Ageing and disability project report—stage 1 literature review

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Ageing and disability project report—stage 1 literature review

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Acknowledgments

The Australian Institute of Health and Welfare (AIHW) has been commissioned by the Disability Services Subcommittee (DSSC) to conduct a study of ageing and disability and the implications for disability support services. This literature review presents the results of Stage 1 of the three-stage study. The report on the whole study is scheduled to be finalised in early 2000.

The AIHW team that prepared this report was:

Principal author Xingyan Wen, advised by Ros Madden and assisted by Nicola Fortune.

The study team was assisted in preparing the report by Chrysanthe Psychogios and Johann Sheehan.

The study has benefited greatly from advice from the Project Reference Group, whose members are:

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- Sharyn Campbell (New South Wales)
- Cathy Ellis and Lara Purdy(Commonwealth)
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1 Introduction

1.1 Project brief

The Australian Institute of Health and Welfare has been commissioned by the Disability Services Subcommittee (DSSC) to conduct a study of ageing and disability. This project is designed to provide information to assist disability support service providers and senior policy makers faced with questions such 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 is to be 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;
- 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 not only entails a library based search of published literature, but also a review of studies now being conducted in Australian policy departments and universities.

Stage 2: Australian population implications

Key findings from the literature review will be weighed up in the context of Australian population data analysis. Data from the three Australian Bureau of Statistics (ABS) disability surveys and other population surveys of national significance (for instance, health and mental health surveys) will be analysed for what they might yield on questions (a) to (h) above, and for their possible confirmation of key findings from the literature review.

Unit record data from the 1998 ABS survey are not expected to be available until September 1999 and analysis of these most recent data should form an important part of this project.

Stage 3: Support service implications

This stage of the project will draw together the results of the two preceding stages, to provide information to answer the questions listed above, and a context within which to examine implications for support services.

Analyses of service use patterns and implications for future service use will be prepared. Outputs will include scenarios of future service provision and use, and availability of informal care.

Cost implications will be prepared, based on assumptions which would need to be constructed in consultation with DSSC nominees on the Reference Group.

Comment on the draft literature review

The draft literature review is now published as a working paper for further comment. The final project report will contain a final literature review, representing a further evolution from the draft review. Any comment on this draft review are welcome and should be forwarded by the end of 1999 to:

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1.2 Background and outline of literature review

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 (eg, 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, which is mainly attributable to lower fertility, and an increase in the absolute number of older people, which is largely a result of lower mortality among older people and a large birth cohort ageing (e.g. when the baby boom generation enter 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 normative 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.

The first part of this 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 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.

2 Population ageing in Australia

2.1 Some demographic features of Australia's population

Prior to 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 elderly 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 as the post Word 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 Word 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 more 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 cannot counteract the severe undercutting of the age pyramid at the youngest ages nor 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 (12.2%) 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 over (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 them 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 1998).

Internal 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 variations 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, 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 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 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 1).

Table 1: Projected changes in median age, proportion of population aged under 15 years and aged 65 years or over, Australia, 1997–2051[(a)]

	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.

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% (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 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 (Table 1).

There are several important features 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.

Table 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).

Table 2: Estimated and projected percentage changes in selected population 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	25.7(a)	5.1	8.4	0.9	1.3	1.7	2.7	-2.5
50-54	-4.9(b)	14.9	19.8	26.9(a)	5.1	8.5	1.5	-2.1	6.7	-0.7
55-59	2.0	-3.9(b)	14.0	21.1	26.9(a)	5.3	9.7	1.6	2.0	3.0
60-64	17.3	2.4	-3.6(b)	13.5	21.3	26.9(a)	14.6	2.0	-1.7	7.0
65-69	6.3	17.8	3.1	-2.8(b)	14.1	21.6	34.2	10.3	2.2	2.5
70-74	17.9	7.9	18.1	3.9	-1.8(b)	14.7	55.2(a)	15.8	3.0	-0.9
75-79	24.5	18.5	10.1	20.7	5.1	-1.0(b)	41.4	36.2	11.8	3.6
80-84	20.1	24.2	22.9	12.9	22.2	6.2	16.4	59.1(a)	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

Notes:

(a) This shift mainly reflects the passage of the larger cohort of the post-World War Two 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 populations and population projections Series II; ABS 1998a.

