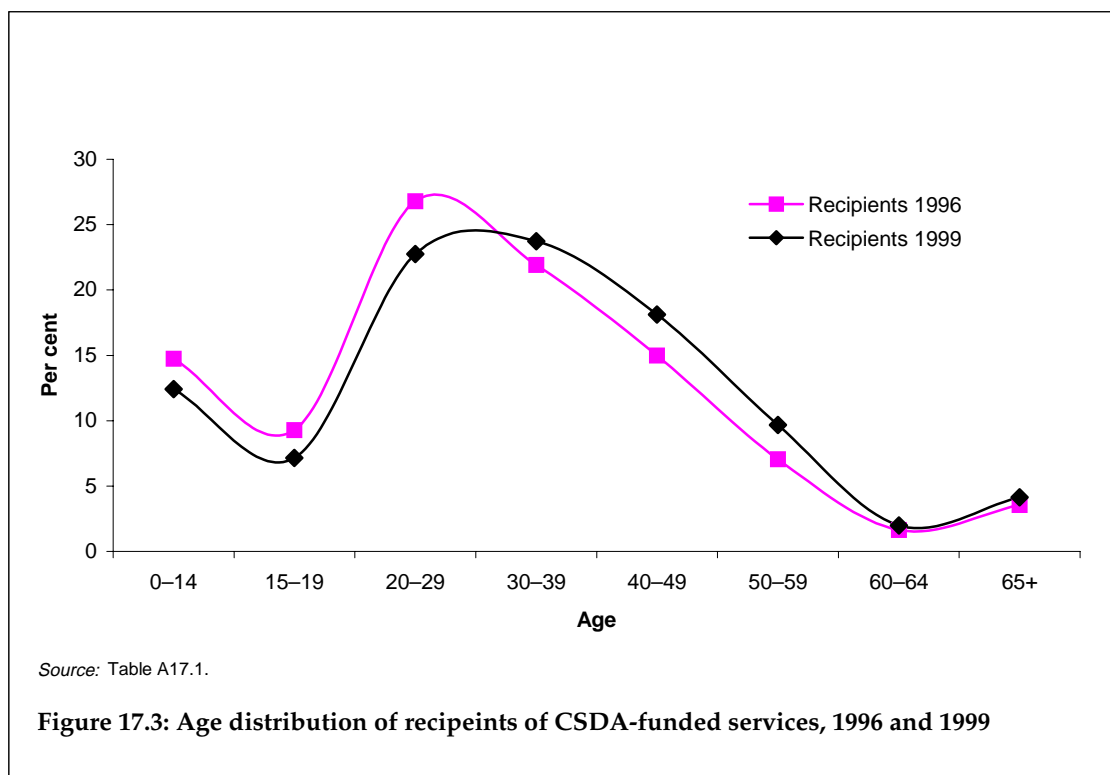


This comparison raises some important questions: Is the current service use pattern, with a peak of consumers aged 20–39, likely to continue in future years? Does the current age distribution of consumers reflect an increase in service use that started 30–40 years ago, combined with a population bulge and longer life expectancies for people with a disability?

Figure 17.3 shows the distribution of CSDA services classified by age of recipients in 1996 and 1999.¹³ The figure suggests the age distribution of service recipients has changed over time. In particular, 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. Throughout the age spectrum the 1999 curve appears to be a few years ahead of the 1996 curve, suggesting that the apparent bulge may be moving through and that, in future years, the age distribution may change in shape, perhaps flattening out. Clearly, it will be important to continue to monitor the age distribution of service recipients over coming years.

If the age distribution of CSDA 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

¹³ 'Recipients' is a count of the number of services received on the 'snapshot' day; it is not a count of individuals, as a person who received services from more than one provider would be counted more than once. In comparing 1996 and 1999 data it is necessary to use 'recipients' rather than consumers, as counts of consumers only became possible in 1999 with the use of the linkage key.



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 (Table 17.1). Could the service use pattern approach the population prevalence pattern, or is there a pattern of ‘retirement’ from CSDA services?

Between 1996 and 1999, the overall growth rate of recipients of CSDA-funded services was 8.4%, or 2.7% per year (Table 17.7). The general shape of the age-specific growth rates of service recipients followed a similar but ‘accelerated’ pattern to that of the population with severe or profound core activity restrictions, in particular from the age group of 35+ (Figure 17.4 and Table 17.7). The high growth rates in service recipients in the upper-end of the working-ages not only partly reflect the effect of the baby-boom generation, but may also relate to a high level of service retention among service users who began receiving services in the 1960s or later decades. The decline in service recipients aged under 25 is consistent with the possibility that service provision for an increasing number of older people could be creating an access trough for younger people, behind this wave.

Table 17.8 and Figure 17.5 illustrate changes in Commonwealth, State and Territory Government recurrent outlays on disability services and aged care services between 1992–93 and 1997–98.¹⁴ During this period, the average annual growth rate in expenditure on welfare services for people with a disability was 4.7%, in contrast to 14.4% for aged care services.

¹⁴ Excluding government pensions and benefits.

Table 17.7 Age-specific growth rates (%) of the population with a severe or profound core activity restriction and recipients of CSDA-funded services, Australia, 1996–1999

Age	Severe or profound ^(a)		Recipients ^(b)	
	Total growth	Annual growth	Total growth ^(c)	Annual growth
0–4			–1.4	–0.5
5–9	1.9	0.6	–10.2	–3.6
10–14	0.9	0.3	–4.9	–1.7
15–19	2.8	0.9	–14.0	–5.0
20–24	–5.5	–1.9	–11.3	–4.0
25–29	5.4	1.7	1.6	0.5
30–34	–1.6	–0.5	13.5	4.2
35–39	3.8	1.2	29.4	8.6
40–44	4.9	1.6	29.8	8.7
45–49	1.9	0.6	42.2	11.7
50–54	18.7	5.7	50.5	13.6
55–59	9.9	3.2	57.6	15.2
60–64	8.5	2.7	35.8	10.2
65+	8.4	2.7	30.1	8.8
Total	6.7	2.2	8.4	2.7

(a) Growth rates were calculated based on estimated numbers of people with a severe or profound core activity restriction in 1996 and 1999.

(b) Growth rates were calculated based on estimated numbers of recipients of CSDA-funded services on the 'snapshot' day in 1996 and 1999.

(c) Total included service recipients who did not state their age.

Source: AIHW 1997; Table A17.1.

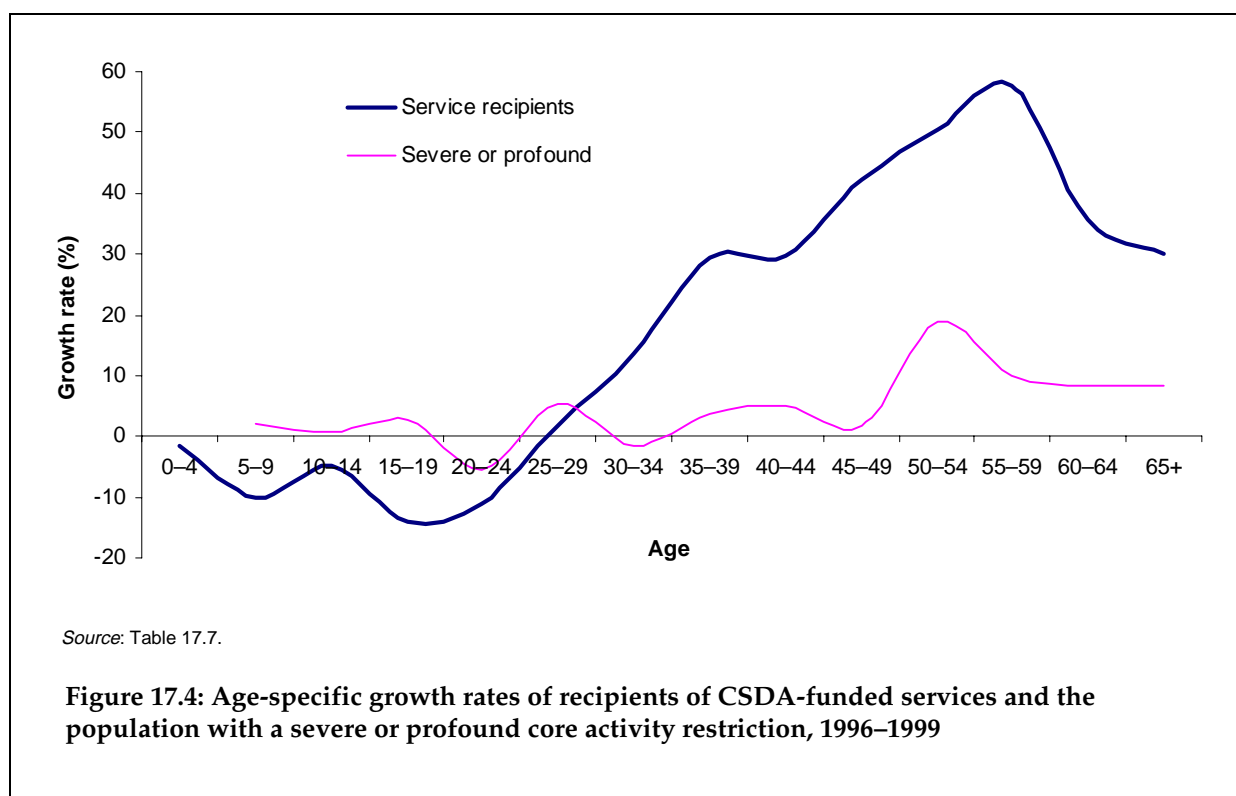
Table 17.8: Commonwealth, State and Territory government recurrent outlays on welfare services^(a) in 1996–97 prices, 1992–93 to 1997–98 (\$ million)

Year	Aged care services	Disability services
1992–93	1,069	1,456
1993–94	1,214	1,594
1994–95	1,450	1,645
1995–96	1,490	1,645
1996–97	1,745	1,737
1997–98	2,092	1,831
Average annual growth rate ^(b)	14.4%	4.7%

(a) Excluding government pensions and benefits.

(b) Five-year average annual growth rates are calculated using exponential growth.

Source: AHIW 1999d:13.



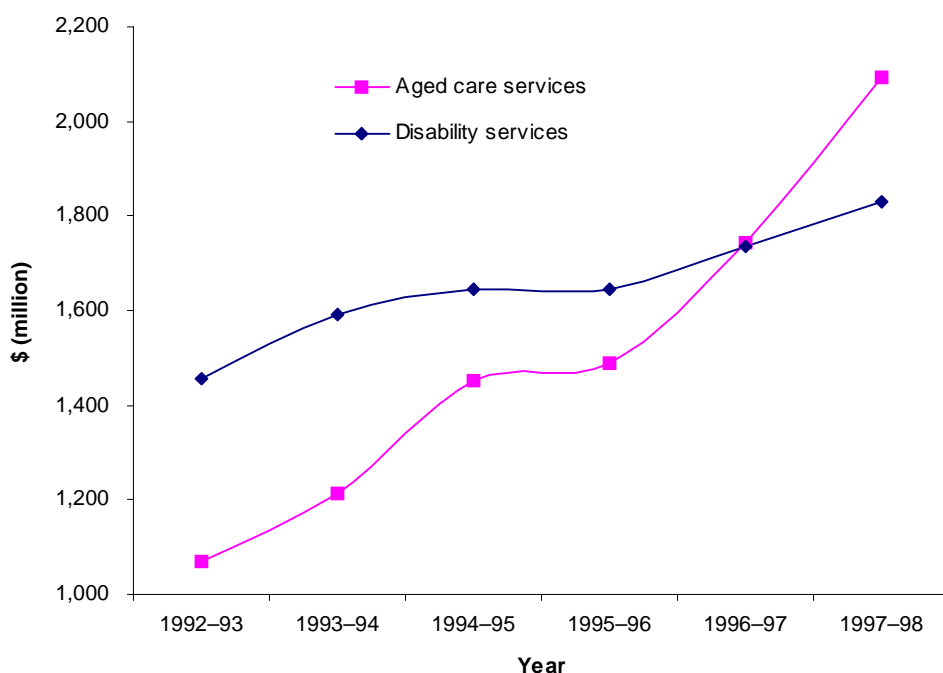
Potential transfer of people from employment services to other disability support services

As people with a disability age their service needs are likely to change. Retirement of people currently in Commonwealth-funded employment services may result in increased demand for alternative services (e.g. community access services), putting pressure on some areas of the CSDA program.

On the 'snapshot' day of the 1999 CSDA MDS data collection, there were 17,734 consumers of CSDA services who were currently in Commonwealth funded employment programs.¹⁵ As these consumers age, many of them may move (or attempt to move) to community access services or other CSDA services. Table 17.9 presents the 1999 CSDA MDS data on consumers of Commonwealth employment services and shows how many of these consumers also received other CSDA services.

Data on consumers in 1999 are derived via the use of a statistical linkage key, which enables removal of double-counting where a person receives more than one service on the snapshot day. However, Western Australia did not use the standard linkage key. Instead, records were pre-matched within the State, and so could not be linked to the Commonwealth data from employment services in Western Australia. This makes it difficult to estimate the number of consumers of employment services in Western Australia who also accessed other CSDA services (AIHW 2000b). Therefore, the estimates in Table 17.9 do not include Western Australian data.

¹⁵ The Commonwealth's final 1999 CSDA MDS data on the 'snapshot' day show that there were 18,392 consumers of CSDA services who were currently in Commonwealth-funded employment programs.



Source: Table 17.8.

Figure 17.5: Commonwealth, State and Territory government recurrent outlays on welfare services in 1996-97 prices, 1992-93 to 1997-98

On the 'snapshot' day of the 1999 collection, 15,558 consumers of CSDA services were in Commonwealth employment programs (excluding Western Australia); of those, 12,873 (or 83%) were not accessing any other CSDA services. Among those not receiving other CSDA services, 2,401 (15% of all consumers of Commonwealth employment services) were aged 45 or over and 1,268 (8%) were aged 50 or over.

