



# 7 Disability services

## 7.1 Introduction

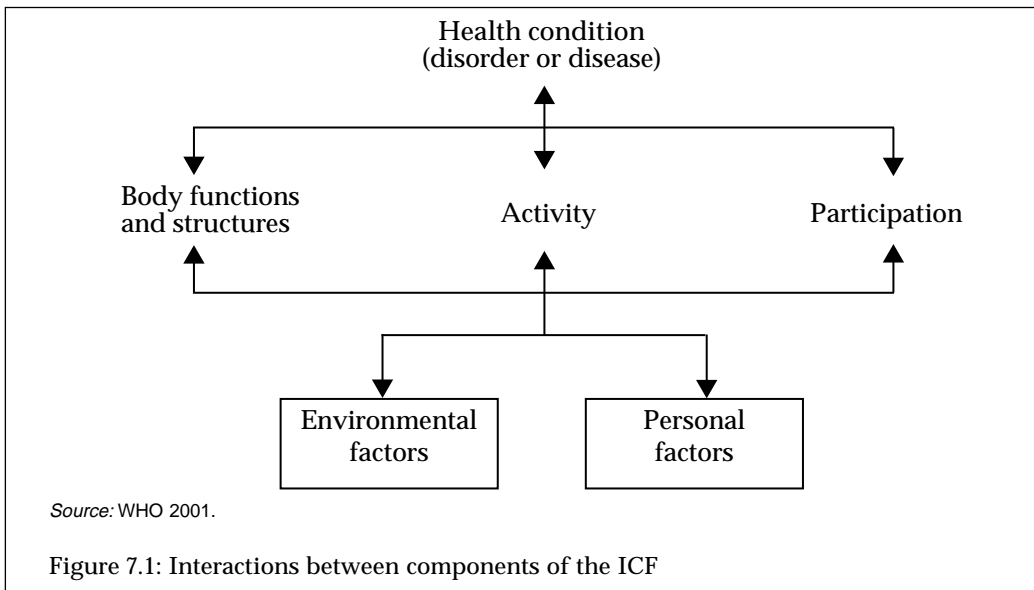
This chapter presents a national picture of disability services in Australia.

Disability is conceptualised as multidimensional, relating to the body functions and structures of people, the activities they do, the life areas in which they participate, and factors in their environment which affect these experiences (see Figure 7.1, Box 7.1).

Services of relevance to people with a disability may seek to ameliorate disadvantage associated with any of these components of disability, including the environmental factors. This chapter focuses chiefly on people aged under 65 years, and on services and assistance directed primarily towards their activities and participation in various areas of life:

- formal services and assistance, such as income support, specialist disability services, and relevant generic services;
- equipment or environmental modifications;
- informal support from family and friends.

In this fifth biennial report it is possible to examine trends over recent years, and this is done in each of the three following sections on population data, service data and outcome data. Section 7.2 provides data on the Australian population with a disability and describes their needs for services and assistance. Section 7.3 provides data on services and assistance and outlines recent developments in the field, including data



developments. Section 7.4 discusses outcomes for people with a disability and presents some data on participation, and Section 7.5 concludes the chapter.

### Box 7.1: The new ICF—a conceptual framework for functioning and disability

*In May 2001 the new International Classification of Functioning, Disability and Health (ICF) was endorsed by the World Health Assembly (WHO 2001). This marked the finalisation of a revision of the ICIDH (WHO 1980), a process involving several years of redevelopment and testing by WHO and its Collaborating Centres including the AIHW. The ICF is a core member of the WHO family of health-related classifications, complementary to the other core member, the ICD, which focuses on diseases and health conditions.*

*The ICF is organised in two parts. The first part recognises two main components of functioning and disability:*

- *a body component comprising classifications of Body Function and Body Structure; and*
- *an Activities and Participation component providing a complete set of domains for aspects of functioning from both an individual and a societal perspective.*

*A person's functioning and disability is conceived as a dynamic interaction between health conditions and environmental and personal factors (WHO 2001:6). Environmental factors are presented in the second part of the classification and represent an important new component. The interactions between the components of functioning, disability and health can be represented visually (Figure 7.1).*

*Disability is the umbrella term for any or all of: an impairment of body structure or function, a limitation in activities, or a restriction in participation. The key components of disability are defined as follows:*

- *Body functions are the physiological functions of body systems (including psychological functions).*
- *Body structures are anatomical parts of the body such as organs, limbs and their components.*
- *Impairments are problems in body function and structure, such as significant deviation or loss.*
- *Activity is the execution of a task or action by an individual.*
- *Participation is involvement in a life situation.*
- *Activity limitations are difficulties an individual may have in executing activities.*
- *Participation restrictions are problems an individual may experience in involvement in life situations.*
- *Environmental factors make up the physical, social and attitudinal environment in which people live and conduct their lives. These are recorded as either facilitators or barriers (both on a 5-point scale) to indicate the effect they have on the person's functioning.*

## 7.2 Prevalence of disability and need for assistance

This section presents an overview of the patterns of prevalence of disability and need for assistance in the Australian population. The impact of population ageing on disability prevalence is analysed, and other factors affecting recent changes in prevalence are reviewed.

### Disability in the Australian population

The most recent national population survey of disability is the Australian Bureau of Statistics (ABS) 1998 Survey of Disability, Ageing and Carers. Previous surveys were conducted in 1981, 1988 and 1993. The 1998 survey reported a great increase in the proportion of people with a disability between 1993 and 1998, largely due to changes in survey design and methods (see pages 267—269).

Table 7.1: People with a disability, by disability status and severity of core activity restriction, as a proportion of the State/Territory or Australian population of that age, 1998 (per cent)

	Severity of core activity restriction				Schooling or employment restriction only	Total with specific restrictions	Total with specific restrictions adjusted	Total with a disability	Total with a disability adjusted	Population ('000)
	Profound	Severe	Moderate	Mild						
<b>0–64 years</b>										
NSW	1.3	2.5	2.5	4.1	1.8	12.2	12.2	14.3	14.2	5,520.7
Vic	1.2	2.4	2.3	3.8	1.8	11.4	11.4	13.2	13.1	4,058.7
Qld	1.6	3.1	2.8	3.3	2.3	13.1	13.3	15.3	15.5	3,061.7
WA	1.2	2.6	3.2	3.9	2.0	12.8	13.0	15.3	15.5	1,629.7
SA	1.6	2.7	3.3	4.7	2.9	15.1	14.8	17.2	16.8	1,273.5
Tas	*1.3	4.1	2.9	3.9	2.2	14.3	14.1	17.0	16.8	409.4
ACT	*1.0	*2.7	*2.3	*3.0	*2.0	10.9	11.4	13.7	14.2	285.6
NT	**1.0	*2.4	*2.4	*2.8	**1.2	9.8	9.0	11.8	10.9	150.1
Australia	1.3	2.7	2.6	3.9	2.0	12.5	..	14.6	..	<b>16,389.4</b>
<b>Australia ('000)</b>	<b>218.1</b>	<b>436.6</b>	<b>433.8</b>	<b>632.2</b>	<b>327.9</b>	<b>2,048.7</b>	<b>..</b>	<b>2,385.1</b>	<b>..</b>	<b>..</b>
<b>All ages</b>										
NSW	2.9	3.1	3.5	5.8	1.6	16.9	16.7	19.3	19.1	6,325.8
Vic	2.8	3.0	3.2	5.3	1.5	15.9	15.7	18.0	17.8	4,644.9
Qld	2.9	3.7	3.7	4.9	2.1	17.3	17.8	19.9	20.5	3,449.2
WA	2.6	3.0	4.0	5.4	1.8	16.8	17.6	19.5	20.4	1,820.4
SA	3.3	3.0	4.2	6.9	2.5	19.9	18.8	22.4	21.2	1,484.7
Tas	3.1	4.5	3.8	5.9	1.9	19.2	18.7	22.3	21.7	471.3
ACT	*2.3	3.1	*2.7	4.2	*1.9	14.2	16.3	17.2	19.5	309.1
NT	**1.2	*2.9	*2.3	*3.6	**1.1	11.2	12.7	13.3	14.8	155.0
Australia	2.9	3.2	3.5	5.5	1.8	16.9	..	19.3	..	<b>18,660.6</b>
<b>Australia ('000)</b>	<b>537.7</b>	<b>598.2</b>	<b>660.3</b>	<b>1,031.8</b>	<b>327.9</b>	<b>3,155.9</b>	<b>..</b>	<b>3,610.3</b>	<b>..</b>	<b>..</b>

#### Notes

1. Estimates marked \*\* are subject to sampling variability too high for most practical purposes. Estimates marked \* have an associated relative sampling error of between 25% and 50%. These estimates should be interpreted accordingly.
2. Core activities comprise communication, mobility and self-care.
3. Adjusted percentages were calculated using the age- and sex-specific rates for the Australian estimated resident population for March 1998.

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

In the 1998 survey, 3,610,300 people reported one or more of 17 limitations, restrictions or impairments (Box A7.1) which had lasted, or were likely to last, for at least 6 months and which restricted everyday activities.<sup>1</sup> Of these, 2,385,100 were aged under 65, of whom 1,283,600 (53.8%) were male and 1,101,500 (46.2%) were female (Tables 7.1, A7.1). The survey also collected information about specific activity restrictions, of which there are five categories: restrictions in the three core activities of daily living (self-care, mobility and communication), and restrictions in schooling and employment (Box 7.2).

### Box 7.2: ABS 1998 Survey of Disability, Ageing and Carers: restrictions and their severity

*Specific restrictions are*

- *core activity restrictions; and/or*
- *schooling or employment restrictions.*

*Core activities are*

- *self-care—bathing or showering, dressing, eating, using the toilet, and managing incontinence;*
- *mobility—moving around at home and away from home, getting into or out of a bed or chair, and using public transport; and*
- *communication—understanding and being understood by others: strangers, family and friends.*

*A core activity restriction may be*

- *profound—unable to perform a core activity or always needing assistance;*
- *severe—sometimes needing assistance to perform a core activity;*
- *moderate—not needing assistance, but having difficulty performing a core activity; or*
- *mild—having no difficulty performing a core activity but using aids or equipment because of disability.*

*Note:* In the text of this chapter, 'a severe or profound core activity restriction' is sometimes referred to as 'severe or profound restriction'.

*Source:* ABS 1999.

In 1998, of those with a disability, 2,048,700 people aged under 65 had at least one specific activity restriction: 12.5% of the population in that age group. Of these people, 655,000 or 4.0% of the population aged under 65, reported a severe or profound restriction, which means that they sometimes or always needed personal assistance or supervision with the activities of daily living.

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1 The 1998 ABS disability survey equates this to 'disability' (ABS 1999).

States with higher proportions of older people, such as South Australia and Tasmania (ABS 1998a), tended to have higher rates of disability and specific restrictions than the national average. The Australian Capital Territory and the Northern Territory have a younger population age structure and correspondingly relatively low disability prevalence rates. When age-adjusted rates are compared, rates in the Australian Capital Territory are close to the national average, although the Northern Territory rates are still lower than the national average (Tables 7.1, A7.2).

Table 7.2: People with a severe or profound core activity restriction living in households, by activity type in which assistance needed and age group, 1998

	Age group (years)					Total<65	65+	All ages
	0-14	15-19	20-29	30-44	45-64			
	<b>Number ('000)</b>							
Self-care	85.2	9.7	22.6	82.5	161.2	361.2	155.2	516.4
Mobility	72.9	22.7	39.7	105.3	210.3	451.0	273.6	724.6
Communication	90.9	12.7	10.3	15.4	*9.0	138.3	28.6	166.9
Health care	72.7	14.0	20.6	68.8	145.8	321.9	216.4	538.3
Housework	..	11.4	19.8	76.6	144.8	252.6	226.2	478.8
Property maintenance	..	11.2	19.6	87.4	192.3	310.6	250.2	560.7
Paperwork	..	17.7	19.4	40.6	52.3	129.9	110.3	240.3
Meal preparation	..	*8.0	14.4	38.9	60.2	121.6	120.2	241.8
Transport	32.4	16.1	22.9	80.9	141.3	293.6	232.2	525.8
Guidance	102.8	21.8	28.8	59.6	87.7	300.7	69.6	370.4
<i>Total needing assistance</i>	<i>142.4</i>	<i>30.7</i>	<i>48.8</i>	<i>135.5</i>	<i>276.0</i>	<i>633.4</i>	<i>324.6</i>	<i>958.0</i>
<b>Total severe or profound</b>	<b>143.6</b>	<b>30.7</b>	<b>49.4</b>	<b>136.2</b>	<b>276.0</b>	<b>636.0</b>	<b>325.6</b>	<b>961.6</b>
	<b>Per cent</b>							
Self-care	2.2	0.7	0.8	1.9	4.0	2.2	6.8	2.8
Mobility	1.9	1.7	1.4	2.5	5.2	2.8	12.1	3.9
Communication	2.3	1.0	0.4	0.4	*0.2	0.8	1.3	0.9
Health care	1.9	1.1	0.7	1.6	3.6	2.0	9.5	2.9
Housework	..	0.9	0.7	1.8	3.6	1.5	10.0	2.6
Property maintenance	..	0.9	0.7	2.0	4.8	1.9	11.0	3.0
Paperwork	..	1.3	0.7	0.9	1.3	0.8	4.9	1.3
Meal preparation	..	*0.6	0.5	0.9	1.5	0.7	5.3	1.3
Transport	0.8	1.2	0.8	1.9	3.5	1.8	10.2	2.8
Guidance	2.6	1.7	1.0	1.4	2.2	1.8	3.1	2.0
<i>Total needing assistance</i>	<i>3.6</i>	<i>2.3</i>	<i>1.7</i>	<i>3.2</i>	<i>6.8</i>	<i>3.9</i>	<i>14.3</i>	<i>5.1</i>
<b>Total population ('000)</b>	<b>3,905.6</b>	<b>1,316.1</b>	<b>2,827.9</b>	<b>4,292.8</b>	<b>4,048.7</b>	<b>16,391.1</b>	<b>2,268.6</b>	<b>18,659.7</b>

*Notes*

1. Estimates marked \* have an associated relative standard error of between 25% and 50% and should be interpreted accordingly.
2. The total number of people needing assistance is less than the sum of activity types since people may need help with more than one activity.
3. Percentages are based on the Australian population for each age group.

Source: AIHW 2000b; AIHW analysis of ABS 1998 Survey of Disability, Ageing and Carers confidentialised unit record file.

## Activities with which assistance is needed

In 1998, 958,000 people (5.1% of Australians) with a severe or profound restriction living in households reported need for assistance with at least one of 10 activities (Table 7.2). This figure included 633,400 people aged under 65 (3.9% of the population of that age) and 324,600 people aged 65 or more (14.3%). Overall, need for assistance was most commonly reported with mobility (3.9% of the total population), property maintenance (3.0%), health care (2.9%), self-care (2.8%) and transport (2.8%). The need for assistance with all activities generally increased with age after age 30.

Of all people with a severe or profound restriction living in households, 386,700 (40.2%) reported need for assistance with more than one core activity. Of these, 73,000 (7.6%) needed help with all three core activities (self-care, mobility and communication). For people aged under 65, about 264,300 (41.6%) needed assistance with more than one core activity, including 56,000 (8.8%) who needed help with all three (Table A7.3).

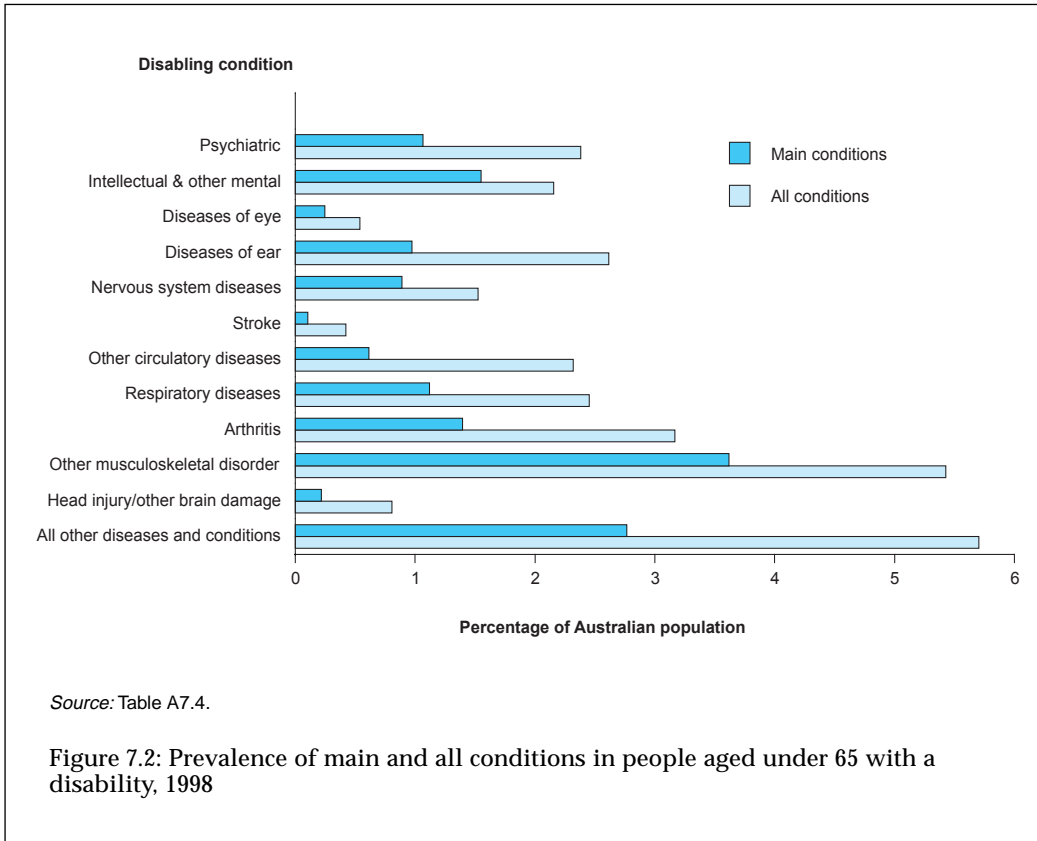
A person's main condition was defined in the 1998 disability survey as a long-term condition identified by a person as the one causing the most problems (ABS 1999:69). For people aged under 65 years in 1998 most disabilities were associated with physical main conditions: 10.7% of the population in this age group reported such main conditions. The most common were arthritis (1.4%) and other musculoskeletal disorders (3.6%). The next most frequent group was disabling conditions affecting intellectual abilities (1.6%), followed by sensory (1.2%) and psychiatric (1.1%) conditions (Table A7.4).

The prevalence of a particular condition will be underestimated if main conditions only are considered, since people with multiple conditions are counted only once, according to the main condition. Figure 7.2 compares the prevalence of various conditions, according to whether they were reported as the main condition or among a number of disabling conditions. Reported prevalence is higher when all conditions are considered, suggesting the common occurrence of multiple conditions in the population with a disability. In particular, head injury and brain damage, stroke and other circulatory diseases were frequently reported in combination with another condition.

## Disability groups

Estimates of the prevalence of main disabling conditions can be obtained directly from the ABS disability surveys; however, a more widely used concept is that of disability groups. Disability groupings, such as intellectual disability and physical disability, are a broad categorisation of disabilities based not only on underlying health conditions, but also on impairment, activity limitations, participation restrictions and related environmental factors. They are generally recognised in the disability field and in legislative and administrative contexts in Australia (AIHW 2000a).

