# 4 Disability and disability services



#### 4.1 Introduction

Disability affects many people, directly or indirectly. It may be a life-altering event or experience; it may have large or small effects on people's daily lives. Increasingly, disability is recognised as something that affects most people in the population, to varying degrees and at varying life stages. It can be measured along a continuum, and estimates of its prevalence vary with the particular definition used.

In 2003 there were an estimated 3.9 million people (20% of the population) in Australia whose lives were affected by an impairment, activity limitation or participation restriction in the environment in which they lived—2.6 million were aged under 65 years (15% of the population aged under 65 years). This is a very broad construct of disability, however, and many of these people would not identify themselves as 'a person with disability'. Among the 3.9 million people, 1.2 million sometimes or always required help or supervision with self-care, mobility or communication. Of these, 0.7 million were aged under 65 years.

This chapter provides a profile of people who are at various points on this disability continuum, but with an emphasis on those facing more severe limitations. Information is presented on both mainstream and sector-specific service use, and the outcomes associated with the use of these services. The focus in this chapter is on people aged under 65 years; Chapter 3 reports on the characteristics and circumstances of older Australians.

Significant social and demographic changes, and current policy trends, have important implications for people with disability. Increases in life expectancy, for example, have occurred for people with disability as well as for the broader population (see the Glossary for definition of life expectancy). Medical advances have increased life expectancy for those with conditions as diverse as Down syndrome and cystic fibrosis, for example. The ageing of people with disability has emerged as a current policy challenge, with a number of policy responses under development or implementation. The Disability Aged Care Interface Pilot projects, for example, were implemented by the Department of Health and Ageing from late 2003. These provided aged care services to people living in supported accommodation funded under the Commonwealth State/Territory Disability Agreement (CSTDA). Attention has also been focused on expanding the services and support available to ageing parents (those aged 65 years or over) still caring for an adult child with disability. More generally, the needs of carers in all age groups have received increased policy attention in recent years, as the importance of the role played by informal assistance has been more widely recognised.

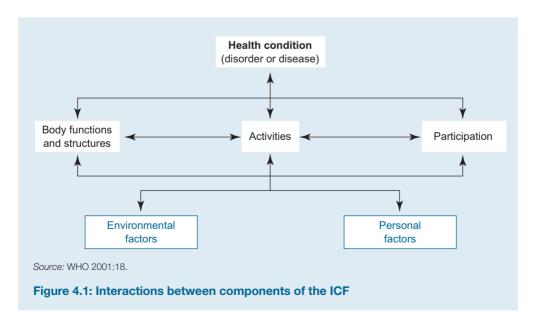
The ageing of the population also has implications for the disability workforce, both from the demand side, as an older population will have, on average, a higher number of people with disability, and the supply side, as the disability workforce is, on average, older than the general Australian workforce and the projected retirements from the disability workforce will put pressure on the size of that workforce.

A policy reform of relevance to people with disability is the emphasis on promoting workforce participation among groups with lower levels of participation, including the long-term unemployed, single parents, mature age workers and people with disability. The Welfare to Work initiative of the Australian Government was introduced from 1 July 2006. Its policy changes include the provision of extra employment services for people with disability to increase their participation in the workforce.

Another important issue in the disability services sector concerns the respective roles of sector-specific and 'generic' or 'mainstream' services; these latter terms are used to refer to services, such as the Pharmaceutical Benefits Scheme or hospital services, which are accessible by all persons regardless of their level of disability. The third CSTDA for funding specialist disability services was scheduled to expire on 30 June 2007, but it has been extended while a fourth agreement is negotiated by the Australian Government and the state and territory governments. Issues recommended for consideration by the Senate Standing Committee on Community Affairs (2007) report *Funding and operation of the Commonwealth State/Territory Disability Agreement* concerned the unmet need for accommodation services and support, the development of appropriate outcomes measures and the further development of disability data in Australia.

Disability is a characteristic that goes beyond the individual; it relates to the way in which the individual functions in his or her society and as such is crucially influenced by environmental factors. The International Classification of Functioning, Disability and Health (ICF) recognises that the components of functioning and disability—body functions and structures, activities and participation—reflect an interaction between health conditions and the person's environment (Figure 4.1). This important conceptual framework underpins much Australian data.

Section 4.2 of this chapter gives an overview of disability in the Australian population, including a brief discussion of the main types of disabling conditions and activity limitations experienced by people with disability, and the effects on disability prevalence of recent gains in life expectancy in the Australian population (see the Glossary for definition of life expectancy). Data on services and assistance for people living with disability are presented



in Section 4.3 while Section 4.4 presents estimates of unmet demand for disability support services and a discussion of broad status indicators relating to a person's quality of life and participation in various life areas. The focus is mainly on trends in three major life areas—community living, employment and school attendance—based on analyses of data from five consecutive disability surveys. Section 4.5 summarises and concludes the chapter.

#### **Box 4.1: Human rights and ethics**

Most modern disability policies are based on a human rights philosophy, and encapsulate the basic principle that people with disability should have the same basic rights and opportunities as other members of society (see, for example, UN 1994).

In March 2007, Australia was among the first of around 80 nations to sign the United Nations Convention (treaty) on the Rights of Persons with Disabilities (HREOC 2007a). The stated purpose of the convention is to 'promote, protect and ensure the full and equal enjoyment of human rights and fundamental freedoms, for all persons with disability, and to promote respect for their inherent dignity' (UN 2007). Australian delegates from government, the disability sector and the Human Rights and Equal Opportunity Commission (HREOC) were involved in the development of the convention. The Australian Government is currently undertaking the process of discussing the convention to decide whether it should be ratified (Downer et al. 2007).

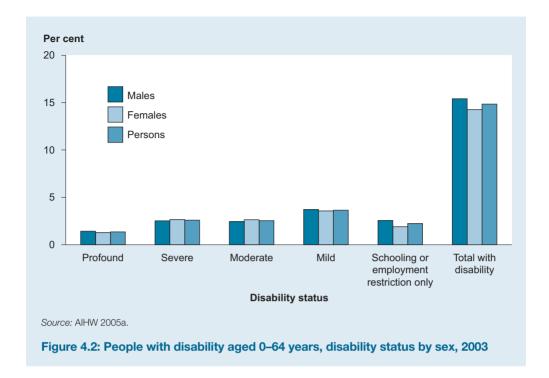
# 4.2 Disability in the Australian population

This section presents an overview of the patterns of prevalence of disability and need for assistance in the Australian population. The effects of population changes on disability prevalence and growth in need for assistance are reviewed. Disabilities among children and Aboriginal and Torres Strait Islander people are also discussed. Chapter 3 includes discussions about disabilities among older Australians.

# **Disability status**

'Disability' is defined by Australian Bureau of Statistics (ABS), Survey of Disability, Ageing and Carers (SDAC) as having one or more of 17 impairments, activity limitations or participation restrictions that have lasted, or are likely to last, for at least 6 months and that restrict everyday activities (ABS 2004). Estimates of the prevalence of disability, based on the most recent ABS SDAC conducted in 2003, reported 3.9 million people with disability (20% of the Australian population). Of these, approximately 2.6 million people were aged under 65 years (15% of the population in that age range) (Figure 4.2, Table 4.1, Table A4.1).

Of the 3.9 million people with disability, 1.2 million (6.3% of the population) had a severe or profound core activity limitation, meaning that they sometimes or always needed personal assistance or supervision with one or more core activities, including self-care, mobility and communication. Among these people, 677,700 were aged under 65 (3.9% of the population aged under 65), of whom 342,800 were male (51%) and 334,900 were female (AIHW 2005a:Table A5.1). In this chapter, 'a severe or profound core activity limitation' is sometimes abbreviated to 'a severe or profound limitation' (see the Glossary for definition of 'core activity').



Although the likelihood of disability generally increases with age, it can also reflect people's life cycle, their changing environments and the risks they encounter. Focusing on the age-specific prevalence rates of a severe or profound limitation, the peak in early childhood and school years may reflect the effects of early intervention services and the school environment on the identification of disability. The prevalence rates were lower among adolescents than children (4.3%), and remained at a rate just under 2.5% among people in their 20s and early 30s (AIHW 2005a:Figure 5.3, Table A5.2). This may be, to some extent, related to a change in the survey collection method—from parental reporting for children under 15 years of age to self-reporting for those aged 15 years or over (with parental permission for those aged 15 to 17 years (also see the section 'Children with disability').

Young adulthood may see the onset of psychiatric disabilities. From age 35, disability prevalence rates increase with age, as risk of injury, including work-related injuries, becomes relatively high. Late working age years may also see the onset of musculoskeletal and other conditions such as arthritis and heart disease associated with physical disabilities.

In the older ages, limitations in functioning are more likely to be associated with diseases and long-term conditions such as cardiovascular diseases, cancers, dementia, and hearing and vision impairments (AIHW 2005a).

States with a relatively higher proportion of older people, such as South Australia and Tasmania, tended to have higher prevalence rates of disability and severe or profound limitation than the national average. The Australian Capital Territory has a younger population age structure and correspondingly relatively low disability prevalence rates (Table 4.1).

Table 4.1: People with disability, by severity of core activity limitation, as a proportion of the state/territory or Australian population of that age<sup>(a)</sup>, 2003 (per cent)

	NSW	Vic	Qld	WA	SA	Tas	ACT	Australia <sup>(a)</sup>
0-64 years								
Profound	1.2	1.5	1.5	1.5	1.3	1.5	*0.7	1.4
Severe	2.0	2.8	3.2	2.6	3.1	3.8	1.9	2.6
Moderate	1.9	2.3	3.4	3.0	3.0	4.2	1.4	2.5
Mild	3.7	3.4	3.5	4.0	4.3	3.6	2.7	3.6
Schooling or employment restriction only	1.6	2.3	2.6	2.6	3.4	2.5	2.0	2.2
Total with profound or severe	3.2	4.2	4.6	4.0	4.5	5.4	2.6	3.9
Total with profound or severe adjusted(b)	3.2	4.2	4.6	4.1	4.4	5.2	2.7	
Total with disability	12.7	14.7	17.1	16.2	18.0	18.2	11.3	14.8
Total with disability adjusted <sup>(b)</sup>	12.6	14.7	17.0	16.3	17.6	17.8	11.6	
Total population ('000)	5,740.2	4,348.4	3,267.2	1,730.1	1,299.9	406.6	289.6	17,222.5
All ages								
Profound	2.9	3.2	3.3	2.7	3.1	3.2	1.5	3.0
Severe	2.6	3.4	4.0	3.1	3.9	4.5	2.7	3.3
Moderate	2.9	3.4	4.5	4.1	4.0	4.7	1.7	3.5
Mild	5.4	5.3	4.8	5.4	6.8	5.7	3.7	5.4
Schooling or employment restriction only	1.4	2.0	2.3	2.4	2.9	2.2	1.8	1.9
Total with profound or severe	5.5	6.6	7.3	5.9	7.0	7.8	4.1	6.3
Total with profound or severe adjusted <sup>(b)</sup>	5.5	6.5	7.5	6.2	6.4	7.3	4.8	
Total with disability	17.9	20.1	22.2	20.6	23.8	23.6	14.2	20.0
Total with disability adjusted <sup>(b)</sup>	17.7	20.0	22.5	21.5	22.5	22.6	15.7	
Total population ('000)	6,597.8	4,999.3	3,712.6	1,947.7	1,523.8	472.9	318.7	19,719.3

<sup>(</sup>a) Estimates for Northern Territory (NT) were included in total Australia. The survey sample in the NT was reduced to a level such that the NT records contributed appropriately to national estimates but could not support reliable estimates for the NT (ABS 2004:58).

Source: Table A4.1.

<sup>(</sup>b) Adjusted percentages were calculated using the age- and sex-specific rates for the Australian population at 30 June 2003

<sup>(</sup>c) The estimates of disability are based on the confidentialised unit record file (CURF) of the ABS 2003 Survey of Disability, Ageing and Carers. To protect confidentiality, some children's records and any households that were identifiable have been dropped from the CURF. Therefore, the estimates based on the CURF do not exactly match those of ABS published reports. CURF estimates are used throughout the chapter for internal consistency.

### **Disability groups**

In Australia, disabilities are often classified into groups that provide a broad categorisation of disabilities based not only on underlying long-term health conditions and impairments but also on activity limitations and participation restrictions (AIHW 2003a). Disability groups are generally recognised in the disability field and in legislative and administrative contexts in Australia such as the CSTDA. Prevalence estimates of disability groups vary with the scope and level of disability under consideration. The last volume of this report presented four sets of prevalence estimates of disability groups using four approaches, to provide a spectrum of estimates that may suit different applications (Box 4.2; AIHW 2005a:Table 5.2).

#### Box 4.2: Four sets of prevalence estimates of disability groups

All the estimates start with the base 'disability' population defined by the SDAC. The four types of estimates differ in terms of their use of SDAC information about impairment, main disabling condition, all disabling conditions, activity limitations and participation restriction, as well as need for assistance with core activities.

Estimates based on reported **main disabling condition** related to conditions that were identified by the survey respondents as causing the most problems.

The remaining three sets of estimates are based on all disabling conditions and are in diminishing size, corresponding to increasingly restrictive definitions of the group according to severity, need for assistance, activity limitation or participation restriction. The estimates based on **all disabling conditions** are the most inclusive of the four sets of estimation. These estimates include all reported disabling conditions, whether or not they are main disabling conditions.

The approach using data on **all disabling conditions plus activity limitations and participation restrictions** relies on multidimensional survey information. The estimates from the previous approach are now narrowed down by applying a 'filter'—only people who have reported activity limitations or participation restrictions in one or more activities of daily or social life are retained in the group.

The approach using data on **all disabling conditions plus a severe or profound core activity limitation** is similar to the previous approach except that a more exclusive 'filter' is used to select only people who reported a severe or profound core activity limitation (refer to the Glossary for definitions of 'main disabling condition' and 'core activity').

Sources: AIHW 2003a, 2005a.

Considering the estimates based on all disabling conditions, with a focus on people aged under 65 years, physical/diverse disability was the most commonly reported disability. Physical/diverse disability is associated with the presence of an impairment that may have diverse effects within and among individuals, including effects on physical activities such as mobility. The next most commonly reported disabilities were sensory/speech disability and psychiatric disability (Table 4.2). Males reported higher prevalence of intellectual, sensory/speech and acquired brain injury-(ABI) related disabilities than females.