If the national age and sex distribution of consumers were applied to the Western Australian data, there would be 335 consumers of Commonwealth employment services in Western Australia who were aged 45 or over, and were not receiving other CSDA services; of those, 178 consumers would be aged 50 or over. If these figures are included in the national estimates then, in 1999, there were 2,736 consumers of Commonwealth employment services who were aged 45 or over and were not accessing any other CSDA services; of these, 1,446 were aged 50 or over.

However, it is important to note that consumers who did not use employment services on the 'snapshot' day were not included in the estimates. Also, some people identified as using only employment services may have used other services during the year but not on the 'snapshot' day. Because of consumer turnover, and because service users may not actually receive a service every day, the estimates for the 'snapshot' day are much lower than the estimates for a full year (AIHW 2000b: Table 4.2).

Among consumers of Commonwealth employment services, 5,211 were aged 30-44 and were not accessing any other CSDA services (Table 17.9). Over the next decade, these consumers will be approaching their late 40s or 50s when many of them might choose to retire and possibly seek access to other types of services.

Table 17.9: Consumers of Commonwealth employment services: whether received other CSDA services, by age and sex, Australia, 1999^(a)

	Does not receive other services			Receives other services			All		
	Male	Female	Total	Male	Female	Total	Male	Female	Total
	Number								
15–19	730	347	1,077	45	23	68	775	370	1,145
20–29	2,611	1,493	4,104	367	252	619	2,978	1,745	4,723
30–44	3,297	1,914	5,211	767	559	1,326	4,064	2,473	6,537
45–64	1,545	782	2,327	414	247	661	1,959	1,029	2,988
65+	60	14	74	5	6	11	65	20	85
Not stated	45	35	80	0	0	0	45	35	80
<i>Total 45+</i>	<i>1,605</i>	<i>796</i>	<i>2,401</i>	<i>419</i>	<i>253</i>	<i>672</i>	<i>2,024</i>	<i>1,049</i>	<i>3,073</i>
<i>Total 50+</i>	<i>868</i>	<i>400</i>	<i>1,268</i>	<i>214</i>	<i>136</i>	<i>350</i>	<i>1,082</i>	<i>536</i>	<i>1,618</i>
Total	8,288	4,585	12,873	1,598	1,087	2,685	9,886	5,672	15,558
	Percentage of all consumers of employment services of that sex								
<i>Total 45+</i>	<i>28.3</i>	<i>14.0</i>	<i>15.4</i>	<i>7.4</i>	<i>4.5</i>	<i>4.3</i>	<i>35.7</i>	<i>18.5</i>	<i>19.8</i>
<i>Total 50+</i>	<i>8.8</i>	<i>7.1</i>	<i>8.2</i>	<i>2.2</i>	<i>2.4</i>	<i>2.2</i>	<i>10.9</i>	<i>9.4</i>	<i>10.4</i>
Total	83.8	80.8	82.7	16.2	19.2	17.3	100.0	100.0	100.0

(a) Consumer data are estimates obtained by adjusting data on service recipients for those who appear to have accessed more than one service type on the 'snapshot' day, using a statistical linkage key. The Western Australian data were excluded as it was not possible to link data from Commonwealth employment services with data from other service types in Western Australia (AIHW *Disability Data Briefing* Number 17, March 2000).

Source: AIHW analysis of the 1999 CSDA MDS collection.

Potential transfer to other services

It may be also useful to examine the profile of need and type of services received among ageing recipients of CSDA-funded services, to indicate their special needs as they potentially approach a service transition. Table 17.10 presents data on reported frequency of need for support for service recipients aged 45–64.¹⁶ In addition to self-care, mobility and communication, the data on areas of support need also include social skills, managing emotions, learning, working, home living, self-direction and other day activities.

Of 14,524 recipients aged 45–64, 5,814 (40%) received accommodation support services, 3,437 (23.7%) received employment services, 2,930 (20.2%) received community access services and 2,039 (14.0%) received community support services. A small proportion (2.1%) used respite services (Table A17.2).

The top section of Table 17.10 presents data on the support needs of recipients across all service types. The percentage who reported a need for frequent or continual assistance ranged from 34% for mobility to 63% for home living activities. The percentage of recipients

¹⁶ Some caution is needed in interpreting these data, because a person may have received services from more than one service provider on the 'snapshot' day, and will therefore be counted more than once.

reporting no need for support was highest for mobility (38%), communication (32%) and self care (30%), and lowest for home living (11%) and working (8%).

In comparison with other service types, higher proportions of accommodation service recipients tended to report need for frequent or continual support. This was the pattern across the range of areas of support. Recipients of employment services were less likely to need frequent or continual support with self-care and mobility than were recipients of other services.

Table 17.10: CSDA services received on the snapshot day: frequency of support needed by recipients aged 45–64, by service type and area of activity in which support needed (per cent), 1999

Area of support	None	Occasional	Frequent	Continual	Total frequent and continual	Not applicable	Not known /not stated
All service types							
Self-care	30.0	25.3	18.4	22.9	41.3	0.0	3.4
Mobility	38.3	25.7	16.5	17.0	33.5	0.0	2.3
Communication	31.7	29.6	17.4	19.0	36.4	0.0	2.3
Social skills	18.8	30.7	23.7	23.4	47.1	0.1	3.3
Managing emotions	16.4	32.3	25.3	24.0	49.3	0.1	2.0
Learning	13.4	25.4	27.9	29.1	57.0	0.7	3.5
Working	7.9	18.0	15.7	44.3	60.0	8.2	5.9
Home living	11.1	18.8	25.2	38.1	63.3	0.5	6.3
Self-direction	13.1	27.3	27.6	28.9	56.5	0.1	2.9
Other day activity	14.3	26.1	24.1	26.5	50.6	1.4	7.5
Accommodation support							
Self-care	17.8	24.4	22.4	33.3	55.7	0.1	2.1
Mobility	30.5	25.4	19.4	22.6	42.0	0.0	2.0
Communication	24.1	28.8	19.7	25.2	44.9	0.0	2.2
Social skills	12.6	26.3	26.2	32.1	58.3	0.2	2.6
Managing emotions	10.6	27.5	27.6	33.4	61.0	0.1	0.8
Learning	8.9	19.9	29.1	38.2	67.3	1.0	2.8
Working	6.6	10.9	12.8	53.0	65.8	10.8	5.8
Home living	3.0	14.4	27.0	52.4	79.4	0.8	2.4
Self-direction	8.0	21.3	29.5	38.6	68.1	0.2	2.4
Other day activity	6.8	23.5	27.1	36.7	63.8	1.8	4.0
Employment							
Self-care	51.2	28.3	10.8	5.8	16.6	—	3.9
Mobility	55.7	27.5	8.8	7.1	15.9	—	0.9
Communication	38.6	34.9	15.9	9.8	25.7	—	0.8
Social skills	25.1	43.4	20.2	9.0	29.2	—	2.3
Managing emotions	22.6	42.6	23.0	9.5	32.5	—	2.3
Learning	13.4	41.0	28.5	15.2	43.7	—	1.9
Working	7.4	45.2	27.8	18.7	46.5	—	0.8
Home living	23.5	26.4	21.5	15.2	36.7	—	13.3
Self-direction	16.4	40.4	27.6	13.6	41.2	—	1.9
Other day activity	29.2	31.2	15.5	7.9	23.4	—	16.3

(continued)

Table 17.10 (continued): CSDA services received on the snapshot day: frequency of support needed by recipients aged 45–64, by service type and area of activity in which support needed (per cent), 1999

Area of support	None	Occasional	Frequent	Continual	Total frequent and continual	Not applicable	Not known/not stated
Community support							
Self-care	33.8	22.3	15.7	21.4	37.1	0.2	6.5
Mobility	35.7	24.6	17.0	18.0	35.0	0.2	4.6
Communication	43.6	27.7	11.8	11.8	23.6	0.2	4.9
Social skills	27.7	29.1	20.0	16.1	36.1	0.2	6.9
Managing emotions	21.5	32.5	23.2	16.6	39.8	0.2	6.0
Learning	25.7	25.4	21.9	17.6	39.5	1.1	8.2
Working	14.8	9.8	8.5	36.7	45.2	16.6	13.6
Home living	15.0	22.1	22.7	32.0	54.7	0.1	8.1
Self-direction	22.0	29.1	23.3	19.1	42.4	0.2	6.3
Other day activity	17.2	27.2	22.3	21.4	43.7	4.1	7.8
Community access							
Self-care	27.8	25.6	21.3	22.3	43.6	—	3.0
Mobility	36.0	25.4	19.0	17.0	36.0	0.0	2.5
Communication	28.4	26.8	18.9	23.5	42.4	0.0	1.3
Social skills	16.8	25.8	26.0	28.4	54.4	0.1	2.9
Managing emotions	15.7	28.3	25.2	29.5	54.7	—	1.2
Learning	12.2	18.3	29.5	36.8	66.3	0.5	2.8
Working	5.9	6.8	13.2	62.4	75.6	6.2	5.4
Home living	10.4	16.1	28.2	40.5	68.7	0.2	4.5
Self-direction	12.0	22.6	27.2	35.5	62.7	0.0	2.7
Other day activity	10.3	24.8	29.1	32.0	61.1	0.5	3.2
Respite							
Self-care	22.4	23.7	16.8	31.3	48.1	—	5.9
Mobility	31.3	24.0	21.1	17.8	38.9	—	4.1
Communication	49.7	22.7	12.8	9.5	22.3	—	5.2
Social skills	25.0	27.6	19.4	18.1	37.5	1.3	8.5
Managing emotions	26.0	32.4	22.4	14.8	37.2	—	4.4
Learning	27.0	24.0	22.4	16.1	38.5	2.0	8.5
Working	10.9	7.6	7.9	44.1	52.0	14.1	15.4
Home living	5.9	19.1	23.4	38.2	61.6	5.3	8.2
Self-direction	24.0	25.7	23.7	19.1	42.8	1.6	5.9
Other day activity	10.2	22.4	28.0	25.0	53.0	1.3	13.1

- (a) An individual may be counted more than once if more than one service type was accessed on the 'snapshot' day.
 (b) Data for recipients of CSDA-funded services with service types Advocacy, Information/referral, Combined advocacy/information, Print disability/alt. formats of communication, Service evaluation/training, Peak bodies, Research/development and Other were not collected.
 (c) Data on managing emotions for recipients of CSDA services funded by Western Australia were not collected and 1,161 recipients are excluded from this support area.
 (d) Data provided by the Commonwealth are preliminary and cover 98% of Commonwealth-funded services.
 — Nil or rounded to zero.

Source: Table A17.2; AIHW analysis of 1999 CSDA MDS collection.

17.4 Summary and discussion

Many of the factors discussed in this report may affect future trends in demand for and provision of disability support services. This chapter has concentrated on the possible effects of population growth and ageing, assuming that the trend in population growth follows the ABS 1998 population projections. Growth estimates of severe or profound core activity restriction were carried out based on a number of assumptions: the age- and sex-specific prevalence rates of severe or profound core activity restriction in 1998 remain constant, and other factors affecting the prevalence rate or service use rates remain unchanged in the future.

Growth estimates of severe or profound core activity restriction

Estimates of future growth in the population potentially needing services are based on simplifying assumptions.

The projected demographic trends, especially population ageing, indicate a significant growth in the estimated number of people with a severe or profound core activity restriction between 2000 and 2006. Estimates based on 1998 age- and sex-specific prevalence rates indicate that:

- The total number of Australians with a severe or profound core activity restriction is estimated to increase by 11.6% (137,600 people). This overall growth is mainly attributable 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 expected increase in the number of people aged 0–65 with a severe or profound core activity restriction is 9.0% (61,300 people).
- The growth in the working age population (age 15–64) is estimated at 12.0% (64,300 people).
- The number of people with a severe or profound core activity restriction aged under 15 is expected to decrease by 2%.

The future number of people with a severe or profound core activity restriction was also estimated using 1993 age- and sex-specific prevalence rates. The estimates based on the two sets of prevalence rates show a similar pattern but the magnitude of the growth differs. In 2000, the estimated number of people with a severe or profound core activity restriction using 1998 rates is higher than the estimated number using 1993 rates by 311,400 for people aged 5 and over, and 338,600 for people of all ages.

The differences between the two sets of estimates are due to differences in age- and sex-specific prevalence rates between 1993 and 1998. In comparison with the 1993 survey, the reported prevalence in 1998 was higher than in 1993 for several age groups, particularly the age groups 45–64 and 70–79 for males and females, and the age group 5–14 for males. The higher overall prevalence in 1998 was also partly due to the inclusion of children aged under 5 with a severe or profound core activity restriction.

The changes between 1993 and 1998 may reflect improved case identification in the 1998 survey, rather than actual increases in disability prevalence and need for support. Hence, the estimated numbers of people with a severe or profound core activity restriction are based on 1998 prevalence rates and the rates are assumed to remain constant over the projection

period. The changes in the prevalence rates between 1993 and 1998 have not been a factor in the assumptions.

Trends in service use

Future trends in service use are determined by the interplay of various factors, including service provision policies and the level of available resources. The increase in the number of people with a severe or profound core activity restriction may not necessarily result in an equivalent increase in the number of consumers of CSDA-funded services.

The current age distribution of CSDA service users may change under the effects of both population ageing and the ageing of people with a disability. There is evidence that age-specific rates of service use have not been stationary over recent years. Between 1996 and 1999, the overall growth rate of service recipients was 8.4%, or 2.7% per year. The general shape of the age-specific growth rates of service recipients followed a similar but 'accelerated' pattern to that of the population with a severe or profound core activity restriction, in particular from the age group of 35+. During this period, the age distribution of service recipients has also changed over time. 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. The current peak of service use in the age group 20–39 years may partly represent a 'new wave' of service users who began receiving services at younger ages, and may be assumed likely to continue to use services.

It could be expected that this trend may continue, with the combined effects of growth in the number of people in the upper end of the working-age population and longer life expectancies of people with a disability. Between 2000 and 2006, the number of people with a severe or profound core activity restriction in the age group 45–64 is projected to increase by 19.3%, or 59,500 (based on 1998 prevalence rates).