Table 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	1029.1	1293.9(a)	1360.5	1475.3	1488.4	1507.5	1532.7	1574.8	1535.2
50-54	774.6	736.9(b)	846.9	1014.9	1287.5(a)	1353.7	1468.8	1491.5	1459.7	1557.2	1546.7
55-59	740.6	755.5	726.0(b)	827.4	1002.1	1271.3(a)	1338.6	1468.7	1492.3	1521.4	1566.6
60-64	613.1	719.4	736.9	710.5(b)	806.4	978.3	1241.9(a)	1423.4	1452.1	1427.1	1527.1
65-69	536.2	570.2	671.4	692.2	673.0(b)	768.1	934.1	1253.9	1383.4	1414.0	1449.9
70-74	401.5	473.2	510.8	603.1	626.5	615.2(b)	705.5	1094.6(a)	1267.4	1305.4	1293.0
75-79	260.6	324.4	384.5	423.4	510.9	536.9	531.7(b)	751.8	1024.0	1145.2	1186.6
80-84	154.1	185.0	229.8	282.5	318.7	389.4	413.4	481.1	765.5(a)	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	1134.8
Total 45-64	2864.0	3054.1	3338.9	3846.8	4456.5	5078.6	5537.7	5891.1	5936.8	6080.5	6175.6
Total 50-64	2128.3	2211.8	2309.8	2552.8	3096.0	3603.3	4049.3	4383.6	4404.1	4505.7	4640.4
Total 65+	1455.0	1682.1	1950.7	2203.1	2384.7	2611.3	2952.8	4021.9	5052.5	5697.0	6027.2
Total 70+	918.8	1112.0	1279.3	1510.9	1711.7	1843.2	2018.7	2768.0	3669.1	4283.0	4577.3
Total 75+	517.3	638.8	768.6	907.7	1085.2	1228.0	1313.2	1673.4	2401.7	2977.6	3284.3

Notes:

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

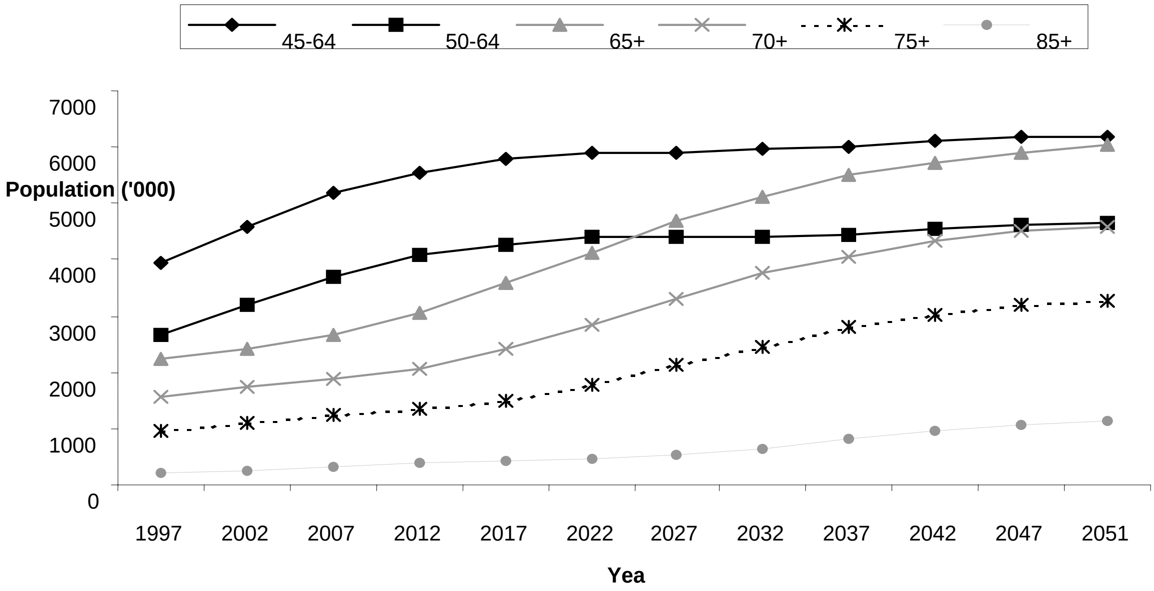
(b) This shift mainly reflects the passage of the people born in the low fertility years of the 1930s.

(c) 10-year period has been applied.

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

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 older age groups (Tables 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 Two (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 2 & 3; Figure 1).