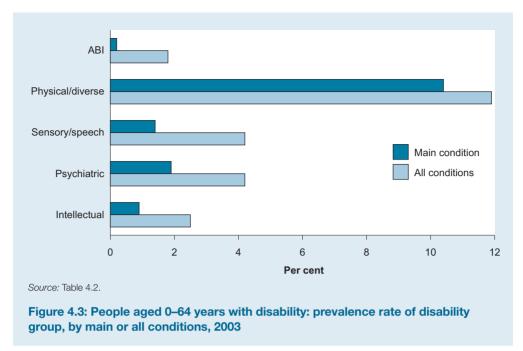
Table 4.2: Estimates of main disability groups in Australia, 2003

		Pers	ons aged und	der 65 yea	ars			
_	Males		Female	•	Person	s	All p	ersons
_	Number ('000)	Per cent	Number ('000)	Per cent	Number ('000)	Per cent	Number ('000)	Per cent
All disabling condition	ons							
Intellectual	279.3	3.2	157.0	1.8	436.2	2.5	588.7	3.0
Psychiatric	346.9	4.0	375.2	4.4	722.1	4.2	1,017.9	5.2
Sensory/speech	465.3	5.3	262.9	3.1	728.3	4.2	1,496.3	7.6
Acquired brain injury <sup>(a)</sup>	216.3	2.5	101.1	1.2	317.4	1.8	438.3	2.2
Physical/diverse	1,022.4	11.8	1,021.0	12.0	2,043.4	11.9	3,350.6	17.0
All disabling condition	s and activity	limitation	s and particip	ation rest	rictions			
Intellectual	276.1	3.2	155.9	1.8	432.0	2.5	584.5	3.0
Psychiatric	345.8	4.0	374.1	4.4	720.0	4.2	1,015.8	5.2
Sensory/speech	454.8	5.2	258.4	3.0	713.2	4.1	1,481.2	7.5
Acquired brain injury <sup>(a)</sup>	211.6	2.4	100.2	1.2	311.8	1.8	432.7	2.2
Physical/diverse	996.8	11.5	998.5	11.7	1,995.3	11.6	3,302.6	16.7
All disabling condition	s and profou	nd or seve	ere core activi	ty limitatio	ons			
Intellectual	134.4	1.5	80.6	0.9	215.1	1.2	351.0	1.8
Psychiatric	132.4	1.5	145.4	1.7	277.7	1.6	492.8	2.5
Sensory/speech	158.2	1.8	96.5	1.1	254.7	1.5	579.8	2.9
Acquired brain injury <sup>(a)</sup>	62.2	0.7	37.8	0.4	99.9	0.6	157.5	0.8
Physical/diverse	239.6	2.8	273.0	3.2	512.6	3.0	1,051.1	5.3
Main disabling condi	ition							
Intellectual	116.2	1.3	46.5	0.5	162.7	0.9	165.7	0.8
Psychiatric	160.7	1.8	165.4	1.9	326.0	1.9	432.2	2.2
Sensory/speech	154.7	1.8	92.4	1.1	247.1	1.4	412.3	2.1
Acquired brain injury <sup>(a)</sup>	20.5	0.2	*6.8	*0.1	27.3	0.2	28.7	0.1
Physical/diverse	888.0	10.2	904.8	10.6	1,792.8	10.4	2,907.4	14.7
Total with disability	1,340.1	15.4	1,215.9	14.3	2,556	14.8	3,946.4	20.0
Total population	8,697.8		8,524.7		17,222.5		19,719.3	

<sup>(</sup>a) Acquired brain injury is included in 'physical/diverse' when only four main disability groups are being considered (see AIHW 2005a: Box 5.3).

Source: AlHW analysis of ABS 2003 Survey of Disability, Ageing and Carers confidentialised unit record file.

The prevalence estimates of particular disability groups are more likely to be underestimated if main conditions only are considered, since people with multiple conditions are counted only once, according to the main condition. Figure 4.3 compares the prevalence of the five main disability groups according to whether they were reported as the main disabling condition or among a number of disabling conditions (see the Glossary for definition of main disabling condition). The differences in prevalence estimates reflect the occurrence of multiple conditions among people with disability, especially those with an ABI or a sensory disability.



For example, estimate based on ABI as one of all disabling conditions and that based on ABI as the main disabling condition reflects high rates of comorbidity and multiple disabilities among people with ABI-related disabilities, and the complex causes and effects of ABI

among people with ABI-related disabilities, and the complex causes and effects of ABI (refer to the Glossary for definitions). More than four-fifths (85%) of people with ABI-related disabilities, defined by all reported disabiling conditions, also had physical/diverse disability, about 47% had sensory/speech disability, 40% had a psychiatric disability, and 26% had an intellectual disability (Figure 4.4). (See AIHW 2007a for more analyses on people with an ABI-related disability).

#### People with incontinence-related disability

In 2003, of almost four million people with disability, 284,500 (1.4% of the population) experienced severe incontinence, that is, they always or sometimes needed assistance with bladder or bowel control and/or used continence aids. A further 320,400 people with disability (1.6% of the population) reported having difficulty with managing their bladder or bowel control but did not need assistance (AIHW 2006a:Chapter 4).

#### Activities with which assistance is needed

In 2003, 1.1 million people (5.3% of Australians) with a severe or profound limitation living in households reported need for assistance with at least one of 10 specific activities (including core activities and non-core activities) (Table 4.3). Of these, 649,500 people were aged under 65 years (3.8% of that age group) and 405,100 people were aged 65 years or more (16% of that age group). Around 243,500 people aged under 65 years (37% of people aged under 65 years with a severe or profound limitation) needed assistance with two or three core activities (AIHW 2005a:Table 5.4).

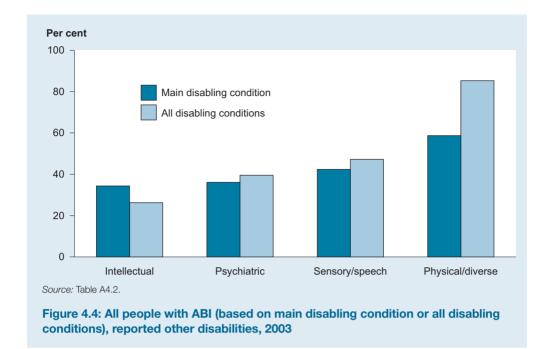


Table 4.3: People with severe or profound core activity limitation living in households, by activity type in which assistance needed and age groups, 2003

			Age (	group (yea	ırs)			
-	0–14	15–19	20–29	30–44	45–64	Total <65	65 or over	All ages
			Per cent	of total se	vere or p	rofound		
Self-care	48.3	33.7	39.1	47.8	51.9	48.2	51.1	49.3
Mobility	47.9	68.3	73.9	79.5	79.4	70.5	83.5	75.5
Communication	63.7	55.9	22.4	*7.8	4.1	23.8	8.8	18.1
Health care	36.2	51.3	48.9	49.2	49.6	46.2	70.4	55.4
Housework		35.9	47.2	51.5	55.6	39.3	69.3	50.7
Property maintenance		*25.2	44.0	53.0	63.6	42.1	71.6	53.4
Paperwork		53.6	41.6	26.2	18.5	19.1	31.8	24.0
Meal preparation		34.3	30.2	25.6	19.7	17.6	36.1	24.6
Transport		37.6	59.3	53.7	54.9	40.6	73.3	53.0
Cognition or emotion	67.3	81.7	63.5	42.3	31.7	47.9	26.3	39.7
Total needing assistance	98.1	97.7	96.9	97.8	98.8	98.2	99.6	98.7
				Number	('000)			
Total needing assistance(a)	161.9	29.9	59.7	124.7	273.4	649.5	405.1	1,054.7
Total severe or profound	165.0	30.6	61.6	127.5	276.7	661.4	406.9	1,068.4
Total population	3,850.6	1,345.1	2,872.5	4,469.5	4,684.7	17,222.5	2,496.8	19,719.3

<sup>(</sup>a) 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.

Source: Table A4.3.

People aged under 65 years with a severe or profound limitation living in households most commonly needed help with mobility (71%), self-care (48%), cognition or emotion (48%) and health care (46%) (Table 4.3). For children aged under 15 years, cognition or emotion (67%) and communication (64%) were the most commonly reported activities in which assistance was needed, reflecting the high prevalence of intellectual disabilities in this age group. The need for assistance with most activities generally increased with age after 45 years.

# Disability, ageing and growth in profound or severe core activity limitations

The number of people with a severe or profound limitation is projected to increase as the population grows and ages. This section provides a brief overview of the influence of two aspects of ageing on the increasing prevalence of disability and the need for services indicated by the growth in severe or profound core activity limitation (see the Glossary for definition of 'core activity'). The two aspects of ageing are the ageing of individuals—getting older and living longer and population ageing—an increasing proportion of older people in the population. Section 4.4 includes more discussion on influences on demand for services.

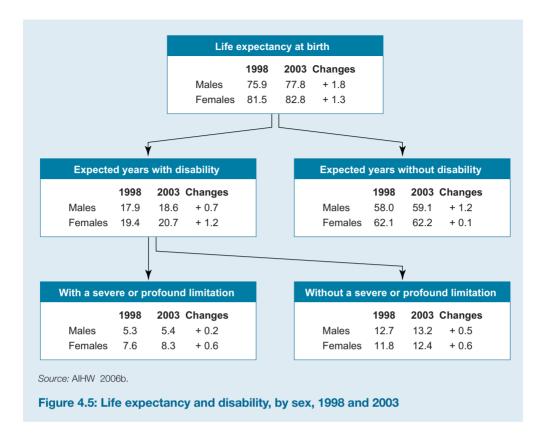
#### **Expected years of life with disability**

Australians are living longer and their life expectancy has increased markedly over the last century. Has the number of years lived with disability fallen or risen as overall life expectancy has lengthened (refer to the Glossary for definitions)? Considering recent changes from 1998 to 2003, as well as the 15 years from 1988 to 2003, gains in life expectancy were accompanied by an increase in expected years of life with disability or a severe or profound limitation (AIHW 2006b). Between 1988 and 2003, the expected years of life with disability increased from 14.7 years to 18.6 years for males, and from 16.0 years to 20.7 years for females. The expected years of life with a severe or profound limitation increased from 3.2 years to 5.4 years for males, and from 6.0 years to 8.3 years for females (AIHW 2006b:Table 2).

Recent trends (1998–2003) showed that, overall, a larger proportion of the gain in female life expectancy comprised extra years with disability (90%), compared with the proportion for males (37%) (Figure 4.5). This pattern applied across all age groups and was particularly evident among the older population aged 65 years or over and children aged under 15 years (AIHW 2006b). For older males, 67% of gains in life expectancy at age 65 years (1.5 years over that period) were years with disability (1 year), including 27% of years with a severe or profound limitation (0.4 year). For older females, over 90% of their gains in life expectancy at age 65 years (1.2 years) were years with disability (1.1 years), and about 58% were years with a severe or profound limitation (0.7 year) (AIHW 2006b:Table 1).

Overall, females had higher expectancies than males in both years lived with disability and years lived free from disability, although these gaps were much smaller at older ages. The proportion of expected life free from disability was lower for females than for males, in particular the proportion of expected life free from a severe or profound limitation among older people (AIHW 2006b).

Overseas analyses of longitudinal survey data have suggested that the greater proportion of years lived with disability or daily activity limitations by women may be explained by the longer survival of women after the development of these problems (Robine et al. 1999).



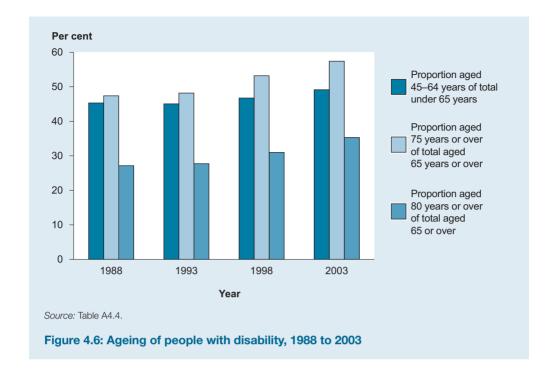
## Ageing of people with disability

On the one hand, like the general population, people with disability are living longer, including many people with an early onset disability (AIHW 2000; AIHW: Hales et al. 2006). On the other hand, in line with the ageing of the Australian population, people with disability are also ageing. This is reflected in an increasing proportion of older people in the population with disability (AIHW 2000). During the 15 years from 1988 to 2003, among people aged under 65 years with disability, the proportion of those aged 45–64 years increased from 45% to 49%. Of all people aged 65 years or more with disability, the proportion of those aged 75 years or more increased from 47% to 57%, and the proportion of those aged 80 years or more increased from 27% to 35% (Figure 4.6).

# Growth in severe or profound core activity limitations

In Australia, there has been no significant change in the age-standardised rates of severe or profound limitations over the last two decades (AIHW 2005a, AHIW 2007b). The reported age-standardised rates of 'severe disability' were fairly stable between 1981 and 1993 (see the Glossary for a definition of age-standardised rate). There was an increase in the rates from 1993 to 1998, largely attributed to changes in the survey methods. The 2003 survey maintained the 1998 survey methods, and the results confirmed the previous, stable rates of 'severe disability'.

Internationally, a recent study on disability trends among the older population in 12 OECD (Organisation for Economic Co-operation and Development) countries found that a majority of the 12 countries either reported an increasing rate of severe disability



(Belgium, Japan and Sweden), a stable rate (Australia and Canada), or no consistent trends (France and United Kingdom). Only five countries reported a decline in the rate (Denmark, Finland, Italy, the Netherlands and the United States) (OECD:Lafortune et al. 2007).

Even though underlying prevalence rates appear relatively stable, the ageing of the Australian population and the greater longevity of individuals, including those with disability, are leading to increasing numbers of people with disability and a severe or profound limitation, especially at older ages.

Based on the age- and sex-specific prevalence rates of the 2003 SDAC, the population aged 0–64 years with a severe or profound limitation is projected to increase to 752,100 people (an increase of 34,700 people, or 4.8%) by 2010. The projected growth in the working-age population (15–64 years) with a severe or profound limitation is 6.9%, or 37,500 people (Table 4.4; AIHW 2007c).

Overall, the total number of Australians of all ages with a severe or profound limitation is projected to increase by 8.7% (116,300 people). This overall projected growth is mainly attributable to rapid growth in the age groups of 65 years or over (13%, or 81,600 people) and 45–64 years (10%, or 32,800 people)(AIHW 2007c).

# **Children with disability**

While in general the likelihood of disability tends to increase with age, the age-specific rate of disability also peaks during early childhood and the school years (see the Glossary for a definition of 'age-specific rate'). In 2003, about 1 in 12 children aged 0–14 years had disability (8.3% of all children, or 317,900 children). About half of these children had a severe or profound limitation (4.3%, 165,300).

Table 4.4: Projected population of persons with a severe or profound core activity limitation by age, 2006 to 2010 ('000)

			Year			Changes 2	006–2010
Age (years)	2006	2007	2008	2009	2010	Number ('000)	Per cent of change
0–14	170.5	169.9	169.2	168.5	167.7	*-2.8	*-1.7
15–19	32.0	32.3	32.6	32.9	33.0	**1.1	**3.3
20–29	62.4	63.2	63.9	64.6	65.2	*2.8	*4.4
30–44	134.5	134.5	134.4	134.7	135.3	**0.8	**0.6
45–64	318.1	327.2	336.5	344.1	350.9	32.8	10.3
65 or over	623.6	642.9	662.3	683.3	705.2	81.6	13.1
Total 0-64	717.5	727.1	736.6	744.7	752.1	34.7	4.8
Total 15-64	547.0	557.2	567.4	576.2	584.5	37.5	6.9
Total	1,341.1	1,370.0	1,399.0	1,428.0	1,457.3	116.3	8.7

Sources: ABS 2003; AlHW 2007c; AlHW analysis of ABS 2003 Survey of Disability, Ageing and Carers confidentialised unit record file.

Overall, boys were more likely than girls to have disability (10% of all children compared with 6.5%), and to have a severe or profound limitation (5.4% compared with 3.1%). Boys also had higher prevalence rates for all of the five main disability groups. Girls and boys differed in their most prevalent disability group: for girls it was physical/diverse disability (3.4% of girls) (Figure 4.7) whereas for boys it was intellectual/learning disability (5.5% of all boys).

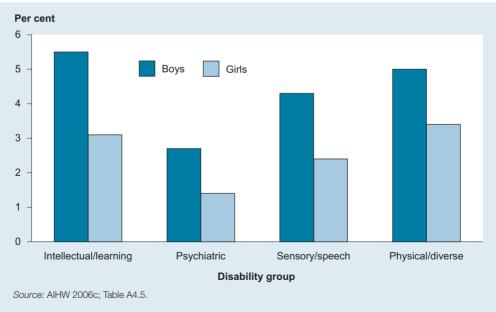


Figure 4.7: Children aged 0–14 years with disability: prevalence rate of disability groups based on all conditions by sex, 2003

There were an estimated 54,600 people who were primary carers of co-resident children with a severe or profound limitation, the great majority of whom (91%) were mothers (see the Glossary for definition of primary carer). Many of these co-resident primary carers of children, about 1 in 2 (48%), reported needing more support—more respite care and financial assistance were their greatest needs.