The prevalence of disability groups can be estimated from the ABS disability surveys using a multidimensional approach that combines information from a number of questions, and this has been done for some significant disability groups using the 1993 survey (AIHW: Fortune & Wen 1999; AIHW: Wen 1997; AIHW: Wen & Fortune 1999). The extended range of questions in the 1998 survey provides new opportunities for refining the prevalence estimates. The AIHW plans to update and extend these estimates using the 1998 survey.



## Disability, population ageing, and growth in severe restriction

Population ageing is indicated by an increase in the proportion of older people in the population. The Australian population will continue to age as the result of declining mortality rates and low levels of fertility over a long period. Population projections indicate a clear long-term trend of decline in growth rate: from 1.2% in 1996–97 to between zero and 0.3% by 2051. The median age of the Australian population is projected to increase from 34.3 years in 1997 to between 43.7 and 46.2 years in 2051. The proportion of people aged 65 years and over is projected to increase rapidly: from 12% (2.2 million) in 1997 to 26% (6.3 million) in 2051 (ABS 1998a).

The bulge of the post—World War II baby-boom generation is currently affecting the population age profile, in particular the structure of the under-65 population. From now to 2006, the 50–64 age group is projected to increase at a markedly higher rate (16.4%) than the 65-plus age group (9.5%). Between 2006 and 2011, the 60–64 age group is expected to increase at a higher rate (26.9%) than any other age group (Table 7.3). Between 1997 and 2051, the greatest growth is occurring in the 45–64 age group from 4 million to over 6 million (AIHW 2000b).

Table 7.3: Estimated and projected percentage changes in selected age groups, 1981–2051

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

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

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

(c) 10-year period has been applied.

Source: ABS 1998a; AIHW 2000b:8.

As a result of general population ageing, the population with a disability is also ageing. Among people aged under 65 with a severe or profound restriction, the proportion aged 45–54 increased from 17.5% in 1988 to 22.3% in 1998, reflecting the fact that the baby-boom generation is now entering age groups associated with high risk of disability (Table 7.4). During the coming decade (2001–11), the progressive upward movement of this generation in the population age pyramid is likely to continue to increase the number of people with a severe or profound restriction in the 55–64 year age group.

Table 7.4: People aged under 65 years with a severe or profound core activity restriction, by age group, 1981, 1988, 1993 and 1998 (per cent)

Age (years)	1981	1988	1993	1998
5–14	16.9	18.1	17.8	19.0
15–24	9.8	9.2	10.9	8.7
25–34	11.9	13.2	14.0	11.3
35–44	14.3	18.6	18.0	15.7
45–54	19.4	17.5	18.8	22.3
55–59	14.0	10.6	11.1	12.4
60–64	13.7	12.9	9.4	10.6
<b>Total under 65</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>
Total 45–64	47.2	40.9	39.3	45.3
Total under 65 ('000)	239.7	297.2	329.4	510.1

Notes

1. Disability data were re-derived using criteria common to the four surveys.

2. In the 1981, 1988 and 1993 disability surveys, severity of core activity restriction was not determined for children aged 0–4 years.

Source: AIHW analysis of the ABS 1981, 1988, 1993 and 1998 Survey of Disability, Ageing and Carers unpublished data tables.

## Ageing of people with an early onset disability

In 1998, of people with a severe or profound restriction living in households, 11.0% (30,200) of those aged 45–64 and 4.1% (13,000) of those aged 65 or over had acquired a disability before age 18 (AIHW 2000b).

Empirical evidence indicates that people with an intellectual disability resulting from certain conditions age earlier. Signs of premature ageing have consistently been reported in people with Down syndrome and intellectual disability resulting from other chromosomal causes (e.g. Janicki et al. 1985; Suttie 1995). Dementia occurs at higher rates among adults and older people with intellectual disability (not related to Down syndrome) than among the general population. Some people with an intellectual disability may acquire dementia relatively early in life, at around age 50 (Cooper 1997).

Some studies show that people with severe physical disabilities such as spinal cord injury and brain injury also show signs of ageing earlier than the general population, and that a range of health conditions worsen with increased duration of disability (Crewe 1990; Fethney 1998; Gething & Fethney 1998; Menter et al. 1993).

## Growth estimates of severe or profound restriction

The projected demographic changes, in particular population ageing, indicate a significant future growth in the number of people with a severe or profound restriction (AIHW 2000b). Based on the age- and sex-specific prevalence rates of the 1998 ABS disability survey, growth estimates suggest that between 2000 and 2006 (Tables 7.5, A7.5):

- the total number of people of all ages with a severe or profound restriction will increase by 12%, from 1,189,500 to 1,327,100;
- the number of people aged 0–64 with a severe or profound restriction will increase by 9%, from 681,600 to 742,900; and
- the greatest increases will be in the age groups 45–64 (19%, or 59,500 people) and 65 and over (15%, or 76,300 people).

Table 7.5: Percentage change in the estimated number of people with a severe or profound core activity restriction, by age group, 2000–06<sup>(a)(b)</sup>

Age (years)	2000–01	2001–02	2002–03	2003–04	2004–05	2005–06	2000–06
0–14	–0.1	–0.1	–0.2	–0.4	–0.6	–0.7	–2.0
15–19	0.8	0.3	0.1	0.3	0.8	0.8	3.0
20–29	–0.9	–0.6	0.0	0.3	0.4	0.8	–0.1
30–44	1.1	0.9	0.5	0.3	0.0	–0.2	2.7
45–64	3.1	3.2	3.1	2.9	2.9	2.8	19.3
65+	2.6	2.3	2.2	2.0	2.4	2.7	15.0
Total 0–64	1.6	1.6	1.5	1.4	1.3	1.3	9.0
Total 15–64	2.0	2.0	1.9	1.9	1.8	1.8	12.0
<b>Total</b>	<b>2.0</b>	<b>1.9</b>	<b>1.8</b>	<b>1.7</b>	<b>1.8</b>	<b>1.9</b>	<b>11.6</b>

(a) ABS 1998 population projections (Series K) as at 30 June.

(b) Estimated numbers were calculated using age- and sex-specific prevalence rates derived from the ABS 1998 Survey of Disability, Ageing and Carers.

Source: ABS 1998a; AIHW 2000b; AIHW analysis of ABS 1998 Survey of Disability, Ageing and Carers data.

It should be noted that the growth estimates rely on two underlying assumptions: the age- and sex-specific prevalence rates of severe or profound restriction in 1998 remain constant over the projection period; and other factors affecting the prevalence of severe or profound restrictions remain unchanged in the future. Therefore, the estimates should be interpreted in the context of these assumptions.

## Changes in the prevalence of disability

### Impact of population changes on prevalence, 1981–98

The number of people with a severe or profound restriction in 1998 was more than twice that in 1981 (Table A7.6). Population change contributed about 45% of this increase. The remaining changes may be attributed to a combined effect of various factors, such as changes in survey design and interview methods, and in community perceptions and awareness of disability (Table A7.7; AIHW 2000b). The overall effects of population change have two major components: change in total population size, and differential growth among age groups, resulting in population ageing. Over the entire 17 years, the contributions of population ageing and increase in population size appeared to be similar (20.5% versus 24.4%). However, during the most recent 10 years (1988–98), the effect of population ageing has contributed much more than growth in population size to this increase (31.0% versus 11.7%).

### Reported changes in prevalence, 1993–98

The age-standardised prevalence rates of severe or profound restriction were relatively stable during the 1980s and early 1990s, remaining at around 4% of the Australian population (AIHW 1997a; AIHW: Wen et al. 1995). However, between 1993 and 1998 the estimated rate of severe or profound restriction, as reported by the ABS, increased from 4.1% (721,000 people) to 6.1% (1,135,900 people), an increase of 2 percentage points or 414,800 people (ABS 1993, 1999). Based on the information and analyses to date, the increase does not reflect a substantial increase in the underlying prevalence of disability. Rather, it is largely due to the changes in design and methods of the 1998 survey which captured a larger number of people with a severe or profound restriction than the 1993 survey (AIHW 1999a, 2000b; ABS: Davis et al. 2001).

It has been suggested that between 1993 and 1998 over half (1.2 percentage points) of the increase in the rate was attributable to improvements in survey method. About 0.3 percentage points resulted from changes in population age structure, and the remaining 0.5 percentage points might be explained by increased awareness of a disability, increased willingness to report a disability, and/or actual increased severe or profound restrictions (ABS: Davis et al. 2001). Box 7.3 details the changes in ABS survey design and implementation methodology.

Three population groups accounted for about 80% of the reported increase in severe or profound restrictions. People aged 45–64, mostly with musculoskeletal conditions other than arthritis, accounted for almost half of the increase. Children, mostly boys, aged 5–14 with intellectual and behavioural disorders, and older people, especially men, aged 75–79 and 85+, made up a third of the increase together (ABS: Davis et al. 2001).

### Box 7.3: Changes in disability survey design and implementation method

*Two aspects of changes in survey method appear to have impacted significantly on the reported rates of prevalence.*

*First, modifications in the 1998 ABS survey screening questions (in effect, the criteria for defining disability) have resulted in an increase in the base disability population who were then asked questions to determine the severity of core activity restrictions. For instance, a new screening question about chronic pain was introduced and changes were made to the wording of other screening questions. People who had been identified by another person as having a long-term health condition but no disability (based on screening questions) were for the first time given an opportunity to answer for themselves whether they were restricted by their condition.*

*Second, some other developments have resulted in increased capture of severe or profound restrictions:*

- The SF-12 assessment instrument of health status was introduced and placed after the survey screening questions but before questions on core activity restriction.<sup>(a)</sup> Although it could not have affected the size of the disability population, it could have prompted respondents to focus on the day-to-day effect of their condition and thus answer more fully in the subsequent questions on core activity restrictions and need for assistance.*
- The use of Computer Assisted Interviewing (CAI) allowed a smoother flow of the interview and may have encouraged more positive responses to questions about core activity restriction.*
- The introduction of severity assessment of activity restrictions for children under age 5 has identified 28,100 children aged 0–4 with a severe or profound restriction.*
- Additional information was collected to distinguish severe from moderate restriction in cared accommodation,<sup>(b)</sup> resulting in an increase in the number of people with a severe restriction in cared accommodation.*

(a) The SF-12 is a commonly used international instrument consisting of 12 questions that provide a generic measure of health status (Ware et al. 1996).

(b) The cared accommodation component of the survey includes hospitals, aged care homes and cared components of retirement villages, and other 'homes', such as children's homes. Smaller disability group homes (with fewer than six people) were not included in the cared accommodation component (ABS 1999).

Source: AIHW 1999a; ABS: Davis et al. 2001.

The factors affecting the reported increase vary for each of the population groups. Increased capture had the greatest impact on the 45–64 age group, resulting in up to 75% of the increase in this group. The new screening question about chronic pain contributed substantially to the increase in reported musculoskeletal disorders other than arthritis (mainly back pain), which was accompanied by an increase in the number of people reporting need for assistance.

For children aged 0—14, especially boys, the change of wording from slow at learning or understanding to difficulty learning or understanding has encouraged more reporting of intellectual, developmental and behavioural disorders. Increase in diagnosis and public awareness of these conditions, in particular Attention Deficit Hyperactivity Disorder (ADHD), may also have contributed to the increase. The number of people with ADHD in 1998 (10,700) was greater than the total number of people reporting mental disorder in 1993.<sup>2</sup>

Among the population aged 65 or more, changes in survey methods mostly affected the 75—79 age group. Most of the increase in this group was made up of people with circulatory conditions. The modification of the screening question on learning and understanding appears to have improved the capture of people with dementia. The specific question about stroke may also have led to increased reporting of these conditions.

The next ABS Survey of Disability, Ageing and Carers (2003) will focus on maintaining comparability of survey methods and data over time, allowing actual changes in prevalence of disability and severe or profound restriction to be more easily measured.

## **Trends in mortality and morbidity**

Changes in mortality and morbidity can influence the prevalence of disability. In Australia, mortality due to a number of significant external causes, such as transport and road injuries, has decreased in recent years (AIHW: Bordeaux & Harrison 1996; AIHW: Bordeaux 1999; AIHW: Delooper & Bhatia 2001). The age-standardised death rate due to all causes of injury fell from 48.9 deaths per 100,000 population in 1989 to 42.7 in 1999. The death rate for road vehicle accidents over the same period has fallen from 17.0 deaths per 100,000 population in 1989 to 9.7 in 1999. The Australian Spinal Cord Injury Register data show that the age-adjusted incidence rate of spinal cord injury was 1.45 per 100,000 in 1998—99, a small decrease from 1.52 per 100,000 in 1997—98 (AIHW: O Connor 2000).

The incidence and prevalence of congenital malformations may also indicate the possibility of early onset of disability. The reported overall incidence of congenital malformations was higher in the late 1980s and the 1990s than in the early 1980s, though the trend varied for different malformations (AIHW: Hurst et al. 1999; AIHW: Lancaster & Pedisich 1995; AIHW: Lancaster et al. 1997).

Perinatal deaths due to congenital malformations declined from 35.9 per 10,000 births in 1973 to 15.6 in 1996. Infant deaths due to congenital malformations also declined from 28.8 per 10,000 live births in 1980 to 14.8 in 1996.

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2 It is not possible to identify those with ADHD in the 1993 disability survey as it was not separately classified (ABS: Davis et al. 2001). For further discussion of ADHD, see also Section 7.3 (new developments) concerning the new ICF and the role of environmental factors in disability creation.

The incidence rate for Down syndrome in births was 12.4 per 10,000 births during the period 1981 to 1997. Incidence of spina bifida in Australia declined gradually from 7.1 per 10,000 births in 1987 to 3.4 in 1997 (AIHW: Hurst et al. 1999; Hurst et al. 2001).

## 7.3 Services and assistance

This section provides data on services and assistance to people with a disability. Formal services include:

- income support, particularly disability-specific income support;
- specialist disability support services; and
- relevant generic services, particularly those that target people with a disability specifically.

Data about informal care and assistance are also presented. First, recent developments in disability services are briefly outlined.

### Recent developments

The disability field remains one of active debate and policy development. Nationally, expenditure on services continues to grow (see Figure 2.5) in response to population growth and ageing as well as recognition of unmet need in the population.

### Commonwealth developments in income support

Developments in the disability services arena are taking place at the time of a wider debate about the purpose and role of welfare services and assistance in Australia.

The Commonwealth Government is playing a leading role in the discussion of income support and its relationship to the idea of mutual obligation: the obligation of individual people, including people with disability, to seek to participate in and contribute to society, and the obligation of government and the wider community to assist them to do so (Reference Group on Welfare Reform 2000 the McClure report; Newman 2000b; see also Chapter 1). This discussion encompasses the role of government, the role of the non-government sector (both not-for-profit and for-profit), the role of families and individuals, and the social structures in which rights and obligations are negotiated. The McClure report recommends a central gateway and assessment approach, designed to enable people to find their way to the right type and level of assistance to meet their needs, for instance financial support with or without general labour market support or specialist disability support services.

Some critics fear that these developments are driven by a desire to control rising public expenditure on income support, and that they reflect diminished social acceptance of the moral duty to protect the vulnerable (Goodin 2000). Accordingly, it will be important to ensure that mutual obligation in operation is capability building rather than merely controlling or even disabling (Yeatman 2000). Non-government service providers, like service recipients, may have little bargaining power in negotiations with government; trust and flexibility can make these partnerships work more effectively (Lyons 2000).

The Commonwealth Government announced a range of initiatives in May 2001 to support the reforms and to promote the goals of: stronger families, stronger communities, and economic and social participation (Commonwealth of Australia 2000; FaCS 2001a). In particular, \$177 million over 4 years was announced to provide people with disabilities with early intervention and more thorough assessment of their work capacity, and to increase their opportunities for employment, education and training. Improved employment assistance will include 7,000 new disability employment assistance places, greater quality assurance of disability employment services, and another 500 places in the FaCS Assessment and Contestability Trial. A further 16,300 employment assistance and rehabilitation places were also announced to assist parents and mature-aged workers with disabilities.

Assessment for the Disability Support Pension will still involve medical assessment by the treating practitioner, but assessment of ability to work will be carried out using a range of external expertise such as psychologists or occupational therapists as well as Centrelink expert staff. Improved financial incentives to take up part-time and casual work are to be supported by the establishment of a Working Credit .

Decisions about assessment and referral to services for people with disabilities are to be informed by the Assessment and Contestability Trial, which is investigating whether a more detailed assessment of an individual's needs and abilities, including capacity to work, leads to better targeting of interventions and better outcomes for the individual.

## **National developments in disability services**

The contractual emphasis of mutual obligation has a counterpart in structures delivering services where, in recent years, purchaser/provider contracts have reflected agreed outputs or outcomes, and service agreements between service providers and recipients often specify amounts or types of service and agreed desired goals. There are pressures to increase competitiveness and efficiency, to ensure the quality of service delivered to vulnerable groups, and a need for services to diversify their incomes to ensure their financial viability (see, for example, ACROD 2001). Adjustments have been made in the FBT area with the introduction of the new tax system in mid-2000. The resulting complexity of the roles and the relationship to government of non-government service providers is reflected in the establishment of an independent inquiry into the definitions of charitable, religious and community service not-for-profit organisations . The aim is to enhance the clarity and consistency of the existing definitions in Commonwealth law and administrative practice , leading to legislative and administrative frameworks that are appropriate for, and adapted to, the social and economic environment of Australia (Commonwealth of Australia 2001; see also Chapter 1).

Nationwide, the focus is on individualised, flexible and local services, accompanied by assessment, targeting and emphasis on performance measurement (see Section 7.4 and Chapter 9). For instance, a FaCS Case Based Funding Trial is examining a range of issues arising from the 1996—97 Budget decision to move from block grant funding to case-based payments for specialist disability employment services, with funding based on job seeker need . The trial aims to test the impact of a new funding method on employment outcomes, the suitability of the classification process, the appropriateness

of funding levels, the impact on service viability and responsiveness, as well as identifying financial incentives and disincentives for service providers (see, for example, FaCS 2000a).

Changes in the way services are funded and delivered to clients (people with disabilities and their families) are wide ranging. Common themes about service flexibility include tailoring services to meet individual needs and encouraging client involvement in service planning and assessment. Efforts to promote linkage and transition are proposed to overcome possible problems with service stovepipes and blockages in programs, such as respite and post-school options (that is, lack of movement through what are designed to be temporary or transitional support arrangements). New accommodation service models of respite care and of shared care (involving a mix of formal and informal care) are also being developed.

Deinstitutionalisation is an ongoing drive in all jurisdictions. Evidence of the overall trend to community care is presented in Section 7.4, and in Chapter 4 where there is a broader discussion across a number of fields. These trends are the result not only of providing community-based alternatives for younger people (non-institutionalisation) but also of efforts to redevelop existing congregate care. In Victoria, for example, Kew Residential Services, now a segregated institution for 460 people with an intellectual disability, is to be redeveloped. Some 50—100 residents are choosing to remain on the site in new homes, but the remainder will relocate to new supported homes in the community, closer to family and friends (Bracks 2001).

Under the Commonwealth/State Disability Agreement (CSDA), all Australian governments Commonwealth, State and Territory cooperate to fund and provide disability support services to people with a disability who need ongoing support (see data later in this section). The second CSDA saw recognition of unmet need for these services and a subsequent total additional commitment, from all jurisdictions, of \$510 million over 2 years (Newman 2000a). A third CSDA is to be negotiated, providing a national framework to underpin future funding and administrative arrangements for disability services from 2001 (Disability Ministers 2000).

Population ageing remains a significant factor affecting the planning of disability services. A study of disability and ageing commissioned by National Disability Administrators (AIHW 2000b) found five main implications for services:

- Demography population growth, ageing and the baby boom is a significant factor for service planning.
- The ageing of the CSDA client population itself appears to be a feature of CSDA service trends.
- The emphasis of governments on individual needs and flexible services is a useful approach. Despite some patterns of difference between older and younger people with disability, it is impossible to generalise on the basis of the statistics.
- Disability service and aged care links are needed, as well as perhaps greater clarity concerning their respective responsibilities for people now ageing with a disability.

