



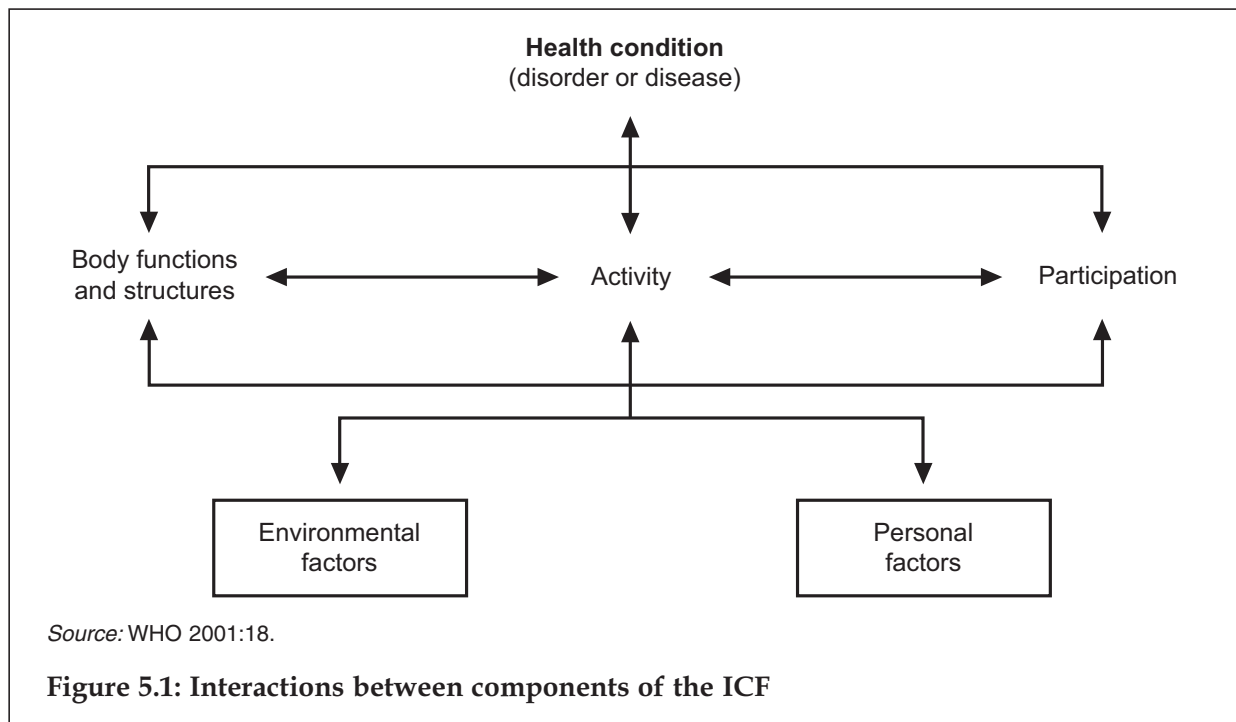
# 5 Disability and disability services

## 5.1 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 different life stages. It can be measured along a continuum and estimates vary with the particular definition used.

In 2003 there were 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. This chapter provides a profile of these people, the services they may use, and the outcomes for them. The focus here is chiefly on people aged less than 65 years; Chapter 4, on ageing and aged care, focuses on older Australians.

The experience of disability 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 5.1; WHO 2001). This important conceptual framework underpins much Australian data.



Section 5.2 outlines recent developments in the disability field, including data developments. Section 5.3 gives an overview of disability in the Australian population, including a brief discussion of disability and ageing, childhood disability, and disability among Aboriginal and Torres Strait Islander peoples. Data on services and assistance are presented in Section 5.4. Section 5.5 outlines participation outcomes for people with disabilities. Section 5.6 summarises and concludes the chapter.

## 5.2 Recent developments

The lives of people with a disability are affected by many social trends and policies. This section provides a brief picture of recent developments affecting people with a disability and the disability services field.

### Human rights and ethics

Many policies in the disability field in Australia are grounded in a human rights philosophy, reflecting the basic principle that people with disabilities should have the same opportunities to participate in society as do others (see, for example, AIHW 1993:266–79; UN 1994). Australia is now participating in the work of a United Nations committee developing proposals for a Convention on the rights of people with disabilities; drafting covers a wide range of rights and freedoms relevant to all areas of life and all age groups. The Human Rights and Equal Opportunity Commission (HREOC) has conducted relevant seminars and consultations in Sydney and Canberra (HREOC 2005a).