Almost all (97%) children aged 5–14 years with disability were attending school—89% of them in 'ordinary' schools and 9% in 'special' schools. Around 63% of school children with disability experienced difficulty at school—intellectual/learning difficulties, fitting in socially and communication difficulties were the most common (AIHW 2006c).

There were reported increases in the last decade or more in the prevalence rates of long-term health conditions associated with childhood, especially attention deficit hyperactivity disorder (ADHD) and autism-related disorders. This increase may largely reflect changes in diagnosis and increased awareness among parents, educators and health professionals, which may have contributed to the increases in the reported prevalence (AIHW 2006c).

Autism and ADHD are two major conditions within the intellectual/learning disability group, in particular among children with a severe or profound limitation. The peak in the prevalence of intellectual/learning disability among children aged 5–14 years with a severe or profound limitation becomes far less pronounced when ADHD and autism are excluded (Figure 4.8).

Autism and intellectual impairment were associated with high proportions of severe or profound limitation—87% and 75% of children with these conditions, respectively, also had a severe or profound limitation.

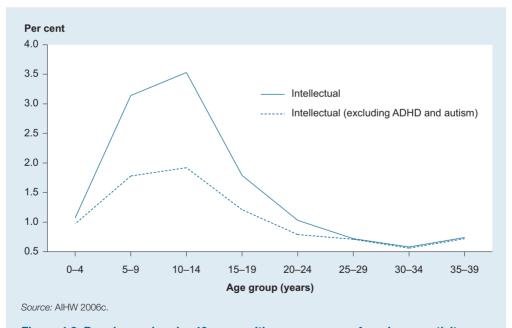


Figure 4.8: People aged under 40 years with a severe or profound core activity limitation: prevalence of intellectual disability, including and excluding ADHD and autism, by age, 2003

# **Disability among Aboriginal and Torres Strait Islander peoples**

Information about the need for assistance with basic daily activities due to disability, long-term health condition or older age was collected in the 2006 Census, which will provide improved disability data for relatively small population groups such as Indigenous Australians. However, the data were not available at the time of preparing this report.

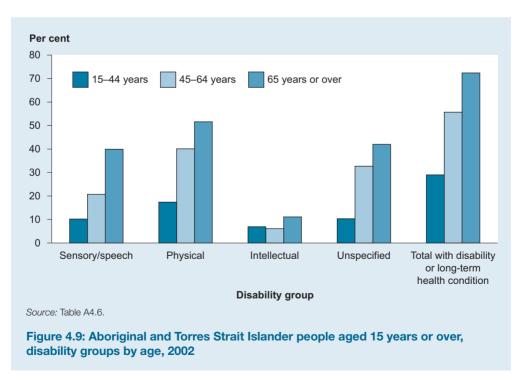
The 2002 National Aboriginal and Torres Strait Islander Social Survey included, for the first time, a short set of screening questions relating to disability that provide data generally comparable with that obtained from the 2002 General Social Survey for the Australian population (ABS & AIHW 2005).

In 2002, 102,900 (37%) Indigenous Australians aged 15 years or over had disability or a long-term health condition. Of these, 21,800, or 8% of the Indigenous population aged 15 years or over, had a severe or profound limitation (ABS & AIHW 2005).

Overall, the prevalence rate of disability or long-term health condition was similar for males (37%) and females (36%). The overall rate of a severe or profound limitation was also similar for males (7.4%) and females (8.0%). These rates increased with age for both sexes (Figure 4.9; ABS & AIHW 2005).

Considering people with different disability types as a proportion of the Indigenous population, around 24% of Aboriginal and Torres Strait Islander peoples had a physical disability, 14% had a sensory/speech disability and 7% had an intellectual disability (Figure 4.9). About 16% of Indigenous Australians had an unspecified long-term health condition that could not be coded to disability type (ABS & AIHW 2005).

A comparison of the disability status of Indigenous and non-Indigenous Australians based on prevalence estimates from the 2002 National Aboriginal and Torres Strait Islander Social Survey and 2002 General Social Survey found that the prevalence of disability among



Indigenous Australians was higher at all ages, and severe or profound disability rates were at least twice as high among Indigenous Australians (ABS & AIHW 2005; AIHW 2006d).

Having an early onset disability and experiencing premature ageing as a result of disability are more common among Indigenous than non-Indigenous Australians. In 2002, one-half of Indigenous Australians aged 45–54 years and over two-thirds of those aged 55–64 years had disability or long-term health condition. Almost three-quarters (72%) of Indigenous Australians aged 65 years or over had disability or long-term health condition, and one-quarter (25%) had a severe or profound limitation. The earlier onset of disability and earlier ageing with disability indicate the comparatively higher need for service provision for Indigenous Australians with disability at younger ages (ABS & AIHW 2005).

The comparative analyses of the two survey data also found that, while Indigenous people are generally disadvantaged when compared with non-Indigenous people, those with disability were likely to experience a further degree of social and economic disadvantage (ABS & AIHW 2005) On average, Indigenous Australians with disability or a long-term health condition had completed fewer years of formal education than Indigenous Australians without disability: they were about half as likely to have completed Year 12, were less likely to participate in the labour force and much less likely to be employed, and had a lower level of income and were more likely to be living in households that had experienced financial stress (ABS & AIHW 2005).

### **Disability data developments**

Disability data continue to improve in Australia. The ABS 2006 Population Census has, for the first time, collected disability-related information. The Census data will provide better information on the need for assistance with core activities due to disability, long-term health condition or older age among relatively small population groups, including Indigenous Australians, and in small geographic areas for planning purposes. The disability information can also be related to a rich array of other social data from the Census. Although the Census data are scheduled for release during 2007, they will not be available in time to be included in the discussion in this chapter. However, detailed discussions of Census-related disability data will be presented in future AIHW reports.

As the currently available disability data do not allow direct estimates of disability prevalence for a small geographic area, the National Disability Administrators have collaborated with the ABS to produce estimates of disability at the local government area across Australia (NDA 2007a). These estimates are based on a modelled combination of data collected from the 2003 Survey of Disability, Ageing and Carers, and the 2001 Census. They are currently available for some jurisdictions and under development in other jurisdictions.

The ABS has developed a disability module, which is a relatively short version of the disability measure used in the major national disability survey. The ABS has been using the disability module to identify the disability population in a range of other national population household surveys, such as education and household expenditure surveys, the General Social surveys and the National Aboriginal and Torres Strait Islander Social Survey. The disability module will also be included in the 2007 National Survey of Mental Health and Wellbeing and the 2007–08 National Health Survey. The data collected from various national population surveys provide integrated and comprehensive information on disability.

# 4.3 Care, services and assistance

#### **Unpaid care**

Around 2.6 million carers in Australia provided unpaid assistance to people with disability or the aged in 2003 (ABS 2004). Discussion of carers' issues usually focuses on the main provider of care, also referred to as the primary or principal carer. These carers are about 20% of the 2.6 million carers identified (ABS 2004). Around 80% of carers are non-primary carers, sometimes called secondary carers (see the Glossary for definition of primary carer). Chapter 3 on ageing and aged care has more detail about the numbers of main and other providers of informal care to people with disability.

The impact of long-term caring has generally been framed either as a stressor that worsens over time or as a process of adaptation whereby carers accumulate coping skills (Cuskelly 2006). The experience of care giving is multifaceted, with positive and negative aspects, and changes over time as the carer and circumstances change (Rowbotham 2005). In addition, carers bring different personal, financial and social resources to the role. Their experiences, and their desire for formal support services, differ (Cuskelly 2006).

The issues for carers of people with different types of disability have been highlighted by recent work. A review of mental health care in Australia found that the carers of people with psychiatric disability may find their role more demanding due to an ongoing lack of treatment and accommodation services for the person they care for (MHCA 2005). Other issues for these carers include the stigma associated with mental illness which can lead to social isolation of the whole family, and a decreased capacity for employment.

A substantial proportion of parents of younger children with disability report a need for more support (48%)(AIHW 2006c). Respite care and financial assistance are the most frequently requested types of support for primary carers of children aged 0–14 years.

Some people with disability provide unpaid care to others in their family or community. For example, parents with disability care for their children and many older spouses care for their partners even though they have significant disabilities themselves. Not surprisingly, the proportion of carers that has a disability increases with age, from 25% of carers aged 15–45 years to 59% of carers aged 65 years and older (Table 4.5).

Table 4.5: Primary carers disability status by age group, 2003

	Age group	of carer (years)		
Disability status	15–45	45–64	65 or over	Total
	Nun	nber ('000)		
Severe or profound	11.9	16.4	15.1	43.4
Moderate or mild	*9.9	51.5	44.0	105.4
Total with disability	35.8	85.4	66.4	187.5
Total without disability	108.9	129.3	46.8	285.0
Total primary carers	144.7	214.7	113.2	472.5
		Per cent of all	primary carers	
Severe or profound	8.2	7.7	13.3	9.2
Moderate or mild	*6.9	24.0	38.9	22.3
Total with disability	24.7	39.8	58.7	39.7
Total without disability	75.3	60.2	41.3	60.3
Total primary carers	100.0	100.0	100.0	100.0

Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers confidentialised unit record file.

#### Box 4.3: Welfare to Work reforms

The Welfare to Work package—an Australian Government initiative designed to support and assist those people that can move off welfare and into work—was introduced on 1 July 2006. A key feature of this reform is that the Disability Support Pension is no longer available to people with disability who are new claimants of income support and who are able to work more than 15 hours per week. These applicants will instead receive the Newstart Allowance. This change was accompanied by extra employment services designed to promote workforce participation: disability open employment services, the Job network, vocational rehabilitation and the Personal Support Program. This program assists people who face multiple non-vocational barriers to employment such as psychological problems, homelessness, drug and alcohol abuse or domestic violence.

The development of the Job Capacity Assessment program is a further significant feature of the Welfare to Work reform for people with disability. Job capacity assessments will identify a person's ability to work and any barriers they face to getting a job. Hence the job capacity assessments will influence both referral to employment assistance and income support entitlement.

### **Income support**

There is a range of payments and allowances available for people with disability and their carers. These payments can be categorised as income support payments and income supplements. Income support payments provide an income to people whose capacity for work is restricted by disability or caring responsibilities. Income support payments include the Disability Support Pension (DSP), Sickness Allowance, Newstart Allowance (Incapacitated), Wife Pension, Carer Payment and Disability Pension (Department of Veterans 'Affairs—DVA). Income supplements may assist with certain costs or recognise activities such as caring. These include the Mobility Allowance, Carer Allowance and Continence Aids Assistance Scheme. Table 4.6 outlines the number of recipients, administered expenses and dollar value of these payments.

The Continence Aids Assistance Scheme was extended to cover people over 5 years of age in July 2007. Previously it was available to those aged 16–64 years. It is anticipated that this will double the number of recipients (Santoro 2007).

The main source of income support for people of working age with disability is the DSP. There has been a steady increase in the number of people receiving the DSP since 1997 (Table 4.7). This increase is part of a longer term trend that started in the 1980s, and accelerated after the 1991 Disability Reform Package changes (DEWR 2005a). The rate of increase has slowed in recent years. In 2004–2005, the relatively smaller increase in the number of recipients was due to fewer men claiming payments together with more rejections and cancellations (DEWR 2005a). There was another small increase in 2006 before the Welfare to Work changes. Under these changes, from July 2006 the DSP is no longer available to applicants who are assessed as being able to work for 15 hours or more a week at award wages or above. These applicants will instead receive the Newstart Allowance together with extra employment assistance. This change may further slow growth in the DSP program.

Table 4.6: Australian Government disability-related payments and allowances, recipients, expenditure and payment rate (all ages), 2005–06

	Recipients as at June 2006	Administered expenses 2005–06 (\$m)	Maximum payment rate for a single adult at 1 July 2006 (per fortnight)
Disability Support Pension	712,163	8,256	\$499.70
Mobility Allowance	51,669	95.9	\$74.30
Sickness Allowance(a)	7,510	85.4	\$420.90
Carer Allowance (Child/Adult)(b)	366,960	1,258.4 <sup>(c)</sup>	\$94.70
Carer Payment (DSP/AP/other)	105,058	1,220.8	\$499.70
Wife Pension (DSP)	24,627	258.5	\$499.70
Newstart Allowance (incapacitated)	40,535	n.a. <sup>(d)</sup>	\$420.90
Youth Allowance (incapacitated)	3,203	n.a. <sup>(d)</sup>	\$348.10
Continence Aids Assistance Scheme	19,599	11.2	\$18.08 <sup>(e)</sup>
Disability Pension (DVA)	145,546	1,327	\$832.10 <sup>(f)</sup>

<sup>(</sup>a) From July 2002 the Australian Government Department of Family and Community Services introduced a revised method of counting Sickness Allowance, Newstart Allowance, Mature Age Allowance, Partner Allowance, Widow Allowance, Special Benefit, Youth Allowance and Austudy Payment clients, based on eligibility and entitlement.

- (b) Excluded from this count: 15,966 who received Carer Allowance (Child) Health Care Card only.
- (c) Administered expenses and recipients for Carer Allowance (Child) and Carer Allowance (Adult) are combined.
- (d) 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.
- (e) The Continence Aids Assistance Scheme payment rate was \$470 per year.
- (f) This payment rate applies to special rate disability pensioners who are totally and permanently incapacitated. Other rates of disability pension (DVA) apply according to eligibility.

Sources: DEWR 2006a, 2006b. DoHA personal communication. DVA 2006. FaCSIA unpublished data.

# **Box 4.4: Advisory bodies**

A range of advisory bodies provide advice to Australian governments as well as information to policy makers and the public more generally. Nationally focused non-government organisations include:

- the National Disability and Carer Ministerial Advisory Council, which met for the first time in October 2006. This body provides the government with advice on issues affecting people with disability and their carers in Australia
- the Australian Federation of Disability Organisations, which was established in November 2004 with a mission to 'champion the rights of people with disability in Australia and help them participate fully in Australian life'
- National Disability Services, formerly known as ACROD, which describes itself as the national industry association for disability services, with a network of state, territory and national offices.
- the Association of Competitive Employment, which describes itself as the national peak body for open employment services to people with disability across Australia.

There are state counterparts of many of these organisations, as well as specific groups representing, for instance, people with particular disabilities or health conditions.