The 'early retirement' of people currently in Commonwealth-funded employment services may create needs for other services to replace the employment services, putting pressure on some areas of the CSDA program. Similarly, 'retirement' of people using accommodation services may result in a need for greater service flexibility, either to enable 'ageing in place' or to facilitate a smooth transition to appropriate residential aged care.

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).

19 Conclusion

This chapter draws out the most salient information on ageing and disability, for disability administrators to consider when planning the evolution of services.

The findings are discussed under three main headings:

- implications of overall demographic change in the Australian population;
- understanding the 'grey' areas in services for people with a disability as they age;
- implications for the nature of services.

It is not the purpose of this report to make specific policy recommendations but to highlight trends and patterns that seem to raise questions and issues for policy makers to consider.

This chapter, therefore, indicates policy implications and may be viewed as a companion to the Summary, which addresses all the questions set out in the project brief.

19.1 Implications of overall demographic change in the Australian population

This section outlines the potential impact of overall demographic change in the Australian population on services relevant to people ageing with a disability, and highlights implications for broad-level resource allocation. The major findings, including scenarios of future trends in service use, are quantified and could be used by policy makers to estimate broad cost implications.

Population growth

The Australian population is projected to grow from 18.5 million in 1997 to between 22.1 and 23.1 million in 2021, and between 23.5 million and 26.4 million in the year 2051. Annual population growth rates are projected to vary between 1.0% and 1.1% during 1997–2001, and there is 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).

Growth in population size is likely to contribute to an increase in the number of people with a disability. Nevertheless, since a low level of overall population growth is projected (at about 1% or lower per year up to 2051), the main impact of demographic change on the number of people with a disability will be the ageing of the Australian population.

Population ageing

The proportion of people aged 65 years and over is projected to increase from 12% (2.2 million people) in 1997 to 18% (4.0 million people) in 2021 and between 24% (6.0 million people) and 26% (6.3 million people) in 2051 (Table 2.1). Two particular aspects of population ageing are likely to impact on services:

- *The rapid pace of ageing of the working-age population:* The greatest growth among the working-age population will be in the population aged 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 number will reduce steadily over the period (ABS 1998a; Tables 2.2 and 2.3; Figure 2.1).

- *The 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 (Table A2.3). The number of people aged 85 and over is projected to increase by around 5.3 times—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 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).

The bulge of the baby-boom generation

The post–World War II baby-boom population has started entering the age groups with significantly higher risks of disability, and its bulge continues to affect the age structure of the population. 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 a higher rate (26.9%) than any other age group (Table 2.2; Figure 2.2).

The baby-boom generation is progressively moving up the age pyramid and will cause rapid growth in the size of the aged population. The growth of the population aged 65 and over is projected to reach record rates—to increase by 36.2%—as the peak of the baby-boom generation reaches retirement age between 2011 and 2021 (Tables 2.2 and 2.3; Figure 2.2).

Growth estimates of severe or profound core activity restriction

The projected demographic trends, especially population ageing, indicate a significant growth in the estimated number of people with a severe or profound core activity restriction between 2000 and 2006. Estimates based on 1998 age- and sex-specific prevalence rates indicate that (Chapter 17):¹⁷

- The total number of Australians with a severe or profound core activity restriction is likely to increase by 11.6% (137,600 people). This overall growth is mainly attributable to the rapid increase in the age groups 45–64 (19.3%, or 59,500 people) and 65 or over (15% or 76,300 people).
- The number of people aged 0–64 with a severe or profound core activity restriction will increase by 9.0% (61,300 people)
- The size of the working-age population (age 15–64) will increase by 12.0% (64,300 people).
- There will be a decrease in the number of people with a severe or profound core activity restriction aged 0–14.

¹⁷ The 1998 disability survey indicated an increase in the prevalence of severe or profound core activity restrictions between 1993 and 1998. On the basis of information and analyses to date, it appears that the increase may be mainly a result of improved survey methodology, which ‘captured’ a large number of people who were not identified in the 1993 survey. In other words, the increase in 1998 may not reflect a significant increase in underlying prevalence of disability and need for support (Chapters 17 and 18). All estimates in the following sections are based on the 1998 disability survey data.

Resource management issues

An assessment of resource implications for the full range of services relevant to people with a disability as they age is beyond the scope of this study. It is nevertheless useful to reflect on the possible lessons from other policy areas concerning ways of addressing increasing demand while recognising the need to limit expenditure. Over the past two decades, there has been an increase in both general health expenditure and health and welfare expenditure on older people. Nevertheless, many changes have been made to the health and aged care systems to maintain care at an affordable level. The controls put in place in health and welfare expenditure to contain costs have resulted in a manageable increase in government expenditure. In comparison with some European developed countries, Australia's relatively young population age structure provides scope for a shift in government expenditure towards older people in the future (Chapter 4).

It is also arguable that the age dependency ratio, commonly defined as the ratio of persons 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 for the purpose of planning disability and aged care services. Many people acquire a disability before age 65. The working-age population therefore includes people with a disability whose labour force participation may be limited, as well as unemployed people who may also receive income support and other welfare services. Also, the majority of people aged 65 to 80 have no need for long-term aged care services and many people aged 65 or over continue to participate in paid or voluntary work.

Trends in CSDA service use

Future trends in service use are determined by the interplay of various factors, including service provision policies and the level of available resources. Between 1996 and 1999, the overall growth rate of recipients of CSDA-funded services was 8.4%, or 2.7% per year.

There is evidence that age-specific rates of service use have not been stationary over recent years and that the sharp peak in service use that was located in the 20–29 year age group in 1996 is moving across into older age groups and flattening out (Figure 17.3). This may be related not only to the baby boom effect, but also to the evolution of new disability services in recent decades. That is, the current peak of service use in the age group 20–39 years may partly reflect a 'new wave' of service users who began receiving services at younger ages, who have retained those services and, it may be assumed, are likely to continue to do so.

If the age distribution of CSDA 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 (Table 17.1).

It is beyond the scope of the study to estimate the potential effects of higher rates of service provision. However it is possible that service provision rates may rise, as significant new resources are being allocated to CSDA disability support services. In August 2000 the Commonwealth Minister for Family and Community Services announced an additional \$510 million funding nationally over two years—\$150 million provided by the Commonwealth Government and the remainder provided by State and Territory Governments (Newman 2000).

19.2 Understanding the ‘grey’ areas in services for ageing people with a disability

As people with a disability age, they may encounter service ‘grey areas’. That is, it may not be clear what services are most appropriate to meet their changing needs, or services that meet their needs may not be available. Alternatively, as people age, their needs may span service types and/or program areas, and they may not fully meet eligibility criteria (e.g. age criteria) for some services that would meet their needs.

Australian support services are traditionally differentiated around the 65-year mark. Accommodation support services provided under the CSDA generally focus on people aged under 65, while in residential aged care it is the 65-plus age group that predominates (Figure 19.1). However, there are grey areas, as can be seen from the numbers of aged care residents between the ages of 45 and 65 years—small numbers in relation to residential aged care services, but significant in relation to CSDA accommodation services. In 1999 there were 6,094 people aged less than 65 years in aged care residential facilities, similar to the number of residents in CSDA-funded institutions or large residential accommodation (5,534) and hostels (914) (AIHW 2000b).

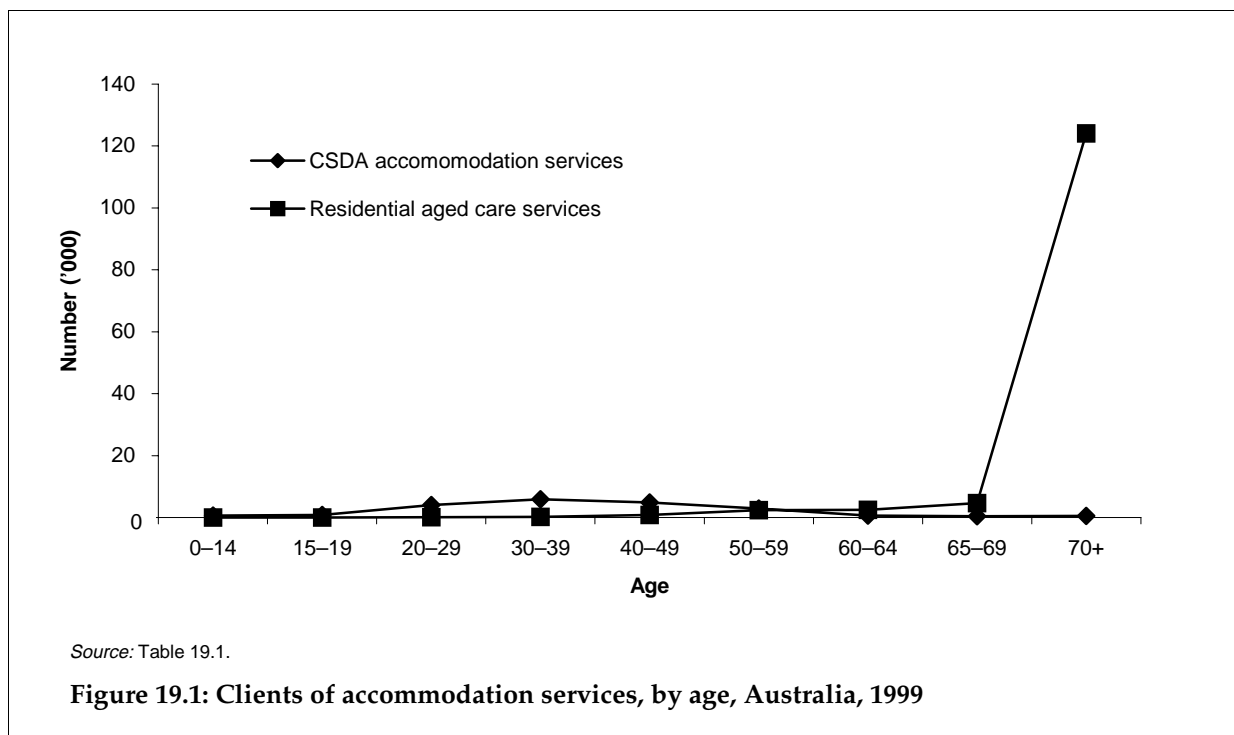
People aged over 65 years also predominate in HACC services, but in 1997–98 about 20% of clients were aged under 65 (Table 6.5).

Table 19.1: Recipients of Disability Support Pension and Age Pension, people with a severe or profound core activity restriction, consumers of CSDA accommodation support services and consumers of residential aged care services ('000), Australia, 1999

	Disability Support Pension recipients ^(a)	Age Pension recipients	Severe or profound core activity restriction	CSDA accom. services	Residential aged care services
0–14	0.0	—	145.2	0.7	0.0
15–19	13.1	—	31.5	0.8	0.0
20–29	47.9	—	51.6	4.0	0.1
30–39	76.5	—	89.2	5.9	0.3
40–49	113.8	—	132.2	4.9	0.9
50–59	196.8	—	153.5	2.9	2.4
60–64	101.0	187.3	67.4	0.6	2.5
65–69	2.7	479.9	57.4	0.4	4.7
70+	—	1,015.5	438.3	0.5	124.1
<i>All ages</i>	<i>551.7</i>	<i>1,682.6</i>	<i>1,166.2</i>	<i>20.7</i>	<i>134.9</i>

(a) Data on DSP recipients for the 15–19 age group are actually the number of recipients aged 16–19 and data for the 65–69 age group are actually the number of recipients aged 65 and over.
— Nil or rounded to zero.

Source: Centrelink, unpublished data; AIHW analysis of ABS 1998 Survey of Disability, Ageing and Carers data; ABS 1998a; AIHW analysis of CSDA Minimum Data Set 1999; AIHW analysis of System of Payment for Aged Residential Care data.

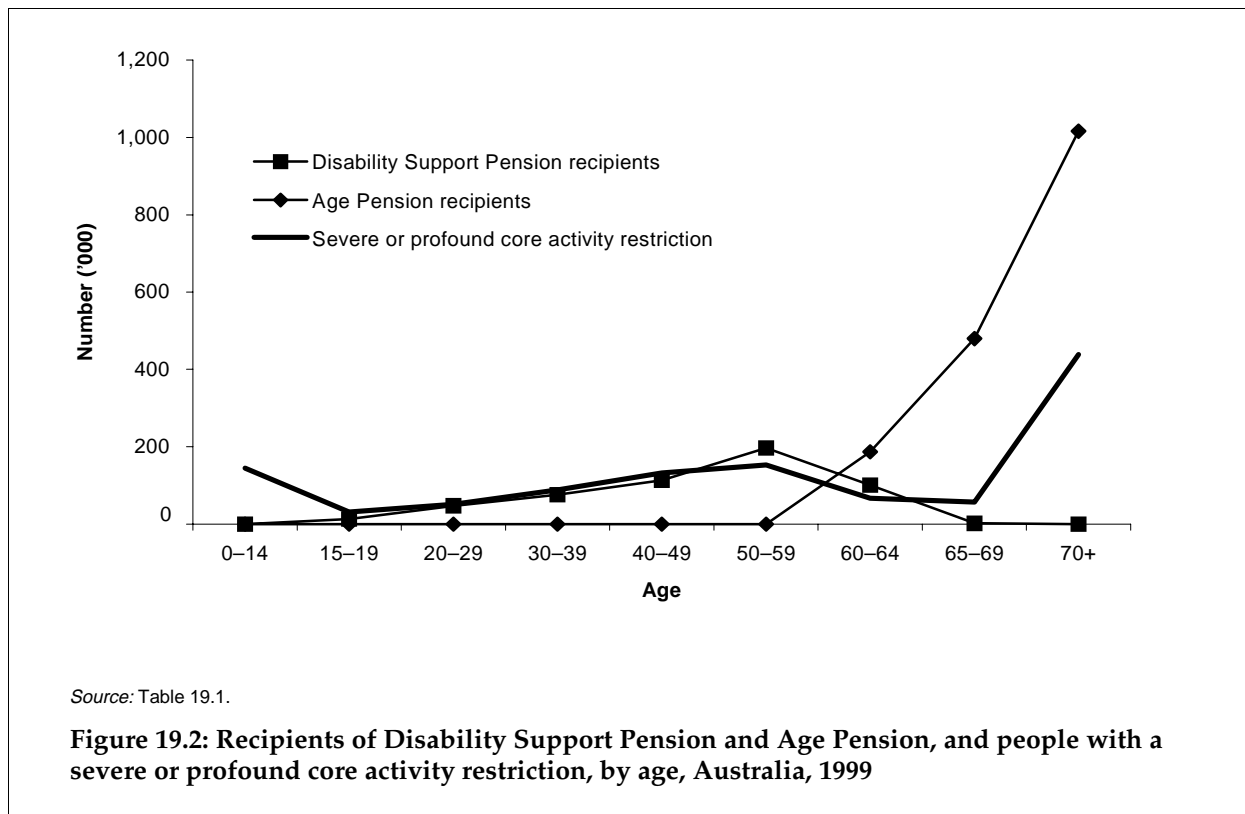


Income support for people with a disability aged under 65 years depends on meeting eligibility criteria. For instance, eligibility criteria for the Disability Support Pension are related to impairment levels and assessed ability to work. Eligibility for the Age Pension is determined on the basis of age (currently a minimum of 61½ years for women and 65 years for men) and income and asset tests. The effect is that the numbers of people receiving the Disability Support Pension are commensurate with numbers of people with severe or profound core activity restriction (although the profile differs—see AIHW 1993: 295). After age 65 years the number of Age Pension recipients rises rapidly, and would subsume previous recipients of the Disability Support Pension (Figure 19.2).