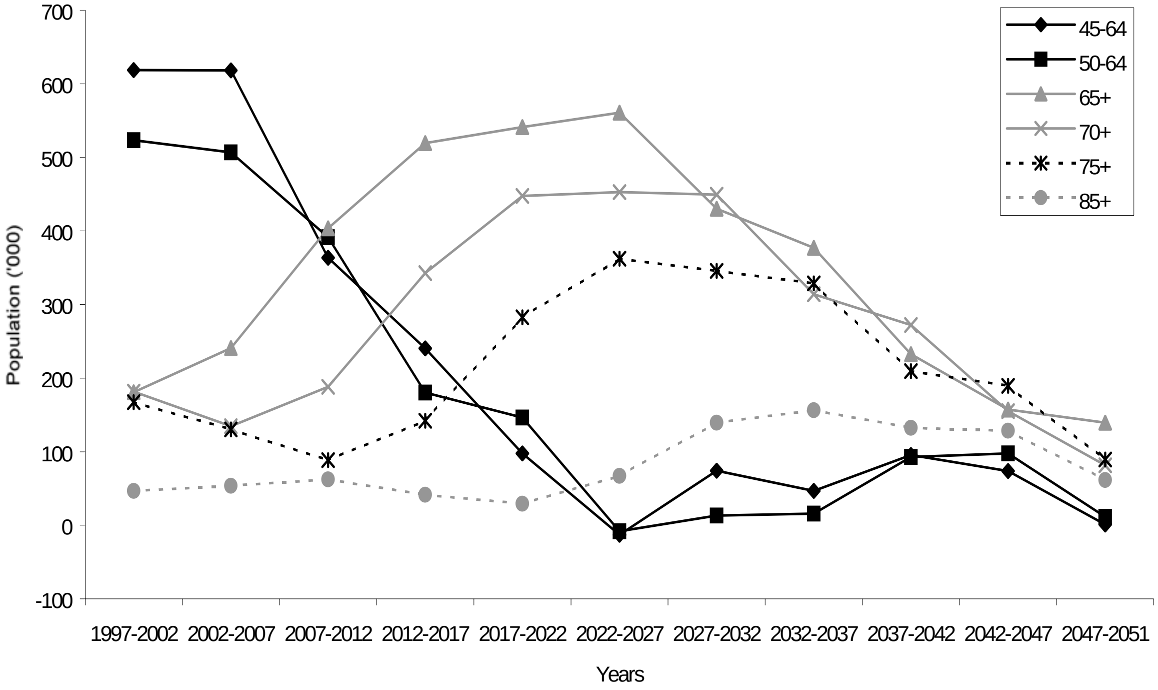
Source: Table A3.

Figure 1: Projected population in selected age groups, Australia, 1997–2051

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 (Table 2; Figure 2). This shift mainly reflects the passage of the post-World War Two baby-boom generation. This generation is progressively moving up the age pyramid causing rapid growth in the number of older people (Tables 2 and 3; Figure 2).

The growth of the population aged 65 years and over is projected to reach record rates (ie, to increase by 36.2% between 2011 and 2021) as the peak of the post-World War Two baby boom generation reaches retirement age (Tables 2 and 3; Figure 2).

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 A3).



Source: Table A2.

Figure 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;
- 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 change 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 increase 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. 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).

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 4). 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.

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 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 analysis will appear in the final report on this topic.

Table 4: Mortality and life expectancy, Australia, 1986-1996

	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

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

Source: Adapted from ABS 1998b: 48.

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). Between 1979 and 1994, the overall number of injury deaths among children aged under 15 years declined by 51.3% and the decline has been smaller for people aged over 15 years (Moller & Kreisfeld 1997).

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 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 because of 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. A US study found that age at onset of disability[1] has shifted to younger ages, and reported duration of disability has increased (Verbrugge 1989:340).

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. Stage 2 of the current project will examine this issue.

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

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[1] Disability was defined as reported limitations in activities (either major or secondary) due to a chronic condition (Verbrugge 1989:340).

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 rising 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 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 rates 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 age specific prevalence rates was equal to or greater than that of the ageing of the population in the early 1980s. However, the influence of changing age specific prevalence rates 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 twelve 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 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.
- Need and difficulty questions for tasks within an activity were re-ordered, to improve interview flow; this may have affected results for the core activities which were used to identify severe or profound handicap.
- The SF12 health status instrument (which included questions on activity) was used before questions on activity restrictions were asked.
- The application of both the profound and severe core activity restriction categories to the cared accommodation component. In 1993 the severe handicap category of the 1981 and 1988 surveys was divided into profound handicap and severe handicap, but the category of 'severe handicap' 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 improvements in survey method and thus an increased 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.

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 most focus on health and aged care costs.

Recently, there have been growing concerns about the extent to which existing disability support services can accommodate increasing number of older people with disability, 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 aged care and disability 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 (EPAC) 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 alarming conclusions:

- Welfare expenditure would rise from 6.9% of 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 massive 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).
- Analysis 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 elderly people in the future. The current level of expenditure in Australia could accommodate a population as old as Sweden 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 study of demographic influences on changes in social security spending over the past three decades (1965–1997) showed that expenditure on Age Pensions increased from 1.65% of GDP to 2.45% of GDP and expenditure on Disability Support Pensions increased from 0.32% of GDP to 0.99% of GDP. Disability Support Pension is the fastest growing payment group (Whiteford & Jackson 1998).

Population ageing has contributed substantially to the growth in numbers of Age Pensions, primarily for females. The highest incidence of receiving the Disability Support Pension (DSP) is in the age group 50–64 years, the upper end of the working age population. Prior to 1997, changes in 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, reflecting in the ageing of the working-age population, will cause further growth of Disability Support Pension (Whiteford & Jackson 1998; Jackson 1999).

If the current growth rate in the number of new DSP recipients continues, the number 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 will 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 the age groups with high grant rate (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;
- HACC utilisation is maintained at about 33% of people with profound or severe handicap in the community; and
- GDP per capita is maintained at 1% per annum in real terms (Walsh & 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).