Table 4.7: Recipients of disability-related payments and allowances (all ages), June 1997 to June 2006

	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006
Disability Support Pension (all) <sup>(a)</sup>		553,336	577,682	602,280	623,926	658,915	673,334	696,742	706,782	712,163
Mobility Allowance <sup>(b)</sup>	26,595	28,975	31,001	35,154	37,574	41,997	44,562	47,402	49,215	51,669
Sickness Allowance <sup>(c)</sup>	15,759	16,285	11,181	10,733	10,942	9,522	8,755	8,478	8,367	7,510
Carer Allowance (Child) <sup>(d)</sup>	95,520	90,830	100,452	116,955	111,691	115,404	119,003	96,153	102,535	106,622
Carer Allowance (Adult) <sup>(e)</sup>	44,103	45,675	51,857	84,104	123,350	156,641	180,606	201,454	237,470	260,338
Carer Payment	29,558	33,979	40,070	47,550	57,190	67,260	75,937	84,082	95,446	105,058
Wife Pension (DSP)	91,307	79,892	68,523	59,935	51,225	44,238	37,880	33,183	28,144	24,627
Newstart Allowance (incapacitated)	n.a.	48,792	59,670	68,016	76,850	76,882	54,243	51,171	47,751	40,535
Youth Allowance (incapacitated)	n.a.	n.a.	3,929	5,883	5,959	5,792	3,941	3,861	3,633	3,203
Disability Pension (DVA)	160,145	161,829	162,810	162,730	162,505	159,425	157,865	154,602	150,615	145,546

- (a) Data for 2005 reflects the number of current and suspended recipients as at 10 June 2005.
- (b) Data for 2005 reflects the number of recipients as at 10 June 2005.
- (c) Data for 2005 reflects the number of current customers (excluding zero paid) as at 17 June 2005.
  From July 2002 the Australian Government Department of Family and Community Services introduced a revised method of counting Sickness Allowance, Newstart Allowance, Mature Age Allowance, Partner Allowance, Widow Allowance, Special Benefit, Youth Allowance and Austudy Payment clients, based on eligibility and entitlement.
- (d) Carer Allowance commenced on 1 July 1999. The figures presented previous to this date relate to recipients of Child Disability Allowance (for children) and Domiciliary Nursing Care Benefit (for adults). Recipients of Carer Allowance (Child) Health Care Card only (for data from 1999 on) are excluded from these counts.
- (e) From 2001 includes those who receive both Carer Allowance (Adult) and Carer Allowance (Child) and those not coded by type of payment. The number of recipients in 2002 has been updated.

Sources: AIHW 2005a, DVA 2005, 2006; FaCSIA unpublished data; DEWR 2005b, 2006, 2006a; DEWR administrative data (SuperSTAR point in time data).

Over the last decade there has been steady growth in the number of recipients of Mobility Allowance (Table 4.7). Most recipients also receive the DSP (DEWR 2005c) so the growth in Mobility Allowance may mirror that of DSP. The number of Carer Payment recipients has increased rapidly, as has the number of Carer Allowance recipients . The closure of the Wife Pension may have contributed to the rise in Carer Payment numbers. The numbers of Sickness Allowance and Newstart (incapacitated) recipients have both been falling in recent years. It is unclear why these payments, which provide income support to people with a temporary inability to work, have fallen.

The longer term trend toward increasing numbers of DSP recipients has generated considerable interest and has been investigated in two recent studies. A Productivity Commission Staff Working Paper looked at male DSP recipients and found a variety of social and economic influences on the number of recipients over time (Lattimore 2007). These influences include social norms, individual motivation and social welfare incentives. They also include labour market factors such as the decreasing demand for unskilled labour. This has had a disproportionate effect on men with disabilities as they generally have lower educational qualifications.

Labour market factors were also identified by the Melbourne Institute in a study of people who had received the DSP. This study found that the people least likely to exit from DSP included those who were receiving unemployment payments before they began receiving the DSP. It was concluded that labour market difficulties, not just disability, affect the the number of people receiving DSP. Other groups who were unlikely to exit the DSP included people with no earnings while on the DSP, Indigenous people, people with psychological or psychiatric conditions, males over 55 years and females with dependent children under 12 years (Cai et al. 2006).

#### **Concessions**

A number of concession cards are issued by Centrelink. These include the Pensioner Concession Card, Health Care Card and Low Income Health Care Card. Core concessions provided include cheaper pharmaceuticals, electricity and public transport. The amount and variety of concessions can vary from state to state.

A companion card scheme now operates in Victoria, Tasmania and Western Australia. This scheme assists businesses to meet their anti-discrimination obligations, and enables a person with disability to attend venues or events that they may previously have been unable to attend without a carer. The scheme allows the carer to be admitted free of charge (Victorian Government 2004).

A recent innovation in the area of concessions has been the introduction of a carer's card. In July 2006, the Northern Territory Government introduced the NT Pensioner and Carer Concession Scheme. This scheme provides recognition of the contribution of carers through extra concessions for people who receive the Carer's Allowance (NT Government 2006). Carers NSW have also proposed a carers' card for their state, based on the extra costs faced by carers (Carers NSW 2007).

#### **Compensation**

Compensation to people who acquire disability through an accident or work-related injury may also be a source of financial assistance. These arrangements are complex and entitlements vary across different schemes. There has been some suggestion that the coverage of workers' compensation schemes is decreasing. Factors contributing to this decrease include changes in the coverage of schemes and the greater proportion of casual jobs in the labour market. These may be leading to a decrease in the number of people claiming workers' compensation and an increase in the number of people claiming income support from Centrelink. However, the magnitude of these changes is unknown (Lattimore 2007).

At the same time, applicants for income support are obliged to take reasonable action to obtain compensation. The receipt of compensation, or the refusal to pursue it, may lead to a non-payment period or a reduction in the amount of income support (Centrelink 2007). In the period 2003–2005, about 2%–3% of DSP claim rejections were due to compensation (DEWR 2005a; FaCS 2003, 2004).

The Office of the Australian Safety and Compensation Council reports data about workers' compensation. A recent report shows that 'body stressing' (comprising muscular stress and repetitive movement injuries) has accounted for around 40% of workers' compensation claims in recent years. When falls, slips and trips, being hit by an object or hitting an object are included, around 80% of claims are accounted for. The duration of claims can give some indication whether workplace injuries are temporary or leading to longer term disability—around 60% of claims were for less than 6 weeks whereas about 9% of claims were for 52 weeks or more (WRMC 2006).

# **Disability support services**

#### CSTDA-funded disability support services and expenditure

Services provided under the Commonwealth State/Territory Disability Agreement (CSTDA) are targeted at people with a need for ongoing support in everyday activities, and aim to 'maximise the opportunity for people with disabilities to participate socially and economically in the community' (CSTDA 2003:12). The 2002–07 Agreement specifies that disability experienced by a CSTDA service user should be manifest before the age of 65 years; however, services generally do not place upper age restrictions on their clients.

Within the CSTDA there are seven service groups that offer specialist support for people with disability. These service groups are accommodation support services; community support services; community access services; respite services; employment services; advocacy, information and print disability services; and other support services. Definitions of these service groups are provided in Box 4.7.

National data on services provided under the CSTDA are collected through the CSTDA National Minimum Data Set (NMDS), which includes information relating to CSTDA-funded services and the people who use these services throughout a financial year. Data are collected by each state and territory and the Australian Government, and forwarded to the AIHW for collation and analysis on an annual basis. Data presented here are from the 2005–06 data collection, the third full year of the CSTDA NMDS data collection.

During the period 1999–2002, the CSTDA NMDS underwent a major redevelopment. Before this, the data were collected on a 'snapshot' (single-day) basis, but since 2003–04 have been collected for all people on a full-year, ongoing basis. Three full financial years of data from the redeveloped CSTDA NMDS collection are now available (2003–04 to 2005–06), which allow some analyses of basic trends for people accessing disability support services in Australia.

# **Box 4.5: The Commonwealth State/Territory Disability Agreement**

The third Commonwealth State/Territory Disability Agreement (CSTDA) for funding specialist disability services was scheduled to expire on 30 June 2007 but it has been extended while a fourth agreement is negotiated between the Australian Government and the state and territory governments. Although a new agreement has not yet been finalised, it is likely to have a greater emphasis than previous CSTDA agreements on the achievement of measurable outcomes for people with disability.

The 2007–08 federal Budget repeated the Commonwealth's current CSTDA offer to the states and territories of \$3.3 billion over 5 years, and assumed an indexation rate of 1.8%. Commonwealth payments to the states and territories in the current CSTDA total \$2.9 billion over 5 years. The Australian Government anticipated spending \$2.5 billion during the course of the next CSTDA agreement on employment services. In April 2007, the Commonwealth made an additional offer to match new state and territory funding for accommodation and respite services dollar-for-dollar.

#### **Box 4.6: Workforce issues**

The ageing of the Australian population is likely to affect the disability workforce in two ways. Firstly, as the population ages, the number of people with disability is projected to rise. Secondly, the disability workforce is, on average, older than the general workforce in Australia and, therefore, is likely to experience a shortage of available workers sooner than other industries, given the number of people projected to retire in the next 10 years. Thus there is a need to develop workforce strategies focused on re-skilling and retention. There is also a need to explore non-traditional sources of workforce, such as workers seeking a second career and workers displaced from other industries (NDA 2006).

### Box 4.7: Definitions of service groups covered by the Commonwealth State/Territory Disability Agreement

Accommodation support

These are services that provide accommodation to people with disability and services that provide the support needed to enable a person with disability to remain in his or her existing accommodation, or move to a more suitable or appropriate accommodation.

Community support

These services provide the support needed for a person with 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).

Community access

These are services designed to provide opportunities for people with 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.

Respite

Respite services provide a short-term and time-limited break for families and other voluntary caregivers of people with disability, to assist in supporting and maintaining the primary caregiving relationship while providing a positive experience for the person with disability. Although there are therefore two 'clients'—the carer and the person with disability—in the CSTDA NMDS collection, the person with disability is regarded as the client. Statistical tables in this report reflect this perspective.

**Employment** 

There are two types of employment services that provide employment assistance to people with disability. The first type, open employment, provides assistance in obtaining and/or retaining paid employment in the open labour market. The second type, supported employment, provides employment opportunities and assistance to people with disability to work in specialised and supported work environments. Before 1 December 2004, there was also a third employment service type, dual open/supported services, which provided a combination of both open and supported employment services.

Continued next page

and print disability

Advocacy, information Advocacy services are designed to enable people with disability to increase the control they have over their lives through the representation of their interests and views in the community. Information services provide accessible information to people with disability, their carers, families and related professionals. This service group also includes mutual support or self-help groups-special interest groups which promote self-advocacy—and print disability, which includes alternative formats of communication for people who by reason of their disability are unable to access information provided in a print medium.

Other

These include research and evaluation, training and development, peak bodies, and any other support services outside any of the defined service types above.

#### **CSTDA** service users

In 2005-06, there were 217,143 service users who accessed CSTDA-funded services (Table 4.8). The highest overall service use in 2005–06 was recorded in Victoria (80,953 service users), followed by New South Wales (51,133) and Queensland (30,804). Of the five major service groups, the highest number of service users were recorded in community support (96,664) followed by employment services (73,157), community access (47,738), accommodation support (35,566) and respite (27,319). Users of accommodation support services include 5,059 service users in institutional/residential care, 11,414 in group homes and a further 19,714 who utilised other accommodation support services (for example, inhome accommodation support or alternative family placement).

The number of service users has steadily risen over the two previous reporting periods, from 187,806 in 2003-04 and 200,493 in 2004-05 (AIHW 2005b, 2006f). The largest increase over this period has been seen in community support (an increase of 17,817 service users from the 2003-04 collection). Additionally, the number of service users accessing employment services and respite services has increased by 8,876 and 6,772 people respectively since 2003-04.

Across all CSTDA service users, the main primary disability reported was intellectual disability (72,226 users), accounting for one-third (33%) of all service users (Figure 4.10). In 2003–04, intellectual disability was reported as a primary disability by 38% of service users. The actual number of service users reporting intellectual disability as a primary disability has seen a slight increase since 2003-04 (by 525 users), although, due to a more rapid increase in other reported primary disabilities, intellectual disability has proportionally decreased as primary disability. Psychiatric disability was the second most frequent primary disability reported (30,064 users or 14%), followed by physical disability (25,712 or 12%) and neurological disability (12,471 or 6%). Comparisons of primary disability with all significant disabilities reveal some marked differences across the types of disability reported. The most notable was that, while only 1,790 people reported speech as a primary disability, 22,387 people reported speech as one of their significant disabilities. Intellectual disability was the highest reported of all significant disabilities (83,733 users), followed by physical disability (46,174), psychiatric disability (38,086) and neurological disability (28,896).

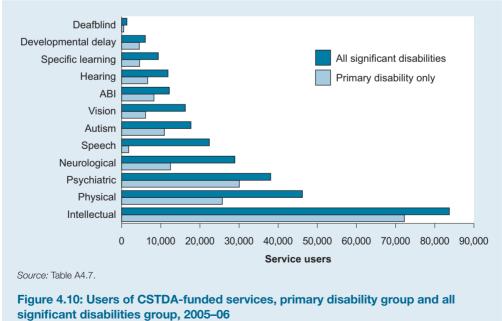
Table 4.8: Number of service users for CSTDA-funded services, by service type, by state and territory, 2005-06

Service type	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Total
State and territory funded	l services								
Institutions/residentials	1,866	739	871	441	908	234	0	0	5,059
Group homes	3,398	4,331	943	1,157	787	452	201	145	11,414
Other accommodation support	1,877	8,813	3,735	1,898	2,734	446	129	86	19,714
Accommodation support total	7,095	13,666	5,394	3,441	4,333	1,100	324	217	35,566
Community support	21,067	34,121	9,654	16,048	11,348	2,163	2,073	423	96,664
Community access	7,690	21,585	7,172	4,358	4,629	1,592	376	355	47,738
Respite	4,593	13,719	4,451	2,293	1,538	279	292	195	27,319
Subtotal (state/territory- funded services)	31,897	64,515	18,190	19,191	15,958	3,902	2,606	1,021	156,878
Australian Government-fu	ınded ser	vices							
Open employment	14,556	15,467	12,079	5,126	3,831	1,540	662	321	53,440
Supported employment	7,797	4,770	2,336	2,195	2,820	607	234	120	20,810
Employment total	21,981	19,949	14,292	7,193	6,536	2,121	887	433	73,157
All services	51,133	80,953	30,804	24,042	20,607	5,716	3,327	1,389	217,143

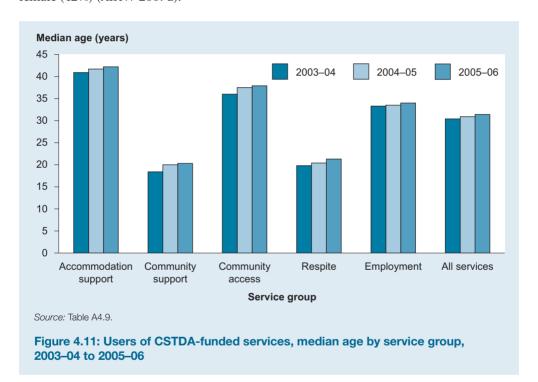
#### Notes

- 1. Service user data are estimates after use of a statistical linkage key to account for individuals who received services from more than one service type outlet during the 12 months from 1 July 2005 to 30 June 2006. Row totals may not be the sum of the components because individuals may have accessed services from more than one state or territory over the 12 month period. Column totals may not be the sum of components because individuals may have accessed services from more than one service type during the 12 month period.
- 2. Data quality—in particular varied response rates—should be considered when making comparisons between jurisdictions. See AIHW 2007d for more information.

Source: AIHW 2007d.



The median age of all service users in 2005–06 was 31.4 years (Figure 4.11). This value has increased across three CSTDA collections from 30.4 years of age in 2003-04. Comparison of median age across the different service groups in 2005-06 shows that accommodation support had a higher median age (42.2 years) than all other service groups, with the lowest median age recorded in community support (20.3 years). The higher median age of persons requiring accommodation support may be partially explained by very young people not generally requiring accommodation assistance. Conversely, the lower median age for community support may be attributed to services which target younger service users, for example early childhood intervention. Over the last three CSTDA collections the median age of those utilising employment services has increased slightly, by 0.7 years, while larger increases were seen in community support and community access (both increased by 1.9 years). Interestingly, the median age for open employment and supported employment service users are quite different. In 2005-06, the median age for supported employment users was 38.7 years and for open employment users was 31.6 years. Since 2003–04, this age difference has slightly narrowed, from 7.4 years to 7.1 years (Table A4.8). As per previous collections, there was a greater proportion of male service users (58%) than female (42%) (AIHW 2007d).