- Informal carers are the main providers of support for people with disabilities, and remain the linchpin of the whole system. It is not possible to predict whether current patterns of informal care will continue unchanged. The challenge for the formal service system is to support this role in the hope that it will continue to be a strong feature of the disability and aged care fields.

This last issue the relationship between formal and informal care is being actively canvassed by some carer organisations. The rights of family carers to an annual holiday, to paid work and to retirement from the caring role have been enunciated by at least one carers group (Gippsland Carers Association 2001). There is growing policy recognition of the importance of respite care in sustaining families involved in such informal care.

These interface issues between the disability and aged care systems, between formal and informal care, between the disability and mental health systems, and between specialist and generic services are very much on the policy agenda for disability administrators around Australia.

### **Indigenous disability**

A new Indigenous disability network has been proposed, to promote better understanding of disability among Aboriginal and Torres Strait Islander peoples, consultation among those responsible for service design and delivery, and cross-border coordination in some areas of Australia. It is proposed that the new network provide advice to the AIHW and the ABS on Indigenous disability data collection (ATSIC and NDAC Joint Working Party 2000). The limits of national understanding of disability among Aboriginal and Torres Strait Islander people have been discussed in previous editions of *Australia's Welfare* (AIHW 1997a, 1999a) and no better population statistics are yet available.

### **National organisations**

The social and physical environment shapes the experience of people with disabilities. Organisations such as the National Disability Advisory Council and the Human Rights and Equal Opportunity Commission (HREOC) continue to work on issues associated with this environment. The current Advisory Council is working in five priority areas: monitoring welfare reform; identifying issues for the CSDA renegotiation; contributing to standards under the Disability Discrimination Act; raising awareness about difficulties encountered by people with disabilities in the health care system; and raising awareness about issues for Indigenous people with a disability.

The HREOC commissioned a report on the sterilisation of young women and girls with a disability following debate about varying estimates of the practice (Brady et al. 2001). The report recognised efforts by the Commonwealth Government to make medical practitioners fully aware that such procedures are unlawful except in the course of treatment for disease (e.g. cancer) or where authorisation is given by the Family Court or a tribunal with jurisdiction. The authors advocated that decisions be made in a non-adversarial atmosphere and pointed to the need for education and support services for these young women and their families.

## Disability Discrimination Act

Progress has been made on developing, consulting on and agreeing standards under the Disability Discrimination Act (DDA), as summarised in Box 7.4.

### Box 7.4: Implementing the Disability Discrimination Act

*Disability Standards for Accessible Public Transport: The Government announced in late 2000 that it would implement Disability Standards for Accessible Public Transport. The Government agreed that the draft standards be amended to exclude dedicated school bus services, small aircraft and airports that do not accept scheduled regular public transport services, limousine, hire cars and charter boats and unresolved technical issues, to vary the requirements in relation to boarding devices and electronic notices and extend the implementation timetable for buses, trains and trams. It also agreed to amend the Disability Discrimination Act 1992 (DDA) so that HREOC may grant exemptions from the Standards in appropriate circumstances.*

*Disability Standards for Access to Premises used by the Public: An amendment to the DDA to add the power to formulate a standard in relation to access to public premises came into effect on 13 April 2000. In April 2001 the Commonwealth formally tasked the Australian Building Codes Board with developing proposals for revisions to be made to the Building Code of Australia to allow it to form the basis of a national disability standard on access to premises, to ensure that buildings do not provide unnecessary and inaccessible barriers to people with disabilities.*

*Disability Standards for Education: A Taskforce on Disability Standards in Education, established by the Ministerial Council on Education, Employment, Training and Youth Affairs, released draft standards for consultations across Australia and sought submissions on them in 2000. The taskforce revised the draft standards in the light of the consultations and submissions and referred them to the Ministerial Council for consideration in July 2001. The Ministerial Council directed the Australian Education Systems Officials Committee (AESOC) 'to consider the Standards, agree on amendments and clarifications and develop a Regulatory Impact Statement to facilitate implementation, and to report back to Ministers by the end of 2001'.*

*Access to Commonwealth Information: The Government OnLine Strategy specifies some new standards for use by agencies in electronic publishing, aimed at extending and standardising the publication of information on the Internet. Commonwealth departments and agencies are already obliged by the DDA to ensure that online information and services are accessible by people with disabilities, and under the strategy they are required to observe the World Wide Web Consortium's (W3C) Web Content Accessibility Guidelines to a sufficient extent that their web sites pass recognised tests of accessibility. The guidelines are widely recognised internationally and have the support of HREOC and disability groups. The Online Council has agreed to the adoption of the W3C Guidelines as the common best-practice standard for all Australian government web sites.*

*Source: Information provided by Civil Justice Division, Attorney-General's Department 2001.*

## Ethics and genetics

The disability field has developed and attempts to base itself on a system of ethics and philosophy relating to human rights (see, for example, UN 1994; AIHW 1993 for history). New developments such as gene technology and the human genome project create the need to refine or defend this philosophy. The promises and threats of the human genome project were discussed by speakers and participants at a workshop convened by the Centre for Developmental Disabilities in May 2000 (CDDS 2000). The challenges of blending and reconciling the various sectors of interest scientific, economic and legal, personal, policy, social and ethical were discussed. While a number of the benefits of genetic testing were recognised, fears were also expressed that a new era of eugenics was dawning, where disability is considered undesirable and preventable, leading to intolerance of those who slip through the scientific detection and intervention net or who are the result of personal and family choice.

## Conceptual and data development

The new International Classification of Functioning, Disability and Health has resulted from some seven years of international collaboration and development involving a range of countries, including Australia (see Box 7.1). Its implementation in Australia should, ideally, introduce a coherent conceptualisation of disability into a wider range of relevant fields than at present, including health and rehabilitation, aged care and other community services, as well as generic services such as education and employment. One mechanism for achieving this will be the inclusion of revised and new items in the two national data dictionaries (AIHW 2000a, 2001a). There are many challenges and opportunities in implementing a multidimensional classification such as the new ICF, perhaps in particular in defining disability in relation to the environment. The rising reported prevalence of ADHD illustrates this point (see Section 7.2). Can we adequately report on such changes without also being able to quantify changes in school organisation, in community tolerance of certain behaviours, in medical and pharmaceutical resources and in the rates of prescribing of related drugs?

## Income support

### Commonwealth programs

The Commonwealth Government is the main source of income support services to people with a disability and their carers in Australia (Box 7.5).

Disability Support Pension (DSP), Disability Pension (DP) and Carer Payment (CP) are the main income support payments assisting people with a disability who are under 65 years and their carers. Several other allowances are available to assist with the extra costs associated with having a disability or caring for someone with a disability.

In June 2000, 602,280 people received DSP and expenditure on DSP payments through 1999—00 was \$5.2 billion (Table 7.6). Expenditure has increased from \$4.6 billion in 1997—98 (AIHW 1999a:Table 7.6).

## Box 7.5: Commonwealth disability-related payments and allowances

*Disability Support Pension (DSP) is an income support payment available to people with a disability who are unable to work full-time in open employment at full award wages, or to be retrained for work, within 2 years. They must have impairment assessed as above a specific level and be at least 16 years old and less than Age Pension age at the time of claiming.*

*Disability Pension (DP) is a compensation payment to veterans for injuries or disease caused or aggravated by war service or certain defence service on behalf of Australia. Non-veterans may also receive DP if they are dependants of deceased or incapacitated veterans.*

*Mobility Allowance is a payment to people with disabilities who are in paid employment, voluntary work, doing vocational training, or are in receipt of Newstart Allowance, Austudy, Youth Allowance, and who cannot use public transport without substantial help.*

*Sickness Allowance is paid to people who are employed or, in some cases, studying full-time and who must temporarily stop working in their job or studying due to an illness, injury or disability.*

*Carer Allowance (CA) is paid to people who are caring at home for a child or an adult with a severe disability or chronic medical condition or who are frail aged. The person being cared for must require a lot more daily care and attention than a person of the same age who does not have a disability. The Child Disability Assessment Tool and Adult Disability Assessment Tool are used to assess eligibility for CA for children and adults respectively.*

*Carer Payment (CP) is an income support payment to those who provide constant care for six months or more to a person aged 16 years or more with a severe physical, intellectual or psychiatric disability. CP may also be available to carers of children under 16 with a profound disability or two or more children with a disability who together need the level of care required by a child with a profound disability. The carer must be a recipient of Commonwealth income support (including DSP, Age Pension, Service Pension) or meet an income and assets test. Care is provided in the person's home or while they are temporarily in respite care or in hospital. The Adult Disability Assessment Tool is the basis for assessment of eligibility of carers of adults for CP. CP recipients may also be eligible for CA.*

*Wife Pension is paid to the wife of a recipient of DSP, Age Pension or other payment who is not receiving a pension in her own right. Since 1 July 1995 Wife Pension has been closed to new applicants (except people transferring from another payment).*

*Newstart Allowance (incapacitated) and Youth Allowance (incapacitated) are provided to people—21 years or more or under 21 years respectively—who, due to illness or injury, are temporarily (up to two years) unable to work for more than 8 hours a week or, in the case of Youth Allowance, to study. Full-time students aged 21–24 may also be eligible for Youth Allowance (incapacitated). Newstart Allowance itself is an income support payment and involves complying with a Preparing for Work Agreement, encompassing possible medical treatment and rehabilitation, and satisfying 'Mutual Obligations'. The*  
(continued)

## Box 7.5 (continued): Commonwealth disability-related payments and allowances

*Activity Test usually applied to unemployed people is waived for those with an illness or injury. 'Mutual Obligations' also does not apply when the person is ill for an extended period or receiving Intensive Assistance, that is one-to-one help for job seekers, including those likely to experience difficulty in getting a job.*

*The Continence Aids Assistance Scheme, which commenced in January 1993, enables people who are employed, doing job training or looking for work to be supplied with continence aids (up to a predetermined credit limit) to defray the costs of their disability.*

Table 7.6: Commonwealth disability-related payments and allowances, recipients and expenditure, 1999–00

	Recipients as at June 2000	Administered expenses 1999–00 (\$m)	Department
Disability Support Pension	602,280	5,238.4	FaCS
Mobility Allowance	35,154	53.4	FaCS
Sickness Allowance	10,733	90.6	FaCS
Carer Allowance (Child) <sup>(a)</sup>	n.a.	n.a.	FaCS
Carer Allowance (Adult) <sup>(a)</sup>	194,887	417.5	FaCS
Carer Payment (DSP)	24,500	<sup>(b)</sup> 368.0	FaCS
Carer Payment (AP)	15,346	<sup>(b)</sup> n.a.	FaCS
Carer Payment (other)	7,704	<sup>(b)</sup> n.a.	FaCS
Wife Pension (DSP)	59,934	486.7	FaCS
Wife Pension (AP)	31,362	241.5	FaCS
Newstart Allowance (incapacitated)	68,016	<sup>(c)</sup> n.a.	FaCS
Youth Allowance (incapacitated) <sup>(d)</sup>	5,883	<sup>(c)</sup> n.a.	FaCS
Continence Aids Assistance Scheme	15,525	7.6	DHAC
Disability Pension	162,730	1,007.8	DVA

(a) Recipients and administered expenses for Carer Allowance (Child) and Carer Allowance (Adult) are combined.

(b) Administered expenses for Carer Payment (DSP), Carer Payment (AP) and Carer Payment (other) are combined.

(c) Administrative expenses for Newstart Allowance (incapacitated) and Youth Allowance (incapacitated) are not available as they are included in the larger funding budget for these two programs.

(d) Data are for March 2001.

### Notes

1. Payments with bracketed qualifiers, for example Carer Payment (DSP), indicate that the recipient's payment depends on a characteristic of another person. In this example, the person being cared for is receiving Disability Support Pension.
2. Expenditure does not include running costs and corporate overheads. It includes any additional allowances such as rent assistance paid to recipients.
3. Carer Allowance (Child) and Carer Allowance (Adult) are income supplements (replacing Domiciliary Nursing Care Benefit and Child Disability Allowance from 1 July 1999) available to people who provide daily care and attention to a person who has a disability or severe medical condition. See also Box 7.5.
4. Disability Pension expenditure is for veterans and their dependants.
5. Disability Pension recipients may also receive Service Pension associated with service in the armed forces. There were 88,502 DP veterans also receiving SP (in March 2000).

Source: Centrelink 2001; DHAC 2000; DVA 2000, 2001; FaCS 2000b, 2001c; FaCS 2001 unpublished data.

Expenditure on DP payments totalled \$1.0 billion in 1999—00 and in June 2000 DP was being paid to 162,730 veterans (Table 7.6). Of veterans receiving DP, 50,360 were under age 65 in March 2001 (Table 7.7). There were 14,998 veterans under age 65 years receiving Service Pension, many of whom were also receiving DP.

Table 7.7: Recipients of disability-related Commonwealth payments and allowances, by sex and age group, June 2000 (FaCS payment) or March 2001 (DVA payment)

	Age (years)								Total
	<16	16–19	20–29	30–39	40–49	50–59	60–64	65+	
<b>Males</b>									
Disability Support Pension	n.a.	8,896	30,157	50,948	74,649	120,293	95,403	2,005	382,351
Mobility Allowance	0	1,462	4,618	5,117	4,342	2,770	715	649	19,673
Sickness Allowance	0	0	1,955	2,087	1,673	1,376	350	2	7,443
Carer All. (Child) <sup>(a)</sup>	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.
Carer Allowance (Adult) <sup>(a)</sup>	13	169	782	3,199	4,496	5,151	2,811	12,866	29,487
Carer Payment (DSP)	1	130	545	1,385	2,426	4,041	1,939	99	10,566
Carer Payment (AP)	0	28	206	737	1,294	1,782	1,310	217	5,574
Carer Payment (other)	1	54	223	646	849	746	187	58	2,764
Newstart All. (incapac.)	1	1	9,235	11,986	11,096	9,190	1,845	9	43,363
Youth All. (incapacitated) <sup>(b)</sup>	11	1,659	814	0	1	0	0	0	2,484
Disability Pension (DVA) <sup>(b)</sup>	0	0	601	6,241	10,211	26,342	5,002	106,937	155,363
<b>Females</b>									
Disability Support Pension	0	6,016	21,252	31,152	51,766	92,575	16,941	227	219,929
Mobility Allowance	0	1,125	3,782	3,920	3,512	2,236	485	421	15,481
Sickness Allowance	0	0	915	694	889	754	38	0	3,290
Carer All. (Child)(a)	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.
Carer Allowance (Adult) <sup>(a)</sup>	20	357	14,408	59,990	43,954	18,202	6,903	21,566	165,400
Carer Payment (DSP)	6	239	896	1,738	4,211	5,867	839	138	13,934
Carer Payment (AP)	0	83	350	1,086	2,671	4,300	983	299	9,772
Carer Payment (other)	1	65	428	1,021	1,495	1,621	193	116	4,940
Wife Pension (DSP)	0	0	534	5,016	15,576	33,062	5,558	98	59,934
Wife Pension (AP)	0	0	28	358	2,184	17,432	10,506	854	31,362
Newstart All. (incapac.)	0	0	6,363	4,816	7,986	5,184	304	0	24,653
Youth All. (incapacitated) <sup>(b)</sup>	18	2,538	843	0	0	0	0	0	3,399
Disability Pension (DVA) <sup>(b)</sup>	1	0	128	1,049	623	136	26	4,869	6,837

(a) Recipients and administered expenses for Carer Allowance (Child) and Carer Allowance (Adult) are combined.

(b) Data are for March 2001.

#### Notes

1. Data for all FaCS payments are as at June 2000 except Youth Allowance (incapacitated), and for DVA payments are as at March 2001.
2. Disability Pension recipient data include 29 male and 5 female veterans of unknown age in the 'all ages' totals.
3. Youth Allowance is paid to job seekers up to and including the age of 20 and students up to and including the age of 24. Students who turn 25 remain on Youth Allowance until completion of their current course.

Source: Centrelink 2001; DVA unpublished data from the Ad hoc Information System; FaCS unpublished data.

Expenditure on CP in 1999–00 was \$368 million and increased from \$259 million in 1997–98 (AIHW 1999a:Table 7.6). About 47,550 people received CP in June 2000, of whom around 24,500 were caring for a person receiving DSP and 15,346 were caring for an age pensioner.

In July 1998, people providing constant care and attention to children aged less than 16 years with profound disabilities became eligible to receive CP. On 1 July 1999, eligibility for CP was extended to carers of an adult with a disability and that adult's dependent child who also needs care or to have their care supervised. Reflecting these changes, between June 1998 and June 2000 recipients of CP (other) increased from 3,683 to 7,704 (FaCS 1999:Table 10).

### Trends in disability-related payment recipients

The number of recipients of most payments increased over the last decade, though the magnitude of the increase has varied with the type of payment (Table 7.8; AIHW 1999a:Table 7.8).

Table 7.8: Recipients of disability-related income support payments, June 1993 – June 2000

	1993	1994	1995	1996	1997	1998	1999	2000
Disability Support Pension	406,572	436,234	464,430	499,235	527,514	553,336	577,682	602,280
Mobility Allowance	16,160	20,795	22,851	24,985	26,595	28,975	31,001	35,154
Sickness Allowance	46,579	47,132	47,311	33,215	15,759	16,285	11,181	10,733
Carer Allowance (Child) <sup>(a)</sup>	61,174	69,693	78,898	90,644	95,520	90,830	100,452	n.a.
Carer Allowance (Adult) <sup>(a)</sup>	35,025	37,169	38,408	42,047	44,103	45,675	51,857	194,887
Carer Payment (DSP)	8,056	9,450	10,633	13,483	15,735	18,556	21,392	24,500
Carer Payment (AP)	6,507	7,441	8,324	9,500	10,954	11,740	13,407	15,346
Carer Payment (other)	482	808	1,141	2,054	2,869	3,683	5,271	7,704
Wife Pension (DSP)	108,327	116,036	121,839	107,803	91,307	79,892	68,523	59,934
Wife Pension (AP)	33,520	36,539	39,611	41,125	36,577	36,233	32,196	31,362
Newstart All. (incapac.) <sup>(b)</sup>	n.a.	n.a.	n.a.	n.a.	n.a.	48,792	59,670	68,016
Youth All. (incapacitated) <sup>(c)</sup>	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	3,929	5,883
Disability Pension (DVA) <sup>(c)</sup>	156,923	156,286	157,298	159,079	160,145	161,829	162,810	162,730

(a) Recipients for Carer Allowance (Child) and Carer Allowance (Adult) are combined.

(b) Data for Newstart Allowance before 1999 may not be comparable with previous years due to a major redevelopment of the Newstart System in May 1998. Youth Allowance was introduced on 1 July 1998 and replaced Newstart Allowance for 16–20 year olds.

(c) Data are for March 2001.