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 mainstream aged care services. This transition is most likely to affect people with an early onset disability in their later working-age years (i.e. the 45–64 age group). For some people this transition may be difficult, and may require substantial personal adjustment and/or changes in informal care arrangements.

These ‘grey areas’ and potential service transitions for people ageing with a disability form a backdrop to the discussion in this section.

National disability and aged care administrators are aiming to ensure that services become more flexible and tailored to individual needs, and the discussion in this chapter strongly confirms the wisdom of this approach. Nevertheless, this approach faces particular challenges at the border between aged care and disability services. The analyses of population survey data provide information about the range of needs of people in this border territory (Chapter 15). This information may assist administrators to identify service gaps, to use existing services more flexibly and to modify services rather than creating new service types or duplicating services in both systems.



Comparing the current disability and aged care service systems

Similarities between the current disability and aged care service systems are mainly in terms of broad service philosophies and policy directions. The two systems differ in their program focus, service types, main target groups and trained personnel (Chapter 9). The main differences that may be relevant to the service transition are:

- Aged care services are mainly geared to provide for the needs of frail older people and older people with a disability, in particular those aged 65 or more, while disability services generally focus on people with a disability 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 services to support employment.

For people with an early onset disability, the perception of 'being older' tends to occur at a younger age, often at age 55 or below. As they age, their health needs may become dominant over their needs for support in other areas of life. Thus, aged care services may be appropriate to meet the needs of some people ageing with a disability, but age-based eligibility may prevent them accessing those services.

Differences between people with a disability aged under 65 and those aged 65 or over

Although people generally have a greater level of need for assistance as they age, this does not mean that, among people with a disability, the older population overall has higher levels of need for assistance than those aged under 65. Among people with a severe or profound core activity restriction living in households in 1998, there were differences in the levels and

profiles of need for assistance between those aged under 65 and those aged 65 or more (Table 19.2; Chapter 15):

- 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.
- 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 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.

Differences between these two broad age groups in terms of the proportion of people with early onset disability and dominant types of main disabling condition may partially explain these observed differences in level and profile of need for assistance (Table 19.3).

In 1998, 42% of people aged under 65 with a severe or profound core activity restriction acquired their disability before age 18. Of people aged 65 or over, 96% acquired their disability at age 18 or older (Table 19.3).

Many disabling conditions have strong associations with particular age groups. 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) and intellectual (102,400 people). For people aged 65 or over, the two largest main condition groups were physical/other (268,900 people) and vision (28,900 people). 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 (Table 19.3; 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 main condition tended to report higher levels of need for assistance in comparison with people in other main condition groups (Chapter 15).

Most people with a severe or profound core activity restriction living in households were assisted by co-resident informal carers. In comparison with people aged 65 or over, people aged under 65 were more likely to rely on a co-resident carer as their main source of assistance with all daily activities except communication, and were less likely to receive formal assistance with self-care, health care, property maintenance, housework and meal preparation. Compared with people aged under 65, those 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 (Chapter 15). These differences in patterns of main sources of assistance may have implications for the nature of the 'service transition' (see Sections 19.3 and 19.4).

Any service transition may be marked by an even sharper division for people ageing with an early onset disability, since they may have a more limited network of informal carers (Chapter 8). In particular, the data suggest that they may be less likely to have a spouse (Chapter 15).

Table 19.2: People with a severe or profound core activity restriction living in households: differences in need for assistance and sources of assistance between people aged under 65 and those aged 65 or over, Australia, 1998

	Under 65 years		65 years or over	
	Number ('000)	%	Number ('000)	%
Need for assistance				
One of ten daily activities ^(a)	633.4	99.6	324.6	99.6
More than one core activity	264.3	41.5	122.4	37.6
All three core activities	56.0	8.8	17.0	5.2
<i>Total severe or profound</i>	<i>636.0</i>		<i>325.6</i>	
Main source of assistance is a formal service provider assistance^(b)				
Self-care	14.5	4.0	17.8	11.5
Mobility	28.6	6.3	22.2	8.1
Communication	18.0	13.0	—	—
Health care	49.8	15.5	95.4	44.1
Housework	18.6	7.4	60.0	26.5
Property maintenance	40.0	12.9	74.9	30.0
Paperwork	*9.0	7.0	*5.1	*4.6
Meal preparation	*6.0	*4.9	23.7	19.7
Transport	18.9	6.4	22.8	9.8
Main source of assistance is a co-resident carer^(b)				
Self-care	305.5	84.6	113.4	73.1
Mobility	343.9	76.2	148.1	54.1
Communication	113.6	82.1	25.3	88.5
Health care	240.9	74.8	92.8	42.9
Housework	207.5	82.2	129.5	57.3
Property maintenance	209.7	67.7	112.9	45.3
Paperwork	98.0	75.4	70.0	63.4
Meal preparation	104.8	86.2	86.3	71.8
Transport	224.3	76.4	108.5	46.7

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

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

— Nil or rounded to zero.

Source: Chapter 15; AIHW analysis of the ABS 1998 Survey of Disability, Ageing and Carers.

Table 19.3: People with a severe or profound core activity restriction living in households: differences in age at onset and main condition between people aged under 65 and those aged 65 or over, Australia, 1998

	Under 65 years		65 years or over	
	Number ('000)	%	Number ('000)	%
Age at onset of disability^(a)				
Before age 18 years	265.1	42.0	13.0	4.1
At age 18 years or over	365.9	58.0	306.3	95.9
Main condition^(b)				
Intellectual	102.4	99.6	**0.4	**0.4
Psychiatric	47.0	75.8	15.0	24.2
Vision	*6.4	*18.1	28.9	82.0
Hearing	16.7	61.1	10.6	38.8
Acquired brain injury	10.0	84.6	**1.8	**15.4
Physical/other	453.5	62.8	268.9	37.2

(a) Total excludes people who did not know their age at onset of disability.

(b) As a percentage of people of all ages in that main condition group (sum horizontally).

Source: Chapter 15; AIHW analysis of the ABS 1998 Survey of Disability, Ageing and Carers.

The needs of people aged 45–64 years

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 and 243,800 acquired a disability during adulthood (Chapter 15). The onset of a disability early in life can affect the development of basic living skills, resulting in higher levels of need for assistance in some areas. The nature of services required by older people with an early onset disability may also differ from that required by their younger counterparts.

People who acquire a disability later in life generally have acquired basic living skills. However, need for assistance may arise because of increasing physical frailty and diminishing functional skills.

Some people with an intellectual disability may acquire dementia relatively early in life, at age around 50 (Chapter 7). They become frail and their need for health and medical care is generally more significant than their need for help with other activities. These people might be more appropriately assisted by aged care services, rather than disability support services, due to their early ageing and deteriorating health.

The retirement of people currently in Commonwealth-funded employment services may give rise to needs for other services, potentially putting pressure on some areas of the CSDA program. Data from the 1999 CSDA MDS collection indicate that there were 2,736 consumers of Commonwealth employment services who were aged 45 or over and were not accessing any other CSDA services; of these, 1,446 were aged 50 or over (Chapter 17).

Implications for services

What are the implications of these comparisons for services for people ageing with a disability? The picture is complex and there are no simple answers.

The literature and data suggest that patterns of need do vary with age, age at onset, type of disability and availability of informal care. People with early onset disability may age earlier and hence have higher levels of need at earlier ages. They may also have different types of needs. Some of these differences may be related to differences in main disabling condition, in comparison with people who acquire disabilities later in life. People with early onset disability are also more likely to be in living in cared accommodation at earlier ages.

However, it does not seem from the foregoing analysis that any of these factors (e.g. age, age at onset, disabling condition) could reliably be used as proxy indicators of need. None could provide a suitable single basis for devising policies and services for particular groups of people. Put another way, the best indicator of need is need—defined and assessed by methods agreed among potential service providers and funders. Factors such as age, age at onset and disabling condition could inform individual needs assessments, but should not be seen primary determinants of need.

Thus, this analysis provides strong confirmation of the wisdom of emerging policies that aim to provide flexible services designed around individual needs. These policies generally result in a mix of services within existing program boundaries, for instance to provide equipment as a substitute for or supplement to personal care. The analysis also provides support for the extension of such flexible approaches to needs assessment and service provision across program boundaries, particularly spanning disability and aged care programs. Models of this kind are already being developed in some States and Territories.

How will it be decided if a person ageing with disability is to make a transition from disability to aged care services? In 1999, about 15.8% of CSDA service recipients (11,563 people) on the snapshot day of the CSDA MDS collection were aged 50 years or over, 9.8% (or 7,173 people) were aged 55 years or over and 6.1% (or 4,491 people) were aged 60 years or over (Chapter 6). These people could be among the candidates for transition to aged care services in the near future or, alternatively, arrangements for ageing in place may be needed. A policy framework, including criteria for decision making and processes designed to involve those with the most relevant information on individuals' needs, would not only guide decisions about the future service needs of individuals, but would also help to refine statistical estimates of the numbers of people involved.

19.3 Implications for the nature of services

This section reviews the analyses presented in previous chapters that explore the potential changing nature of support needs as people with a disability age. The findings in this section, while containing much quantitative data, give policy makers directional implications concerning these changes, rather than quantified profiles of future client needs.

Ageing trends of people with a disability

As a result of general population ageing and longer life expectancy of people with a disability (including people with an early onset disability) the population with a disability is also ageing, in particular the population with a severe or profound core activity restriction. Among people aged under 65 with a severe or profound core activity restriction, the proportion of people aged 45–54 increased from 19% in 1981 to 22% in 1998. During the next decade, the progressive upward movement of the baby-boom generation in the population age pyramid is likely to continue to cause an increase in the number of people with severe or profound core activity restriction in the 55 to 64 year age group (Chapter 13). Of all people

aged 65 or over with a severe or profound core activity restriction, the proportion aged 75 or over increased from 66% in 1981 to 73% in 1998. The ageing of older people with a severe or profound core activity restriction is likely to be very significant from the second decade of this century because of the baby-boom generation moving into older age groups (Chapter 13).

Special needs of people ageing with an early onset disability

For people with an early onset disability, support needs may vary depending on the nature of the disability and stage of the ageing process. Review of the literature found that, in comparison with the general ageing population, people ageing with an early onset disability tend to need a different range of psychological and social support services, although their physical support needs may be quite similar. Older people with an early onset disability may also differ from their younger counterparts in terms of the nature of services they require (Chapter 8).

The 1998 disability survey data suggest that people ageing with an early onset disability may need higher level support at earlier ages and are more likely to live in cared accommodation, although the evidence is not strong. 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 (Chapter 15).

Modification in some key service areas, such as accommodation support and day activities, may be required to meet the needs of people ageing with an early onset disability.¹⁸ Age-appropriate day activity services for people ageing with an early onset disability may have potential to increase individuals' independent living skills. Such services may also have a respite effect, and could potentially reduce demand for more intensive services by supporting carers.

Carers and ageing

Informal care is the main source of assistance for people with a disability living in households. In 1998, over 80% of people with a severe or profound core activity restriction were assisted by informal carers with activities of self-care, mobility and communication (Chapter 15).

The combined effects of increases in life expectancy for the general population and for the population with a disability may extend the already long years of care for parents of a people with early onset disability. Ageing of carers, in particular ageing of parents caring for their child with an early onset disability, is likely to continue as a major issue (Chapter 16).

Assisting people with a disability and their families to plan for the transition from parental to non-parent care will be an important issue for service planning and provision. One approach may be to develop flexible residential options for families that can no longer provide all necessary care in the home but wish to remain a family unit (Chapter 5). The need for supported accommodation may also occur at earlier ages for people ageing with an early onset disability, because of their own ageing and because of limited informal support networks.

¹⁸ A research project on day support services has been commissioned by the NDA. The project aims to evaluate current service models and identify key issues regarding the development and provision of day support services for people ageing with an early onset disability.

Trends in de-institutionalisation and informal care

The shift from residential care to community care is happening. There has been a large increase in the number and proportion of people with a severe or profound core activity restriction aged under 65 living with their relatives. While there have been major 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 (Chapter 5). The trend in de-institutionalisation is due largely to potential new service users remaining in community-based living arrangements, mainly with their relatives.

The combined effect of trends in de-institutionalisation and ageing of carers further emphasises the importance of community-based programs to support carers and help maintain the stability of community living and caring arrangements (Chapter 5; Madden et al. 1999). The effect may also put ongoing pressure on accommodation support services. The demand for in-home support and respite care may increase, especially from carers who have chosen to continue to care for their ageing relatives with a disability in the family home (AIHW 1997a; Gatter 1996). Day activity programs may be expected to support people with higher dependencies than did community access services in the past (AIHW 1997a).