4.3 Impact on demand for disability support services

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

The projected demographic trends, particularly population ageing, result 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% or 32,600 people) and 65 years and over (17.3% 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 is likely to result in the ageing of the client population of disability support services. The high growth in the population aged 45–64 years will put particular 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. The assumption is based on the results of a comparative analysis of data from the three ABS disability surveys (1981, 1988, 1993), which showed that age-standardised prevalence rates of severe or profound handicap remained fairly steady between 1981 and 1993 (AIHW 1997a; Wen et al. 1995). In stage 2 of the current project, this assumption will be reviewed by analysing the 1998 ABS disability survey data when the unit record file of the survey is available.

4.4 Impact on residential 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 in during a time of rapid ageing of the aged population in Australia (Gibson 1998). Nevertheless, this shift is largely carried out in a way of a deinstitutionalisation of program structures rather than a deinstitutionalisation 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 deinstitutionalisation is largely due to non-admission rather than of 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.

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 shortage of residential aged care from the turn of the century, including a likely shortage 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 significant 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[2]. 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 June 1998, almost half (48%) of residential aged care facility residents were aged 85 years and over, and nearly 60% of residents were in high-care categories (AIHW 1999a).

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 great 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 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 1991; Borowski & Hugo 1997;

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[2] 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 (Australia, 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).

Easterlin 1991). Another refinement—the labour force dependency ratio—is suggested, comparing the number of children, elderly 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 1998).

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 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).

The survey data also show that for 82% of people with profound or severe handicap, the main provider of assistance with self-care activities was an informal carer, usually resident in the same household. 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, and some of them are countervailing. First, it appears that there will be an increase in the number of potential carers for older people in the next century, since the number of people in the age group 45-64 is projected to be substantially higher than that in the age group 65 and over, particularly in the next two decades (Table 3 and Figure 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 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 baby-boom cohorts. This will result in an increase in the number of people with severe or profound handicap among people aged under 65 years. The increase of profound or severe handicap 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, 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[3]. 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).

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

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 the changes could potentially diminish the pool of family carers and the commitment within families to provide 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, as well as increasing in acceptance of remaining single, reduces 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 Section 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, as has acceptance of remaining single. 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, marriage rate[4] declined from 47.6 per 1,000 unmarried males to 34.7 per 1,000 (Table 5).
- 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).

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[4] The number of registered marriages per 1,000 not married male aged 15 and over.

- 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).
- There has been an increase in marital dissolution, which stabilised in the 1980s but has 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 males in 1996 (Table 5).

Table 5: Australian social trends – family formation, 1986-1996

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

Reference periods: Data on family formation are for the calender year.

Source: Adapted from ABS 1998b: 26.

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 6).
- The average family size became smaller, from 3.3 persons in 1987 to 3.1 persons in 1997 (Table 6).
- 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 6).
- 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 6).
- Female labour force participation rates have risen from 48.7% in 1987 to 53.9% in 1997 (ABS 1998b).

Table 6: Australian social trends – living arrangements, 1987-1997

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

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

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 establishments[5] 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, whereas by 1993 this ratio had dropped to 3.1 for every 100 living in households (AIHW 1997; 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

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

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).

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, rather than any radical change in living arrangement for the current 'institutionalised' population. The results of the analysis also indicate the possibility that individual de-institutionalisation efforts may be focussed on younger people (Wen & Madden 1998a).

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 growing numbers of people with 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 to 37% in 1966. However, of females aged 45–54 years in 1992, only just 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 principal carers reported that their caring role had not affected their friendships with others, or 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 broaden 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 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 life-long 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).

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. Stage 2 of this project will examine the changes in age structure of people with a disability and the potential impact of these changes on disability service planning. This section reviews trends in ageing of clients of disability and aged care services.

Many disability support services are provided or funded by Australian governments under the Commonwealth/State Disability Agreement (CSDA), with State governments taking responsibility for accommodation support and other services, and the Commonwealth government responsible for employment support services. The CSDA Minimum Data Set showed that about 14.9% (or 9,614) of CSDA service recipients on a snapshot day in 1997 were aged 50 years or over, 9.2% (or 5,940 people) were aged 55 years and over and 5.8% (or 3,762 people) were aged 60 years and over (Table 7)[6].

Of service recipients aged 45–64 years, 68.2% reported their primary disability type as intellectual and 12.0% as physical. Among those recipients aged 65 years and over, 37.3% reported intellectual and 29% reported vision as their primary disability type (Table 8).

Information about the living arrangements of service recipients showed that the proportion of recipients living alone increased with age: 8.1% of those aged under 45, 12.7% of those aged 45–64, and 20.1% of those aged 65 and over. The proportion of recipients living with their families declined from 45.8% for those aged under 45 years to less than 25% for those aged 45–64 years and 65 years or more (Table 9).