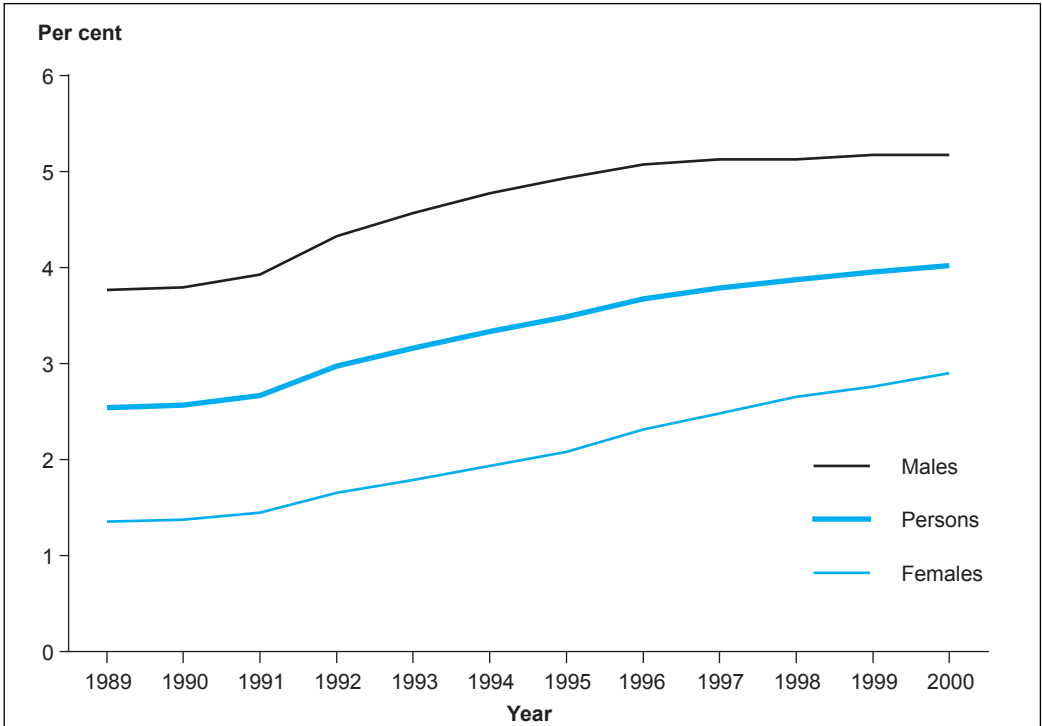
#### Notes

1. Payments with bracketed qualifiers, for example Carer Allowance (Child), indicate that the recipient's payment depends on characteristics of another person. In this example, the person being cared for is the recipient's child with a disability and is aged less than 25 years.
2. Carer Allowance (Adult) was introduced in July 1999 following transfer of 51,857 recipients from the former Domiciliary Nursing Care Benefit. CA (Adult) recipient data for 1993 are estimated using the numbers of people being cared for from 1993, and the average ratio of recipients to people being cared for from 1994 to 1998.
3. CA (Child) was also introduced in July 1999 following transfer of 100,666 recipients from the former Child Disability Allowance.
4. From 1 July 1998, Carer Payment (CP) recipients can include carers of a child with a profound disability. In June 1999, there were 762 people receiving CP on this basis. On 1 July 1999, eligibility for CP was extended to carers of an adult and that adult's dependent child who also needs care or to have their care supervised. CP recipients may also be eligible for CA.

Source: Centrelink 2001; DVA 2000, 2001; FaCS 1999, 2000b, 2001b; FaCS 2001 unpublished data.

Between June 1989 and June 2000, DSP recipient numbers nearly doubled (Table A7.8; FaCS 2001b:Table 2.4.1). The increase in DSP numbers between June 1991 and June 1992 was particularly high (13.3%). Rates of growth have generally declined each year since then, with the exception of 1995–96, to 4.3% for 1999–00. After adjusting annual DSP recipient growth rates for growth of the Australian population and for changes in age and sex distribution of the population, the annual growth rate for 1999–00 was 1.8%.

DSP recipient numbers have grown as a proportion of the Australian population (Figure 7.3). In June 2000, 4.0% of Australians were receiving DSP compared with 2.4% 10 years earlier (or 2.6% after adjustment for population changes (Table A7.8)). For men, after June 1996, the proportion slowed its growth and was 5.2% in June 2000. Male DSP recipients aged 50–64 years the age group with by far the highest proportion of the population receiving DSP accounted for this slowing of growth after June 1996; rates dropped a little for men 50–64 years. For women, the proportion continued increasing and was 2.9% in June 2000. Like men under 50 years, the proportion of women under 50 years receiving DSP has gradually increased over the last decade. However, female DSP recipients aged 50 and over have shown more substantial increases, particularly for women 60–64 years after June 1995. This may reflect recent adjustments to the eligibility ages for Age Pension and the closure of Wife Pension to new recipients. It is also contributing to declines in the percentage of DSP recipients who are male. In June 1989, 74% of DSP recipients were men (FaCS 2001b:Table 2.4.1), while 63% were men in June 2000 (see Table 7.7).



Source: Table A7.8.

Figure 7.3: Disability Support Pension recipients in the Australian population, 1989–2000

## Concession cards

Some concessions are available to people with a disability if they are eligible for certain identification cards (Box 7.6). The cards entitle the holder to concessions for specific Commonwealth, State/Territory and local government services and some private sector concessions. Possession of a Commonwealth-issued concession card is also often used as the eligibility criterion for concessions available from other jurisdictions. The concession areas covered are at the discretion of each jurisdiction and may include ambulance services, travel for isolated patients, glasses, dental care, taxi subsidies, and so on. The core areas agreed by State and Territory Governments are energy consumption, water and sewerage, municipal rates and transport (including public transport, motor vehicle registration and licence fees). The value of concessions in each area varies and data are not available on the total.

### Box 7.6: Commonwealth concession cards

*A Pensioner Concession Card is automatically available to DSP, CP and Wife Pension recipients, as well as Age Pensioners. It entitles them to Pharmaceutical Benefits Scheme prescription medicines at a small cost per prescription, free hearing assessments and aids, some public transport concessions, and so on. In May 2001, 3.0 million people were covered by a Pensioner Concession Card.*

*The Gold Repatriation Health Card entitles some veterans, including disabled veterans and their dependants, to free treatment for all health conditions. There were 287,476 Gold Card holders as at 30 June 2000.*

*A Health Care Card may be available to Sickness, Newstart, Youth and Mobility Allowance recipients, and Carer Allowance (Child) recipients for the child's use. It entitles them to Pharmaceutical Benefits Scheme prescription medicines at a small cost per prescription. In May 2001, 1.7 million people were covered by a Health Care Card.*

*Source: FaCS unpublished data; DVA 2000: Table 74.*

## Personal injury compensation schemes

Other significant sources of income support for people with a disability are the personal injury compensation schemes, mainly for work- and transport-related injuries. These schemes operate under specific legislation in each State and Territory and require contributions from employers and road users respectively. They generally aim to replace lost income and to cover medical expenses incurred.

During 1998–99, 29,637 claims were made for worker s compensation involving events with non-fatal outcomes in the most serious category recorded, that is resulting in 60 days or more absence from work (Table 7.9). Of these, most involved injury/poisoning (24,711 or 83% in fact, only 42 cases of poisoning were recorded). Next most prominent were claims involving people with mental disorders (1,971 or 7%), followed by diseases of the musculoskeletal system and connective tissues (1,725 or 6%). The large injury category comprises mainly sprains and strains of joints and muscles (16,477 or 67% of the injuries), and fractures (3,499 or 14%). There were 171 fractures of the vertebral column. Men made up 65% of the claimants for these events.

Table 7.9: Worker's compensation claims with non-fatal outcomes resulting in work absences of 60 days or more, by nature of injury or disease and age group, 1998–99

	Age (years)						Total
	<20	20–29	30–39	40–49	50–54	55+	
<b>Injury/poisoning</b>							
Fractures	168	779	849	858	385	460	3,499
Fracture of vertebral column	8	41	43	40	17	22	171
Sprains/strains of joints and adjacent muscles	345	3,068	4,573	4,844	1,946	1,696	16,477
Open wounds	107	377	357	273	95	97	1,306
Contusions with intact skin surface & crush injuries	51	299	400	385	174	168	1,477
Other injury/poisoning	95	467	601	423	168	173	1,927
<i>Total injury/poisoning</i>	<i>774</i>	<i>5,031</i>	<i>6,680</i>	<i>6,823</i>	<i>2,785</i>	<i>2,616</i>	<i>24,711</i>
Nervous system/sense organ diseases	8	62	108	137	61	50	426
Musculoskeletal system and connective tissue diseases	29	269	492	550	209	176	1,725
Mental disorders	21	307	551	673	276	143	1,971
Other diseases/not stated/not available	26	135	180	205	123	135	804
<b>Total</b>	<b>858</b>	<b>5,804</b>	<b>8,011</b>	<b>8,388</b>	<b>3,454</b>	<b>3,120</b>	<b>29,637</b>

*Notes*

1. Claims made in the Australian Capital Territory are excluded.
2. Some figures include minor random adjustments in order to account for small cell values, for confidentiality reasons.
3. Of the 24,711 claims in the injury/poisoning category, 24,669 involved injury and 42 involved poisoning.

Source: National Occupational Health and Safety Commission 2000.

The area of medical indemnity is becoming of greater interest and significance. Although medical defence organisations collect information to support the processing of medical negligence claims, there is at present no system in Australia for collating and analysing these data.

## Disability support services

### CSDA-funded disability support services

Services provided under the Commonwealth/State Disability Agreement (CSDA) are designed for people who need ongoing support with everyday life activities. While, in practice, services are generally directed to people aged under 65 years, the CSDA places no age-based restrictions on access to them. Under the second CSDA (1998), it is agreed that the Commonwealth has responsibility for the planning, policy setting and management of employment services, while the States and Territories have these responsibilities for all other specialist disability services (see Box 7.7 for definitions of service types). Advocacy, print disability and information services are considered shared responsibilities under this agreement.

Information on disability support services provided or funded under the CSDA is collected in the framework of the CSDA Minimum Data Set (MDS), jointly developed and maintained by the AIHW and the Commonwealth, States and Territories, under the auspices of the National Disability Administrators (comprising the heads of government disability services throughout Australia). Consumers and service providers supply data on a snapshot day to funding departments in each jurisdiction, and the

### Box 7.7: Definitions of service types covered by the CSDA

<i>Accommodation support</i>	<i>Services that provide accommodation to people with a disability and services that provide the support needed to enable a person with a disability to remain in their existing accommodation.</i>
<i>Community support</i>	<i>Services that provide the support needed for a person with a disability to live in a non-institutional setting (not including support with the basic needs of living such as meal preparation and dressing included under accommodation support).</i>
<i>Community access</i>	<i>Services designed to provide opportunities for people with a disability to gain and use their abilities to enjoy their full potential for social independence. People who do not attend school or who are not employed full-time mainly use these services.</i>
<i>Respite</i>	<i>Respite services provide a short-term and time-limited break for families and other voluntary caregivers of people with a disabilities, to assist in supporting and maintaining the primary care-giving relationship, while providing a positive experience for the person with a disability.</i>
<i>Employment</i>	<i>Services that either provide employment assistance to people with a disability in obtaining and/or retaining paid employment in another organisation (open employment), and/or that support or employ people with a disability within the same organisation (supported employment).</i>
<i>Other</i>	<i>Other services include service evaluation and training, research and development, and services provided by peak bodies.</i>

Source: AIHW 2001b.

Institute collates these data nationally. In 1999 and 2000 for the first time, a statistical linkage key was collected, which enables the number of consumers to be estimated from data on services received without any consumer being personally identified (see Box 7.8). As part of the current redevelopment of the MDS, it is planned to extend the collection to cover consumers for the full financial year (see Box 7.9).

### **CSDA service types, funding and service numbers**

The total expenditure on disability support services by Australian governments under the CSDA in 1999—00 was \$2,246 million, an increase of 8.8% in real terms from the level in 1998—99 (Table 7.10; SCRCSSP 2000). Accommodation support services accounted for over half of this expenditure (\$1,157 million or 52%), with about one-tenth of funding each for community support (\$250 million), community access (\$221 million) and employment support (\$221 million) services. The remaining expenditure was for administration (\$204 million), respite services (\$119 million) and other support services (\$74 million).

## Box 7.8: Definitions and major counts of the CSDA MDS collection

### **Services received**

*A service is a support activity delivered to a consumer, in accord with the CSDA. Services within the scope of the collection are those for which funding has been provided by a government organisation operating under the CSDA. The number of services received are not counts of individual consumers, since a person may have received more than one service on the snapshot day and hence may be counted more than once.*

### **Consumers**

*A consumer is a person who receives a CSDA service.*

*In 1999 and 2000 a statistical linkage key was collected as part of the CSDA MDS. This statistical linkage key enables the number of consumers to be estimated from the data on services received without any consumer being personally identifiable. In both 1999 and 2000 the number of services received was about 20% greater than the estimated number of consumers.*

### **Service outlets and types**

*A service outlet is a service provider funded to provide a particular CSDA service type at a discrete location. The CSDA MDS is progressing towards an outlet-based collection but this has not been completely achieved in all jurisdictions, because of some of the complexities of funding processes. Service type is the support activity which the service outlet has been funded to provide under the CSDA (see Box 7.7 for definitions of the main service types).*

### **Snapshot day**

*The use of a snapshot day permits the number of consumers to be estimated at a point in time and can also be regarded as a sample of the people who use CSDA-funded services. The number of consumers in this snapshot sample, as a proportion of consumers over the year, will differ by service type. In particular, it will be greater for accommodation and community access services, which in general are used on a more frequent and regular basis than employment, recreation and respite services.*

*The statistical linkage key makes it possible to analyse the use of multiple services by consumers on the snapshot day. This will not give the full picture of multiple service use, because the snapshot day provides only a sample of service usage. However, it provides an indication of some common combinations of services used and the groups of consumers who are likely to use them.*

*Source: AIHW 2000c, 2000d, 2001b.*

The Commonwealth Government's direct funding (\$276 million) to disability support services under the CSDA was mostly for employment services. The Commonwealth also provided some of the funds expended by State and Territory Governments (\$356 million). Its overall contribution to total CSDA funding was 29%.

## Box 7.9: Redevelopment of the CSDA Minimum Data Set

*The AIHW and the National Disability Administrators are working together to redevelop the CSDA MDS collection. The AIHW is managing the redevelopment project, working closely with a Facilitation and Implementation Group that includes coordinators from each State and Territory and the Commonwealth, as well as two representatives for non-government organisations and one consumer representative.*

*The CSDA MDS collection is being redeveloped in order to align it more closely with changing service delivery and funding models, and to enable it to meet a wider range of information needs, including gaining insights into the duration and intensity of service provision. The multi-faceted project plan includes a number of rounds of field testing with administrations, service providers and consumers; development of data principles to govern the collection, transmission and collation of data; development and testing of data transmission methods; and ensuring improved data outputs from the collection. The most significant change to the collection is that, for most service types, a profile of all consumers during the year will be available, rather than information only about consumers who access services on a selected snapshot day.*

*The redevelopment project is planned to proceed over 2 years, with implementation of a redeveloped collection from July 2002.*

*Further information is available at  
[www.aihw.gov.au/disability/csda\\_public/index.html](http://www.aihw.gov.au/disability/csda_public/index.html).*

Table 7.10: CSDA funding of services by Australian governments, by service type (with administration expenditure), 1999–00 (\$m)

Service type	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	C'wealth	Australia
	<b>Amount</b>									
Accommodation support	417.80	334.84	133.49	117.78	89.72	40.13	16.28	7.03	—	1,157.07
Community support	75.70	62.67	31.47	7.86	46.75	4.71	4.68	3.81	12.57	250.21
Community access	60.35	106.31	24.34	14.42	5.40	8.01	1.73	1.07	0.07	221.70
Respite	33.82	28.56	20.81	19.53	5.15	3.96	2.16	0.73	4.05	118.75
Employment	—	—	—	—	—	—	—	—	220.99	220.99
Other support	5.58	22.91	4.21	20.47	6.64	0.29	0.07	0.08	13.74	73.98
<i>Subtotal</i>	<i>593.24</i>	<i>555.28</i>	<i>214.32</i>	<i>180.06</i>	<i>153.66</i>	<i>57.09</i>	<i>24.92</i>	<i>12.71</i>	<i>251.41</i>	<i>2,042.70</i>
Administration	67.51	58.01	32.30	7.20	5.79	2.86	4.02	1.32	24.70	203.71
<b>Total</b>	<b>660.75</b>	<b>613.29</b>	<b>246.62</b>	<b>187.25</b>	<b>159.46</b>	<b>59.95</b>	<b>28.94</b>	<b>14.03</b>	<b>276.11</b>	<b>2,246.41</b>

### Notes

1. Figures for community access services in Victoria do not include funds previously directed to independent living training services.
2. Data provided by the Commonwealth are preliminary and cover 99% of Commonwealth-funded services.

Source: SCRCSSP 2001:Table 13A.8.

The CSDA MDS collection reported on 7,378 service outlets in 2000 (Table A7.9). The majority (75%) were provided by the non-government sector for all service types. Accommodation support services had the most outlets (3,143 or 43%).

The average number of full-time equivalent (FTE) staff for all service outlets for the week leading up to the snapshot day was 6.7 (Table 7.11). Community support services reported the lowest average staff hours per week (142) and accommodation support services, the highest (322). This is at least partly because most accommodation services operate 7 days a week (AIHW 1999b:Table A3.29). Non-government-aided services reported higher mean staff hours for all service types except community support and accommodation support. The large difference between the government and non-government sectors for the latter service type results mainly from higher average staff hours worked in government institutions and outreach services (AIHW 2001b).

Table 7.11: Mean hours worked by all staff and volunteers for CSDA-funded service outlets, by service type and auspicing organisation, 2000

Service type	Government		Non-government		All services		
	No. of service outlets	Mean hours per week per service	No. of service outlets	Mean hours per week per service	No. of service outlets	Mean hours per week per service	Mean no. of FTE staff per week
Accommodation support	911	502	1,580	218	2,491	322	8.5
Community support	306	195	997	126	1,303	142	3.7
Community access	79	209	762	226	841	224	5.9
Respite	117	222	277	252	394	243	6.4
Employment support	14	193	830	258	844	257	6.8
Other/not stated	11	236	29	171	40	189	5.0
Total with known staff hours	1,438	393	4,475	208	5,913	253	6.7
Staff hours not known	409	..	1,056	..	1,465	..	..
<b>Total</b>	<b>1,847</b>	<b>..</b>	<b>5,531</b>	<b>..</b>	<b>7,378</b>	<b>..</b>	<b>..</b>

#### Notes

1. A service outlet may be a single outlet, or an aggregation of two or more outlets of the same service type, for a service provider.
2. Data for hours worked are the mean number of hours worked over one 7-day week in May. They are used here as a guide and should not be considered a typical week in 2000 for all service types.
3. Government-aided employment services are not directly provided by the Commonwealth but by organisations classified as Commonwealth-related (such as universities).
4. Full-time equivalent (FTE) staff numbers are based on a 38-hour working week.
5. Data provided by the Commonwealth are preliminary and cover 99% of Commonwealth-funded services.

Source: AIHW 2001a:Table 5.4.

## Consumers of CSDA services

In 2000, 62,341 consumers received 74,929 CSDA-funded services on the snapshot day (see Box 7.8 for explanation of terms). Over one-third of consumers (34%) received an accommodation support service, and group homes were the most commonly used accommodation support service type (45% of accommodation consumers). A total of 17,373 consumers (28%) received an employment support service on the snapshot day, with about two-thirds of these (66%) using supported employment (Table 7.12; AIHW 2001b:Table 3.22).

Over a quarter of consumers (27%) used community support services and almost another quarter (24% or 14,658) used a community access service, with 56% of these using post-school options, social community support or access services. Respite services were used by only 4% of consumers on the snapshot day, with 44% of these being a centre-based respite service.