19.4 Planning the evolution of support services

Ageing people with a disability have particular support needs, and there are increasing numbers of people ageing with a disability in community settings. This trend and the overall growth in numbers of people ageing with a disability have important implications for service planning.

The information presented in this report suggests four broad areas of focus for service planners:

The importance of individual needs and circumstances

People with a disability are not a homogeneous group. Factors such as age, age at onset of disability, condition and disability type interact to affect levels of need for assistance, but none of these factors can be used as simple indicators. Individual needs should be the most important factor in determining the suitability of support services and assistance.

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. Day services may need to be restructured from full-day 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 with a disability or the carers to modify their balance between these two service types. Reassessment of support needs may be necessary for people with an early onset disability as they age.

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 (see Section 19.2). 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.

Carers and de-institutionalisation

The data suggest countervailing trends in levels of informal care, making it difficult to draw any firm conclusions about the likely future levels of availability. However, assuming that current patterns continue, 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 1981 and 1993 there was an increase of 105,000 people aged 5–64 years with severe or profound core activity restrictions living in the community, mainly with relatives (Section 5.3). Support resources play a significant role in assisting carers and reducing the stress of caring, particularly among ageing carers.

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Appendix tables

Table A2.1: Projected percentage increase in selected population age groups, Australia, 1997–2051

Age	1997–2002	2002–07	2007–12	2012–17	2017–22	2022–27	2027–32	2032–37	2037–42	2042–47	2047–51
45–49	7.4	8.0	–1.9	4.1	–3.2	–0.3	4.1	2.0	0.1	–1.5	–0.7
50–54	17.2	7.5	8.1	–1.8	4.2	–3.1	–0.2	4.2	2.1	0.2	–1.4
55–59	(a)26.6	17.4	7.6	8.2	–1.7	4.2	–3.0	–0.2	4.2	2.1	0.6
60–64	14.9	(a)26.9	17.4	7.7	8.3	–1.6	4.4	–2.9	0.0	4.3	1.6
65–69	–0.2	15.5	(a)27.2	17.5	7.9	8.5	–1.4	4.6	–2.8	0.2	4.1
70–74	2.4	0.7	15.9	(a)27.5	17.7	8.3	8.8	–1.2	5.0	–2.6	–0.6
75–79	16.0	3.6	1.6	16.5	(a)28.3	18.1	8.8	9.3	–0.8	5.5	–0.7
80–84	17.1	17.2	4.5	2.7	17.5	(a)29.7	18.8	9.8	10.2	–0.2	3.9
85+	21.6	20.4	19.7	11.0	7.0	14.9	(a)27.0	23.8	16.3	13.6	5.7
Total 45–64	15.6	13.5	7.0	4.3	1.7	–0.2	1.3	0.8	1.6	1.2	0.0
Total 50–64	19.6	15.9	10.6	4.4	3.4	–0.2	0.3	0.4	2.1	2.1	0.2
Total 65+	8.0	9.9	15.1	16.9	15.1	13.6	9.2	7.4	4.2	2.7	2.4
Total 70+	11.7	7.7	10.0	16.6	18.6	15.9	13.6	8.4	6.7	3.6	1.8
Total 75+	17.6	11.7	7.1	10.7	19.1	20.6	16.3	13.3	7.5	6.3	2.8

(a) This shift mainly reflects the passage of the large cohort of the post–World War II baby-boom generation.

Source: Calculated on the basis of ABS population projections Series II; ABS 1998a.

Table A2.2: Projected increase in the number of selected population age groups ('000), Australia, 1997–2051

Age	1997–2002	2002–07	2007–12	2012–17	2017–22	2022–27	2027–32	2032–37	2037–42	2042–47	2047–51
45–49	95.1	111.2	–27.9	60.1	–48.7	–4.6	60.8	31.1	2.2	–23.7	–10.4
50–54	188.3	95.8	111.4	–26.5	60.8	–47.3	–3.6	61.2	31.7	3.0	–22.2
55–59	(a)227.0	187.4	96.1	111.2	–24.8	61.6	–45.6	–2.3	61.6	32.5	9.1
60–64	108.0	(a)223.6	183.9	95.5	110.4	–22.4	62.4	–43.1	–0.4	61.9	24.6
65–69	–1.2	106.1	(a)215.2	176.5	93.9	108.1	–19.2	63.1	–39.6	2.3	57.8
70–74	14.7	4.6	99.8	(a)200.5	164.7	90.3	103.7	–14.8	63.0	–34.4	–7.6
75–79	71.3	18.4	8.4	89.5	(a)179.2	147.4	84.8	97.0	–8.8	62.5	–8.7
80–84	49.1	58.1	17.7	11.1	74.2	(a)147.9	121.3	75.3	85.6	–1.6	36.6
85+	46.7	53.7	62.5	41.6	29.2	67.1	(a)139.4	156.4	132.4	128.4	61.4
Total 45–64	618.5	618.0	363.5	240.4	97.8	–12.8	73.9	46.9	95.2	73.8	1.1
Total 50–64	523.4	506.8	391.4	180.3	146.4	–8.2	13.2	15.8	93.0	97.4	11.5
Total 65+	180.5	240.8	403.5	519.2	541.2	560.8	430.0	376.8	232.7	157.2	139.4
Total 70+	181.8	134.8	188.3	342.7	447.4	452.7	449.2	313.8	272.3	154.9	81.7
Total 75+	167.1	130.2	88.6	142.2	282.7	362.3	345.5	328.6	209.3	189.4	89.3

(a) This shift reflects the passage of the large cohort of the post–World War II baby-boom generation.

Source: Calculated on the basis of ABS population projections Series II; ABS 1998a.

Table A2.3: Projected population ('000) in selected age groups, Australia, 1997–2051

Age	1997	2002	2007	2012	2017	2022	2027	2032	2037	2042	2047	2051
45–49	1,289.9	1,385.0	1,496.2	1,468.3	1,528.4	1,479.8	1,475.1	1,535.9	1,567.0	1,569.2	1,545.6	1,535.2
50–54	1,094.2	1,282.6	1,378.3	1,489.8	1,463.3	1,524.0	1,476.7	1,473.1	1,534.3	1,566.0	1,569.0	1,546.7
55–59	852.6	1,079.6	1,267.0	1,363.1	1,474.4	1,449.6	1,511.2	1,465.6	1,463.3	1,524.9	1,557.5	1,566.6
60–64	722.7	830.7	1,054.4	1,238.2	1,333.8	1,444.2	1,421.7	1,484.1	1,441.0	1,440.6	1,502.5	1,527.1
65–69	687.1	685.8	791.9	1,007.1	1,183.6	1,277.5	1,385.6	1,366.4	1,429.4	1,389.9	1,392.2	1,449.9
70–74	608.7	623.4	628.0	727.8	928.3	1,092.9	1,183.2	1,286.9	1,272.1	1,335.0	1,300.6	1,293.0
75–79	445.5	516.8	535.2	543.6	633.1	812.4	959.7	1,044.6	1,141.5	1,132.7	1,195.3	1,186.6
80–84	287.6	336.8	394.9	412.6	423.6	497.8	645.8	767.0	842.3	928.0	926.4	962.9
85+	216.1	262.8	316.4	378.9	420.5	449.8	516.8	656.2	812.6	945.0	1,073.4	1,134.8
Total 45–64	3,959.5	4,578.0	5,195.9	5,559.4	5,799.8	5,897.6	5,884.8	5,958.7	6,005.6	6,100.8	6,174.5	6,175.6
Total 50–64	2,669.6	3,192.9	3,699.7	4,091.1	4,271.4	4,417.8	4,409.6	4,422.8	4,438.6	4,531.6	4,629.0	4,640.5
Total 65+	2,245.1	2,425.6	2,666.4	3,069.9	3,589.1	4,130.3	4,691.1	5,121.1	5,497.9	5,730.6	5,887.9	6,027.3
Total 70+	1,558.0	1,739.8	1,874.5	2,062.8	2,405.5	2,852.9	3,305.6	3,754.7	4,068.5	4,340.8	4,495.7	4,577.4
Total 75+	949.2	1,116.3	1,246.5	1,335.1	1,477.3	1,760.0	2,122.3	2,467.8	2,796.4	3,005.7	3,195.1	3,284.3

Source: Calculated on the basis of ABS population projections Series II; ABS 1998a.

Table A12.1: Disability prevalence, Australia, 1981, 1988, 1993 and 1998^(a)

Year	Age	Severe or profound core activity restriction^(b)	Specific restrictions^(b)	Total with disability
Reported number ('000)				
1981	Under 65	239.7	855.0	1,348.1
	65+	213.2	449.3	594.1
	<i>Total</i>	<i>452.9</i>	<i>1,304.3</i>	<i>1,942.2</i>
1988	Under 65	297.2	1,300.6	1,622.7
	65+	303.3	782.5	920.4
	<i>Total</i>	<i>600.5</i>	<i>2,083.1</i>	<i>2,543.1</i>
1993	Under 65	329.4	1,364.6	1,839.6
	65+	337.6	893.1	1,081.0
	<i>Total</i>	<i>667.1</i>	<i>2,257.7</i>	<i>2,920.5</i>
1998	Under 65	510.1	1,761.9	2,263.5
	65+	444.8	1,034.5	1,240.2
	<i>Total</i>	<i>954.9</i>	<i>2,796.4</i>	<i>3,503.7</i>
Increases in reported number ('000)				
1981–1988	Under 65	57.5	445.6	274.6
	65+	90.1	333.3	326.3
	<i>Total</i>	<i>147.6</i>	<i>778.8</i>	<i>600.9</i>
1988–1993	Under 65	32.2	64.0	216.9
	65+	34.3	110.6	160.6
	<i>Total</i>	<i>66.6</i>	<i>174.6</i>	<i>377.5</i>
1993–1998	Under 65	108.7	379.3	423.9
	65+	107.2	141.4	159.2
	<i>Total</i>	<i>287.9</i>	<i>538.7</i>	<i>583.2</i>
1981–1993	Under 65	89.8	509.6	491.4
	65+	124.4	443.9	486.9
	<i>Total</i>	<i>214.2</i>	<i>953.4</i>	<i>978.3</i>
1988–1998	Under 65	212.9	461.3	640.8
	65+	141.5	252.0	319.8
	<i>Total</i>	<i>354.5</i>	<i>713.3</i>	<i>960.6</i>
1981–1998	Under 65	270.4	906.9	915.4
	65+	231.6	585.2	646.1
	<i>Total</i>	<i>502.0</i>	<i>1,492.1</i>	<i>1,561.5</i>

(a) Disability data were re-derived using criteria common to the four surveys.

(b) Only people aged 5 years and over are included.

Source: AIHW analysis of the ABS 1998 Survey of Disability, Ageing and Carers unpublished data tables.

Table A13.1: People with a severe or profound core activity restriction aged under 65 years^(a), by age and by sex ('000), Australia, 1981, 1988, 1993 and 1998^(b)

Age/sex	1981	1988	1993	1998
Males				
5-14	25.4	31.4	35.8	66.0
15-24	11.0	12.6	17.2	24.0
25-34	15.3	17.6	22.7	30.7
35-44	15.6	24.3	29.9	34.1
45-54	22.4	24.1	29.0	55.3
55-59	17.3	14.6	18.9	34.6
60-64	16.0	18.7	15.6	26.3
Total 35-64	71.3	81.7	93.5	150.2
Total 45-64	55.7	57.4	63.6	116.2
Total 55-64	33.3	33.3	34.6	60.8
<i>Total number under 65</i>	<i>123.0</i>	<i>143.2</i>	<i>169.1</i>	<i>270.9</i>
Females				
5-14	15.1	22.3	22.8	30.8
15-24	12.4	14.8	18.7	20.5
25-34	13.2	21.6	23.6	27.1
35-44	18.7	31.1	29.3	46.1
45-54	24.2	27.8	33.0	58.5
55-59	16.2	16.9	17.6	28.5
60-64	16.9	19.6	15.4	27.8
Total 35-64	76.0	95.3	95.3	160.8
Total 45-64	57.3	64.3	66.0	114.8
Total 55-64	33.1	36.5	33.0	56.3
<i>Total number under 65</i>	<i>116.7</i>	<i>154.0</i>	<i>160.4</i>	<i>239.2</i>
Persons				
5-14	40.5	53.7	58.6	96.8
15-24	23.4	27.4	35.9	44.5
25-34	28.5	39.2	46.2	57.8
35-44	34.3	55.4	59.2	80.1
45-54	46.6	51.9	62.1	113.8
55-59	33.5	31.4	36.6	63.1
60-64	33.0	38.3	31.0	54.1
Total 35-64	147.3	177.0	188.8	311.1
Total 45-64	113.0	121.7	129.6	230.9
Total 55-64	66.4	69.8	67.6	117.1
Total number under 65	239.7	297.2	329.4	510.1

(a) Only people aged 5 years and over are included.

(b) Disability data were re-derived using criteria common to the four surveys.

Source: AIHW analysis of the ABS 1998 Survey of Disability, Ageing and Carers unpublished data tables.

Table A13.2: People with specific restrictions aged under 65 years^(a), by age and by sex ('000), Australia, 1981, 1988, 1993 and 1998^(b)

Age/sex	1981	1988	1993	1998
Males				
5-14	63.7	90.3	94.9	143.0
15-24	39.8	64.1	70.0	107.4
25-34	56.1	89.1	94.2	116.4
35-44	64.4	115.0	128.6	159.6
45-54	91.2	122.0	156.0	207.2
55-59	82.6	92.2	92.6	116.9
60-64	81.1	134.6	119.4	129.7
Total 35-64	319.3	463.7	496.5	613.5
Total 45-64	254.9	348.7	368.0	453.8
Total 55-64	163.7	226.7	212.0	246.6
<i>Total number under 65</i>	<i>478.9</i>	<i>707.2</i>	<i>755.5</i>	<i>980.3</i>
Females				
5-14	35.8	60.6	55.3	72.6
15-24	40.1	57.2	63.7	75.8
25-34	51.5	79.6	87.3	93.9
35-44	55.0	114.1	114.9	152.6
45-54	82.1	120.5	135.0	192.2
55-59	55.6	70.2	78.1	101.5
60-64	56.0	91.2	74.7	93.0
Total 35-64	248.7	396.0	402.7	539.4
Total 45-64	193.7	281.9	287.8	386.7
Total 55-64	111.6	161.4	152.8	194.5
<i>Total number under 65</i>	<i>376.2</i>	<i>593.4</i>	<i>609.0</i>	<i>781.6</i>
Persons				
5-14	99.5	150.9	150.2	215.6
15-24	79.9	121.2	133.7	183.2
25-34	107.7	168.7	181.5	210.2
35-44	119.4	229.1	243.5	312.2
45-54	173.3	242.5	290.9	399.5
55-59	138.2	162.4	170.8	218.3
60-64	137.1	225.8	194.0	222.8
Total 35-64	568.0	859.7	899.2	1,152.8
Total 45-64	448.6	630.6	655.7	840.6
Total 55-64	275.3	388.2	364.8	441.1
Total number under 65	855.0	1,300.6	1,364.6	1,761.9

(a) Only people aged 5 years and over are included.