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. It should be noted that 69% of all recipients of this service

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[6] The data on service recipients are counts of services provided, on one day, by providers who receive at least some CSDA funding. They are not counts of service recipients since a recipient may have received a service from more than one provider on the day and thus may be counted more than once (Black & Maples 1998: 8).

category attended specialist agencies catering for people with disabilities associated with ageing, such as arthritis, visual and hearing impairments (Stevenson 1999).

Table 7: Recipients of CSDA-funded services, primary disability type by age, 1997

	<45 years	45-64 years	65+ years	Total	Total 50+	Total 55+	Total 60+	Total
Disability Type	**%**	**%**	**%**	**%**	**%**	**%**	**%**	**number**
Developmental	98.2	0.6	0.3	100.0	0.6	0.3	0.3	1,174
Intellectual	78.2	19.2	2.2	100.0	12.9	7.0	3.9	43,378
Learning	96.4	3.4	0.2	100.0	2.4	1.0	0.2	411
Autism	97.1	2.5	0.0	100.0	1.0	0.4	0.1	1,330
Physical	74.9	19.1	5.5	100.0	17.7	12.2	8.1	7,718
ABI	68.0	28.0	3.1	100.0	20.5	12.2	6.4	1,935
Deafblind	75.0	10.3	12.8	100.0	19.9	16.7	13.5	156
Vision	37.6	16.5	45.3	100.0	57.0	51.8	48.5	1,619
Hearing	73.4	13.8	12.5	100.0	22.9	19.6	14.6	608
Speech	93.6	4.4	1.6	100.0	2.8	2.4	1.6	250
Psychiatric	72.0	24.4	3.0	100.0	17.3	10.1	5.6	3,782
Neurological	64.7	27.1	6.7	100.0	24.4	16.7	10.2	1,756
Not Stated	59.7	14.9	8.6	100.0	18.7	14.3	11.7	315
Total	**76.5**	**19.0**	**3.9**	**100.0**	**14.9**	**9.2**	**5.8**	**64,432**

Source: AIHW analysis of the 1997 CSDA MDS collection. For detailed background information see Black and Maples 1998.

Table 8: Distribution of primary disability type of recipients of CSDA-funded services, by age, 1997

	<45 years		45-64 years		65+ years		
Disability Type	**Number**	**%**	**Number**	**%**	**Number**	**%**	**Total**
Developmental	1,153	2.3	7	0.1	3	0.1	1,174
Intellectual	33,927	68.8	8,339	68.2	941	37.3	43,378
Learning	396	0.8	14	0.1	1	0.0	411
Autism	1,292	2.6	33	0.3	0	0.0	1,330
Physical	5,781	11.7	1,472	12.0	427	16.9	7,718
ABI	1,316	2.7	541	4.4	60	2.4	1,935
Deafblind	117	0.2	16	0.1	20	0.8	156
Vision	609	1.2	267	2.2	734	29.1	1,619
Hearing	446	0.9	84	0.7	76	3.0	608
Speech	234	0.5	11	0.1	4	0.2	250
Psychiatric	2,723	5.5	923	7.5	112	4.4	3,782
Neurological	1,137	2.3	476	3.9	118	4.7	1,756
Not Stated	188	0.4	47	0.4	27	1.1	315
Total	**49,319**	**100.0**	**12,230**	**100.0**	**2,523**	**100.0**	**64,432**

Source: AIHW analysis of the 1997 CSDA MDS collection. For detailed background information see Black and Maples, 1998.

Table 9: Recipients of CSDA-funded services, living arrangements by age, 1997

	<45 years		45-64 years		65+ years	
Living Arrangement	**Number**	**%**	**Number**	**%**	**Number**	**%**
Lives alone	3,978	8.1	1,549	12.7	508	20.1
With family	22,585	45.8	2,692	22.0	588	23.3
Disability community accom	14,233	28.9	4,293	35.1	541	21.4
Other community accom	1,526	3.1	559	4.6	69	2.7
Nursing home	175	0.4	214	1.7	90	3.6
Hospital	218	0.4	79	0.6	5	0.2
Other institution	5,880	11.9	2,699	22.1	664	26.3
No usual residence	39	0.1	3	0.0	1	0.0
Not known	556	1.1	107	0.9	43	1.7
Not stated	129	0.3	35	0.3	14	0.6
Total	**49,319**	**100.0**	**12,230**	**100.0**	**2523**	**100.0**

Source: AIHW analysis of the 1987 CSDA MDS collection. For detailed background information see Black and Maples 1998.

Western Australia Disability Services Commission Reports have identified major changes occurring in the age profile of people registered with the Commission (that is, people who have a developmental disability or autism). In 1988, people aged 55 years or over represented 2.6% of total client numbers. This had risen to 5.0% by 1995 and was projected to rise to 7.4% by 2001. In 1988, people aged 35 to 45 years represented 30% of the total and this figure was projected to rise to 45% by 2001 (Gatter 1996:15).

There are people with early onset disability who are unknown 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 of 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).