Table 7.12: Consumers of CSDA-funded services on a snapshot day, by service type and State/Territory, 2000

Service type	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Total	%
Accommodation support	6,027	6,700	3,273	2,156	2,009	789	292	112	21,356	34.3
Community support	3,415	5,902	1,430	3,919	1,855	182	251	63	17,011	27.3
Community access	3,089	7,575	2,192	666	434	544	113	47	14,658	23.5
Respite	567	929	460	333	169	54	51	35	2,598	4.2
Employment	5,847	3,783	2,663	2,247	1,871	549	294	119	17,373	27.9
<b>Total consumers</b>	<b>16,441</b>	<b>21,104</b>	<b>8,324</b>	<b>8,004</b>	<b>5,566</b>	<b>1,719</b>	<b>864</b>	<b>354</b>	<b>62,341</b>	<b>100.0</b>

*Notes*

1. Consumer data are estimates after use of a statistical linkage key to account for individuals who have received more than one service on the snapshot day. Totals may not be the sum of the components since individuals may access more than one service type on the snapshot day. There were 35 consumers who accessed services in more than one State or Territory, mainly in 'border' towns.
2. Data for consumers of CSDA-funded services with the following service types were not collected: advocacy; information/referral; combined advocacy/information; print disability/alternate formats of communication; service evaluation/training; peak bodies; research/development; and other services.
3. Data provided by the Commonwealth are preliminary and cover 99% of Commonwealth-funded services.

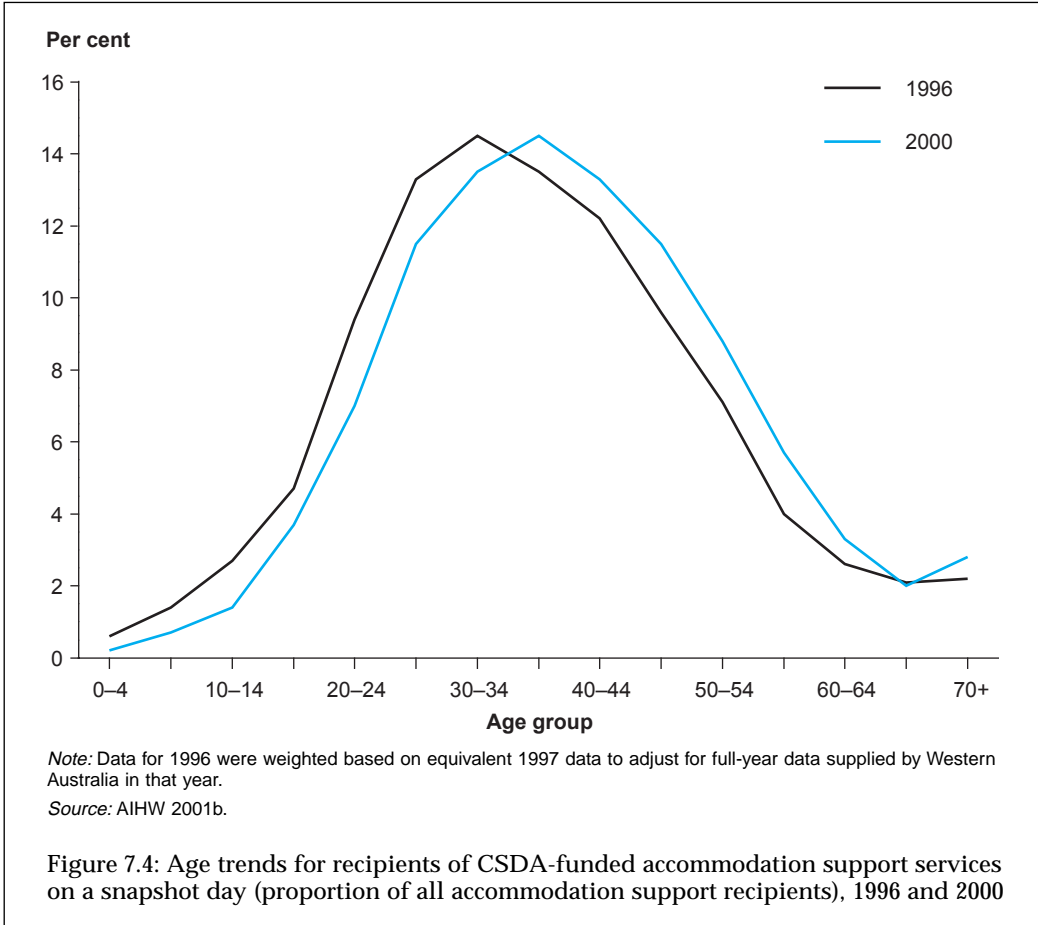
Source: AIHW 2001a:Table 1.1.

Nearly three-fifths of consumers (36,353 or 58%) were male, which was similar to previous years. There was considerable variation between the sexes in service use patterns. In particular, males used employment services comparatively more frequently (64%) and community support services comparatively less frequently (54%; AIHW 2001b). Overall, the age distribution was similar for the two sexes, although females were slightly older on average, with a median age of 34 years compared to 32 years for males (Table A7.10).

The age pattern of consumers varied with service type: consumers of community support and respite services were generally much younger than those of accommodation, community access and employment (AIHW 2001b). From 1996 to 2000, there has been a consistent increase in the average age of recipients of accommodation services.<sup>3</sup> The median age increased from 36 to 39 and the peak age group shifted from 30—34 to 35—39 (Figure 7.4). There was a smaller increase in age for employment, community access and some respite services (AIHW 2001b).

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3 For the first four CSDA MDS collections (1995–98), there was no way to determine consumer counts from the data on services received. Hence, trends in consumer characteristics in the 1996–00 period have to be examined at the level of services received or 'recipients'.



Three-fifths (60%) of people receiving CSDA services in 2000 had an intellectual disability as their primary disability (Table 7.13). The next most frequently reported were physical disability (12%) and psychiatric disability (9%). Since 1996 the proportion of CSDA recipients with a psychiatric disability or autism as their primary disability has increased (AIHW 2001b).

Overall, 1,629 or 2.6% of CSDA consumers (or 2.8%, excluding the 8% of consumers for whom Indigenous status was not known) were identified as being of Aboriginal or Torres Strait Islander origin or both (AIHW 2001b:Table 3.10). This figure is similar to their estimated representation in the population, which in 2000 was 2.4% of Australians aged less than 65 years (ABS 1998a). However, the proportion of Aboriginal or Torres Strait Islander consumers on the snapshot day varied from 1.7% for employment services to 5.7% for respite services (excluding consumers for whom Indigenous status was not known, and all Queensland consumers of whom 29% were of unknown Indigenous status; AIHW 2001b:Table 3.12).

Table 7.13: Consumers of CSDA-funded services on a snapshot day, by primary disability group and all significant disability groups, 2000

Disability group	Primary disability group reported for each consumer		All significant disability groups reported by consumers, including primary	
	Number	% of all consumers	Number	% of all consumers
Developmental delay	1,576	2.5	2,200	3.5
Intellectual	37,484	60.1	42,446	68.1
Specific learning/ADD	923	1.5	2,062	3.3
Autism	2,133	3.4	4,064	6.5
Physical	7,673	12.3	17,826	28.6
Acquired brain injury	2,285	3.7	3,122	5.0
Deafblind	168	0.3	518	0.8
Vision	1,359	2.2	5,930	9.5
Hearing	847	1.4	3,736	6.0
Speech	335	0.5	12,450	20.0
Psychiatric	5,381	8.6	9,323	15.0
Neurological	1,738	2.8	9,002	14.4
Not stated	439	0.7	439	0.7
<b>Total</b>	<b>62,341</b>	<b>100.0</b>	<b>112,679</b>	<b>. .</b>

*Notes*

1. Consumer data are estimates after use of a statistical linkage key to account for individuals who have received more than one service on the snapshot day.
2. Data for consumers of CSDA-funded services with the following service types were not collected: advocacy; information/referral; combined advocacy/information; print disability/alternate formats of communication; service evaluation/training; peak bodies; research/development; and other services.
3. The data for all significant disability groups reported adds to more than the total number of consumers since consumers may be counted in more than one disability group.
4. Data provided by the Commonwealth are preliminary and cover 99% of Commonwealth-funded services.

Source: AIHW 2001a:Table 3.5.

Compared to other consumers, those of Aboriginal and Torres Strait Islander origin reported a need for more frequent support in activities of daily living, that is in the areas of self-care, mobility and/or communication (Table 7.14). About two-thirds (887 of 1,360, or 65%, excluding Queensland consumers) of Indigenous consumers needed frequent or continual support with these activities, compared to 56% of non-Indigenous consumers (28,060 of 50,217).

Thus, it appears that Aboriginal and Torres Strait Islander consumers have higher support needs than other consumers of CSDA services. Therefore the provision of some disability support services to Indigenous people at higher rates per capita than for the non-Indigenous population could be considered well-targeted. These higher support needs may also indicate higher levels of unmet need in the Indigenous community than in the rest of the population, but it is not possible to draw this conclusion without better data on the distribution of disability in the Indigenous population.

Table 7.14: Consumers of CSDA-funded services on a snapshot day, by frequency of support needed in activities of daily living and by Indigenous status, 2000

Frequency of support needed	Indigenous		Non-Indigenous		Total	
	Number	%	Number	%	Number	%
None	133	9.8	7,226	14.4	7,676	14.2
Occasional	296	21.8	13,246	26.4	14,117	26.1
Frequent	364	26.8	11,368	22.6	12,197	22.6
Continual	523	38.5	16,692	33.2	17,837	33.0
Not stated	44	3.2	1,685	3.4	2,194	4.1
<b>Total</b>	<b>1,360</b>	<b>100.0</b>	<b>50,217</b>	<b>100.0</b>	<b>54,021</b>	<b>100.0</b>

*Notes*

1. Consumer data are estimates after use of a statistical linkage key to account for individuals who have received more than one service on the snapshot day.
2. Data for consumers of CSDA-funded services with the following service types were not collected: advocacy; information/referral; combined advocacy/information; print disability/alt; formats of communication; service evaluation/training; peak bodies; research/development; and other.
3. Totals include 2,444 consumers whose Indigenous status was not known or not stated.
4. Data for consumers in Queensland have not been included due to a high 'not known' rate of Indigenous status (29%).
5. Data provided by the Commonwealth are preliminary and cover 99% of Commonwealth-funded services.

Source: AIHW 2001a:Table 3.15.

## Use of CSDA services

Most consumers (84%) received a service in only one of the five service type categories of accommodation, community support, community access, respite and employment, on the snapshot day. The other 16% received between two and four services in the different categories (AIHW 2001b). Table 7.15 shows the different combinations of service types. The shaded figures in the central diagonal show those consumers who used only one service type on the snapshot day in 2000. For example, 13,406 consumers used an accommodation service only and they were 63% of all consumers who used an accommodation service.

Consumers of community access and accommodation were the most likely to have used another service type (38% of consumers using community access services and 37% of those using accommodation services on the snapshot day used another service type). These two service types formed the most common combinations of multiple service usage.

The level and pattern of multiple service usage varied among consumers depending upon such characteristics as primary disability group, number of disabilities, method of communication, frequency of support needed for activities of daily living and main source of income. In particular, people with an intellectual primary disability were the most likely to have used more than one service type, and multiple service use tended to increase with the number of disability groups and the frequency of support needed (AIHW 2001b).

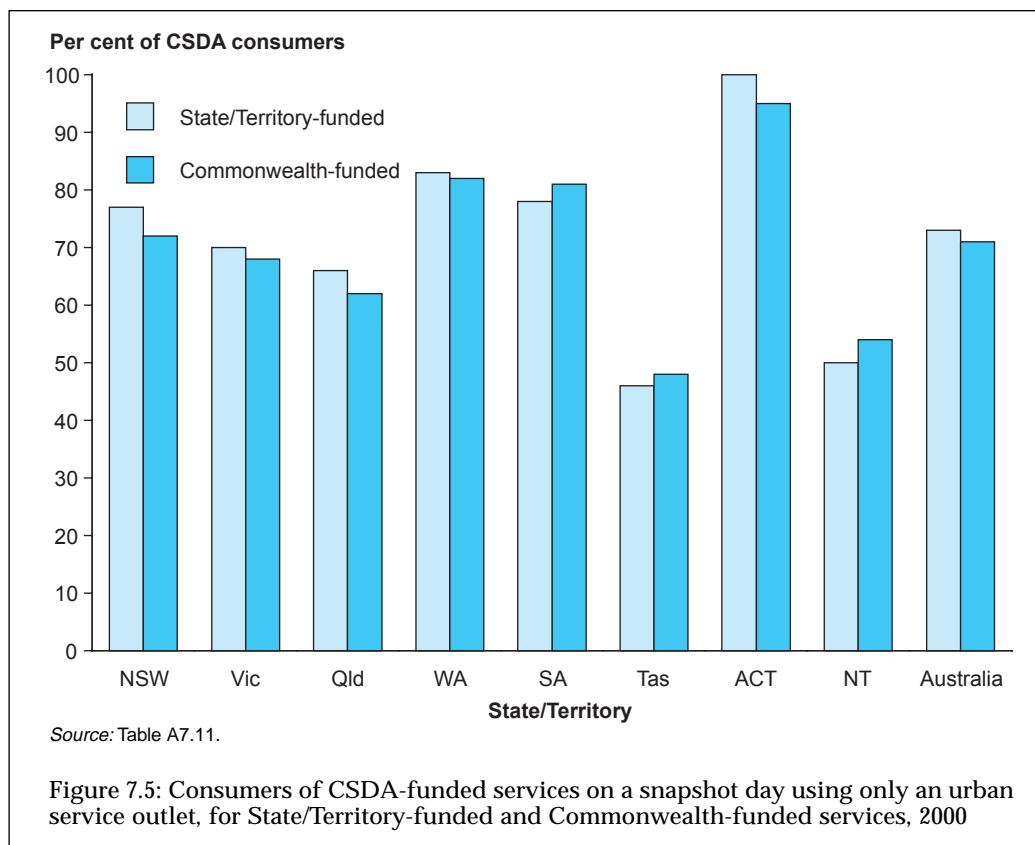
Table 7.15: Consumers of CSDA-funded services on a snapshot day, by service type combinations received, 2000

Service type 2	Service type 1									
	Accommodation		Community support		Community access		Respite		Employment	
	No.	%	No.	%	No.	%	No.	%	No.	%
Accommodation	13,406	62.8	1,468	8.6	4,542	31.0	87	3.3	2,594	14.9
Community support	1,468	6.9	14,243	83.7	930	6.3	379	14.6	649	3.7
Community access	4,542	21.3	930	5.5	9,074	61.9	317	12.2	421	2.4
Respite	87	0.4	379	2.2	317	2.2	1,814	69.8	100	0.6
Employment	2,594	12.1	649	3.8	421	2.9	100	3.8	13,968	80.4
<b>Total consumers</b>	<b>21,356</b>	<b>100.0</b>	<b>17,011</b>	<b>100.0</b>	<b>14,658</b>	<b>100.0</b>	<b>2,598</b>	<b>100.0</b>	<b>17,373</b>	<b>100.0</b>

Notes

1. Consumers with service types 1 and 2 the same (shaded) are those consumers who used only one service type, for example, 13,406 consumers used an accommodation service only and they were 62.8% of all consumers who used an accommodation service.
2. Consumers with three or four service types are included under all relevant combinations. Thus numbers in a column do not necessarily add up to the total number of consumers.
3. Data provided by the Commonwealth are preliminary and cover 99% of Commonwealth-funded services.

Source: AIHW 2001a:Table 4.2.



The geographic distribution of outlets among urban, rural and remote areas is similar for State and Territory-funded services, and Commonwealth-funded services within each State and Territory (Figure 7.5). Apart from the Australian Capital Territory, which is almost all urban, Western Australia and South Australia had the highest proportion of consumers using urban-located service outlets (83% and 78% respectively for State-funded services, and 82% and 81% for Commonwealth-funded services), followed by New South Wales, Victoria and Queensland. Tasmania has by far the highest rural proportion (54% for State-funded, 52% for Commonwealth-funded), and the Northern Territory has the highest proportion of remote service outlets (50% and 46% respectively). These data will become more informative with the redeveloped CSDA MDS collection, with improved data on the location of all service users in the year, enabling a meaningful comparison with relevant population data.

### CSDA accommodation support services: trends in use

The proportion of recipients receiving accommodation support services as group homes or in-home support (rather than in institutions and hostels) increased from 60% in 1995 to 71% in 2000 (Table 7.16). This proportion increased in the six States over the period, although in 2000 it varied from 52% for South Australia to 86% for Queensland. It has remained at 100% in the Australian Capital Territory since 1997 and in the Northern Territory since 1995.

The collection of the statistical linkage key in 1999 and 2000 makes it possible to match the services used by consumers on the snapshot day in both years (see Box 7.8). Such analysis suggests that there was little movement of consumers among the three major

Table 7.16: Consumers of CSDA-funded community-based accommodation support services on a snapshot day, by State/Territory, 1995–00

	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Australia
	<b>Percentage of all consumers of accommodation support</b>								
1995	51.30	64.17	79.72	59.84	42.65	54.35	92.03	100.00	60.37
1996	53.96	66.40	77.08	65.95	46.51	54.35	n.a.	100.00	61.88
1997	53.94	70.27	79.55	58.19	46.60	56.07	100.00	100.00	62.93
1998	53.78	75.70	83.81	66.90	45.08	66.28	100.00	100.00	65.90
1999	57.21	75.73	84.95	73.43	45.63	68.94	100.00	100.00	68.84
2000	61.76	79.25	85.60	75.15	51.62	61.34	100.00	100.00	71.39

#### Notes

1. Community-based or 'in-home' accommodation support services are group homes, attendant care, outreach/other 'in-home'/drop-in support, alternative family placement, and other accommodation.
2. Data for consumers or recipients of CSDA-funded accommodation support services exclude services identified by jurisdictions as being psychiatric services.
3. Data for 1995–98 are numbers of services received by consumer. An individual may be counted more than once if they used more than one accommodation support service type on the snapshot day.
4. Data for 1999–00 are estimates of consumers after use of a statistical linkage key to account for individuals who have received more than one service on the snapshot day. Where the accommodation support service type was inconsistently recorded for the same consumer, the consumer was counted as not receiving a community-based service.
5. Data provided by the Commonwealth are preliminary and cover 99% of Commonwealth-funded services.

Source: AIHW 1997b: 21, 1999b: Table 5.11, 2000c: Table A5.12, 2000d: Table A.14; AIHW: Black & Maples 1998: Table 5.11; AIHW: Black et al. 1998: Table 5.11.

accommodation service groupings institutions and hostels, group homes and other forms of accommodation services (AIHW 2001b:Table 4.8) over 1999 to 2000. Instead, the growth in the number of consumers in group homes appears to have been mainly due to an influx of people who had not been using an accommodation service previously, or possibly may have been using an intermittent service not picked up on the snapshot day. Conversely, most of the decline in the numbers using institutions and hostels appears to be due to people previously using these services no longer using a CSDA accommodation service at all.

These service trends are consistent with trends in the living arrangements of CSDA service consumers from 1997 to 2000. Over this period, the proportion of consumers living with family members gradually increased, while the proportion of those living in institutional accommodation decreased (AIHW 2001b:Table 3.20).

The improved ability to monitor service trends is a vital policy tool in a climate where there is active debate about the value and appropriateness of varying service models (see also Chapter 4).

## Other disability support services

### Residential aged care and HACC

People who have a disability and are aged less than 65 years may have their accommodation and other support needs met through services within the aged care sector. Nationally, there were 6,151 such people in aged care homes in June 2000 (Table 7.17).<sup>4</sup> Of these 6,151 people, 4,976 were aged 50–64 years, of whom 161 were Aboriginal and Torres Strait Islander people.