(b) Disability data were re-derived using criteria common to the four surveys.

Source: AIHW analysis of the ABS 1998 Survey of Disability, Ageing and Carers unpublished data tables.

Table A13.3: People with a disability aged under 65 years, by age and by sex ('000), Australia, 1981, 1988, 1993 and 1998^(a)

Age/sex	1981	1988	1993	1998
Males				
0-4	23.2	24.8	29.5	31.3
5-14	96.3	106.4	118.5	166.2
15-24	74.2	88.1	94.0	123.9
25-34	98.8	115.1	135.5	154.2
35-44	106.5	148.3	176.8	219.0
45-54	139.3	148.9	211.8	275.5
55-59	112.4	108.7	117.8	152.5
60-64	103.5	156.0	148.6	157.6
Total 35-64	461.7	562.0	655.1	804.6
Total 45-64	355.2	413.7	478.3	585.6
Total 55-64	215.9	264.8	266.5	310.1
<i>Total number under 65</i>	<i>754.2</i>	<i>896.3</i>	<i>1,032.6</i>	<i>1,280.2</i>
Females				
0-4	16.3	15.8	23.7	15.6
5-14	60.5	75.3	70.6	88.6
15-24	71.3	77.4	89.8	94.5
25-34	90.0	99.6	119.8	127.0
35-44	88.9	136.8	152.7	191.0
45-54	115.8	138.3	161.6	236.3
55-59	76.2	80.0	94.6	123.7
60-64	74.9	103.3	94.2	106.5
Total 35-64	355.8	458.3	503.1	657.5
Total 45-64	266.9	321.5	350.4	466.5
Total 55-64	151.2	183.2	188.8	230.2
<i>Total number under 65</i>	<i>593.9</i>	<i>726.4</i>	<i>807.0</i>	<i>983.2</i>
Persons				
0-4	39.5	40.7	53.3	47.0
5-14	156.7	181.6	189.1	254.8
15-24	145.5	165.5	183.8	218.4
25-34	188.8	214.7	255.3	281.2
35-44	195.4	285.0	329.5	410.0
45-54	255.1	287.2	373.4	511.8
55-59	188.6	188.7	212.4	276.2
60-64	178.4	259.3	242.8	264.1
Total 35-64	817.5	1,020.2	1,158.1	1,462.1
Total 45-64	622.1	735.2	828.7	1,052.1
Total 55-64	367.1	448.0	455.2	540.3
Total number under 65	1,348.1	1,622.7	1,839.6	2,263.5

(a) Only people aged 5 years and over are included.

Source: AIHW analysis of the ABS 1998 Survey of Disability, Ageing and Carers unpublished data tables.

Table A14.1: Grouping of main conditions for analysis of the 1998 ABS survey data

Main condition group	Conditions included
Intellectual	Mental and behavioural disorders nfd Intellectual and developmental disorders nfd Mental retardation/intellectual disability Autism and related disorders Developmental learning disorders Other developmental disorders ADD/hyperactivity Other mental and behavioural disorders Down syndrome
Psychiatric	Psychoses and mood affective disorders nfd Dementia Schizophrenia Depression etc. (excl. postnatal) Other psychoses Phobic and anxiety disorders Nervous tension/stress Other neurotic and stress-related disorders
Vision	Cataracts Retinal disorders/defects Glaucoma Sight loss Other diseases of the eye/adnexa
Hearing	Tinnitus Deafness/hearing loss nfd Deafness/hearing loss—noise-induced Deafness/hearing loss—congenital Deafness/hearing loss—due to accident Other deafness/hearing loss Other diseases of the ear and mastoid process
Acquired brain injury	Head injury/acquired brain damage
Physical/other	Poliomyelitis Other infectious and parasitic diseases Skin cancer Breast cancer

(continued)

Table A14.1 (continued): Grouping of main conditions for analysis of 1998 ABS survey data

Main condition group	Conditions included
Physical/other (continued)	Prostate cancer Other malignant tumors Other neoplasms (incl. benign) Diseases of the blood and blood-forming organs Disorders of thyroid Diabetes High cholesterol Other endocrine, nutritional and metabolic disorder Speech impediment Parkinson disease Alzheimer disease Brain disease—acquired Multiple sclerosis Epilepsy Migraine Cerebral palsy Paralysis Other diseases of the nervous system incl. transient ischaemic attacks Heart disease nfd Angina Myocardial infarction (heart attack) Other heart disease Hypertension Stroke Other diseases of circulatory system Bronchitis/bronchiolitis Respiratory allergies(excl. allergic asthma) Emphysema Asthma Other diseases of the respiratory system Stomach/duodenal ulcer Abdominal hernia (except congenital) Enteritis, colitis and other disease of the intestine Other diseases of the digestive system Diseases of the skin and subcutaneous tissue Arthritis and related disorders Back problems (dorsopathies)

(continued)

Table A14.1 (continued): Grouping of main conditions for analysis of 1998 ABS survey data

Main condition group	Conditions included
Physical/other (continued)	Synovitis/tenosynovitis Other soft tissue/muscle disorders (incl. rheumatism) Osteoporosis Other disorders of musculoskeletal and connective tissue Disorders of the urinary system Disorders of the genital system Other diseases of the genitourinary system Spina bifida Deformities of joints/limbs—congenital Other congenital/chromosomal abnormalities Breathing difficulties/shortness of breath Pain nfd Unspecified speech difficulties Blackouts, fainting, convulsions nec Other symptoms and signs nec Arm/hand/shoulder damage from injury, amputation of finger/thurmb/hand/arm Leg/knee/foot/hip damage from injury, amputation of toe/foot/leg Complications/consequences of surgery and medical care nec Other injury, poisoning and consequences of external causes Limited use of arms or fingers Difficulty gripping or holding things Limited use of feet/legs Restricted in physical activity or physical work All other conditions

nfd Not further defined
nec Not elsewhere classified

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

Table A14.2: People aged 45–64 with a disability: distribution of age at onset of disability by main condition, by age, Australia, 1998^(a)

Main condition	Age at onset				Living in cared accommodation	Total
	0–17	18–44	45–64	Not known		
Number ('000)						
Intellectual	*7.6	*4.0	**0.4	—	*3.5	15.4
Psychiatric	*7.9	36.7	30.0	—	**2.4	77.1
Vision	*2.9	*4.9	*8.0	—	**0.1	15.9
Hearing	16.1	39.3	26.5	**0.2	—	82.1
Acquired brain injury	**2.5	*6.1	**2.8	—	**0.4	11.8
Physical/other	75.6	412.0	413.4	*6.6	*5.7	913.3
Total	112.5	503.0	481.2	*6.8	12.2	1,115.7
Per cent (sum horizontally)						
Intellectual	49.0	*25.9	**2.6	—	*22.6	100.0
Psychiatric	*10.3	47.7	39.0	—	**3.1	100.0
Vision	*18.0	*30.9	50.4	—	**0.8	100.0
Hearing	19.6	47.8	32.3	**0.2	*0.1	100.0
Acquired brain injury	*21.0	51.8	**23.8	—	**3.4	100.0
Physical/other	8.3	45.1	45.3	*0.7	*0.6	100.0
Total	10.1	45.1	43.1	*0.6	1.1	100.0
Per cent (sum vertically)						
Intellectual	*6.7	*0.8	**0.1	—	*28.6	1.4
Psychiatric	*7.0	7.3	6.2	—	*19.6	6.9
Vision	*2.5	*1.0	*1.7	—	**1.0	1.4
Hearing	14.3	7.8	5.5	**2.7	**0.4	7.4
Acquired brain injury	**2.2	*1.2	**0.6	—	**3.3	1.1
Physical/other	67.2	81.9	85.9	97.3	*47.1	81.9
Total	100.0	100.0	100.0	100.0	100.0	100.0

(a) Estimates marked with ** have an associated relative standard error (RSE) of 50% or more. Estimates marked with * have an associated RSE of between 25% and 50%. These estimates should be interpreted accordingly.
— Nil or rounded to zero.

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

Table A14.3: People aged 45–64 with a severe or profound core activity restriction: distribution of age at onset of disability by main condition by age, Australia, 1998^(a)

Main condition	Age at onset				Living in cared accommodation	Total
	0–17	18–44	45–64	Not known		
	Number ('000)					
Intellectual	*3.4	**1.3	**0.4	—	*3.3	*8.3
Psychiatric	*3.8	10.2	*6.0	—	**2.0	21.9
Vision	**0.7	**1.4	**0.3	—	**0.1	**2.6
Hearing	**1.1	*3.0	**1.0	—	—	*5.2
Acquired brain injury	**1.6	**1.9	**0.8	—	**0.3	*4.6
Physical/other	19.5	115.4	102.3	**2.0	*5.5	244.6
Total	30.2	133.1	110.7	**2.0	11.2	287.2
	Per cent (sum horizontally)					
Intellectual	*40.7	**15.3	**4.8	—	*39.2	100.0
Psychiatric	*17.4	46.5	*27.2	—	**8.9	100.0
Vision	**28.8	**53.0	**13.4	—	**4.8	100.0
Hearing	**21.7	*57.9	**19.4	—	**0.9	100.0
Acquired brain injury	**35.3	*41.0	**16.8	—	**6.9	100.0
Physical/other	8.0	47.2	41.8	**0.8	*2.2	100.0
Total	10.5	46.4	38.6	**0.7	3.9	100.0
	Per cent (sum vertically)					
Intellectual	*11.3	**1.0	**0.4	—	*29.3	*2.9
Psychiatric	*12.6	7.7	*5.4	—	**17.5	7.6
Vision	**2.5	**1.0	**0.3	—	**1.1	**0.9
Hearing	**3.7	*2.3	**0.9	—	**0.4	*1.8
Acquired brain injury	**5.4	**1.4	**0.7	—	**2.8	*1.6
Physical/other	64.6	86.7	92.3	100.0	*48.8	85.2
Total	100.0	100.0	100.0	100.0	100.0	100.0

(a) Estimates marked with ** have an associated relative standard error (RSE) of 50% or more. Estimates marked with * have an associated RSE of between 25% and 50%. These estimates should be interpreted accordingly.
— Nil or rounded to zero.

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

Table A14.4: People with a disability aged 65 or over: distribution of age at onset of disability by main condition, Australia, 1998^(a)

Main condition	Age at onset					Living in cared accom.	Total
	0–17	18–44	45–64	65+	Not known		
Number ('000)							
Intellectual	**0.5	**0.8	**0.5	**1.1	—	*4.5	*7.5
Psychiatric	*3.2	*7.4	*7.4	*7.8	**1.4	56.3	83.5
Vision	*4.6	*5.2	14.5	43.3	**0.5	*4.3	72.5
Hearing	10.4	22.0	41.2	40.5	**2.5	*4.0	120.7
Acquired brain injury	—	**1.0	**2.2	—	—	**0.3	*3.5
Physical/other	31.2	144.5	318.3	339.2	*9.2	92.5	935.0
Total	49.9	180.9	384.3	432.0	13.6	161.9	1,222.6
Per cent (sum horizontally)							
Intellectual	**7.2	**10.2	**7.2	**15.1	—	60.4	100.0
Psychiatric	*3.9	*8.8	*8.9	*9.4	**1.6	67.4	100.0
Vision	*6.3	*7.2	20.0	59.8	**0.8	*5.9	100.0
Hearing	8.6	18.2	34.2	33.6	**2.0	*3.3	100.0
Acquired brain injury	—	**27.8	*63.4	—	—	**8.8	100.0
Physical/other	3.3	15.5	34.0	36.3	*1.0	9.9	100.0
Total	4.1	14.8	31.4	35.3	1.1	13.2	100.0
Per cent (sum vertically)							
Intellectual	**1.1	**0.4	**0.1	**0.3	—	*2.8	*0.6
Psychiatric	*6.5	*4.1	*1.9	*1.8	**10.0	34.7	6.8
Vision	*9.2	*2.9	3.8	10.0	**4.0	*2.6	5.9
Hearing	20.8	12.2	10.7	9.4	*18.1	*2.5	9.9
Acquired brain injury	—	**0.5	**0.6	—	—	**0.2	*0.3
Physical/other	62.5	79.9	82.8	78.5	67.9	57.1	76.5
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0

(a) Estimates marked with ** have an associated relative standard error (RSE) of 50% or more. Estimates marked with * have an associated RSE of between 25% and 50%. These estimates should be interpreted accordingly.
— Nil or rounded to zero.