6.2 Aged care services

The average age of Home and Community Care (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%. There were also slight declines in the proportion of clients aged 15–64 years (from 17.7% to 17.4%) and 0–14 years (from 3.1% to 2.3%) (Department of Health and Aged Care 1998:62)[7].

Analysis of the national data collected between 1993 and 1994 showed that, of clients of aged care services in either hostels or nursing homes, less than 6% aged under 65 years. However, among clients of home-based services of HACC and Community Options Projects (COP), about 19% and 26%, respectively, were aged under 65 years (Jenkins 1996:55).

Of the four service types (nursing homes, hostels, HACC and COP), nursing homes had the lowest proportion of clients who had lived alone prior to admission (33%), and hostels had the highest proportion (56%). Like hostel clients, a large proportion of HACC clients lived alone (52%). The living arrangements of clients of aged care services were considered to be affected by the confounding impacts of lifestyle factors and care needs (Jenkins 1996). According to the analysis, about 58% of HACC clients had a carer who was defined as a friend or relative who was providing informal assistance with tasks of daily living, or who was monitoring the person's well-being on a reliable and sustained basis. There were 72% of Community Option Projects clients who had a carer (Jenkins 1996:13).

HACC services can supplement informal care of people living at home, and may help to maintain the caring relationship for as long as possible. This projected increase in demand for HACC services is related to the ageing of both people with a disability and their carers (Gatter 1996).

It was observed in some cases that HACC services were easier to get if they were requested for the carer, and not the care recipient, even though both people in the relationship might equally benefit from the services (Gatter 1996:41).

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[7] The statistics were derived from the HACC Service User Characteristics Survey data, so that the estimated proportions are subject to sampling errors.

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 of 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 trends in prevalence of congenital malformations relating to early onset disability?

7.1 Early start of individual ageing

Theories of biological ageing can be divided into three broad categories: genetic, non-genetic, and physiological. 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 as increased risks 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 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 (eg, 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).

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 US and UK, 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 community (Anderson 1989; Badry et al. 1989).

7.2 Decline in mortality and increase in life expectancy

International studies show 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 is evidence to show that survival into older age is now a reality for people with an intellectual disability, including some people with more severe disabilities (Eyman & Borthwick-Duffy 1994). Nevertheless, 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 UK study of trends in incidence and survival in Down syndrome also found that the number of young adults with Downs 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 US 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 US 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 ages (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 nueropathological 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 percent prior to death (Barcikowska et al. 1989 cited in Suttie 1995:53).

With the exception of people with Down syndrome, studies so far have found little evidence indicating significant differences between ageing people with an intellectual disability and the general ageing population in the incidence of major illnesses and diseases (eg, heart disease, arthritis and higher blood pressure) attributable to individual biological ageing (Suttie 1995).

However, international studies found that dementia occurred at much higher rate among adult and older people with intellectual disability (not related to Down syndrome) than it did among the general population (Cooper 1997)

A study of adults with intellectual disability aged 20–50 years in Sydney showed that they have increased cardiovascular risk factors, more chronic diseases, and experience increased morbidity and mortality compared with the general population. They find it difficult to access health services because of problems with communication and mobility and low income (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, some assessment tools used in medical diagnosis have limitations. Improved assessment tools may lead to an increase in the detection of medical conditions and diseases.

Thirdly, 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-Duffy1994; 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 of the health and functional status of 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 do not increase at an exponential or nearly exponential rate with age). Because this distinction may reflet 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 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%[8] of all cases of severe intellectual disability (Alberman, 1978; McGrother & Marshall 1990; McLaren & Bryson 1987). Therefore, changes in incidence and the prevalence of these conditions have direct implications for services.

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

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 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 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 known whom outcome is, 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 abut specific impairments, activity limitations or restrictions). This additional information may allow us to analyse 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 diseases 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 change or affect their social, physical or cognitive behaviour (McPherson 1990). However, people with a disability may have experience losses of functional ability at different stages of their life, depending on the nature and time of onset of their specific disabilities. There are variations among older people in the rate and degree of change their biological and psychological systems undergo.

Nevertheless, the range of life circumstances and personality characteristics of older people with a disability is similar to the range found in the general community (Ashman & Suttie 1995). There are needs common to all older people, which are related to their biological, psychological and social ageing. Older people generally 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 results from biological, psychological and social ageing outlined below.

Biological ageing

Assistance as a result of biological ageing 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. people's personalities become deficient 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, health problems and sensory losses)—transportation and mobility assistance to maintain community contact and support in facilitating contacts.

8.2 Special characteristics of older people with an early onset disability

The above section reviewed some typical 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 Section 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 to one who have 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.

Differences in the support needs of people with a lifelong disability and people with a late onset disability are less apparent among people requiring nursing home care than among people whose support needs can be met by community-based services (Gatter 1996). This may be partly a result of the targeting of residential care to those with highest support needs.