Table 7.17: People aged less than 65 years living in aged care homes, by State/Territory of the home, 30 June 1997 – 30 June 2000

	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Australia
	<b>Number</b>								
1997	2,136	1,374	1,111	534	318	157	60	78	5,768
1998	2,231	1,435	1,162	488	318	156	64	70	5,924
1999	2,302	1,482	1,202	525	313	151	54	65	6,094
2000	2,367	1,454	1,232	505	332	150	40	71	6,151
	<b>Number per 100,000 population</b>								
1997	39.0	34.1	36.8	33.2	25.0	38.1	20.9	43.1	35.4
1998	40.3	35.2	37.9	29.8	24.9	38.1	22.5	38.1	36.0
1999	41.2	36.0	38.6	31.5	24.5	37.1	18.9	34.9	36.6
2000	42.0	35.0	39.0	30.0	25.9	36.9	14.0	37.6	36.6

*Note:* Data for 1997 combine nursing homes and hostels. These categories of residential care were restructured from 1 October 1997 into a single program of residential aged care.

*Source:* AIHW 1998a:Tables 1.1 and 2.1, 1998b:Table 2.1, 1999c, 2000e, 2001b.

4 This compares with 5,702 people of all ages living, on snapshot day in 2000, in institutions and hostels funded under the CSDA (AIHW 2001b).

Overall, there were 37 residents aged under 65 years per 100,000 Australians of that age, varying from 14 in the Australian Capital Territory to 42 in New South Wales. There has been an increase in the proportion of the population under 65 years using aged care homes, from 35 in June 1997 to 37 in June 2000.

Of the 6,151 people aged under 65 in residential aged care, 6,004 were living permanently in aged care homes, accounting for 4.5% of permanent residents of all ages. Over 80% (4,855) were aged 50–64. However, there were 87 permanent residents aged 10–29. Permanent residents aged under 65 as a percentage of all permanent residents varied considerably among States and Territories, ranging from 2.5% in South Australia to 20.1% in the Northern Territory (Table 7.18).

Table 7.18: People aged under 65 years living in aged care homes, by age group and State/Territory, 30 June 2000

Age (years)	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Australia
10–29	37	17	22	2	4	2	0	3	87
30–49	416	228	230	95	50	27	5	11	1,062
50–64	1,846	1,184	952	398	271	119	32	53	4,855
<b>Total 10–64</b>	<b>2,299</b>	<b>1,429</b>	<b>1,204</b>	<b>495</b>	<b>325</b>	<b>148</b>	<b>37</b>	<b>67</b>	<b>6,004</b>
Total 10–64 (% of all residents)	4.9	4.4	5.0	4.5	2.5	4.1	2.7	20.1	4.5

Note: 147 residents aged 10–64 years receiving respite care are excluded.

Source: AIHW analysis of data supplied by the Department of Health and Aged Care from the ACCMIS Warehouse.

The Home and Community Care (HACC) program also provides services for younger people with a disability and their carers. The services include home help and home maintenance, home nursing and personal care, delivered meals, transport and shopping assistance, paramedical services, home- and centre-based respite care, and advice and assistance of various kinds (see Chapter 6). While a new HACC Minimum Data Set is being implemented, the data will not be available for analysis until late 2001.

### Rehabilitation and hearing services

CRS Australia (formerly known as the Commonwealth Rehabilitation Service) provides rehabilitation assistance to people aged 15–65 with disabilities. The aim is to maintain people with a disability in their current employment or return them to suitable employment. CRS Australia deals with people from a diverse set of disability groups. Over half of their clients have a physical disability and 25% have a psychiatric disability. Around 7% have an acquired brain injury (ABI), 5% an intellectual disability and 5% a sensory disability. CRS Australia provided programs to 17,759 new clients in the financial year 1999–00. Of the 8,560 clients who completed a rehabilitation program, a total of 6,108 (71%) achieved a durable employment outcome of 13 weeks or more (FaCS 2000b).

Australian Hearing is the sole government-funded provider of hearing services. In 1999–2000, Australian Hearing provided services to 108,447 pensioners and veterans, 43,321 children (aged under 21 years), and 7,219 COMCARE and CRS clients and Defence personnel. These figures included 12,046 adult clients (8% of all clients) who

were identified as having severe/profound hearing loss and/or severe communication problems. The total 159,987 clients represented a 4% decrease from 1997—98 (Australian Hearing Services 2000).

The voucher system has operated since late 1997. This allows eligible clients (including Pensioner Concession Card holders, people on Sickness Allowance and those holding a Health Care Card) to obtain vouchers to receive services from any hearing service provider whether it be public or private. In 1999—00, almost 121,000 eligible adult clients received a Hearing Services Voucher (Australian Hearing Services 2000).

Table 7.19: People aged 5–64 years with a disability, by use of aid/equipment and by disability status, 1998

	Core activity restriction								Total with disability	
	Profound		Severe		Moderate		Mild			
	'000	%	'000	%	'000	%	'000	%	'000	%
<b>Aid/equipment used</b>										
Eating aids	14.2	7.0	*3.0	0.7	**0.5	0.1	**1.7	0.3	19.4	0.8
Showering aids	41.6	20.4	30.5	7.2	12.2	2.9	*4.3	0.7	88.6	3.8
Toilet aids	26.9	13.2	15.4	3.6	*5.0	1.2	**0.6	0.1	48.0	2.1
Incontinence aids	16.6	8.1	*6.6	1.6	*6.6	1.5	—	—	29.8	1.3
Dressing aids	14.6	7.1	10.0	2.4	**2.1	0.5	—	—	26.7	1.1
Electric wheelchair/scooter	13.9	6.8	*2.9	0.7	**0.1	0.0	**1.2	0.2	17.9	0.8
Manual wheelchair	26.7	13.1	*7.9	1.9	**0.9	0.2	**1.8	0.3	37.2	1.6
Cane	*6.3	3.1	*4.1	1.0	**1.8	0.4	**1.1	0.2	13.4	0.6
Crutches/walking stick	13.9	6.8	37.5	8.8	14.4	3.3	*5.7	0.9	71.4	3.1
Walking frame	12.1	5.9	*3.1	0.7	**0.9	0.2	**0.9	0.1	17.0	0.7
Seating/bedding aids	14.4	7.1	19.0	4.5	*5.3	1.2	—	—	38.7	1.7
Car aids	*7.3	3.6	*3.2	0.7	**0.7	0.2	**0.2	0.0	11.3	0.5
Other mobility aids	13.5	6.6	17.7	4.2	*7.0	1.6	*3.7	0.6	41.9	1.8
Reading/writing aids	16.6	8.1	13.9	3.3	**2.0	0.5	*8.7	1.4	41.2	1.8
Speech aids	*7.5	3.7	**0.9	0.2	**0.3	0.1	**0.7	0.1	9.4	0.4
Mobile/cordless phone (communication)	26.2	12.8	57.7	13.6	32.5	7.6	26.0	4.1	142.4	6.1
Fax machine (communication)	*3.7	1.8	11.5	2.7	*4.5	1.1	*5.7	0.9	25.4	1.1
Meal preparation aids	13.3	6.5	15.7	3.7	*4.5	1.1	*4.2	0.7	37.7	1.6
Medical aids	67.9	33.2	161.7	38.1	151.7	35.3	150.1	23.7	531.3	22.7
<b>Total</b>	<b>204.3</b>		<b>424.2</b>		<b>430.1</b>		<b>631.9</b>		<b>2,340.0</b>	

*Notes*

1. Estimates marked \*\* are subject to sampling variability too high for most practical purposes. Estimates marked \* have an associated relative sampling error of between 25% and 50%. These estimates should be interpreted accordingly.
2. Aids or equipment used are those needed because of disabling conditions.
3. Reading/writing and speech aids include both low and high technology aids.
4. Totals are not the sum of the components because more than one aid or piece of equipment may be used by each person, or because people with schooling or employment restriction are included.

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

## **Equipment services**

The use of aids and equipment can substantially improve function and reduce or resolve difficulties in task performance (Verbrugge et al. 1997; Verbrugge and Sevak, in prep.). Compared to personal assistance, equipment use may be associated with feelings of autonomy and self-sufficiency, may be adapted to specific functional problems, and may be more readily to hand when needed.

A total of 936,600 people with a disability and aged 5–64 years used aids and equipment in 1998 (AIHW 1999a). Medical aids were the most common form of aid or equipment, used by 22.7% of people with a disability (Table 7.19). Communication aids mobile or cordless phones (6.1%) and fax machines (1.1%) required due to condition were the second most used form, followed by crutches/walking sticks (3.1%) and showering aids (3.8%).

People with profound restrictions were more likely to be using aids and equipment than were other disability groups. Use of aids for showering (20.4%), the toilet (13.2%), eating (7%) and other self-care requirements was higher, as was the use of mobility aids such as manual wheelchairs (13.1%).

## **Relevant generic services**

People with a disability use the same services that all members of the community require and use. It is only possible here to report on some generic services that are perhaps of special relevance. Some other chapters report on access to services by people with a disability. Chapters 3 and 8 on housing and homelessness do so (see some highlights following) and Chapter 5 on child care, where it is noted that the proportion of children with a disability in child care was lower than their proportion in the general population (Table 5.12 and related discussion).

## **Health services**

While people with a disability have frequently wished to distance themselves from a medical model of disability, it is nevertheless recognised that, when they are sick, they need access to appropriate health services (see, for example, Parmenter 2000). This need occurs whether people are in residential care or in the community.

A recent review of the 211 deaths of people with disabilities who died in care in New South Wales between 1991 and 1998 pointed to a range of improvements needed to avoid premature death: the need for health screening and reviews by health professionals, for better training of other staff and for adequate monitoring systems, for instance in the handling of epilepsy (NSW Community Services Commission 2001).

As systems promote deinstitutionalisation, it becomes crucial to ensure that the health needs of vulnerable people in the community can be ascertained and met. The health status of people with intellectual disability in a Sydney area has been suggested to be considerably worse than the rest of the population in Australia (Beange et al. 1995) and there have been more recent, similar findings in the United States of America (Horwitz et al. 2000).

People with mental illness often have associated disabilities. Almost one in five adult Australians were found to have had a mental disorder at some time during the 12 months prior to an ABS survey in 1997 (ABS 1998b). Of these, 44% had mild, moderate

or severe disability, as measured by the Brief Disability Questionnaire. Only a small proportion of people with mental disorders now spend extended periods in psychiatric hospitals or residential facilities; most are cared for in the community. There were 1,301 available beds in public community residential mental health care services that were staffed for 24 hours a day (AIHW 2001c).

There is generally no systematic information on the experience of people with disability in the health service system.

### **Education and training**

Students with disabilities may attend special schools or mainstream schools, either in regular classes or in special or support units or classes. Enrolment in special education settings, both in mainstream and special schools, requires formal assessment of the student in terms of severity of disability and need for support. Students with a range of profound, severe or multiple disabilities can enrol in special schools, although in South Australia only students with intellectual disabilities can be enrolled. Jurisdictional variation occurs in services provided and the definitions of disability used to regulate eligibility for education support funding. In some jurisdictions, such as Tasmania, full education support funding is only available to students with severe disabilities, excluding students with lower support needs from the data. In New South Wales, specialised support may be provided in any of the settings by itinerant teachers; this applied to 780 students with vision impairment and 1,089 students with hearing impairments not included in Table 7.20.

There were 97,546 students recorded with disabilities in 2000: 77,977 in government schools, of whom 81% attended mainstream schools, and 19,569 attending non-government schools, of whom 91% attended mainstream schools (Table 7.20). Variation between jurisdictions in the proportion of students attending mainstream schools in the government sector was marked: from 65.3% in Victoria to 97.2% in the Northern Territory. This may reflect the variation in the availability of special schools and the different integration policies in place.

Students with a disability as a proportion of all students attending government and non-government schools ranged from 0.9% in Tasmania to 10.6% in the Northern Territory. In all jurisdictions, attendance was greater in government schools than in non-government schools, with the exception of Tasmania.

Post-school education data are available for apprentices and trainees. In 1999, a total of 63,200 apprentices and trainees enrolled in a course or completing a qualification were reported as having a disability (Australian National Training Authority 2000). The national percentage of trainees and apprentices with a reported disability was 3.8%, with State and Territory percentages ranging from 2.5% in Western Australia to 4.8% in New South Wales and the Australian Capital Territory. Physical disabilities were the most common form of disability reported (22%), followed by visual (18.2%), intellectual (14.1%) and hearing disabilities (11.7%). Chronic illnesses were also classified as a disability type.

Section 7.4 provides information on trends in education participation among people aged 5–20 years with a disability.

Table 7.20: Students with disabilities attending government and non-government schools, by State/Territory, 2000 (full-time-equivalents)

	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Total
<b>Government schools</b>									
Mainstream	24,748	10,142	8,213	3,746	10,009	382	1,153	4,894	63,287
Special	3,620	5,396	2,304	1,938	855	152	284	141	14,690
<i>Total</i>	<i>28,368</i>	<i>15,538</i>	<i>10,517</i>	<i>5,684</i>	<i>10,864</i>	<i>534</i>	<i>1,437</i>	<i>5,035</i>	<i>77,977</i>
Percentage attending mainstream schools	87.2	65.3	78.1	65.9	92.1	71.5	80.2	97.2	81.2
Percentage of all government school students	3.8	2.9	2.4	2.1	6.1	0.8	3.8	12.5	3.4
<b>Non-government schools</b>									
Mainstream	7,559	3,903	2,292	1,270	2,032	249	271	212	17,788
Special	1,039	470	100	19	139	13	1	0	1,781
<i>Total</i>	<i>8,598</i>	<i>4,373</i>	<i>2,392</i>	<i>1,289</i>	<i>2,171</i>	<i>262</i>	<i>272</i>	<i>212</i>	<i>19,569</i>
Percentage attending mainstream schools	87.9	89.3	95.8	98.5	93.6	95.0	99.6	100.0	90.9
Percentage of all non-government school students	2.6	1.6	1.3	1.3	2.9	1.3	1.2	2.5	1.9
<b>Total students with disabilities</b>									
<i>Total all students ('000)</i>	<i>36,966</i>	<i>19,911</i>	<i>12,909</i>	<i>6,973</i>	<i>13,035</i>	<i>796</i>	<i>1,709</i>	<i>5,247</i>	<i>97,546</i>
Percentage of all school students	3.4	2.5	2.1	1.9	5.2	0.9	2.8	10.6	2.9

*Notes*

1. Full-time equivalent (FTE) students are not the actual number attending. For example, a student attending for half the normal school hours will be half a FTE student. The number of enrolled students will normally be greater than the number of FTE.
2. Data for non-government schools include students at kindergarten level. Data for government schools in New South Wales include students at kindergarten level; in Victoria, exclude students at kindergarten level and in early special education facilities; in Queensland, exclude students at kindergarten level and may include students at early special education facilities depending on where they are based; in Western Australia, include students at kindergarten or pre-primary level; in South Australia, exclude students at preschools; in Tasmania, include students at kindergarten level but exclude students in early special education facilities; in the Northern Territory, include students at preschools; and in the Australian Capital Territory, include students at kindergarten or pre-primary level.
3. Data for government special schools in Western Australia include education support schools and education support centres.

*Source:* DETYA 1998 Non-government Schools Census, unpublished data; and data provided by State education authorities (NSW Department of Education and Training, Education Victoria Office of Schools, Education Queensland, Department of Education Training and Employment (South Australia), Education Department of WA, Department of Education, Tasmania, ACT Department of Education and Community Services, NT Department of Education).

## Employment assistance

From 1 May 1998, Centrelink became responsible for assessing and referring all eligible job seekers to appropriate employment assistance services. Centrelink staff use the Job Seeker Classification Instrument (JSCI) to identify the relative difficulty that job seekers have in gaining employment and to classify the level of assistance they should receive (DEWRSB 1998:2). Job seekers identified by certain trigger questions in the JSCI process are referred to a Centrelink Disability Officer for a secondary classification process, generally undertaken using the Work Ability Tables, or WATs. These tables determine the impact of a job seeker's disability on their capacity to work. Job seekers with severe

to moderate disability impacts are streamed to CSDA-funded specialist disability employment services (see Tables 7.10—7.15). Those with milder disabilities are considered for access to the Job Network, funded by the Department of Employment, Workplace Relations and Small Business.

During the period 1 October 1999 to 30 September 2000, 77% (52,972) of job seekers who were classified using the JSCI and the WATs, were referred to CSDA-funded specialist disability employment services. The remaining 23% (15,692) of job seekers were assessed as having a disability of a low to moderate impact on their ability to work and were referred to Job Network (DEWRSB unpublished information).

The vast majority of job seekers with a disability do not undergo the WATs and are streamed directly to Job Network, where in 1999 they comprised approximately 15.5% of the total Job Network register (DEWRSB 2000a). The Job Network provides three major types of employment service: Intensive Assistance, Job Search Training and Job Matching (DEWRSB 2000a). Intensive Assistance generally provides up to 12 months of personalised assistance to a disadvantaged job seeker (DEWRSB 2001). Post-assistance outcomes for people with disabilities accessing these Job Network services appear to be poorer than for the Job Network population as a whole: nearly one-third (33.1%) of people with disabilities receiving Intensive Assistance achieved positive outcomes (employment or education/training), compared with 42.5% of all Intensive Assistance participants; 44% of those receiving Job Search Training, compared with 51% overall; and 54.9% of those receiving Job Matching assistance, compared with 70.6% of overall (DEWRSB 2000b).

### **Housing and homelessness**

Some data on housing services and assistance for people with a disability are provided in Chapter 3 (see Tables 3.13, 3.16, 3.17). In June 2000, 17% (157,169) of the total number of income units receiving FaCS Commonwealth Rent Assistance were recipients of Disability Support Pension. During 1999—00, 44.6% of housing allocations were made to households with special needs, including people with a disability. Of households that rated dwelling modifications for special needs as important, 74% had their needs met, and of households that rated ease of access and entry to dwelling as important, 89% had their needs met.

The Housing Ministers Advisory Committee (2000) has established a working group to address issues associated with the accommodation and support requirements of people with complex needs. People with a disability are included in the target client group with complex needs.

Homelessness among people receiving disability pensions is discussed as a feature of Chapter 8 of this report. People receiving disability pensions accounted for 17% of people using supported accommodation services under the Supported Accommodation Assistance Program. They reported financial difficulty (48%) more often than any other reasons for seeking assistance, and were more likely than other groups to report psychiatric illness, and drug and alcohol abuse, as reasons for seeking assistance (see Table 8.10).

## Informal assistance

In 1998, 450,900 people, or 2.4% of the total population, were primary carers. A primary carer is defined as the person who provides the most informal assistance to a person with one or more disabilities (ABS 1999). Of primary carers, 78.6% were aged under 65 years and 70.4% were females (AIHW 2000b). Some 247,000 primary carers were caring for a main recipient aged less than 65 years (AIHW 1999a:Table A7.6).

Informal carers were the main source of assistance with self-care, mobility and communication for more than 80% of people with a severe or profound restriction and living in households. In 1998, 9,700 parent primary carers were aged 65 years or over. Most ageing parent carers (8,800) were mothers living with a son or daughter. Many carers had been in their caring role for a long time: 40% (178,300) for at least 10 years and 13% (59,600) for at least 25 years. Thirty-six per cent of primary carers (161,300) spent, on average, 40 hours or more per week providing care (AIHW 2000b:Tables 16.2, 16.4).

There are many positive aspects of caring. Regarding their relationship with their main care recipient, 32.7% of primary carers said that they had been brought closer together and 39.7% said that their relationship remained unaffected. More than half (55.3%) reported that their caring role had not affected their friendships with others (AIHW 2000b:Table 16.8).