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

Table A14.5: People with severe or profound core activity restriction aged 65 or over: distribution of age at onset of disability by main condition, Australia, 1998^(a)

Main condition	Age at onset					Living in cared accom.	Total
	0–17	18–44	45–64	65+	Not known		
Number ('000)							
Intellectual	—	—	—	**0.4	—	*4.4	*4.8
Psychiatric	**1.2	*3.1	*3.1	*6.3	**1.4	55.2	70.2
Vision	**1.9	**1.3	*6.0	19.1	**0.5	*4.0	32.9
Hearing	**0.8	**0.7	**2.5	*6.1	**0.6	*3.1	13.7
Acquired brain injury	—	**0.6	**1.3	—	—	**0.3	**2.1
Physical/other	*9.0	43.3	80.6	132.2	*3.8	87.7	356.6
Total	13.0	48.9	93.4	164.0	*6.3	154.8	480.4
Per cent (sum horizontally)							
Intellectual	—	—	—	**8.5	—	91.5	100.0
Psychiatric	**1.8	*4.3	*4.4	*8.9	**2.0	78.6	100.0
Vision	**5.9	**3.9	*18.2	58.0	**1.7	*12.3	100.0
Hearing	**5.8	**5.2	*18.0	*44.1	**4.2	*22.7	100.0
Acquired brain injury	—	**25.9	**59.7	—	—	**14.4	100.0
Physical/other	*2.5	12.2	22.6	37.1	*1.1	24.6	100.0
Total	2.7	10.2	19.4	34.1	*1.3	32.2	100.0
Per cent (sum vertically)							
Intellectual	—	—	—	**0.2	—	*2.8	*1.0
Psychiatric	**9.5	*6.2	*3.3	*3.8	**21.7	35.7	14.6
Vision	**15.0	**2.6	*6.4	11.7	**8.6	*2.6	6.9
Hearing	**6.1	**1.4	**2.6	*3.7	**9.2	*2.0	2.9
Acquired brain injury	—	**1.1	**1.4	—	—	**0.2	**0.4
Physical/other	69.4	88.6	86.3	80.6	*60.5	56.7	74.2
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0

(a) Estimates marked with ** have an associated relative standard error (RSE) of 50% or more. Estimates marked with * have an associated RSE of between 25% and 50%. These estimates should be interpreted accordingly.
— Nil or rounded to zero.

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

Table A15.1: People with a severe or profound core activity restriction living in households: main condition by activity type in which help needed, by age ('000), Australia, 1998^(a)

Age/activity type	Intellectual ^(c)	Psychiatric	Vision	Hearing	ABI ^(c)	Physical/other	Total
Age 0–64							
Self-care	58.5	15.8	**1.8	**2.1	*4.0	279.1	361.2
Mobility	61.1	39.3	*5.7	*5.9	*9.3	329.7	451.0
Communication	73.3	*4.8	—	10.6	**2.7	46.9	138.3
Health care	58.5	19.8	**2.2	**2.5	*7.1	231.8	321.9
Housework	15.6	15.5	**1.4	**0.6	*4.2	215.2	252.6
Property maintenance	16.9	17.7	**2.7	**2.5	*4.1	266.7	310.6
Paperwork	31.3	19.0	**2.4	**1.5	*7.1	68.6	129.9
Meal preparation	14.4	10.7	**0.5	—	*4.6	91.5	121.6
Transport	37.1	27.1	*5.3	*3.6	*8.2	212.4	293.6
Guidance	88.0	40.3	**1.5	*9.0	*5.3	156.7	300.7
Total need assistance ^(b)	102.4	47.0	*6.4	15.4	10.0	452.2	633.4
Total number ('000)	102.4	47.0	*6.4	16.7	10.0	453.5	636.0
Age 65 or over							
Self-care	—	*6.4	11.3	*2.8	—	133.8	155.2
Mobility	—	13.4	27.6	*7.9	—	222.9	273.6
Communication	—	*6.7	**0.8	**1.7	—	18.8	28.6
Health care	—	*8.6	20.2	*4.8	—	180.6	216.4
Housework	—	10.6	15.8	*3.5	—	194.9	226.2
Property maintenance	—	11.5	20.8	*6.7	—	208.9	250.2
Paperwork	—	*8.4	22.9	**1.9	—	76.2	110.3
Meal preparation	—	*8.3	13.0	*2.8	—	95.3	120.2
Transport	—	12.0	24.3	*5.6	—	188.9	232.2
Guidance	—	*8.7	*4.3	*3.6	—	52.2	69.6
Total need assistance ^(b)	—	15.0	28.9	10.0	—	268.4	324.6
Total number ('000)	**0.4	15.0	28.9	10.6	**1.8	268.9	325.6

(a) Estimates marked with ** have an associated relative standard error (RSE) of 50% or more. Estimates marked with * have an associated RSE of between 25% and 50%. These estimates should be interpreted accordingly.

(b) The total number of people needing assistance may be less than sum of the number of people needing assistance with each activity type, as people may need help with more than one activity.

(c) Numbers of people with intellectual disability and acquired brain injury aged 65 or over and living in households were too small to allow meaningful analysis of activities in which assistance was needed.

— Nil or rounded to zero.

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

Table A15.2: People with a severe or profound core activity restriction living in households: main condition by core activities in which help needed, by age ('000), Australia 1998^(a)

Age/activity type	Main condition						Total
	Intellectual ^(b)	Psychiatric	Vision	Hearing	ABI ^(b)	Physical/other	
Age 0–64							
Self-care only	*7.1	*5.8	**0.7	**0.3	—	98.0	111.8
Mobility only	14.1	26.3	*4.6	*3.1	*5.3	151.0	204.3
Communication only	21.7	**0.8	—	*8.2	**0.7	18.5	49.9
Self-care and mobility	*7.9	*9.0	**1.1	**0.7	**2.0	155.1	175.8
Self-care and communication	12.5	—	—	**0.3	—	*4.9	17.6
Mobility and communication	*8.1	*3.0	—	**1.3	—	**2.5	14.9
All three activities	31.1	**1.0	—	**0.9	**2.0	21.1	56.0
Total	102.4	45.9	*6.4	14.6	10.0	451.1	630.3
<i>Two or more activities</i>	<i>59.5</i>	<i>13.0</i>	<i>**1.1</i>	<i>*3.1</i>	<i>*4.0</i>	<i>183.6</i>	<i>264.3</i>
Total number ('000)	102.4	47.0	6.4	16.7	10.0	453.5	636.0
Age 65 or over							
Self-care only	—	**0.8	**1.3	**0.4	—	36.7	39.5
Mobility only	—	*5.8	16.8	*4.9	—	124.3	152.7
Communication only	—	**0.8	—	**0.7	—	**1.7	*3.2
Self-care and mobility	—	**1.7	10.0	**2.0	—	82.9	97.1
Self-care and communication	—	—	—	—	—	**1.5	**1.5
Mobility and communication	—	**1.9	**0.8	**0.6	—	*3.0	*6.8
All three activities	—	*4.0	—	**0.4	—	12.6	17.0
Total	—	15.0	28.9	*8.9	—	262.8	317.9
<i>Two or more activities</i>	—	*7.6	<i>10.8</i>	<i>*3.0</i>	—	<i>100.1</i>	<i>122.4</i>
Total number ('000)	**0.4	15.0	28.9	10.6	**1.8	268.9	325.6

(a) Estimates marked with ** have an associated relative standard error (RSE) of 50% or more. Estimates marked with * have an associated RSE of between 25% and 50%. These estimates should be interpreted accordingly.

(b) Numbers of people with intellectual disability and acquired brain injury aged 65 or over and living in households were too small to allow meaningful analysis of activities in which assistance was needed.

— Nil or rounded to zero.

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

Table A15.3: People with a severe or profound core activity restriction living in households: main source of assistance by activity type in which help needed, by age ('000), Australia, 1998^(a)

Age/activity type	Type of provider				Total
	No provider	Informal co-resident	Informal non-co-resident	Formal provider	
Under 65 years					
Self-care	26.7	305.5	14.5	14.5	361.2
Mobility	30.6	343.9	47.9	28.6	451.0
Communication	*6.0	113.6	**0.8	18.0	138.3
Health care	16.6	240.9	14.6	49.8	321.9
Housework	*8.6	207.5	17.9	18.6	252.6
Property maintenance	21.0	209.7	39.1	40.0	309.9
Paperwork	*8.7	98.0	14.2	*9.0	129.9
Meal preparation	*6.0	104.8	*4.8	*6.0	121.6
Transport	*8.8	224.3	41.5	18.9	293.6
65 years and over					
Self-care	14.0	113.4	10.0	17.8	155.2
Mobility	16.1	148.1	87.3	22.2	273.6
Communication	*3.1	25.3	**0.2	—	28.6
Health care	11.8	92.8	16.4	95.4	216.4
Housework	*6.1	129.5	30.6	60.0	226.2
Property maintenance	10.0	112.9	51.7	74.9	249.5
Paperwork	*3.3	70.0	31.9	*5.1	110.3
Meal preparation	**1.9	86.3	*8.3	23.7	120.2
Transport	13.3	108.5	87.6	22.8	232.2
All ages					
Self-care	40.7	418.9	24.5	32.3	516.4
Mobility	46.7	491.9	135.2	50.8	724.6
Communication	*9.0	138.9	**1.0	18.0	166.9
Health care	28.4	333.7	31.0	145.2	538.3
Housework	14.6	337.1	48.4	78.6	478.8
Property maintenance	31.0	322.7	90.8	114.9	559.4
Paperwork	12.0	168.0	46.1	14.2	240.3
Meal preparation	*7.9	191.1	13.1	29.7	241.8
Transport	22.2	332.8	129.1	41.7	525.8

(a) Estimates marked with ** have an associated relative standard error (RSE) of 50% or more. Estimates marked with * have an associated RSE of between 25% and 50%. These estimates should be interpreted accordingly.
 — Nil or rounded to zero.

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

Table A15.4: People aged 5–64 years with a severe or profound core activity restriction who needed help and were living in households: activity type in which help needed by type of main provider ('000), Australia, 1993–1998^(a)

Activity type	Type of main provider				Total
	No provider	Informal co-resident	Informal non-co-resident	Formal provider	
1993					
Self-care	14.3	169.1	9.2	13.8	206.3
Mobility	24.3	215.1	29.1	11.7	280.2
Communication	*6.9	44.3	**1.1	*6.7	59.0
Health care ^(b)	*3.1	81.2	*4.7	18.1	107.1
Housework	17.5	112.9	*6.4	12.5	149.2
Property maintenance	8.2	125.8	18.9	24.9	177.7
Paperwork	*2.4	66.5	*7.5	*7.5	83.9
Meal preparation	*6.8	45.9	**0.6	*4.5	57.8
Transport	15.0	111.8	19.1	17.2	163.2
1998^(c)					
Self-care	24.4	277.4	14.5	14.2	330.4
Mobility	26.7	317.0	46.8	28.2	418.8
Communication	*5.4	96.4	**0.8	14.6	117.3
Health care ^(b)	15.1	166.4	13.9	44.5	240.0
Housework	*8.6	201.3	17.4	18.4	245.6
Property maintenance	20.2	200.8	38.3	39.3	298.6
Paperwork	*8.7	98.0	14.2	*8.4	129.3
Meal preparation	*6.0	103.4	*4.8	*6.0	120.1
Transport	*8.8	217.9	39.4	18.9	285.1

(a) Estimates marked with ** have an associated relative standard error (RSE) of 50% or more. Estimates marked with * have an associated RSE of between 25% and 50%. These estimates should be interpreted accordingly.

(b) 71,100 people aged 5–14 years who needed assistance with health care in 1998 were excluded to allow comparisons between 1993 and 1998 data, as data on this age group were not collected in the 1993 survey.

(c) For comparative purposes, 1998 data were re-derived using the 1993 operational definition of disability.

Source: AIHW analysis of ABS 1998 Survey of Disability, Ageing and Carers Confidentialised Unit Record File. and 1993 Survey of Disability, Ageing and Carers data.

Table A15.5: People aged 65 years or over with a severe or profound core activity restriction who needed help and were living in households: activity type in which help needed by type of main provider ('000), Australia, 1993–1998^(a)

Activity type	Type of main provider				Total
	No provider	Informal co-resident	Informal non co-resident	Formal provider	
1993					
Self-care	*4.9	98.6	*5.6	15.7	124.8
Mobility	23.7	115.5	62.1	12.8	214.1
Communication	*5.1	19.9	**0.8	—	25.9
Health care ^(b)	*7.7	76.2	13.8	64.3	161.9
Housework	*4.6	119.5	17.2	47.1	188.4
Property maintenance	*3.9	108.7	53.0	54.1	219.7
Paperwork	**1.4	60.8	22.4	**0.9	85.4
Meal preparation	*4.0	65.9	*3.7	*7.5	81.1
Transport	8.8	108.9	73.0	18.6	209.3
1998^(c)					
Self-care	13.8	113.2	10.0	17.8	154.9
Mobility	15.0	144.0	86.8	22.2	268.1
Communication	*3.1	25.3	**0.2	—	28.6
Health care ^(b)	10.7	91.8	16.4	94.9	213.8
Housework	*5.3	127.5	30.6	59.4	222.8
Property maintenance	10.0	111.5	51.7	74.9	248.1
Paperwork	*3.3	70.0	31.8	*5.1	110.2
Meal preparation	**1.9	86.3	*8.3	23.7	120.2
Transport	13.3	105.9	87.6	22.8	229.6

(a) Estimates marked with ** have an associated relative standard error (RSE) of 50% or more. Estimates marked with * have an associated RSE of between 25% and 50%. These estimates should be interpreted accordingly.

(b) 71,100 people aged 5–14 years who needed assistance with health care in 1998 were excluded to allow comparisons between 1993 and 1998 data, as data on this age group were not collected in the 1993 survey.

(c) For comparative purposes, 1998 data were re-derived using the 1993 operational definition of disability.
— Nil or rounded to zero.

Source: AIHW analysis of ABS 1998 Survey of Disability, Ageing and Carers Confidentialised Unit Record File and 1993 Survey of Disability, Ageing and Carers data.