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

Some important differences between ageing people with lifelong 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 characteristics 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 had limited education, particularly those with intellectual or learning disability.
- Most people 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.
- They are more likely to live in residential care and less likely to live alone or live with their families.
- They have poor social networks outside the family or their place of residence.
- Those relying on informal support from aged parents or carers are at risk of losing their support.
- They may be particularly disadvantaged due to their poor 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 skills and poor 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 been the main source of their life long 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 characteristics.

8.3 Special needs of older people with an early onset disability

Although their physical support needs may be very similar in some respects to those of the general ageing population, people with an early onset disability, in particular intellectual disability, often have psychological and social needs that require a different range of responses. The nature of services required by older people with an early onset disability also differs 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 have poor 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 impact of disability changes throughout the lifespan 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.
- The extra costs incurred by people with lifelong disability can mean that they face old age with few financial resources.

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 (eg. Williams & Chad 1998). These factors can be summarised as follows:

- Many people with 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 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 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 aide to support older adults with intellectual disability.

9 Existing problems and emerging services needs

9.1 General issues concerning the needs 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).

It is important to recognise that functional abilities, not age, should be the factor in determining the suitability of services and supports (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 of services 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, in recognising the special needs of older people with an early onset disability, specialist services may be necessary to assist people in accessing generic services or to ensure that they provide more sensitive or appropriate services.

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 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 then the general ageing population. Day services may need to be restructured from full day to part day activities, or to find more flexible ways 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 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 (New South Wales Ageing and Disability Department). 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 in to account a person's overall needs. This new initiative has the potential to assist in resolving the issues arising for older people a 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 is to investigate the nature and extent of retirement issues for people with disability in Commonwealth-funded employment services and identify strategies that may facilitate the transition from work to retirement for this group of people (Commonwealth Department of Family and Community Services 1999).

The study will examine both mainstream and specialist options for retirement support services, and identify client needs and best practice models. The study will particularly consider:

- 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 current scoping study on older people and mental health aims 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). 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 (ACAT) data set as the most promising potential sources of data to gain information about service target group (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

There are currently no specialist services providing day activity or leisure services for older people with an intellectual disability, although special services that focus on assisting and supporting people with an intellectual disability to access generic community services or day activities are being developed in some areas (Bigby 1992).

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[9]. 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

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[9] 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).

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).

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 (Seltzer 1988: 181):

- an age-integrated mental retardation service sector, which consists of programs that were developed for younger adults but also caters for some elderly clients;
- an age-specialised sector for elderly people with mental retardation, which consists of services designed exclusively or primarily for elderly persons; and
- a generic ageing service sector, which consists of programs for older people generally, but also serves some older people with mental retardation.

The study found that nearly 62% of the services used by elderly 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 elderly 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 weakness. 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 10) 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 10: A proposed integrated framework for service delivery to people with a disability who are ageing

	Strengths	Weaknesses
Age Integrated Disability Services eg: • 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.	• 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	• Programs not always are 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
Age Specialised Disability Services eg: • 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.	• 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	• Potential to isolate, stigmatise and segregate clients because of age and disability • Clients may be separated from past friends and service settings • Expectation of client may be lower than realistic • Programs may be less stimulating with fewer options
Generic Aged Services eg: • HACC Day Care Centres; • Meals on Wheels; • Senior Cits Centres; • Home Help Services.	• Age appropriate situations and services • Generally flexible and community integrated • Normalising and beneficial to relationships with age peers	• Some staff and non disabled clients not receptive • Staff lack specialist expertise • Services not always appropriate
Generic Aged Services "topped up" with specialist Disability Services resources, services (eg training and consultancy advice) and funds • A new concept.	• 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	• 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 Needs 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 home, but the question is will the support there to enable them to do so? A study of the needs of members in 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 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. Elderly 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 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. The future costs of supporting group home residents could then be significantly reduced, because by next decade, a majority of group homes will require staff to be on duty during the day due to an increasing number of ageing residents in group homes (Gatter 1996).

The design of group homes is aiming at meeting 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 ageing people with an early onset disability, this group has a low participation rate in both formal and informal 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 briefly to summarise 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 needs 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 lifelong disability. For example, programs targeted at frail elderly 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 old people with early onset disability who are relatively young.
- The existing types of residential aged care facilities cannot meet the needs of ageing people with an early onset disability who are much younger and perhaps much more physically able than most frail elderly 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 much less clear whether these services may be accessed by people with disability living in supported accommodation.
- The more intensive in-home support services developed by the HACC program for older people rely on both a co-resident carer and securing affordable housing. For ageing people with an early onset disability this could be difficult when their parents die and their estate is divided among family members.
- 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 disabilities.

10 Emerging planning and service models

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 currently 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 Service 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 a clear individual care plan and improved coordination between the health, Home and Community Care (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 in to account a person's total needs, it may assist in resolving the issues arising for older people a with disability whose needs cannot be met due to current program boundaries (Response from ADD 1999; Gething et al. 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:

- ‘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.
- Women as carer project (need more information).