However, many primary carers reported that the caring role impacted on their financial situation, their relationships with others, and their health and wellbeing. Nearly a quarter said that they had lost or were losing touch with existing friends, and 22% said that their relationship with the main care recipient had become strained as a result of the caring role. Nearly 30% of primary carers reported difficulty in meeting living costs. About 34% said they frequently felt weary or lacked energy, and 17% said that they felt angry or resentful, due to their caring role. Over 10% reported a stress-related illness. Nearly half of primary carers relied on a government pension or allowance as their principal source of income, compared with 20% of those who were not in a caring role (AIHW 2000b:Tables 16.5, 16.8, 16.9, 16.10).

In 1998, 24,100 (9.7%) primary carers of recipients aged under 65 reported that they needed assistance but did not receive any, and 39,200 (15.8%) needed more assistance than they currently received (Table 7.21). Over 150,000 (60.8%) reported that a fall-back carer was available, but 77,900 (31.5%) did not have a fall-back carer.

Most primary carers (86.9% or 215,000 people) had never received respite care services, and the majority of them (191,400) stated that they did not need or want such services. However, 23,600 said that they needed respite services but had never received them. Some 22,600 (9.1%) had used respite care services and, of them, 13,900 (5.6%) needed more assistance.

Table 7.21: Primary carers aged over 14 years of people aged under 65 years, by age group of carer and whether assistance is needed and received, 1998

	15–64 years		65+ years		Total 15+ years	
	No.	%	No.	%	No.	%
<b>Need for and receipt of assistance</b>						
Receives assistance and:						
- does not need further assistance	70,100	30.4	*4,900	29.3	75,000	30.3
- needs further assistance	35,500	15.4	*3,700	22.1	39,200	15.8
Does not receive assistance and:						
- does not need assistance	102,500	44.4	*6,700	40.1	109,200	44.1
- needs assistance	22,700	9.8	**1,400	8.5	24,100	9.7
<b>Total</b>	<b>230,700</b>	<b>100.0</b>	<b>16,800</b>	<b>100.0</b>	<b>247,500</b>	<b>100.0</b>
<b>Availability of a fall-back carer</b>						
Available	142,400	61.7	*8,000	47.7	150,400	60.8
Not available	70,300	30.5	*7,600	45.4	77,900	31.5
Don't know if available	18,000	7.8	**1,200	6.9	19,200	7.8
<b>Total</b>	<b>230,700</b>	<b>100.0</b>	<b>16,800</b>	<b>100.0</b>	<b>247,500</b>	<b>100.0</b>
<b>Need for and receipt of respite care</b>						
Received in the last three months and:						
does not need further care	*8,700	3.8	—	—	*8,700	3.5
needs further care	12,600	5.5	**1,300	7.6	13,900	5.6
None received in the last three months and:						
- does not need care	*4,600	2.0	**2,100	12.6	*6,700	2.7
- needs care	*3,200	1.4	—	—	*3,200	1.3
<i>Total received in the last three months</i>	<i>21,300</i>	<i>9.2</i>	<i>**1,300</i>	<i>7.6</i>	<i>22,600</i>	<i>9.1</i>
Never received respite care and:						
- does not need or want care	179,700	77.9	11,700	70.0	191,400	77.3
- needs care	21,900	9.5	**1,700	9.9	23,600	9.5
<i>Total never received respite care</i>	<i>201,600</i>	<i>87.4</i>	<i>13,400</i>	<i>79.8</i>	<i>215,000</i>	<i>86.9</i>
<b>Total</b>	<b>230,700</b>	<b>100.0</b>	<b>16,800</b>	<b>100.0</b>	<b>247,500</b>	<b>100.0</b>

*Notes*

1. People being cared for are main care recipients aged under 65 years with a severe or profound disability.
2. Numbers are estimates rounded to the nearest thousand carers. Estimates marked with \*\* have an associated relative standard error (RSE) of 50% or more. Estimates marked with \* have an associated RSE of between 25% and 50%. These estimates should be interpreted accordingly.

Source: AIHW analysis of ABS 1998 Survey of Disability, Ageing and Carers confidentialised unit record file.

## 7.4 Outcomes

Outcomes for people may be measured as broad status indicators relating, in the disability services field, to a person's quality of life and participation in various life domains. They may also be measured in a service-specific context, to relate to service goals and to gauge service effectiveness. The latter outcome indicators are less well defined nationally in the disability services field, but significant progress has been made over the last two years. This section outlines this progress, in particular the agreement on an enhanced framework for indicators. Data for some service-related outcomes are presented, followed by some data on trends in participation outcomes for people with a disability.

## An indicator framework

An indicator framework for the disability services field has now been developed by the AIHW in partnership with disability administrators, and accepted as the basis for further work in the CSDA MDS redevelopment (AIHW 2000f). The framework is depicted in two main diagrams (Figures 7.6, 7.7).

### A broad contextual framework

First, a broad indicator framework reflects the person in society, those components of their wellbeing that are relevant to the disability services field, and the personal and environmental factors that also affect them (Figure 7.6). This framework reflects and synthesises high-level themes and goals in the disability field nationally and internationally:

- High-level goals are well articulated in the disability services field in Australia, most particularly in the main goal statement of the 1998 CSDA (Clause 4(1)):

The Commonwealth and the States strive to enhance the quality of life experienced by people with a disability through assisting them to live as valued and participating members of the community.

- The themes of participation and quality of life are reflected strongly in many jurisdictional policy statements and in the National Disability Standards.
- The United Nations Standard Rules on the Equalization of Opportunities for Persons with Disabilities (UN 1994:8—9) also highlight participation as a key goal:

In all societies of the world there are still obstacles preventing persons with disabilities from exercising their rights and freedoms and making it difficult for them to participate fully in the activities of their societies. It is the responsibility of States to take appropriate action to remove such obstacles.

- The conceptual framework of the new ICF (see Box 7.1) which is recognised as relating to the UN Standard Rules (1994).

Participation and quality of life should clearly, then, be the themes of indicators of outcomes for people with disabilities. The framework offered by the ICF classification can be used for monitoring broad participation outcomes in the population and for the construction of performance indicators for disability services; this framework is represented in the Figure 7.6 under Functioning and disability .

The social system of services and assistance formal and informal, government and non-government is depicted in the lower half of the diagram. Three categories of outcomes are represented: consumer outcomes, community outcomes and service-related outcomes. These three categories should be related.



### **Individual (consumer) outcomes**

Individual outcomes in the disability services field should be defined in terms of broad participation in the community. In a specific service setting, service goals that relate to the specific enhancements of participation and quality of life shape the specific form of the indicators.

Many jurisdictions are moving on defining consumer outcomes, in areas where they consider that services may affect these outcomes. Victoria has tested a question on consumer participation in various life domains in the course of the redevelopment of the CSDA MDS collection, the question being based on trial items in the National Community Services Data Dictionary (DHS Victoria 2000; AIHW 2000a). There are well-recognised difficulties in attributing outcomes to service interventions, and complexities in measuring outcomes with a broad focus and subjective components, such as quality of life and participation (AIHW 2000f). The alternative is to maintain a narrower, service-oriented focus. Under the Commonwealth's proposed case-based funding trial, payments to service providers are based on the achievement of employment outcomes for individuals. Employment outcome is defined as work of at least 8 hours per week and at a wage which is either award-based or part of a legal industrial agreement, or self-employment. Payments are linked to the amount of time an individual has been in employment. Thus, client outcomes are defined specifically to relate to one area of participation (i.e. paid work). Taking this approach, achievement of outcomes can be assessed, and more probably attributed to the service intervention. Concerns have nevertheless been expressed about the performance indicators used, the possible incentives to move high support needs clients out of employment services and into activity services, and the quality of the employment outcomes achieved (see, for instance, Knowles 2001; DICE 2001).

With the rise of consumer-based funding models, there is a trend towards individuals being involved in specifying their own outcome goals, against which service outputs are purchased (for instance, the Adult Lifestyle Support program in Queensland, Individual Service Plans in the Australian Capital Territory, and the Post School Options program in Tasmania AIHW 2000f).

### **Community-level outcomes**

Community-level outcomes should reflect an aggregation of individual consumer outcomes, plus factors that can only be measured at the community level, such as community attitudes to disability and equity of access to services. They commonly incorporate notions of participation, rights and inclusion. Such outcomes, articulated by governments, are often about providing access to appropriate services that will help improve the quality of life of people with disabilities.

### **Service-related outcomes**

Service funding and administration have undergone considerable change over the last 10–15 years; in particular, models of commercial or market practice have been integrated into the funding relationships and processes. Service providers funded by government are often required to report on achievement of outcomes, to demonstrate accountability. Information on outcome achievement may also be used for internal service management purposes. A distinction can be made between service provider

outcomes and service-level outcomes (AIHW 2000f). Service-level outcomes are based on aggregations of individual outcomes, and thus reflect how well a service is achieving outcomes for its clients. Service provider outcomes, in contrast, relate to how a service is conducting its business. A service provider outcome may be improved efficiency, or compliance with quality standards. There should be a relationship between these two, because a service agency that is conducting its business well might be expected to be better at delivering outcomes to its clients.

Increasingly, service agreements between funding bodies and service delivery agencies specify outcome of the purchased activity. These outcomes frequently focus on outcomes for clients, such as health, safety, rights and opportunities, friendships, employment, flexibility and appropriateness of the service for the client, and client satisfaction with the service. The push for systems that have a focus on client satisfaction is geared to achieving positive outcomes for clients in a more contestable and accountable service market .

Service-related outcomes may be aggregated to program-level outcomes as well as to community outcomes (see also Chapter 9).

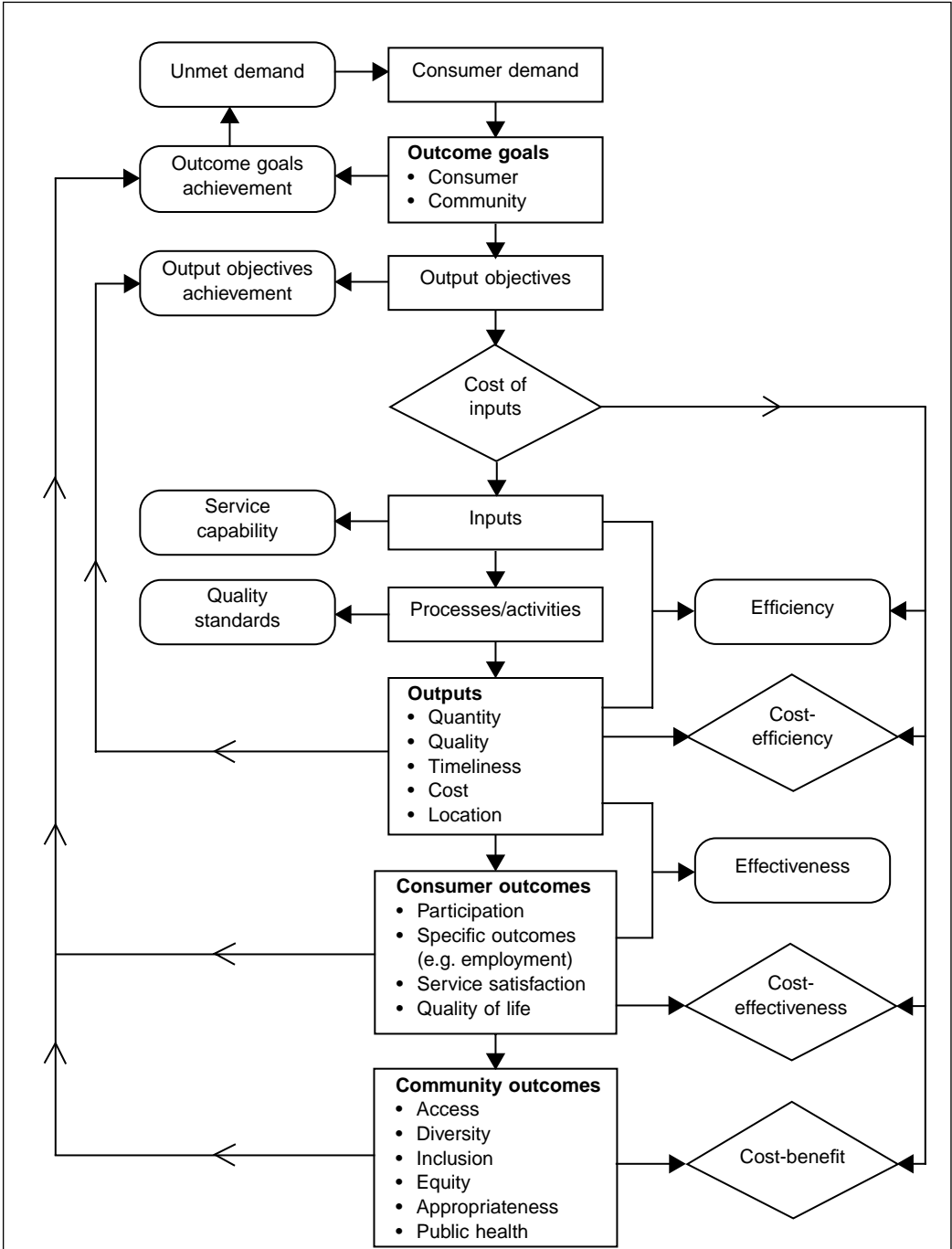
## **A performance indicator framework**

The second part of the new indicators framework for the disability services field is the performance indicator framework (Figure 2.3 in AIHW 2000f), which expands on the lower half of Figure 7.6 and illustrates the relationships between performance-related concepts and measures.

The central column of Figure 7.7 shows flowing from consumer demand outcome goals (often specified at whole-of-government level) and output objectives (specified at program level or in service funding contracts), which determine the service outputs purchased. Service or program funding is used to purchase inputs (resources) which, through service processes or activities, are used to produce outputs (goods or services). From a performance perspective, there may be interest in measuring or assessing the quantity, quality, timeliness and cost of outputs produced, and perhaps also where the outputs were provided (i.e. location). The quality of service processes (as distinct from outputs) may also be assessed, perhaps against specific quality standards.

Service outputs contribute to outcomes for consumers, which may be defined narrowly (e.g. finding a job) or more broadly (e.g. quality of life). Community outcomes reflect an aggregation of individual consumer outcomes, plus factors that can only be measured at the community level, such as community attitudes to disability. These other factors may potentially be influenced by disability services.

The boxes in the right-hand column represent performance indicators of efficiency (the rate of translation of inputs into outputs), effectiveness (the rate of translation of outputs into outcomes), and various related measures that involve an element of cost (represented by diamond-shaped boxes).



Source: AIHW 2000f.

Figure 7.7: Performance indicator framework

On the left side of the figure, performance indicators related to the achievement of output objectives and outcome goals are represented. Output objectives may be specified not only in terms of the quantity of outputs produced, but also in terms of the quality, timeliness and, in some cases, where the outputs are delivered (i.e. location). The extent of achievement of outcome goals is expected to impact on the level of unmet demand in the community or the target population.

## Some service-related outcomes

National Disability Administrators, during the redevelopment of the CSDA MDS, are working with the AIHW to improve performance indicators for disability services in Australia. It is anticipated that these efforts, together with ongoing work in the context of the Report on Government Services, will continue to improve the quality of reporting on services and outcomes in the future.

Some highlights of current service-related outcome indicators information include:

- greater use of community-based or in-home accommodation support services, rather than institutional: the proportion of recipients receiving community-based or in-home support increased from 60% in 1995 to 71% in 2000 (Table 7.16); and
- a national client satisfaction survey sponsored by disability administrators: despite the acknowledged difficulties of such a methodology, there were some interesting results, including an overall satisfaction level of 75—85% among CSDA clients and 65—76% among their families (E-Qual and Donovan Research 2000).

## Access to services

Access to services is an important indicator of service or program outcome.

National studies, based on 1993 data, were commissioned to examine the level of unmet demand for disability support services funded or provided under the CSDA (e.g. AIHW 1997c). Additional funds of \$510 million have since been allocated to CSDA services by Australian governments (Newman 2000a; Section 7.3).

In 1998, 958,000 people with a severe or profound restriction living in households reported the need for assistance with at least one of the 10 activities listed in Table 7.2. A substantial number of people with a severe or profound restriction in 1998 reported no main provider of assistance with activities of mobility (46,700), self-care (40,700), property maintenance (31,000), health care (28,400) and transport (22,200) (AIHW 2000b). Health care, property maintenance and housework were the activities with which people were most likely to rely on formal services as their main source of assistance.

Government organisations played a greater role than non-government organisations as the main formal service providers for core activities, in particular mobility and communication. Private organisations, in particular private for profit organisations, were more likely to be the main providers of formal services with health care and property maintenance (AIHW 2000b:Table 15.7).

Support services and other resources play an important role in reducing the stress of carers, particularly among ageing carers. However, in 1998, 24,100 primary carers of main recipients aged under 65 reported that they needed assistance but did not receive any, and 39,200 needed more assistance than they currently received. Some 23,600 primary carers needed respite services but had never received them (Section 7.3).

## Outcomes for people with a disability

The previous edition of this biennial report presented information on participation outcomes for people with a disability in various life domains: living arrangements, housing, self-care, self-perceived health, mobility and transport, communication, social relationship and community life, time use and leisure, education, employment and economic life (AIHW 1999a:255—63).

This section uses available time-series data from the four ABS disability surveys to examine some trends in community living, employment status and school attendance among people with a disability for almost two decades.<sup>5</sup>

### Trends towards community living

Living in community settings is a common goal of people with a disability and increasingly an explicit goal of service programs. There is a continuing shift from residential care to community care in the fields of aged care, disability services and mental health, although there are some variations between the fields in terms of how this shift is occurring (Chapter 4; AIHW: Madden et al. 1999). The sense of inclusion in the community, as well as residence there, is more difficult to measure.

Marked increases in the number and proportion of people with a severe or profound restriction living in households have been reported previously, based on comparative analyses of data from the ABS 1981, 1988 and 1993 disability surveys (AIHW 1997a, 1997c; AIHW: Wen & Madden 1998). The most recent survey (1998) showed that the trend towards community living has continued (AIHW 1999a).