Overall, 7,182 service users (3.3%) reported that they were of Aboriginal and/or Torres Strait Islander origin (Table 4.9). This increase from 2.7% in 2003–04 may be attributed to a variety of factors, including better self-identification, more accurate identification of Indigenous people in the data set or an increase in service use by Indigenous people (AIHW 2005b). As would be expected from general population patterns, representation of Indigenous service users was lower in Major Cities (2.0%) and Inner Regional areas (3.4%) than in other areas. Around 8% of service users in Outer Regional areas were Indigenous, compared with 19% in Remote areas and 39% in Very Remote areas (Table 4.9). This is similar to the profile of Indigenous people in the general population—the 2001 Census

identified that about one in four (26%) of Indigenous Australians was living in Remote or Very Remote areas compared with one in fifty (2%) non-Indigenous people (ABS 2006b). As a greater number of Indigenous than non-Indigenous Australians are living in Remote areas, it is likely that Indigenous people may experience additional disadvantage as some services may not be available to them.

Table 4.9: Users of CSTDA-funded services, location by Indigenous status, 2005-06

	Major Cities	Inner Regional	Outer Regional	Remote	Very Remote	Not Known	Total
				Number			
Indigenous	2,629	1,761	1,756	459	431	146	7,182
Non-Indigenous	118,955	45,630	18,309	1,773	514	1,624	186,805
Not stated	12,456	5,080	2,002	237	172	3,209	23,156
Total	134,040	52,471	22,067	2,469	1,117	4,979	217,143
				Per cent			
Indigenous	2.0	3.4	8.0	18.6	38.6	2.9	3.3
Non-Indigenous	88.7	87.0	83.0	71.8	46.0	32.6	86.0
Not stated	9.3	9.7	9.1	9.6	15.4	64.5	10.7
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0

#### Notes

- Service user data are estimates after use of a statistical linkage key to account for individuals who received services from more than one service type outlet during the 12-month period.
- 2. The number of service users in each remoteness area (RA) were estimated based on service users' residential postcodes. Some postcode areas were split between two or more RAs. Where this was the case the data were weighted according to the proportion of the population of the postcode area in each RA.

Source: AIHW 2007d.

The most commonly reported primary disability groups for Indigenous service users were intellectual (39%), physical (14%) and psychiatric (12%). Indigenous service users were more likely than other service users to report a primary disability of developmental delay (3.8% of Indigenous service users compared with 2.2% of non-Indigenous) and ABI (6.3% of Indigenous service users compared with 4.0% of non-Indigenous), and less likely to report a psychiatric primary disability (12% compared with 15%) (AIHW 2007d).

In order to provide a holistic view of disability service users, the CSTDA collects information on the carers of people with disability as well as those with disability who are using the services. Information is requested about the existence of an informal carer, whether the carer is a primary carer and whether the carer lives with the person for whom they provide care. An informal carer is considered to be a person, such as a family member, friend or neighbour, who provides regular and sustained care and assistance to the person requiring support, usually on an unpaid basis (AIHW 2005c). A primary carer is defined as a carer who assists with at least one activity of daily living (ADL); ADLs included are help with self-care, mobility and communication (AIHW 2005c).

In 2005–06, 45% of service users reported the existence of an informal carer. Approximately 37% of service users reported that they had a primary carer and just over one in four people (26%) indicated they had a co-resident carer (Table 4.10). People who utilised respite services were most likely to report having an informal carer (90%), followed by those who accessed community support services (55%). People using employment services

were the least likely to report an informal carer (33%); this is due to employment service users having a high proportion of people who do not require assistance with ADLs and are therefore less likely to need a carer (AIHW 2007d). Those who used respite services were the most likely service users to report the existence of a primary carer (84% of all users and 93% of all users with a carer).

Service users accessing respite services (52%) were most likely to report a co-resident carer; however, users of community support services had the highest proportion of co-resident carers (78%) when only those with an informal carer were considered (Table 4.10). Overall, the proportion of informal care, primary carer status and co-residency status was generally lower for service users of accommodation support services than other service groups. This may be partially due to the 'formal' nature of these services.

Table 4.10: Users of CSTDA-funded services, existence of an informal carer, primary carer and co-resident carer by service group, 2005–06

	Has an ii car		Has a	primary o	arer	Has a c	Has a co-resident carer		
Service group	Number	Per cent of all users	Number	Per cent of all users	Per cent of users with a carer	Number	Per cent of all users	Per cent of users with a carer	
Accommodation support	14,696	41.3	11,247	31.6	76.5	5,502	15.5	37.4	
Community support	53,341	55.2	47,611	49.3	89.3	41,641	43.1	78.1	
Community access	22,396	46.9	18,674	39.1	83.4	14,118	29.6	63.0	
Respite	24,648	90.2	22,854	83.7	92.7	14,146	51.8	57.4	
Employment	24,448	33.4	_	_	_	_	_	_	
Total	97,410	44.9	79,316	36.5	81.4	55,619	25.6	57.1	

#### Notes

- 1. Service user data are estimates after use of a statistical linkage key to account for individuals who received services from more than one service type outlet during the 12-month period. Column totals may not be the sum of components because individuals may have accessed services in more than one service group over the 12-month period.
- 2. Service users accessing employment services were not required to report 'carer-primary status' or 'carer-residency status'; however, some users did so. These counts are not reported separately but are included in totals.

Source: AIHW 2007d.

The reported relationship of the primary carer to the service user in 2005-06 identified that mothers were by far the most commonly reported primary care givers, accounting for 65% of all relationships for those with a primary carer (Table 4.11). The spouse of the service user was the next most common primary care-giver (8%), followed by fathers (6%) and other family members (for example in-laws) (also 6%). Comparatively, populationbased data from the 2003 SDAC yielded somewhat different results, and indicated that spouses provided the most common form of primary carer relationship for people with disability (44%), followed closely by mothers (41%) (AIHW analysis of ABS 2003 SDAC confidentialised unit record file). However, the difference between the CSTDA and the SDAC may be attributed to the age of the person receiving care. Approximately 60% of the SDAC population with a primary carer is aged over 24 years, compared with only 47% for CSTDA service users (AIHW 2007d; AIHW analysis of ABS 2003 SDAC confidentialised unit record file). As the SDAC has a greater proportion of recipients above the age of 24 years, it is more likely that a spouse or partner would be the primary carer than a mother. Conversely, the younger CSTDA service users are more likely to have a mother as a primary carer.

Table 4.11: Users of CSTDA-funded services who reported the presence of a primary carer, relationship of carer by age of service user, 2005–06

			Age group	(years)			
Relationship of service user to carer	Under 15	15–24	25–44	45–64	65 or over	Not stated	Total
				Number			
Spouse	_	147	1,689	2,950	1,190	13	5,989
Mother	23,034	13,560	12,056	2,723	33	18	51,424
Father	1,320	1,421	1,620	483	7	2	4,853
Child	_	44	116	383	525	2	1,070
Other family	676	730	1,162	1,507	302	3	4,380
Friend/neighbour	136	253	498	438	139	_	1,464
Not stated	3,194	2,433	2,528	1,637	342	2	10,136
Total	28,360	18,588	19,669	10,121	2,538	40	79,316
				Per cent			
Spouse	_	0.8	8.6	29.1	46.9	32.5	7.6
Mother	81.2	73.0	61.3	26.9	1.3	45.0	64.8
Father	4.7	7.6	8.2	4.8	0.3	5.0	6.1
Child	_	0.2	0.6	3.8	20.7	5.0	1.3
Other family	2.4	3.9	5.9	14.9	11.9	7.5	5.5
Friend/neighbour	0.5	1.4	2.5	4.3	5.5	_	1.8
Not stated	11.3	13.1	12.9	16.2	13.5	5.0	12.8
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0

Note: Service user data are estimates after use of a statistical linkage key to account for individuals who received services from more than one service type outlet during the 12-month period.

Source: AIHW 2007d.

Across CSTDA service user age groups, mothers held the primary care-giving role for 81% of service users under the age of 15 years and 73% of service users between the ages of 15 and 24 years (Table 4.11). Primary care-giving from a spouse was most common for the age groups of 45–64 years and 65 years and over, which accounted for 29% and 47% of carer relationships respectively. For those aged 65 years and over, a child was the primary care-giver more than one-fifth of the time (21%), although the specific ages of the child carers were not collected.

For service users needing support with the three 'core' activities of daily living (self-care, mobility and/or communication), the proportion of service users who reported an informal carer tends to decrease with age (Figure 4.12). The vast majority of service users under 15 years of age who always or sometimes require assistance with ADL (87%) reported that they had an informal carer, whereas this was significantly lower for those aged 65 years or more (41%).

Expenditure by the Australian Government and all state and territory governments on disability support services during 2005–06 totalled \$3.95 billion (Table 4.12). Of this total, just under half (\$1.92 billion) was used to fund accommodation support services. Community support services accounted for a further \$484 million (or 12%), community access funding totalled \$463 million (12%), employment \$400 million (10%) and \$228 million (6%) went towards funding for respite services. Administration costs over the year totalled \$315 million, with a further \$138 million in funding spent on advocacy, information and print disability as well as other forms of support.

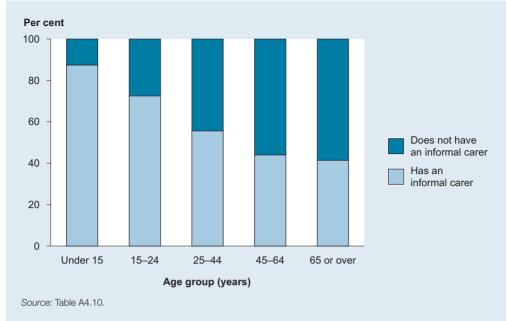


Figure 4.12: Existence of an informal carer for service users who always or sometimes need support for activities of daily living by service user age group, 2005–06

Table 4.12: Expenditure on disability support services by Australian, state and territory governments, by service group and administration expenditure, 2005–06 (\$m)

Service group	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Aus Govt	Australia
Accommodation support	672.9	590.0	237.3	171.6	145.0	59.5	29.9	16.1	_	1,922.3
Community support	98.4	193.5	70.3	54.5	38.1	9.1	11.8	8.2	_	483.9
Community access	139.5	169.7	83.7	24.5	16.8	15.1	4.7	2.3	7.0 <sup>(a)</sup>	463.3
Respite	73.0	59.8	48.6	20.9	8.7	5.9	4.5	1.9	4.9 <sup>(a)</sup>	228.2
Employment	_	_	_	_	_	_	_	_	400.2	400.2
Advocacy, information and print disability	6.9	7.4	7.3	4.9	2.8	1.9	1.1	0.2	13.8	46.3
Other support	2.6	22.9	9.3	11.2	21.6	1.5	2.1	0.0	20.9	92.1
Subtotal	993.3	1,043.3	456.5	287.6	233.0	93.0	54.1	28.7	446.7	3,636.2
Administration	122.0	78.3	49.2	15.9	8.1	8.7	5.3	1.6	26.1	315.2
Total	1,115.3	1,121.6	505.7	303.5	241.1	101.7	59.4	30.3	472.8	3,951.4

<sup>(</sup>a) Some Australian Government-funded community access and respite services are funded under the CSTDA from the Employment Assistance and Other Services appropriation.

Note: Figures may vary from those published in the Report on government services 2007 (SCRGSP 2007) owing to the use of different counting rules in particular jurisdictions (e.g. some jurisdictions may include funding for psychiatric-specific services in Table 4.12 but not in SCRCSSP 2007).

Sources: SCRCSSP 2007; unpublished data provided to AIHW from each jurisdiction.

### Other disability-specific services

#### **Home and Community Care**

The Home and Community Care (HACC) program is jointly funded by the Australian Government and state and territory governments. It provides services to frail older people, people with disability and their carers. HACC services aim to increase independence and prevent admission to residential care (DoHA 2004). In the period from 2002–03 to 2005–06 there was a small increase in the proportion of HACC clients aged under 65 years (Table 4.13). At the same time, the average number of support hours received by people under 65 years declined from 64 to 58 hours per year. For further information about people aged over 65 years, see Chapter 3 on ageing and aged care.

There are also differences between the service types used by the under and over 65 years age groups. Younger people with disability are more likely to receive counselling and respite care, but less likely to receive home help or meals (AIHW 2007c).

Table 4.13: HACC clients: clients and average hours received per year, by age<sup>(a)</sup>, 2001–02 to 2004–05

Age group (years)	2001-2002 <sup>(b)</sup>		2002–2003		2003-	2004	2004–2005			
	Number	Per cent	Number	Per cent	Number	Per cent	Number	Per cent		
0–39	43,161	7.4	48,268	7.3	52,823	7.5	56,489	7.6		
40–49	24,667	4.2	28,165	4.3	32,051	4.5	34,489	4.6		
50-54	17,034	2.9	19,407	3.0	21,775	3.1	22,177	3.0		
55–59	20,218	3.5	24,279	3.7	27,324	3.9	30,594	4.1		
60–65	28,391	4.9	33,101	5.0	36,101	5.1	38,659	5.2		
Total under 65	133,471	22.9	153,220	23.3	170,074	24.0	182,408	24.5		
65 or over	449,711	77.1	504,046	76.7	537,133	76.0	561,789	75.5		
All clients(c)	583,182	100.0	657,266	100.0	707,207	100.0	744,197	100.0		
	Average hours received per year <sup>(d)</sup>									
0–39	75.2		74.8		70.5		62.8			
40–49	71.9		72.3		68.9		63.7			
50–54	61.5		59.0		61.1		58.6			
55–59	55.6		55.3		55.3		54.4			
60–64	47.7		47.7		48.1		46.4			
Total under 65	64.2		63.6		61.9		57.6			
65 or over	45.0		45.2		45.7		45.3			
All clients	49.6		49.6		49.8		48.6			

<sup>(</sup>a) Clients with missing age are included in 65 or over totals, and 'all clients'. Only clients with recorded assistance are included in this table.

<sup>(</sup>b) The Home and Community Care (HACC) Program NMDS collection commenced in January 2001. The 2001–02 data were the first data extraction and should therefore be interpreted with caution.

<sup>(</sup>c) Client numbers include all clients who received assistance, although around 10%–13% of clients (2001–02 = 73,600; 2002–03 = 73,900; 2003–04 = 79,200; 2004–05 = 80,000) only received assistance which is not measured in hours of service (that is, home modification, receipt of goods and equipment, meals, transport and linen deliveries).

<sup>(</sup>d) Amount of service measured in hours is averaged only over HACC clients receiving services measured in hours. Source: AIHW analysis of the HACC NMDS.

#### Young people in residential aged care

As at 30 June 2006, 6,562 younger people (under 65 years of age) were permanent residents of Australian Government-funded residential aged care services. Seventy per cent of these younger people were aged between 55 and 64 years; a further 26% were aged 40 to 54 years; the rest were people younger than 40 years of age (AIHW 2007e :Table 4.29). Younger residents are mostly in high care, with 70% at Resident Classification Scale levels 1 to 3 in 2006 (AIHW 2007e).

In recognition that residential aged care is often unsuitable for younger people with disability, the COAG has funded a new program to relocate younger people in residential aged care and to divert younger people at risk of entering residential aged care to more appropriate forms of accommodation (COAG 2006). Initial priority will be given to people under 50 years of age, currently numbering about 1,000 in residential aged care.