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 these 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 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 the intellectually disabled residents of the hostel were mostly over the age of 55, were becoming increasingly frail, and had their health needs that were becoming more dominant 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 WA for a recognised provider of high quality aged care services.

10.4 South Australia

In SA, 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 intellectual disability who are ageing (Response from Richard Bruggemann, 1999).

Aiming to assist people with intellectual disability in understanding the ageing process, and to assist generic aged care service providers in meeting the needs of people with intellectual disability, IDSC Aged Care Services will be set up. The services are expected to meet the ongoing needs of people with intellectual disability and to provide specialist support to other agencies assisting people with intellectual disability (Response from Richard Bruggemann, 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 ACT 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 ACT 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 ACT 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).

Comment on the draft literature review

The draft literature review is now published as a working paper for further comment. The final project report will contain a final literature review, representing a further evolution from the draft review. Any comment on this draft review are welcome and should be forwarded by the end of 1999 to:

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Appendix

Appendix Tables

Table A1: Projected percentage increase in selected population age groups, Australia

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	26.6(a)	17.4	7.6	8.2	-1.7	4.2	-3.0	-0.2	4.2	2.1	0.6
60-64	14.9	26.9(a)	17.4	7.7	8.3	-1.6	4.4	-2.9	0.0	4.3	1.6
65-69	-0.2	15.5	27.2(a)	17.5	7.9	8.5	-1.4	4.6	-2.8	0.2	4.1
70-74	2.4	0.7	15.9	27.5(a)	17.7	8.3	8.8	-1.2	5.0	-2.6	-0.6
75-79	16.0	3.6	1.6	16.5	28.3(a)	18.1	8.8	9.3	-0.8	5.5	-0.7
80-84	17.1	17.2	4.5	2.7	17.5	29.7(a)	18.8	9.8	10.2	-0.2	3.9
85+	21.6	20.4	19.7	11.0	7.0	14.9	27.0(a)	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

Note: This shift mainly reflects the passage of the larger cohort of the post-World War Two baby-boom generation.

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

Table A2: 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	227.0(a)	187.4	96.1	111.2	-24.8	61.6	-45.6	-2.3	61.6	32.5	9.1
60-64	108.0	223.6(a)	183.9	95.5	110.4	-22.4	62.4	-43.1	-0.4	61.9	24.6
65-69	-1.2	106.1	215.2(a)	176.5	93.9	108.1	-19.2	63.1	-39.6	2.3	57.8
70-74	14.7	4.6	99.8	200.5(a)	164.7	90.3	103.7	-14.8	63.0	-34.4	-7.6
75-79	71.3	18.4	8.4	89.5	179.2(a)	147.4	84.8	97.0	-8.8	62.5	-8.7
80-84	49.1	58.1	17.7	11.1	74.2	147.9(a)	121.3	75.3	85.6	-1.6	36.6
85+	46.7	53.7	62.5	41.6	29.2	67.1	139.4(a)	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 larger cohort of the Post-World War Two baby-boom generation.

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

Table A3: 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	1289.9	1385.0	1496.2	1468.3	1528.4	1479.8	1475.1	1535.9	1567.0	1569.2	1545.6	1535.2
50-54	1094.2	1282.6	1378.3	1489.8	1463.3	1524.0	1476.7	1473.1	1534.3	1566.0	1569.0	1546.7
55-59	852.6	1079.6	1267.0	1363.1	1474.4	1449.6	1511.2	1465.6	1463.3	1524.9	1557.5	1566.6
60-64	722.7	830.7	1054.4	1238.2	1333.8	1444.2	1421.7	1484.1	1441.0	1440.6	1502.5	1527.1
65-69	687.1	685.8	791.9	1007.1	1183.6	1277.5	1385.6	1366.4	1429.4	1389.9	1392.2	1449.9
70-74	608.7	623.4	628.0	727.8	928.3	1092.9	1183.2	1286.9	1272.1	1335.0	1300.6	1293.0
75-79	445.5	516.8	535.2	543.6	633.1	812.4	959.7	1044.6	1141.5	1132.7	1195.3	1186.6
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	1073.4	1134.8
Total 45-64	3959.5	4578.0	5195.9	5559.4	5799.8	5897.6	5884.8	5958.7	6005.6	6100.8	6174.5	6175.6
Total 50-64	2669.6	3192.9	3699.7	4091.1	4271.4	4417.8	4409.6	4422.8	4438.6	4531.6	4629.0	4640.5
Total 65+	2245.1	2425.6	2666.4	3069.9	3589.1	4130.3	4691.1	5121.1	5497.9	5730.6	5887.9	6027.3
Total 70+	1558.0	1739.8	1874.5	2062.8	2405.5	2852.9	3305.6	3754.7	4068.5	4340.8	4495.7	4577.4
Total 75+	949.2	1116.3	1246.5	1335.1	1477.3	1760.0	2122.3	2467.8	2796.4	3005.7	3195.1	3284.3

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