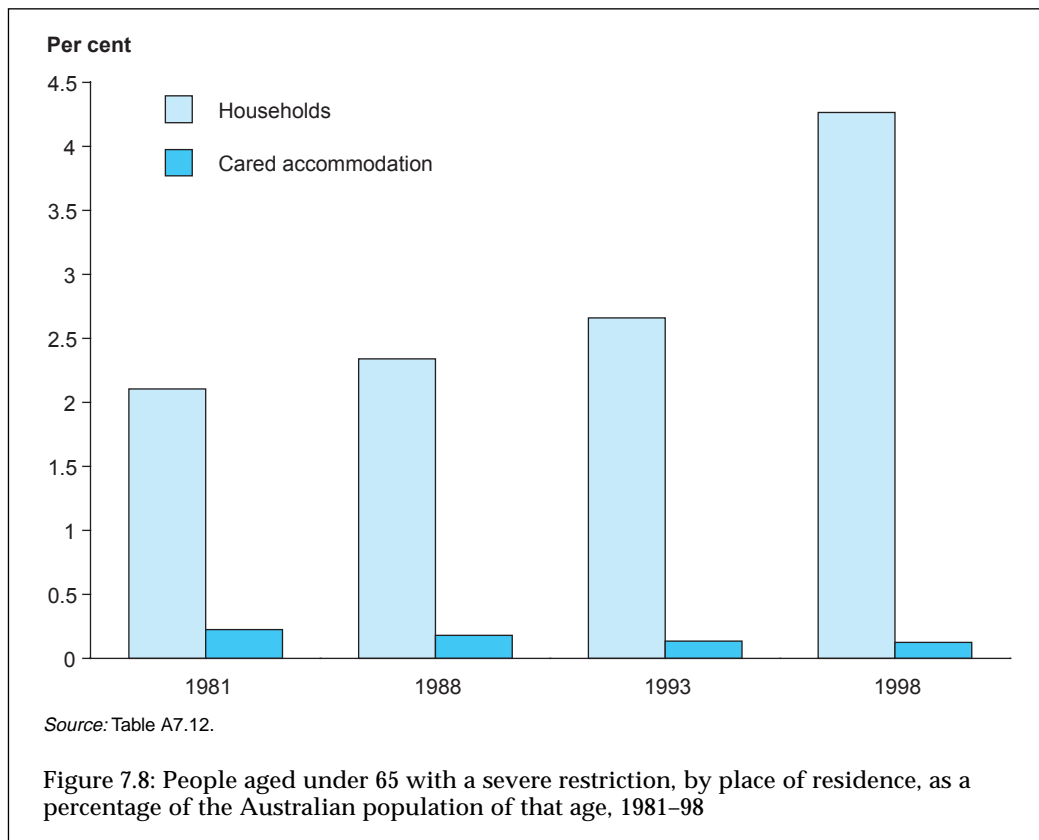
For almost two decades (1981—98), there has been a consistent increase in the rates of people living in households and a decline in the rates of living in institutional-style cared accommodation<sup>6</sup> among people aged under 65 with a severe or profound restriction (Figure 7.8). The largest increase in community living was in the rate and number of people with a severe or profound restriction living with their families (Table A7.12; AIHW: Wen & Madden 1998). The increase in the number of people living in the community was markedly greater than the decrease in the number of those living

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5 The 1993 and 1998 disability survey data were re-derived using definitions as close as possible to the definitions of the 1981 and 1988 disability surveys. However, some of the changes between surveys are difficult to be controlled for (see Section 7.2).

6 'Cared accommodation' in the survey includes hospitals, aged care homes and cared components of retirement villages, and other 'homes', such as children's homes. Smaller disability group homes (with fewer than six people) were not included in the cared accommodation component (ABS 1999).

in cared accommodation (AIHW 1999a:Table 7.19). The large difference suggests that these reflect non-institutionalisation, that is, people staying in the community throughout their life rather than ever living in an institution.



The deinstitutionalisation trend is particularly evident among younger people with a severe or profound restriction. In 1981, of people with a severe or profound restriction, the proportion aged under 30 living in cared accommodation was substantially higher than that for people aged 30–64. In 1988, the proportions for the two age groups were the same, reflecting a great decline in the under-30 age group during 1981–88. By 1998, the proportion for people aged under 30 was 60% lower than the proportion for those aged 30–64 (Figure 7.9; Table 7.22). This comparison suggests that the individual deinstitutionalisation and non-institutionalisation efforts have been focused on younger people. For example, in New South Wales, priority has been placed on minimising the institutionalisation of children (AIHW 2000b:Section 5.3).

Findings from analysis of data on CSDA-funded services are consistent with trends reflected in population data. Between 1995 and 2000, the proportion of recipients receiving accommodation support services as community-based or in-home support increased from 60% to 71%. During 1997–2000, the proportion of consumers of CSDA-funded services living with family members gradually increased, while the proportion of those living in institutions declined (Section 7.3). (See also Chapter 4 for further discussion.)

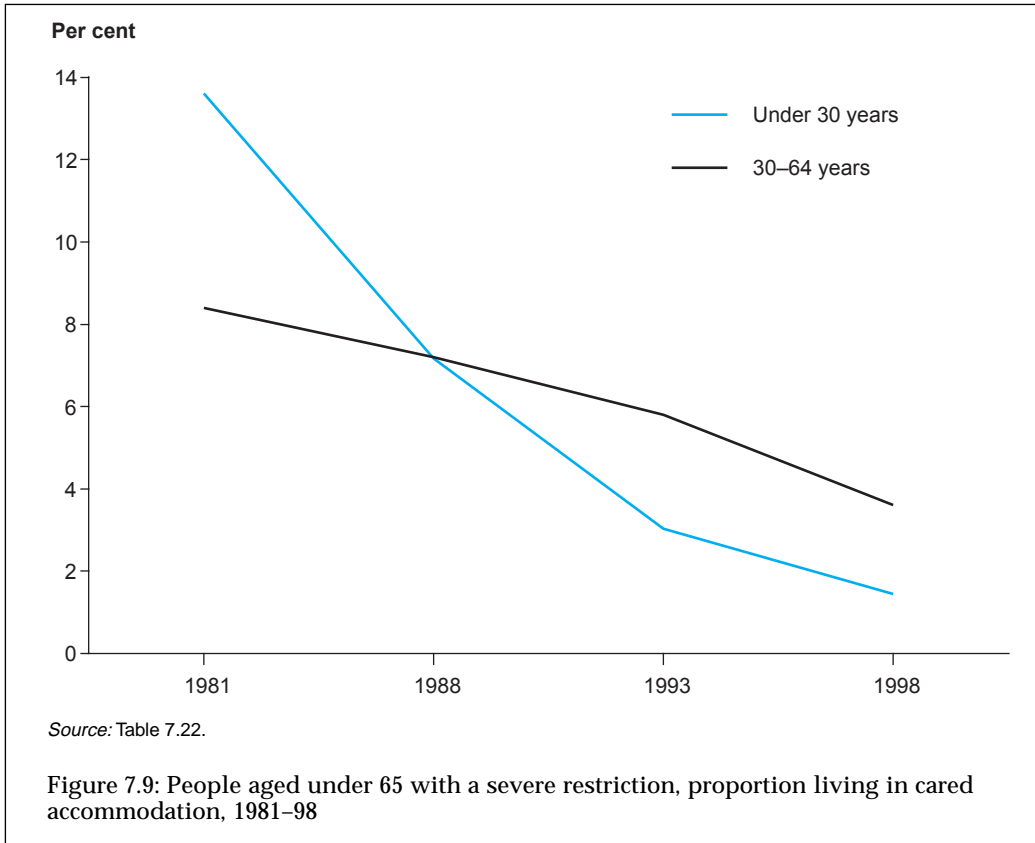


Table 7.22: People aged under 65 with a disability living in cared accommodation, by age and disability status,<sup>(a)</sup> 1981, 1988, 1993, 1998 (per cent)

Age (years)	1981	1988	1993	1998
<b>Severe restrictions</b>				
Under 30	13.6	7.2	3.0	1.4
30-64	8.4	7.2	5.8	3.6
Total <65	9.7	7.2	4.9	2.9
<b>Total with specific restrictions</b>				
Under 30	4.8	2.1	1.2	0.7
30-64	3.1	2.0	1.8	1.4
Total <65	3.5	2.0	1.6	1.2
<b>Total with a disability</b>				
Under 30	2.8	1.7	1.2	0.6
30-64	2.0	1.8	1.5	1.1
Total <65	2.2	1.8	1.4	1.0

(a) The proportions have been age standardised using the age and sex distributions of the Australian estimated resident population for March 1998 for comparative purposes. The estimates for the 1993 and 1998 disability survey data were made using definitions as close as possible to the definitions of the 1981 and 1988 disability surveys.

Source: Unpublished data tables from the ABS 1981 and 1988 disability surveys; AIHW analysis of ABS 1993 and 1998 Survey of Disability, Ageing and Carers confidentialised unit record file.

## Employment

In 1998, the level of labour force participation was significantly lower for people with a disability (53.2%) than for people with no disability (80.1%). The participation rate for people with a severe or profound restriction was even lower, 40.2% and 18.9% respectively. Participation rates for females were lower than those for males across different severities of disability (ABS 1999:Table 20).

Over the past 17 years (1981—98), although overall participation rates for people with a disability varied slightly between 51.8% and 53.9%, participation rates for people with a schooling or employment restriction only increased markedly: from 40.0% to 61.7% (Table 7.23). Overall participation rates for people with specific restrictions rose from 39.9% to 47.4% between 1981 and 1993, while the rates dropped slightly between 1993 and 1998. These changes may partially reflect an increasing effort by people with a disability to join the labour force, or an increased number of people in the labour force who were experiencing, or willing to report, restrictions (AIHW 1997a), or an increase in the proportion of people reporting a disability generally.

In 1998, the unemployment rate among people with a disability (11.2%) was well above that for people with no reported disability (7.9%). There was a sharp increase in the unemployment rate for people with specific restrictions between 1988 and 1993. The rate has fallen since 1993, reflecting an improvement in the labour market since then and possibly also reflecting improved capture in the 1998 survey (AIHW 1999a: Chapter 3; Section 7.2).

## Education

People of working age (aged 15—64) with a disability, in particular with a severe or profound restriction, had participated less in the education system than had people with no disability. According to the 1998 disability survey, 38.8% of people with a severe or profound restriction had post-school qualifications, compared with 46.8% of people with no disability. Only about one in five people with a severe or profound restriction completed Year 12, in contrast to 43.9% of people with no disability (AIHW 1999a:Table 7.23).

Comparative analysis of data from the four ABS disability surveys provides some insights on trends in education participation among people aged 5—20 with a disability<sup>7</sup>. Based on self-reported school attendance data from the surveys, overall, there was a higher percentage of people aged 5—20 years in school and reporting a disability in 1998 than in 1981. This trend occurs irrespective of disability status. In 1981, 5.7% of people aged 5—20 were in school and reporting a disability. This figure had risen to 9.2% in 1998. For people with a severe restriction in this age group, the rise was 1.2% to 3.7%, and it occurred across all school types, including, notably, the rise from 0.5% to 1.8% in ordinary school classes (Table 7.24).

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7 The disability survey data on education among people with a disability are not directly comparable to the collections of education departments (see Table 7.20). Some students reported in the survey as having a disability were not recognised by the education departments.

Table 7.23: People aged 15–64 years in households: unemployment and labour force participation rates, <sup>(a)</sup> by disability status, 1981–98<sup>(b)</sup>

	Year	Core activity restriction			Schooling or employment restriction only	Total with specific restrictions	Without specific restrictions	Total with a disability	No disability	Total with & without a disability
		Severe	Moderate	Mild						
<b>Unemployment rate</b>										
Males	1981	6.6	7.6	8.7	19.9	10.1	4.7	6.9	n.a.	n.a.
	1988	7.9	10.5	8.0	17.2	11.1	6.7	9.9	6.5	6.9
	1993	17.8	14.3	22.2	20.5	19.5	14.6	17.7	11.5	12.2
	1998	12.9	20.2	11.8	18.6	15.0	9.7	12.9	7.8	8.4
Females	1981	13.1	12.4	16.3	21.2	15.4	12.0	13.6	n.a.	n.a.
	1988	13.9	9.3	12.1	16.7	12.8	14.4	13.1	9.5	9.8
	1993	18.4	18.2	18.5	15.5	17.5	17.1	17.4	12.1	12.5
	1998	7.6	9.7	5.3	11.6	8.0	9.1	8.4	8.1	8.1
Persons	1981	9.3	9.0	11.1	20.4	11.9	6.8	9.0	n.a.	n.a.
	1988	10.9	10.1	9.5	17.0	11.7	9.1	11.0	7.7	8.0
	1993	18.1	15.8	20.7	18.7	18.7	15.4	17.6	11.8	12.3
	1998	10.6	16.1	9.3	16.3	12.3	9.5	11.2	7.9	8.3
<b>Participation rate</b>										
Males	1981	37.2	55.3	57.1	51.2	49.8	90.2	67.5	n.a.	n.a.
	1988	37.3	49.4	62.0	68.3	55.0	88.7	61.6	90.0	86.0
	1993	34.2	47.5	54.8	70.7	53.0	84.9	61.4	88.3	84.2
	1998	38.5	40.0	57.8	67.8	50.4	85.5	59.8	89.1	84.1
Females	1981	23.9	32.1	33.3	28.1	28.7	50.2	37.2	n.a.	n.a.
	1988	31.2	33.4	41.1	45.3	37.1	56.4	40.2	62.4	59.7
	1993	25.5	38.8	44.7	56.5	40.7	56.8	44.4	65.3	62.8
	1998	31.5	33.4	42.2	52.2	38.2	62.4	44.4	70.7	67.0
Persons	1981	30.4	45.6	46.6	40.0	39.9	73.2	53.9	n.a.	n.a.
	1988	34.0	42.2	52.3	58.9	46.6	75.5	51.8	76.1	73.0
	1993	29.7	43.7	50.1	65.0	47.4	73.1	53.8	76.7	73.6
	1998	35.1	37.1	50.7	61.7	44.9	75.4	52.9	79.8	75.6

(a) Data in this table may differ from those reported in the ABS Labour Force Survey due to differences in survey sample size, the scope rules applied and the complexity of questions asked to determine labour force status.

(b) The rates have been age standardised using the age and sex distributions of the Australian estimated resident population for March 1998 for comparative purposes.

The estimates for the 1993 and 1998 disability survey data were made using definitions as close as possible to the definitions of the 1981 and 1988 disability surveys.

Source: Unpublished data tables from the ABS 1981 and 1988 disability surveys; AIHW analysis of ABS 1993 and 1998 Survey of Disability, Ageing and Carers confidentialised unit record file.

The increase in the percentage of people aged 5–20 attending school (and those not attending) among people with a disability was partly associated with the increase in reported disability prevalence among the population of that age.

In previous editions of this biennial report, as in this one, the focus has been on broad outcomes for people in the community, outcomes not necessarily attributable to any particular cause or service that is, on status measures. Now that the indicator framework described in this chapter has been agreed, it should be possible, in future editions, to enhance the service-related outcome data and better relate them to population data.

Table 7.24: People aged 5–20 years with a disability: school attendance by type of school and class, by disability status, as a percentage of the Australian population of that age, 1981–98<sup>(a)</sup>

Type of school/class	Core activity restriction			Schooling or employment restriction only	Total with specific restrictions	Total with a disability
	Severe	Moderate	Mild			
<b>Ordinary school class</b>						
1981	0.5	0.2	0.2	0.6	1.5	3.1
1988	0.8	0.5	0.9	0.9	3.0	4.0
1993	0.8	0.2	0.5	0.8	2.3	3.6
1998	1.8	0.4	0.6	0.8	3.5	n.a.
<b>Ordinary school (special class)</b>						
1981	0.2	0.1	0.0	0.3	0.6	0.6
1988	0.3	0.1	0.1	0.3	0.8	0.8
1993	0.6	0.1	0.1	0.5	1.4	1.4
1998	0.8	0.1	0.1	0.6	1.6	n.a.
<b>Special school</b>						
1981	0.3	0.0	0.0	0.1	0.4	0.4
1988	0.4	0.0	0.0	0.1	0.5	0.5
1993	0.3	0.0	0.0	0.0	0.3	0.3
1998	0.5	0.0	0.0	0.0	0.6	n.a.
<b>Total attending school</b>						
1981	1.0	0.3	0.3	0.9	2.5	4.2
1988	1.5	0.6	1.0	1.2	4.3	5.2
1993	1.8	0.4	0.6	1.3	4.0	5.3
1998	3.1	0.5	0.7	1.3	5.7	7.1
<b>Not attending school</b>						
1981	0.2	0.1	0.1	0.1	0.6	1.5
1988	0.3	0.2	0.3	0.3	1.1	1.4
1993	0.5	0.1	0.3	0.3	1.2	1.6
1998	0.6	0.1	0.4	0.3	1.5	2.1
<b>Total</b>						
1981	1.2	0.4	0.4	1.1	3.1	5.7
1988	1.7	0.8	1.3	1.6	5.3	6.7
1993	2.2	0.5	0.9	1.6	5.2	7.0
1998	3.7	0.6	1.1	1.6	7.1	9.2

(a) The percentages have been age standardised using the age and sex distributions of the Australian estimated resident population for March 1998 for comparative purposes. The estimates for the 1993 and 1998 disability survey data were made using definitions as close as possible to the definitions of the 1981 and 1988 disability surveys

Source: Unpublished data tables from the ABS 1981 and 1988 disability surveys; AIHW analysis of ABS 1993 and 1998 Survey of Disability, Ageing and Carers confidentialised unit record file.

## 7.5 Conclusion

Disability is a multidimensional experience described in terms of the person's body, their activity limitations and participation restrictions, and the environmental factors affecting them. Statistically, disability can be measured along a continuum, and estimates of disability vary with the particular definition. Thus, the ABS estimates that some 14.6% (2,385,100 people) of the population aged under 65 had a disability, which means that they reported at least one of a list of activity limitations, health conditions or impairments. This compares with an estimate of 4.0% (655,000 people) who had a severe or profound restriction, which means that they reported needing assistance with one or more of the core activities of self-care, mobility and communication.

Whatever definition is used, the impact of population ageing is reflected in the numbers of people reporting disability and in the population projections. The number of people aged 0—64 years with severe or profound restrictions is projected to increase by 9% between 2000 and 2006, with the number aged 45—64 years increasing by 19% over the same period.

These trends appear to be reflected in the ageing of people with a disability receiving accommodation support services under the CSDA. The policy trends towards flexible, individualised disability support services hold out hope for providing suitable services for people ageing with a disability, but there is evidence of the need also for policy and administrative links between aged care, health and disability services.

Funding for disability support services provided under the CSDA totalled \$2.246 billion nationally in 1999—00, an increase in real terms of 8.8% over the previous year. On a snapshot day in 1999—00, an estimated 62,341 people accessed 74,929 services.

Growth in expenditure and recipient numbers has also been a characteristic of income support programs. There were over 600,000 recipients of the Disability Support Pension in June 2000, and the administered expenses of the program were \$5.2 billion in 1999—00. The number of recipients almost doubled between June 1989 and June 2000, although rates of growth are much lower when the growth and ageing of the general population are allowed for (for instance, the annual growth rate for 1999—00 becomes 1.8% rather than 4.3%).

Informal carers remain the main providers of support for people with disabilities and are the mainstay of deinstitutionalisation trends. The challenge for the formal service system is to support this role in the hope it will continue. Some carer groups are beginning to outline the support they need, for instance by enunciating their rights to holidays, access to paid work and retirement from the caring role.

Outcomes for people with a disability are mixed. Service-specific outcomes range from the positive for instance, evidence of a consistent trend towards the provision of more community-based accommodation services, relative to institutional services to the negative, with deaths in institutions resulting in calls for significantly improved health care in these institutions and in the community generally.

Trends in educational participation suggest that there are increasing rates of school attendance by people with disabilities, especially in ordinary school classes, and that this trend holds irrespective of disability status, including for people with severe

restrictions. Employment trends confirm previous findings that people with a disability have poorer labour market outcomes (participation and employment) than do others, but that improvements in the general labour market do flow through to people with disabilities.

The emergence of a new Indigenous disability network holds out the promise of a clearer understanding of the needs of Indigenous people, as well as a new source of advice to organisations such as the AIHW with the responsibility of improving data in this area. The particular needs of Aboriginal and Torres Strait Islander people for disability services are indicated by their high reported support needs, even allowing for their over-representation (in population terms) in some CSDA service types.

There are significant ongoing efforts to improve disability data in Australia, and significant challenges to be met.

National Disability Administrators, in partnership with the AIHW, are working to improve national data on CSDA disability support services and associated performance indicators. Mainstream services are variable in their ability to report on people with a disability. Education departments nationally are able to report on access to specialist programs and mainstream schools by children with disability. Given the range of changes occurring in the Commonwealth sphere, in income support and employment assistance, it will be vital to maintain effort on data quality to ensure that outcomes for people can be monitored over time.

The Institute plans to place particular emphasis, in the immediate future, on publishing advice on the use of the new International Classification of Functioning, Disability and Health, with the aim of improving the availability, quality and consistency of disability data in Australia, not only for specialist services but also for mainstream services.

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