#### Box 4.8: Young people in residential aged care

At its February 2006 meeting, the Council of Australian Governments (COAG) made a commitment to reduce the number of younger people with disability living in residential aged care. COAG agreed to establish a 5-year program, beginning in July 2006, with three elements:

- move younger people with disability currently accommodated in residential aged care into appropriate supported disability accommodation where it can be made available and if this is what clients choose
- divert future admission of younger people with disability who are at risk of admission to residential aged care into more appropriate forms of accommodation
- enhance the delivery of specialist disability services to those younger people with disability who choose to remain in residential aged care or for whom residential aged care remains the only available suitable supported accommodation option.

The AIHW has been commissioned to develop a national data set and collection process that enables each jurisdiction to collect the data necessary to meet performance reporting and evaluation elements of the younger people in residential aged care program.

# Rehabilitation, hearing services and equipment

CRS Australia is the Australian Government's vocational rehabilitation service. It provides services for people with disability, both lifelong and acquired through injury or illness. From 1 July 2006, referral to CRS Australia is based on a job capacity assessment organised by Centrelink (CRS Australia 2007).

Vocational rehabilitation services provided by CRS Australia encompass both assistance to the individual with disability, and changes to the workplace to facilitate the person's participation. Services include counselling, job search training, injury management and workplace modifications (CRS Australia 2007). In 2005–06, 25,482 new assistance programs were provided by CRS Australia. Over 44,000 clients were assisted in total. In 2005–06, 36% of clients assisted through vocational rehabilitation found employment of at least 8 hours per week for a period of 13 weeks. This proportion is slightly less than in 2004–05 (38%). The capacity of CRS Australia is being increased by \$192 million over the 3 years to June 2009. It is expected that an additional 48,000 people will receive services over the period (DEWR 2006a).

The Office of Hearing Services manages a voucher system whereby eligible adults can access hearing services from the provider of their choice. Services include hearing assessment, fitting and maintenance of hearing devices, counselling and rehabilitation. Australian Hearing is the Australian Government provider of voucher services, and also provides services to children, young people up to age 21 and Indigenous people under community service obligations (Australian Hearing 2006). A total of 461,976 clients received services in 2005–06 from Australian Hearing or one of 199 other contracted providers. An extension of services to Aboriginal and Torres Strait Islander people aged over 50 years and Community Development Employment Program participants in 2005 led to services being provided to an extra 501 people by June 2006 (DoHA 2006).

The provision of equipment, such as aids and home modifications, to people with disability in Australia is complex. The health, community and public sectors all have some involvement. There are no national data available.

### **Relevant generic services**

#### Health

Access to generic health services for people with disability is often restricted by issues such as insufficient training of the health workforce, communication difficulties associated with some disability, and the misinterpretation of symptoms (Lennox et al. 2007). The University of Queensland recently completed a trial of a comprehensive health assessment program for people with intellectual disability. They found significant improvements in several areas compared with the control group. These included the detection of new disease, which increased by 1.6 times. Health promotion and disease prevention activities also increased. These effects were due to a more systematic approach to gathering health information, which in turn improved health review and planning (Lennox et al. 2007).

## **Box 4.9: Disability Discrimination Act**

The *Disability Discrimination Act 1992* is a significant piece of Australian legislation that makes discrimination on the grounds of disability unlawful and provides a framework and process for the setting of a range of disability standards. Recent developments relating to the Act include:

- the commencement in mid-2007 of a review of the 2002 Disability Standards for Accessible Public Transport
- the availability of on-line information relating to progress against the compliance targets for the Disability Standards for Accessible Public Transport, available in all Australian jurisdictions
- drafting of guidelines for access to buildings and services, for use by a range of parties including businesses, service providers and governments.

Source: HREOC 2007b.

#### **Transport**

Access to transport is fundamental for people with disability to participate in community and economic life. Public transport infrastructure has not always been able to meet the needs of everyone, including older people, parents with prams and people with disability. The Disability Standards for Accessible Public Transport commenced in October 2002.

These standards clarify the obligations of transport providers under the *Disability Discrimination Act 1992*. Under the standards, public transport infrastructure will be updated over a period of 30 years to increase its accessibility (Attorney-General's 2006).

There has been some progress towards accessibility goals since the introduction of the standards. For example, in New South Wales, 43% of State Transit buses were accessible by April 2006 (NSW MoT 2007). The first 5 year review of the efficiency and effectiveness of the standards is due in late 2007.

#### **Education and training**

Students with disability in state and territory public schools overwhelmingly attend mainstream, rather than special schools (Table 4.14). This reflects the continuum of support that is available to students with disability. That is, most jurisdictions offer support ranging from assistance or adjustment for students with disability in mainstream classes, through to specialised support units in mainstream schools, and special schools.

Generally, eligibility for support is based on a formal assessment of the student's disability by an appropriate professional. The effects of the disability on the student's ability to participate in the academic program is central to the assessment. Support is provided for a range of disabilities including physical, sensory, intellectual, language, mental health and autism. There is flexibility to support students with other conditions as recognised by the *Disability Discrimination Act 1992*. Family input also influences the type of educational support provided to students in several jurisdictions.

Students with disability in non-government schools are even more likely to be in a mainstream rather than a special school. In the Australian Capital Territory and Northern Territory there are no students with disability in non-government special schools.

A new class of non-government school was recognised in April 2006 through amendments to the *Schools Assistance (Learning Together—Achievement Through Choice and Opportunity) Act 2004.* This new type of school aims to meet the needs of students with social, emotional and behavioural difficulties. Unlike mainstream schools, the funding provided is not influenced by the socioeconomic status of the school community. In 2006, Special Assistance Schools catered for 1,119 students (full-time equivalent)(DEST personal communication).

The Australian Government is also addressing flexibility and choice for parents of students with disability in the non-government sector. It has committed \$5.8 million to investigate alternative funding models for students with disability. The aim of any new model adopted would be to provide greater flexibility, particularly in portability of funding (Bishop 2006).

The Vocational Education and Training sector (VET) in Australia aims to deliver technical skills to students for use in the workforce. It includes technical and further education colleges across the country. The proportion of students reporting a disability in VET has grown slowly over the past few years, from under 4% in 2000 to 6% in 2005 (NCVER 2006).

Students with disability in higher education are supported by the Australian Government through the Higher Education Disability Support Program. This program included funding of \$1.3 million in 2006 to assist higher education providers to attract and retain students with disability. It also includes around 30 staff across Australia who assist people with disability with their post-school options. The support and equipment needs of people with disability in higher education are addressed by the Additional Support for Students with Disability program (DEST 2006).

Table 4.14: Students with disability attending government and non-government schools, 2006 (FTE)<sup>(a)</sup>

	NSW(b)	Vic	Qld	WA <sup>(c)</sup>	SA	Tas	ACT	NT	Total
Government schools(d)	)								
Mainstream	36,147	9,371	14,409	4,251	13,428	2,802	1,403	3,886	85,697
Special	4,573	7,299	2,960	3,126	976	174	287	254	19,649
Total	40,720	16,670	17,369	7,377	14,404	2,976	1,690	4,140	105,346
Percentage attending mainstream schools	88.8	56.2	82.9	57.6	93.2	94.1	83.0	93.9	81.3
Percentage of all government school students	5.5	3.1	3.8	2.9	8.6	4.8	4.8	12.5	4.6
Non-government schools									
Mainstream	10,107	6,662	3,417	1,845	2,463	355	331	214	25,394
Special	1,405	134	150	37	135	18	0	0	1,879
Total <sup>(e)</sup>	11,512	7,132	3,614	1,903	2,598	373	332	214	27,678
Percentage attending mainstream schools	87.8	93.4	94.5	96.9	94.8	95.1	99.7	100.0	93.1
Percentage of all non- government school students	3.1	2.4	1.7	1.7	3.0	1.7	1.3	2.4	2.4
Total students with disability	52,232	23,802	20,983	9,280	17,002	3,349	2,022	4,354	133,024
Total all students ('000)	1,110.8	832.8	670.2	365.7	253.2	83.4	59.6	42.2	3,417.9
Percentage of all school students	4.7	2.9	3.1	4.6	6.7	4.0	3.4	10.3	3.9

<sup>(</sup>a) FTE (full-time equivalent) students are not the actual number attending. For example, a student attending for half the normal school hours will be half an FTE student. The number of enrolled students will normally be greater than the number of FTE.

Sources: DEST unpublished data; data provided to AIHW by state and territory education authorities.

In August 2005 the Disability Standards for Education 2005 came into effect. These standards clarify the responsibilities of education providers under the *Disability Discrimination Act 1992*. Under the standards, schools and other education providers are required to make 'reasonable adjustments' to allow a student with disability to participate in a manner comparable with students without disability. In the process of considering adjustments, education providers are to have regard for both the student's learning needs and the interests of other parties involved, such as staff and other students. An education provider may refuse to make an adjustment where it would impose an 'unjustifiable hardship'(Attorney–General's 2006b). National data are not yet available regarding

<sup>(</sup>b) Data for government mainstream schools in New South Wales includes students in support classes in regular schools and students with confirmed disability, some of whom are supported through the Integration Funding Support Program and some through the Learning Assistance Program.

<sup>(</sup>c) Western Australia introduced new data collection methods in 2005 that include extra eligibility groups and unverified disabilities; eliminated double counting.

<sup>(</sup>d) Data for government schools in New South Wales exclude students in preschools; in Queensland exclude kindergarten level and may include early special education facilities depending on where they are based; in Western Australia, include kindergarten; in South Australia exclude preschools but includes adults enrolled in Adult School Re-Entry Colleges; in Tasmania exclude kindergarten and early special education facilities; in the Northern Territory include preschools; and in the Australian Capital Territory include kindergarten.

<sup>(</sup>e) Totals include students at Special Assistance Schools—a new class of schools established in April 2006 to cater for students with social, emotional or behavioural difficulties.

expenditure on changes made under the standards. However, the ACT Department of Education's 2005–06 annual report stated that \$890,000 was allocated for capital works to schools arising from the disability standards. This has resulted in physical modifications to 13 schools throughout the territory (ACT DET 2006).

#### Box 4.10: National inquiry into employment and disability

In late 2005, HREOC released a report of the national inquiry into employment and disability. The 30 recommendations included:

- the development of a whole-of-government approach to ensuring financial and practical support to people with disability
- improvement of the effectiveness of government-funded service delivery for people with disability and their employees
- improvement of transition-to-work strategies
- · increasing of recruitment and retention of people with disability
- the development of a benchmarking, monitoring and reporting system to ensure accountability and ongoing improvement to the incentives, supports and services available to people with disability and employers.

Source: HREOC 2005.

#### **Employment assistance**

The Australian Government Department of Employment and Workplace Relations (DEWR) provides an avenue that allows people with disability to access mainstream employment services. The Active Participation Model is available to all job seekers and is designed to improve access for job seekers with disability by more actively engaging them through Job Network and other complementary employment and training programs. Following registration with Centrelink, job seekers with disability are referred to a single Job Network member who will provide Job Search support and Intensive Support. The level of support provided to each job seeker is tailored to meet their individual support requirements. Those who are unemployed for at least 12 months, or who are deemed to be highly disadvantaged, are eligible to receive Intensive Support customised assistance. This type of support, including \$1,350 for purchasing services and products to assist in gaining employment, is designed to address the individual barriers that some job seekers encounter when seeking employment.

From 1 July 2005 to 30 June 2006, more than 56,100 people with disability were placed into the Job Placements program, with nearly 76,000 people with disability placed into Intensive Support employment assistance (respectively 8.8% and 12% of all 638,200 job seekers in the program) (DEWR 2006c).

A 'positive outcome' through the Job Network program is achieved through an individual's gaining employment, or participating in training or education 3 months after the completion of the program. The data, collected from 1 April 2005 through to 30 March 2006, shows the proportion of positive outcomes achieved at 30 June for job seekers with disability and for all job seekers (Table 4.15). Of the 5,341 job seekers with disability who exited the Job Placements program, 61% achieved positive outcomes compared with 76% of all job seekers. Of the job seekers with disability exiting customised Intensive Support, 47% achieved positive outcomes compared to the 54% of all job seekers exiting this type

of support. Additionally, 52% of the 3,814 job seekers with disability, compared with 60% for all job seekers, had positive outcomes while after exiting Job Search training support.

The number of exits for customised Intensive Support has increased substantially since 2003–04 from 18,984 to 43,858 for job seekers with disability and from 185,126 to 313,723 for all job seekers (DEWR 2004, 2006c). Those exiting Job Search training have increased from 2,907 to 3,814 exits for those with disability, and from 133,136 to 136,524 for all job seekers. Overall, while these figures do fluctuate over time, the proportion of positive outcomes has remained fairly constant over the past 3 years.

Table 4.15: Job seekers exiting Job Network programs and proportion achieving positive outcomes, 2005–06

	Job seekers w	ith disability	All job seekers		
	Number of exits	Positive outcomes (per cent)	Number of exits	Positive outcomes (per cent)	
Job Placements	5,341	61.2	96,569	76.1	
Intensive Support: customised assistance	43,858	46.9	313,723	54.0	
Intensive Support: Job Search training	3,814	51.8	136,524	59.9	

Note: Information relates to job seekers exiting services, as at June 2006.

Source: DEWR 2006c.

The Australian Government also provides online employment assistance to people with disability through JobAccess. JobAccess provides free information to people with disability and offers assistance in gaining and maintaining employment. As well as providing job network services, JobAccess offers advice and refers people who believe their job may be in jeopardy as a result of their disability. In addition to this, the Workplace Modification Scheme assists people with disability by covering the costs of purchasing adaptive equipment and making workplace modifications. This helps people with disability to overcome some of the environmental obstacles in the workplace and makes it easier for people with more severe disabilities to begin and keep employment. Some more specialised employment assistance services are available such as the Disability Employment Network and Business Services (see Box 4.11 for information).

# Housing and accommodation assistance

Ideally, people with disability would be able to choose a housing option from the full range of options typically available to other community members. In practice, however, people with disability are often limited in their options. For example, while around 19% of the population has a disability, only around 12% of home purchasers have a disability (AIHW 2005a:Table A6.8).

Public housing is an important source of housing for people with disability. While the number of public dwellings has steadily fallen over recent years, the proportion of tenants with disability has risen. Public tenants with disability usually pay the same proportion of their income in rent as people without disability—commonly around 25% (SCRGSP 2006). People with disability may have extra expenses than those without disability (Saunders 2006). They may also require adjustments to their dwellings. No data are compiled on modifications made to public housing dwellings to meet the needs of people with disability. However, tenant surveys have found that around 77% of tenants who required them, were satisfied with modifications to their dwelling (AIHW 2006e).

Low income private renters are assisted through the Commonwealth Rent Assistance (CRA) program. The amount of assistance provided by CRA is influenced by the cost of rent. Between 2000 and 2005 average private rents rose \$64 per fortnight whereas average CRA payments rose \$18 (ABS 2006a). A substantial proportion of people with disability pay more than 30% of their income in rent. This is often referred to as being in 'housing stress'. In 2006 32% of Disability Support Pension households remained in housing stress even after CRA had been received (SCRGSP 2006).

## **Box 4.11: CSTDA-funded employment services**

CSTDA-funded employment services are aimed at assisting people with disability who are unable to attain or retain employment without assistance. Supported employment services support or employ people with disability within the service provider organisation, while open employment services provide assistance to help people get or keep a job in another organisation.

In late 2004, administration of CSTDA open employment services moved from the then Department of Family and Community Services to the Department of Employment and Workplace Relations. The Disability Employment Network (DEN) is designed to assist job seekers with employment preparation, job search, job placement and post-placement support. A person may be referred to the DEN program if they:

- have a permanent (or likely to be permanent) disability and
- · have a reduced capacity for communication, learning or mobility and
- will require support for more than 6 months after placement in employment and/or
- · require specialist assistance to build capacity in order to meet participation requirements.