Table A15.6: People aged 45 years or over with a severe or profound core activity restriction living in households: marital status and housing tenure type, by age at onset of main condition ('000), Australia, 1998^(a)

	Current age 45–64 years				Current age 65 or over		
	Age at onset of main condition				Age at onset of main condition		
	0–17	18–44	45–64	Total	0–64	65+	Total
Marital status							
Married or de facto	20.9	104.3	85.4	210.7	82.7	72.9	155.6
Separated or divorced	*3.4	19.3	12.2	34.9	*8.3	*4.8	13.1
Widowed	**0.6	**2.4	*7.8	10.8	58.6	80.7	139.3
<i>Total ever married</i>	<i>24.8</i>	<i>126.1</i>	<i>105.5</i>	<i>256.4</i>	<i>149.6</i>	<i>158.4</i>	<i>308.0</i>
Never married	*5.3	*7.1	*5.3	17.7	*5.7	*5.6	11.3
Housing tenure type							
Owner without mortgage	10.7	58.5	56.9	126.2	101.7	90.4	192.2
Owner with mortgage	*7.8	45.9	23.4	77.2	13.7	14.9	28.5
Renter	*7.5	23.7	20.7	51.9	20.4	19.5	39.9
Boarder	**1.5	*2.8	**2.7	*6.9	*7.5	12.2	19.7
Living rent-free	**2.6	**1.6	*4.3	*8.5	*6.9	16.0	22.9
Other	—	—	—	—	**1.2	*5.0	*6.1
Not applicable	—	**0.7	**2.7	*3.4	*3.9	*6.1	10.0
Total persons	30.2	133.1	110.7	274.1	155.3	164.0	319.3

(a) Estimates marked with ** have an associated relative standard error (RSE) of 50% or more. Estimates marked with * have an associated RSE of between 25% and 50%. These estimates should be interpreted accordingly.

— Nil or rounded to zero.

Source: AIHW analysis of ABS 1998 Survey of Disability, Ageing and Carers Confidentialised Unit Record File, and 1993 Survey of Disability, Ageing and Carers data.

Table A16.1: People living in households: carer status, by age and sex ('000), Australia, 1998^(a)

	Age groups							Total
	0-14	15-29	30-44	45-64	65+	0-64	15-64	
Males								
Primary carer	**1.2	*6.1	28.3	61.8	36.1	97.4	96.2	133.5
Not a primary carer	51.9	175.7	195.1	288.4	177.3	711.0	659.1	888.4
Total carer	53.1	181.8	223.4	350.2	213.5	808.4	755.3	1,021.9
Not a carer	1,946.8	1,923.0	1,909.5	1,689.6	729.7	7,468.9	5,522.1	8,198.6
Total	1,999.9	2,104.8	2,132.8	2,039.7	943.2	8,277.3	6,277.4	9,220.5
Females								
Primary carer	**1.5	22.5	101.1	132.0	60.2	257.1	255.6	317.3
Not a primary carer	50.5	196.0	267.7	348.1	126.2	862.3	811.8	988.4
Total carer	52.0	218.5	368.8	480.0	186.4	1,119.4	1,067.4	1,305.8
Not a carer	1,852.8	1,817.3	1,784.9	1,516.5	972.2	6,971.5	5,118.7	7,943.7
Total	1,904.8	2,035.8	2,153.7	1,996.5	1,158.6	8,090.9	6,186.1	9,249.5
Persons								
Primary carer	*2.8	28.6	129.4	193.7	96.4	354.5	351.7	450.9
Not a primary carer	102.4	371.7	462.8	636.4	303.5	1,573.3	1,470.9	1,876.8
Total carer	105.1	400.3	592.2	830.2	399.9	1,927.8	1,822.6	2,327.7
Not a carer	3,799.6	3,740.4	3,694.4	3,206.0	1,701.9	14,440.4	10,640.8	16,142.3
Total	3,904.7	4,140.7	4,286.5	4,036.2	2,101.8	16,368.2	12,463.4	18,469.9

(a) Estimates marked with ** have an associated relative standard error (RSE) of 50% or more. Estimates marked with * have an associated RSE of between 25% and 50%. These estimates should be interpreted accordingly.

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

Table A16.2: People living in households: carer status, by age and sex, as a percentage of the total population in each age and sex group, Australia, 1998^(a)

	Age groups						Total	
	0-14	15-29	30-44	45-64	65+	0-64		15-64
Males								
Primary carer	**0.1	*0.3	1.3	3.0	3.8	1.2	1.5	1.4
Not a primary carer	2.6	8.3	9.1	14.1	18.8	8.6	10.5	9.6
Total carer	2.7	8.6	10.5	17.2	22.6	9.8	12.0	11.1
Not a carer	97.3	91.4	89.5	82.8	77.4	90.2	88.0	88.9
Total number ('000)	1,999.9	2,104.8	2,132.8	2,039.7	943.2	8,277.3	6,277.4	9,220.5
Females								
Primary carer	**0.1	1.1	4.7	6.6	5.2	3.2	4.1	3.4
Not a primary carer	2.7	9.6	12.4	17.4	10.9	10.7	13.1	10.7
Total carer	2.7	10.7	17.1	24.0	16.1	13.8	17.3	14.1
Not a carer	97.3	89.3	82.9	76.0	83.9	86.2	82.7	85.9
Total number ('000)	1,904.8	2,035.8	2,153.7	1,996.5	1,158.6	8,090.9	6,186.1	9,249.5
Persons								
Primary carer	*0.1	0.7	3.0	4.8	4.6	2.2	2.8	2.4
Not a primary carer	2.6	9.0	10.8	15.8	14.4	9.6	11.8	10.2
Total carer	2.7	9.7	13.8	20.6	19.0	11.8	14.6	12.6
Not a carer	97.3	90.3	86.2	79.4	81.0	88.2	85.4	87.4
Total number ('000)	3,904.7	4,140.7	4,286.5	4,036.2	2,101.8	16,368.2	12,463.4	18,469.9

(a) Estimates marked with ** have an associated relative standard error (RSE) of 50% or more. Estimates marked with * have an associated RSE of between 25% and 50%. These estimates should be interpreted accordingly.

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

Table A16.3: People aged 15–64 years living in households, carer status, by income, labour force status and tenure type ('000), Australia 1998^(a)

	Carer status				Total
	Primary carer	Carer (not primary)	Total carer	Not a carer	
Labour force status					
Employed full-time workers	75.9	609.3	685.2	5,432.4	6,117.6
Employed part-time workers	80.8	313.2	394.0	2,128.8	2,522.8
Total employed	156.8	922.5	1,079.2	7,561.1	8,640.4
Unemployed	21.2	113.1	134.3	646.6	781.0
Not in the labour force	173.8	435.3	609.1	2,433.0	3,042.1
Principal source of cash income					
Wages or salary	116.8	730.7	847.5	6,234.4	7,081.9
Own business or partnership income	21.6	113.0	134.6	888.4	1,023.0
Other private income ^(b)	19.5	76.6	96.1	410.9	507.0
Government pension or allowance	173.2	436.3	609.5	2,156.7	2,766.3
Not stated ^(c)	20.7	114.3	135.0	950.3	1,085.4
Total cash income					
First income quintile ^(d)	65.4	282.4	347.9	2,146.7	2,494.6
Second income quintile	91.7	279.8	371.6	1,302.6	1,674.2
Third income quintile	87.0	271.4	358.3	1,760.2	2,118.5
Fourth income quintile	55.1	308.9	364.0	2,348.5	2,712.6
Fifth income quintile	34.9	230.0	264.9	2,223.7	2,488.6
Income not known ^(e)	17.6	98.4	116.0	859.1	975.0
Tenure type					
Owner without mortgage	123.8	438.4	562.2	2,436.2	2,998.4
Owner with mortgage	120.7	512.0	632.7	3,967.1	4,599.7
Public renter	33.6	64.6	98.2	345.3	443.5
Private renter	49.0	196.6	245.7	2,343.0	2,588.7
Boarder	*6.1	120.6	126.7	647.2	774.0
Living rent-free	15.0	114.8	129.9	731.6	861.5
Other ^(f)	**0.9	12.1	13.0	40.0	52.9
Not applicable	**2.6	11.8	14.4	130.5	166.8
Total persons	351.7	1,470.9	1,822.7	10,640.8	12,463.4

(a) Estimates marked with ** have an associated relative standard error (RSE) of 50% or more. Estimates marked with * have an associated RSE of between 25% and 50%. These estimates should be interpreted accordingly.

(b) Includes child support or maintenance, workers compensation, profit or loss from rental property, dividends or interest, superannuation or annuity.

(c) Includes people who report no source of income and main source of income not known.

(d) Includes people with nil income, and no source of income.

(e) Includes refusals.

(f) Includes life tenure schemes and rent/buy or shared equity schemes.

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

Table A17.1: Age distribution of recipients of CSDA-funded services, 1996 and 1999

Age	1996 recipients ^(a)		1999 recipients ^(a)	
	Number ('000)	Per cent	Number ('000)	Per cent
0–14	9.6	14.7	9.1	12.4
15–19	6.1	9.3	5.2	7.1
20–29	17.5	26.8	16.6	22.8
30–39	14.3	21.9	17.3	23.7
40–49	9.8	15.0	13.3	18.1
50–59	4.6	7.1	7.1	9.7
60–64	1.1	1.6	1.5	2.0
65+	2.3	3.6	3.0	4.1
Total	65.4	100.0	73.1	100.0

(a) This is a count of the number of times services were received on the 'snapshot' day from providers who received at least CSDA funding. It is not a count of individuals, as a person who received services from more than one provider would be counted more than once.

Source: AIHW analysis of CSDA MDS 1996 and CSDA MDS 1999.

Table A17.2: CSDA services received on the snapshot day: frequency of support needed by recipients aged 45–64, by service type and area of activity in which support needed, 1999

Area of support	None	Occasional	Frequent	Continual	Total frequent and continual	Not applicable	Not known/not stated	Total
All service types								
Self-care	4,364	3,671	2,667	3,321	5,988	7	494	14,524
Mobility	5,569	3,739	2,399	2,476	4,875	5	336	14,524
Communication	4,600	4,295	2,522	2,762	5,284	7	338	14,524
Social skills	2,727	4,456	3,448	3,394	6,842	21	478	14,524
Managing emotions	2,195	4,313	3,377	3,204	6,581	13	261	13,363
Learning	1,941	3,693	4,050	4,231	8,281	100	509	14,524
Working	1,150	2,610	2,283	6,438	8,721	1,192	851	14,524
Home living	1,613	2,728	3,667	5,527	9,194	72	917	14,524
Self-direction	1,905	3,960	4,007	4,200	8,207	20	432	14,524
Other day activity	2,084	3,785	3,502	3,852	7,354	209	1,092	14,524
Accommodation support								
Self-care	1,032	1,421	1,300	1,936	3,236	3	122	5,814
Mobility	1,776	1,478	1,127	1,314	2,441	0	119	5,814
Communication	1,404	1,675	1,143	1,465	2,608	1	126	5,814
Social skills	733	1,530	1,526	1,868	3,394	10	147	5,814
Managing emotions	549	1,425	1,432	1,732	3,164	6	39	5,183
Learning	517	1,157	1,693	2,223	3,916	57	167	5,814
Working	386	635	743	3,084	3,827	628	338	5,814
Home living	177	839	1,568	3,047	4,615	47	136	5,814
Self-direction	466	1,239	1,714	2,247	3,961	10	138	5,814
Other day activity	396	1,364	1,576	2,133	3,709	107	238	5,814
Employment								
Self-care	1,760	972	370	200	570	—	135	3,437
Mobility	1,915	944	303	243	546	—	32	3,437
Communication	1,325	1,201	545	338	883	—	28	3,437
Social skills	863	1,492	694	309	1,003	—	79	3,437
Managing emotions	776	1,463	792	327	1,119	—	79	3,437
Learning	462	1,408	979	523	1,502	—	65	3,437
Working	256	1,554	956	643	1,599	—	28	3,437
Home living	808	908	740	523	1,263	—	458	3,437
Self-direction	565	1,388	950	467	1,417	—	67	3,437
Other day activity	1,004	1,072	532	270	802	—	559	3,437

(continued)

Table A17.2 (continued): CSDA services received on the snapshot day: frequency of support needed by recipients aged 45–64, by service type and area of activity in which support needed, 1999

Area of support	None	Occasional	Frequent	Continual	Total frequent and continual	Not applicable	Not known/not stated	Total
Community support								
Self-care	690	455	321	436	757	4	133	2,039
Mobility	727	501	347	367	714	4	93	2,039
Communication	889	564	241	241	482	5	99	2,039
Social skills	564	593	407	329	736	5	141	2,039
Managing emotions	365	551	393	281	674	3	101	1,694
Learning	524	518	447	359	806	23	168	2,039
Working	301	199	174	749	923	338	278	2,039
Home living	305	451	462	653	1,115	3	165	2,039
Self-direction	449	593	475	389	864	4	129	2,039
Other day activity	351	554	455	436	891	84	159	2,039
Community access								
Self-care	814	751	625	654	1,279	—	86	2,930
Mobility	1,056	743	558	498	1,056	1	74	2,930
Communication	831	786	554	689	1,243	1	69	2,930
Social skills	491	757	762	833	1,595	2	85	2,930
Managing emotions	440	793	704	827	1,531	—	35	2,799
Learning	356	537	863	1,077	1,940	14	83	2,930
Working	174	199	386	1,828	2,214	183	160	2,930
Home living	305	472	826	1,188	2,014	6	133	2,930
Self-direction	352	662	796	1,039	1,835	1	80	2,930
Other day activity	302	727	854	937	1,791	14	96	2,930
Respite								
Self-care	68	72	51	95	146	—	18	304
Mobility	95	73	64	54	118	—	18	304
Communication	151	69	39	29	68	—	16	304
Social skills	76	84	59	55	114	4	26	304
Managing emotions	65	81	56	37	93	—	11	250
Learning	82	73	68	49	117	6	26	304
Working	33	23	24	134	158	43	47	304
Home living	18	58	71	116	187	16	25	304
Self-direction	73	78	72	58	130	5	18	304
Other day activity	31	68	85	76	161	4	40	304

- (a) An individual may be counted more than once if more than one service type was accessed on the 'snapshot' day.
 (b) Data for recipients of CSDA-funded services with service types Advocacy, Information/referral, Combined advocacy/information, Print disability/alt. formats of communication, Service evaluation/training, Peak bodies, Research/development and Other were not collected.
 (c) Data on managing emotions for recipients of CSDA services funded by Western Australia were not collected and 1,161 recipients are excluded from this support area.
 (d) Data provided by the Commonwealth are preliminary and cover 98% of Commonwealth-funded services.
 — Nil or rounded to zero.

Source: AIHW analysis of 1999 CSDA MDS collection.