The DEN program has capped and uncapped streams. The capped stream caters to people who need ongoing support in the workplace or are unable to work at award wages. It has 38,000 places nationally. The DEN uncapped stream is designed to support job seekers who are receiving Newstart Allowance, Youth Allowance or Parenting Payment, and who have the ability to work independently at full wages in the open labour market after receiving up to 2 years' assistance.

The Department of Employment and Workplace Relations also funds Vocational Rehabilitation Services , which provides employment assistance to job seekers with disabilities, injuries or health conditions with the aim of enabling them to work independently in the open labour market. Like DEN, there is a capped and uncapped stream.

CSTDA-supported employment services (also known as 'business services') are administered by the Department of Families, Community Services and Indigenous Affairs. Business services are targeted at people with 'significant disability who are not able to make an immediate attachment to the open labour market at or above the relevant award wage or its equivalent and who need ongoing support for a substantial period to obtain or retain paid employment'. To be eligible, a person must have a disability, be of working age, be able to work for at least 8 hours a week, and require ongoing assistance in the workplace to maintain employment.

The DEN, the Personal Support Program and Vocational Rehabilitation Services all received funding for new places in the 2007–08 federal Budget. The DEN capped program will grow by 987 places and Vocational Rehabilitation by 1,480 places. The Personal Support Program will grow by 2,000 places.

Boarding houses have traditionally provided an alternative to private rental for people on low incomes, including those with disability. Boarding houses can be supportive of people with disability because they often provide services such as the provision of meals (Anderson et al. 2003). However, the number of boarding houses has declined due to influences such as the imposition of the GST, the retirement of older proprietors and increased fire and safety regulations (Bleasdale 2006; Anderson et al. 2003; Greenhalgh et al. 2004). There have been two views about the decline in boarding houses. On the one hand, concerns have been raised that closures are further limiting the housing options available to people with disability (Greenhalgh et al. 2004). On the other hand, standards in boarding houses were often below community expectations and government regulation helps to raise standards (SA DFC 2006).

Data on people with disability accessing homelessness services are limited. The primary support service for people who are homeless is the Supported Accommodation Assistance Program (SAAP). Disability status is not included as a data item in the SAAP national data collection. A special report on people with mental health and substance use issues, some of whom have an associated disability, in SAAP services was released in 2007. See Chapter 6 for more information.

People with disability are often discussed in the homelessness literature, particularly those with disabilities associated with mental illness or substance use. While mental illness and substance use can make people more vulnerable to homelessness, recent research has supported the notion that these difficulties often develop after a person becomes homeless. In the case of substance abuse, it was found that two-thirds developed problematic use after they became homeless. Just over half of people with mental health problems developed them after they became homeless (Chamberlain et al. 2007).

### 4.4 Outcomes

This section provides an overview of outcomes for people with disability from two broad aspects. The first aspect is outcomes measured in a service-specific context, relating to service goals, effectiveness and access to services; the focus is on a recent major AIHW study of unmet demand for disability support services. The second aspect is outcomes measured as broad status indicators relating to a person's quality of life and participation in various life areas; the focus is on trends in three major life areas, community living, employment and school attendance, based on analyses of data from five consecutive disability surveys.

# **Box 4.12: The Senate Standing Committee on Community Affairs report**

The Senate Standing Committee on Community Affairs report Funding and operation of the Commonwealth State/Territory Disability Agreement was released in February 2007. Its primary recommendation was that Commonwealth, state and territory governments jointly commit as part of the fourth CSTDA to substantial additional funding to address identified unmet need for specialist disability services, particularly accommodation services and support. Other recommendations include those supporting the inclusion of outcomes data in the CSTDA NMDS, the addition of realistic outcomes-based performance reporting requirements to the CSTDA and the provision of funding to improve NMDS data and further its analysis to better inform policy makers and the public about the effectiveness of disability services.

#### **Service-related outcomes**

The Australian National Audit Office noted in its report on the CSTDA that, while the objective of the CSTDA is to enhance the quality of life experienced by people with disability, there are currently no adequate measures of whether, or to what extent, the CSTDA is meeting its objective (ANAO 2005). Further, as noted in Box 4.12, the Senate Committee on Community Affairs recommended a greater focus on outcomes and service effectiveness in the monitoring of services funded under the CSTDA.

The Australian Government has made the focus on outcomes a central feature of its offer as part of the fourth CSTDA negotiations and, although the negotiations have yet to be finalised, it is likely that any final agreement will include outcomes reporting requirements.

## Demand and unmet demand for disability support services

The AIHW was commissioned by the Disability Policy and Research Working Group (DPRWG) to conduct a study on current and future demand for specialist disability services (AIHW 2007c). The DPRWG provides advice and assistance to the Commonwealth and state/territory governments on the implementation of the CSTDA. The findings of the study were to inform discussion and negotiations regarding the fourth CSTDA. The study addressed the following questions:

- What is the profile of current CSTDA-funded service users (see Section 4.2)?
- How much unmet demand is there currently for accommodation and respite services, community access services and disability employment services?
- What factors affect levels of demand, and how are levels of demand expected to change over coming years?
- What are the important interfaces with other service sectors, and what issues at these interfaces affect levels of demand for disability services?

#### Estimated unmet demand for specific disability services

Unmet demand was estimated through analysis of the 2003 SDAC. The CSTDA target group corresponds closely to the SDAC definition of people with a 'severe or profound core activity limitation'—that is, people who sometimes or always need help with activities of self-care, mobility or communication (see the Glossary for definition of 'core activity'). The baseline estimates, derived from the 2003 SDAC data, were updated to 2005 to account for population growth and increased supply of CSTDA services between 2003 and 2005. These were compared with jurisdictional waiting list information to produce three consolidated estimates of unmet demand. All three estimates of unmet demand are considered conservative (AIHW 2007c:Chapter 5).

It was estimated that in 2005 there were 23,800 people with unmet demand for accommodation and respite services. The estimate is subject to a relative survey standard error of 17% (4,000). Therefore, there are about 19 chances in 20 that the number of people is within the range of 15,900 to 31,700.

In 2005 unmet demand for community access services was estimated at 3,700 people. The estimate is subject to a relative standard error of 40% (1,500)—therefore, there are about 19 chances in 20 that the number of people is within the range of 1,000 to 6,600.

The 2005 estimate suggests a low level of unmet demand for disability employment services (1,700 people). The estimate is subject to a very high relative standard error (55%) and is considered too unreliable for general use. However, the very low estimate should not be interpreted as an indication of no unmet demand for disability employment services. It is partly due to the decline in the number of people of working age with a severe or profound limitation who were in the labour force (a decrease of 21,200 people between 1998 and 2003) (AIHW 2007c:Table 5.6). Recent changes in disability employment policy and programs are not reflected in the available data used as basis for the 2005 estimate. Some of the policy changes are aimed at encouraging people with disability to move into the labour market. This may increase the demand as well as unmet demand for disability employment services.

Based on projected trends in the ageing of the Australian population, the broad CSTDA target population is projected to grow substantially between 2006 and 2010 (see Section 4.2). Other factors that may contribute to an increase in future demand for disability services include:

- increases in the prevalence of some long-term health conditions particularly related to disability
- increases in levels and types of need for assistance, due to ageing of the CSTDA serviceuser population and ageing of their carers
- the ongoing trend towards community-based living arrangements for people with disability
- decreases in access to some mainstream housing options of particular relevance to people with disability, particularly public housing and boarding houses
- a projected fall in the ratio of informal carers to people with disability.

#### Issues relating to interfaces with other service sectors

Like the general population, people with disability rely on a range of government-funded services to meet their various needs. Disability services alone cannot meet all the needs of people with disability. Levels of access to generic services, such as aged care and health, can affect levels of demand and unmet demand for CSTDA services (AIHW 2007c:Chapter 7).

Ageing of the general population, and of the population with disability, is likely to increase the demand for complementary services provided by both the disability and aged care sectors. The interface between the two sectors is of particular relevance to people ageing with an early onset disability and younger people with disability living in residential aged care accommodation.

The Aged Care Innovative Pool Disability Aged Care Interface Pilot, an initiative of the Australian Government Department of Health and Ageing that commenced in November 2003, trialled a new approach to providing aged care for people in the CSTDA target group. The initiative targeted people living in disability supported accommodation facilities at risk of entering residential aged care. It made available a limited pool of service places that delivered individually tailored aged care services to people in their current residential setting. An evaluation of the pilot (AIHW: Hales et al. 2006) found that the benefits of this approach include helping people to age in place and avoid or delay entry into residential aged care, improving the quality of life of participants as a result of receiving community-based aged care, and helping to identify factors that contribute to premature entry into residential aged care.

Regarding the demand for disability employment services, it is important to consider both the interface between CSTDA-funded employment services, generic employment services, and other general service programs such as education and health, and between CSTDA-funded employment services and other CSTDA service types.

National research (commissioned by the Australian Government Department of Families, Community Services and Indigenous Affairs on behalf of the DPRWG) is under way into how to improve the day activity options and employment interface (NDA 2007b).

## Therapy and equipment needs of people with cerebral palsy and like disabilities

A joint study by the AIHW and CP Australia found that there were approximately 33,800 people in Australia in 2003 with cerebral palsy or similar disabilities who may need therapy and equipment services (AIHW 2006g).

While many of their needs were met, people with cerebral palsy or like disabilities, and their families and therapists, did report unmet need in a number of areas, as well as long waiting times for accessing therapy and equipment. Many people did not have enough access to 'hands on' therapy, especially physiotherapy, social work, psychology and family support. Unmet need was particularly high for services that support participation, especially in employment and social activities, and also higher for adults than for children.

## **Outcomes for people with disability**

The previous volumes of this biennial report presented analyses of outcomes of participation in Australian society for people with disability, with reference to the ICF 'activities and participation' life areas in which all people, irrespective of disability, expect to participate. Although people with disability are participating actively in all areas of Australian life, the analyses showed that very large numbers of people experienced difficulties in mobility, interpersonal relationships and other 'major life areas' such as employment. The areas in which the need for personal assistance was most often reported were mobility, domestic life, interpersonal interactions and relationships, and employment (AIHW 2005a).

The analyses also found that people with disability tended to report lower levels of health, and were less likely to have finished school or be active in the paid labour force. They tended to have lower incomes than the rest of the population, although the receipt of government payments diminished these differences (AIHW 1999; 2003b). Their predominant social activities were visits from and to family and friends, who were also the main providers of assistance to them (AIHW 1999, 2003b, 2005a).

This section uses available time-series data from the five ABS SDAC surveys (1981, 1988, 1993, 1998 and 2003) to examine trends in community living, employment status and school attendance among people with disability over the last two decades. For comparative purposes, disability data for the 1981, 1988 and 1993 SDAC were re-derived using criteria common to the three surveys. Some substantial changes were made to the 1998 SDAC methods and maintained in the 2003 SDAC, which 'captured' a larger number of people with a severe or profound limitation than the previous SDAC. Therefore, the analyses focuse on broad trends over the two decades, and percentages have been age-standardised using the age and sex distribution of the 2003 Australian population.

# **Trends towards community living**

Living in community settings is a common goal of people with disability and, as with aged care, deinstitutionalisation has also been a policy driver nationally in the disability field. In disability services, group homes emerged as a dominant service model in the

deinstitutionalisation process in the 1980s. In more recent years there has been an increasing awareness that a mix of services is preferred. There is recognition of the need to offer genuine choice, including not only group homes, home-based support services and individualised funding packages but also redesigned facilities, such as cluster housing developments (AIHW 2001: Chapter 4).

Comparative analyses of the five SDAC data, including the most recent 2003 SDAC, confirm the continued trends towards community care and away from institutional care that have been reported previously (AIHW 1999, 2001). For over two decades (1981–2003), there have been consistent increases in the number and rate of people living in households and decreases in the number and rate of people living in institutional settings—'cared accommodation'—among people aged under 65 years with a severe or profound limitation (Figure 4.13; Table 4.16).

The increase in the number of people living in the community was markedly greater than the decease in the number of those living in cared accommodation (Table 4.16). Between 1981 and 2003, the number of people living in households increased by 156%. Over the same period, the number of those who lived in cared accommodation declined by 40%. The large difference suggests that the trend towards community living is mainly due to potential new service users remaining in community–based living arrangements, rather than changes by the population currently in cared accommodation.

Table 4.16: Number of people with a profound or severe core activity limitation aged 5–64 years, by place of residence, selected years

	Number of people ('000)						
_	1981	1988	1993	1998	2003		
Households	244.1	302.5	349.1	608.5	625.7		
Cared accommodation(b)	27.0	24.2	19.2	20.0 <sup>(a)</sup>	16.1 <sup>(a)</sup>		
	Per cent changes						
	1981–1988	1988-1993	1993-1998	1998-2003	1981-2003		
Households	23.9	15.4	74.3	2.8	156.3		
Cared accommodation(b)	-10.4	-20.7	4.3	-19.4 <sup>(a)</sup>	-40.3 <sup>(a)</sup>		

<sup>(</sup>a) In the 1981, 1988 and 1993 surveys three levels of severity of core activity limitation (severe, moderate and mild) were applied to both household and cared accommodation components. In 1993 the severe limitation was further divided into severe or profound limitation, but the severe limitation category was not applied to the cared accommodation component. In the 1998 and 2003 surveys both the severe or profound limitation categories were applied to the cared accommodation components.

Sources: AIHW analysis of ABS 1993, 1998 and 2003 Survey of Disability, Ageing and Carers confidentialised unit record file, unpublished data tables from the ABS 1981 and 1988 disability surveys.

The trend is even clearer among younger people with a severe or profound limitation. The proportion of people aged under 30 years living in cared accommodation in 1981 was substantially higher than that of those aged 30–64 years (14% versus 8.4%). By 1988, the proportions for the two age groups were the same (7.3%), reflecting a particularly strong trend towards community living among young people in the 1980s. By 2003 only 0.7% of people aged under 30 years were in cared accommodation, compared with 3.4% for those aged 30–64 years (Figure 4.14; Table A4.12).

<sup>(</sup>b) 'Cared accommodation' in the survey includes hospitals, homes for the aged such as nursing homes and aged-care hostels, cared components of retirement villages, and other 'homes' such as children's homes (ABS 2004:71). Smaller disability group homes (with fewer than six people) were not included in the cared accommodation component (ABS 2004:57).

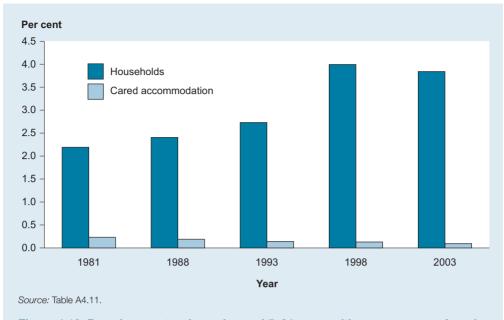


Figure 4.13: Prevalence rate of people aged 5–64 years with a severe or profound core activity limitation, by place of residence, 1981 to 2003

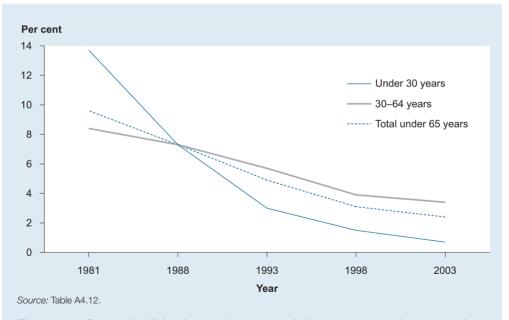


Figure 4.14: Proportion living in cared accommodation among people aged under 65 years with a severe or profound core activity limitation, by age, 1981 to 2003

The findings from analysis of data on users of CSTDA-funded services are in line with the trend reflected in population data. Data from snapshot day collections indicated that, between 1997 and 2001, community-based accommodation support services increased by 3,500, while there was a decrease of 1,700 services received in institutions, large residentials and hostels (AIHW 2002). Full-year data collections showed that the increase in community-based accommodation support service users and the decrease in service users in institutional settings had continued between 2003–04 and 2005–06 (Table A4.13; AIHW 2005b, 2007d).

These trends suggest that the future growth in demand for disability support services, in particular accommodation services, is more likely to be met through a further increase of community-based care rather than an expansion of institutional care. The trends also show clearly the importance of service programs to support carers, and to support the stability of community living and caring arrangements.

The nature and quality of community-based service and caring arrangements remain important issues. The planning for the development of community-based services must take into account not only those who would previously have been cared for in an institution, but also those who always have been and continue to be cared for in the community (AIHW 2001:Chapter 4).

## **Trends in employment participation**

The most recent SDAC (2003) data showed that the labour force participation rate was markedly lower for people with disability (53%) than for people with no disability (81%). The participation rate for people with a severe or profound limitation was even lower (30%). Participation rates for females were consistently lower than for males across different disability status (Table 4.17).

Table 4.17: People aged 15–64 years living in households: labour force participation rates<sup>(a)</sup> by disability status by sex, selected years (per cent)

		Core activity limitation			Schooling or employ- ment restriction	Total with specific limita-tions or	Disability without	Total with dis-	No	
	Year	Severe	Moderate	Mild		restrictions	restriction	ability	disability	Total
Participat	ion rate									
Males	1981	36.2	54.5	56.3	49.5	48.8	90.0	66.5	n.a.	n.a.
	1988	36.4	48.0	61.0	67.1	53.8	88.3	60.5	90.0	85.7
	1993	33.4	46.6	54.0	69.9	52.1	84.3	60.4	88.3	83.9
	1998	36.5	49.8	64.4	69.9	54.8	85.8	59.3	89.0	83.7
	2003	33.9	56.3	53.1	73.1	53.4	85.5	59.3	89.0	84.0
Females	1981	23.0	31.1	31.9	27.1	27.6	49.4	36.1	n.a.	n.a.
	1988	30.3	32.3	39.6	44.1	35.9	55.6	39.0	61.7	58.9
	1993	24.9	37.5	43.2	55.4	39.5	56.0	43.3	64.8	62.0
	1998	31.4	40.2	45.3	55.4	41.3	65.4	44.6	70.6	66.3
	2003	26.9	40.3	48.1	61.8	42.1	73.9	47.0	72.3	68.1
Persons	1981	29.4	44.8	45.7	38.7	38.9	72.7	52.8	n.a.	n.a.
	1988	33.0	41.0	51.0	57.9	45.5	75.0	50.7	75.8	72.4
	1993	29.1	42.6	49.0	64.1	46.4	72.5	52.8	76.4	73.0
	1998	33.9	45.2	55.4	63.7	48.3	76.3	52.2	79.8	75.1
	2003	30.1	48.0	50.6	68.4	47.8	80.4	53.3	80.6	76.1

<sup>(</sup>a) The rates have been age standardised using the age and sex distributions of the Australian population as at June 2003 for comparative purposes.

Sources: AIHW analysis of ABS 1993, 1998 and 2003 Survey of Disability, Ageing and Carers confidentialised unit record file; unpublished data tables from the ABS 1981 and 1988 disability surveys.

In 2003, the unemployment rate for people with disability (8.5%) was higher than that for people with no disability (5.0%). The unemployment rate for people with a severe or profound limitation (10.1%) was twice as high as that for those with no disability (5.0%) (Table 4.18).

Over the last two decades (1981–2003), there was little change in overall labour force participation rates for people with disability, varying slightly between 51% and 53%, while the rates for people with no disability increased from 76% in 1988 to 81% in 2003 (Table 4.17). However, among people with disability, participation rates varied depending on the severity of limitations and employment restrictions. For people with disability but no employment restrictions or activity limitations, the rate increased from 73% in 1981 to 80% in 2003, similar to that for people with no disability. Participation rates for people with a 'schooling or employment restriction only' increased most significantly: from 39% to 68%. In contrast, participation rates for people with a severe or profound limitation did not increase over the period, remaining at around 30% or slightly above. The marked increase in participation rates for people with less severe disability may reflect a greater effort by those people to join the labour force, or an increasing number of people in the labour force experiencing, or willing to report, restrictions (AIHW 1997). Another explanation may be an increase in the proportion of those people reporting disability generally (AIHW 2001).

Table 4.18: People aged 15–64 years living in households: unemployment rate<sup>(a)</sup> by disability status by sex, selected years

		Core activity limitation			Schooling or employ- ment	Total with specific limitations	Dis- ability without	Total with		
	Year	Severe	Moderate	Mild	restriction only	or restric- tions	restric- tion	dis- ability	No dis- ability	Total
Unempl	oymen	t rate								
Males	1981	6.5	7.4	8.4	19.3	9.8	4.5	6.7	n.a.	n.a.
	1988	*7.5	10.2	7.8	16.9	10.9	6.5	9.6	6.5	6.8
	1993	17.2	13.7	21.9	20.5	19.2	14.5	17.5	11.4	12.1
	1998	11.8	15.6	11.6	18.6	14.0	11.0	13.4	7.6	8.4
	2003	*9.8	*7.2	9.0	14.3	10.3	4.4	8.7	4.8	5.3
Females	1981	12.8	12.1	15.7	21.0	15.0	11.7	13.2	n.a.	n.a.
	1988	13.6	9.0	11.9	16.7	12.5	13.9	12.9	9.4	9.7
	1993	17.9	18.5	17.8	15.1	17.1	16.6	17.0	11.9	12.4
	1998	*9.8	*9.1	*5.5	*9.4	8.0	9.8	8.4	8.0	8.0
	2003	*10.5	*8.1	*6.3	14.3	9.3	4.5	8.2	5.2	5.6
Persons	1981	9.0	8.8	10.6	19.9	11.5	6.6	8.7	n.a.	n.a.
	1988	10.6	9.8	9.3	16.8	11.5	8.8	10.8	7.7	8.0
	1993	17.5	15.6	20.3	18.6	18.4	15.2	17.3	11.6	12.2
	1998	10.8	12.8	9.2	15.2	11.5	10.5	11.3	7.8	8.2
	2003	10.1	7.6	7.7	14.3	9.8	4.4	8.5	5.0	5.4

<sup>(</sup>a) The rates have been age standardised using the age and sex distributions of the Australian population as at June 2003 for comparative purposes.

Sources: AIHW analysis of ABS 1993, 1998 and 2003 Survey of Disability, Ageing and Carers confidentialised unit record file; unpublished data tables from the ABS 1981 and 1988 disability surveys.

There was a sharp increase in the unemployment rate for people with disability between 1988 (11%) and 1993 (17%). The rate has fallen since 1993, and dropped to 11% in 1998 and 8.5% in 2003 (Table 4.18). This change partly reflects the general improvement of the labour market, and is similar to patterns for those without disability.

## Trends in education participation

Integration of students with disability into the mainstream school environment is now a general policy of most state and territory governments. A comparative analysis of reported school attendance data from the five SDAC surveys sheds light on trends in the type of school attended by people with disability aged 5–20 years.

Overall, there was a higher proportion of students aged 5–20 years with a severe or profound limitation attending 'ordinary' (mainstream) schools in 2003 than in 1981. This trend can be observed in two ways. The first is to look at students with disability attending ordinary or special class in ordinary school. The proportion of those with a severe or profound limitation attending ordinary classes in ordinary school in 2003 was twice (35%) as high as in 1981 (15%). The proportion attending special classes in ordinary schools also increased, from 30% in 1981 to 50% in 2003 (Figure 4.15; Table A4.14).

Another perspective looks at the proportion of students attending specific types of school as a proportion of total students with a severe or profound limitation who were attending school. The time series data show that they were more likely to attend ordinary schools (including special classes in ordinary schools) and less likely to attend special schools in 2003 than in 1981. The proportion of those attending special schools dropped from 35% in 1981 to 22% in 2003, while the proportion attending ordinary schools increased (Figure 4.16; Table A4.15).

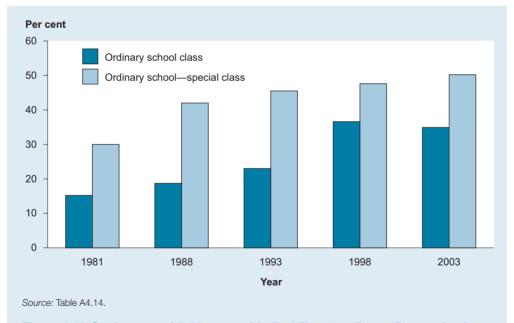
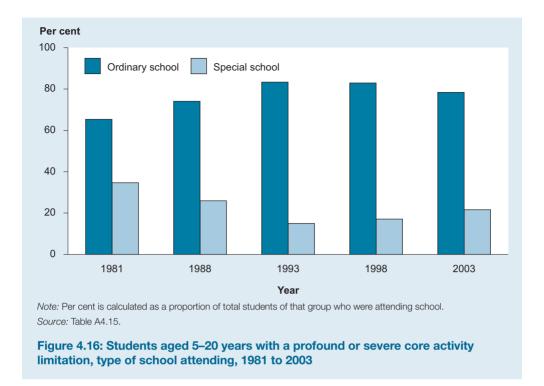


Figure 4.15: Students aged 5–20 years with disability attending ordinary schools, proportion with a profound or severe core activity limitation, by type of class, 1981 to 2003



The rising percentage of people with disability, and of those with a severe or profound limitation attending schools, partly reflects the increase in disability prevalence in the school age population over the years (see Section 4.2 for more information about children with disability).

Although the disability survey data on participation in education among people with disability are not directly comparable with the collections of education departments (see Table 4.14), the trend towards enrolment in mainstream schools evident in the reported survey data is consistent with the trends reflected in administrative data. Of all students with disability across all levels of severity, the proportion of those attending special schools declined from 21% in 1998 to 7% in 2006 (AIHW 1999:Table 7.16; Table 4.14).

# 4.5 Summary

Disability services are being delivered in Australia in a context of continuing change, presenting a number of challenges. Although the prevalence of people living with a severe or profound activity limitation in each specific age group (who are the primary users of disability services) is not projected to change greatly in the foreseeable future, the ageing of the Australian population means that the number of people in those age groups where disability is most prevalent is projected to grow. This means that the total number of people with a severe or profound activity limitation will also grow. Unpaid carers remain the main providers of assistance to people with disability and the ratio of informal carers to the number of people with disability is projected to fall.

A further challenge is the increasing emphasis on measuring the outcomes of the provision of disability services for people living with disability. Current monitoring of disability services has traditionally focused on inputs (the costs of providing the services) and

outputs (the number of services provided and the number of people accessing the services). While these are important in monitoring service provision, there is an increasing focus on measuring the extent to which the services have achieved their goals in improving the quality of life for people with disability. This presents significant challenges in defining measurable outcomes and developing reliable data to monitor these outcomes.

This chapter, and the AIHW's work in this field, attempt to provide statistics that inform people interested in disability and those attempting to meet the challenges of this changing context.

## **Population**

In 2003, there were 3.9 million people with disability (20% of the Australian population). Of these, the majority (2.6 million) were aged under 65 years (15% of the population aged under 65 years). Of the people with disability, 1.2 million (6.3% of the population) had a severe or profound limitation. Among these people, 677,700 were aged under 65 years (3.9% of the population aged under 65 years), of whom 342,800 were male (51%) and 334,900 were female (49%). Among people aged under 65 years, physical/diverse disability were the most commonly reported disability, followed by sensory/speech disability and psychiatric disability.

In Australia, gains in life expectancy were accompanied by an increase in expected years of life with disability or a severe or profound limitation (see the Glossary for definition of expected years of life with disability). Even though underlying prevalence rates appear relatively stable, the ageing of the Australian population and the greater longevity of individuals, including those with disability, are leading to increasing numbers of people with disability and a severe or profound limitation. The population aged 0–64 years with a severe or profound limitation is projected to increase to 752,100 people (an increase of 34,700 people, or 4.8%) by 2010. The projected growth in the working-age population (15–64 years) with a severe or profound limitation is 6.9%, or 37,500 people.

The prevalence rates of severe disability among Indigenous Australians were at least twice as high as those of other Australians.

#### Services and assistance

The largest income support programs in 2005–06 were the DSP, the Carer Allowance (Child/Adult) and the Carer Payment (DSP/AP/other); and the Disability Pension (DVA).

In 2005–06, there were 217,143 service users who accessed CSTDA-funded services. Of the five major service groups, the highest number of service users was recorded in community support followed by employment services, community access, accommodation support and respite. Government spending on disability support services during 2005–06 totalled \$3.95 billion. Of this total, just under half was used to fund accommodation support services.

The number of CSTDA service users has steadily risen over the two previous reporting periods, with the largest increase in community support and significant increases in employment services and respite services.

Overall, 3.3% of service users reported that they were Aboriginal and/or Torres Strait Islanders. This increase from 2.7% in 2003–04 may be attributed to a variety of factors, including better self-identification, more accurate capturing of Indigenous people in the data set or an increase in service use by Indigenous people. As would be expected

from general population trends, representation of Indigenous service users was lower in Major Cities (2.0%) and Inner Regional areas (3.4%) than in other areas. Around 8% of service users in Outer Regional areas were Indigenous, compared with 19% in Remote areas and 39% in Very Remote areas—this is similar to the profile of Indigenous people in the general population.

Many CSTDA service users rely on informal carers. People who utilised respite services were most likely to report having an informal carer (90%), followed by those who accessed community support services (55%). People using employment services were the least likely to report an informal carer (33%).

As at 30 June 2006, 6,562 younger people (under 65 years of age) were permanent residents of Australian Government-funded residential aged care services. Seventy per cent of these younger people were aged between 55 and 64 years; a further 26% were aged 40 to 54 years; the rest were people younger than 40 years of age.

#### **Outcomes**

For over two decades (1981–2003), there have been consistent increases in the number and rate of people living in households and decreases in the number and rate of people living in institutional settings—'cared accommodation'—among people aged under 65 years with a severe or profound limitation. Over the same period, there have been consistent trends towards community-based care for people with a severe or profound disability, largely due to potential new service users remaining in community-based living arrangements rather than changes in the current population in cared accommodation. These trends suggest that the future growth in demand for disability support services, in particular accommodation services, is unlikely to be met through the expansion of institutions. The trends also show clearly the importance of service programs to support carers and to support the stability of community living and caring arrangements.

In 2003, the labour force participation rate was markedly lower for people with disability (53.3%) than for people with no disability (80.6%). The participation rate for people with a severe or profound limitation was even lower (30.1%). The unemployment rate for people with disability (8.5%) was higher than that for people with no disability (5.0%). The unemployment rate for people with a severe or profound limitation (10.1%) was twice as high as that for those with no disability (5.0%).

Over the last two decades (1981–2003), there was little change in overall labour force participation rates for people with disability, remaining between 51% and 53%, while the rates for people with no disability increased from 76% in 1988 to 81% in 2003. There was a sharp increase in the unemployment rate for people with disability between 1988 (10.8%) and 1993 (17.3%). The rate has fallen since 1993, and dropped to 11.3% in 1998 and 8.5% in 2003. This change partly reflects the general improvement of the labour market and is consistent with trends in the general population.

Integration of students with disability into the mainstream school environment is now a general policy of most state and territory governments. The analyses of time series data show that the 'inclusion' policy in school education resulted in a significantly higher proportion of students with disability, especially a severe disability, attending mainstream schools.

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