The Biwako Millennium Framework for Action was adopted by the UN Economic and Social Commission for Asia and the Pacific in 2002, setting out a ‘framework for action towards an inclusive, barrier-free and rights-based society for persons with disabilities’ (UNESCAP 2002). The framework proposes action in a number of target areas, including early intervention, training and employment, access to built environments and to information, poverty alleviation, self-help organisations, families and women. The Department of Family and Community Services and the AIHW both participated in a regional forum on employment, in April 2004, contributing (respectively) on Australian government policies and initiatives, and on data developments focusing on rights and participation. The relevance of the ICF for data development was recognised, with its focus on participation and the key role of environment in the creation and experience of disability. The ICF ‘has been accepted as one of the United Nations social classifications and is referred to in and incorporates the Standard Rules on the Equalization of Opportunities for Persons with Disabilities’ (WHO 2001:5).

In May 2005 the World Health Assembly passed a resolution on ‘Disability, including prevention, management and rehabilitation’ (WHA 2005). This resolution recognised the important contribution of people with disabilities, the need for prevention, health, rehabilitation and support services, and the need to provide equipment and recognise environmental (including cultural) barriers. Member states were urged to act on these matters, and to gather ‘more reliable data’; the ICF was specifically recognised in the resolution.

## Disability Discrimination Act

The *Disability Discrimination Act (DDA) 1992* is one of the major national expressions of the human rights approach to disability, making discrimination on the grounds of disability unlawful, and providing a framework and process for the setting of disability standards (Box 5.1).

### **Box 5.1: Recent progress in implementing the Disability Discrimination Act 1992**

#### ***Disability Standards for Access to Premises***

*A draft standard was released for public comment and consultation on 9 January 2004. A large number of submissions (almost 300) were received relating to the draft standards. Work on finalising these standards is continuing during 2005.*

#### ***Disability Standards for Education***

*Education standards were tabled in Parliament on 17 March 2005 and came into effect on 18 August 2005. These Standards clarify the obligations of education and training providers in relation to students with disabilities, including providing guidance as to how these obligations can be met.*

#### ***Insurance and superannuation***

*Revised guidelines are designed to assist providers of insurance and superannuation in complying with the DDA.*

#### ***Mental health consultations***

*A report on the experiences of mental health consumers in each state and territory is due for release in late 2005. This report is being produced by the Mental Health Council of Australia and the Brain and Mind Research Institute, with guidance from HREOC.*

#### ***Voluntary banking standards***

*HREOC has recently reviewed voluntary banking standards (released in April 2002) for electronic banking services such as ATMs, Internet banking and EFTPOS. Preliminary results showed some progress towards achievement of accessibility to these products for people with disabilities, but a lack of awareness of the availability of these products.*

*Sources: DEST 2005a; HREOC 2005b; Ruddock 2005.*

A review of the Act was conducted by the Productivity Commission in 2004 (Box 5.2). In response to the review, the government accepted '26 of those recommendations either in full, in part or in principle' (Attorney-General's Department 2005). Recommendations not accepted include those relating to insurance, wages and immigration.

## Whole-of-government policies

Whole-of-government approaches to disability have been recognised as essential for some years. The Commonwealth Disability Strategy, in existence for more than a decade, provides a whole-of-government strategy aimed at 'enabling full participation of people with disabilities' (FaCS 2005a). In 1997 a whole-of-government Disability Policy Framework was developed in New South Wales to promote a holistic approach

to service delivery, addressing the diverse needs of people with a disability (NSW Government 1997). The framework was initially based on a categorisation of needs and services, developed by the Institute for its study of unmet demand for disability support services (AIHW 1997). This study reflected the 'whole person' approach which is at the heart of whole-of-government approaches to human need. The ICF (then in draft) provided an essential framework for understanding the needs of people with disabilities across the spectrum of activities, participation and the life-cycle.

### **Box 5.2: Main findings of the review of the Disability Discrimination Act 1992**

*Overall, the DDA has been reasonably effective in reducing discrimination. But its report card is mixed and there is some way to go before its objectives are achieved.*

- *Access to public transport and education has improved more than employment opportunities. (Finding 5.1 states that 'disability discrimination in employment remains a significant issue' and Finding 5.7 that the 'Commonwealth Disability Strategy ... has been ineffective in improving employment opportunities for people with disabilities in the Australian Public Service'.)*
- *People with physical disabilities have been helped more than those with mental illness or intellectual disabilities – but other factors might be relevant.*
- *People with disabilities in regional areas, from non-English-speaking backgrounds and Indigenous Australians still face particular disadvantages – but race discrimination, language, socioeconomic background and remoteness also play a part.*
- *The nature of the challenge facing the DDA will change as the focus shifts from removing physical barriers to addressing attitudinal barriers.*

*The DDA meets the Competition Principles Agreement legislation review requirements.*

- *Many benefits are intangible but widespread.*
- *Costs of compliance are likely to be quite small for many organisations.*
- *In-built safeguards help ensure a net benefit to the Australian community.*
- *Its impact on competition appears to have been limited.*
- *No satisfactory alternatives for achieving its objectives exist.*

*Care needs to be taken in the way the DDA is implemented through disability standards if it is to continue to produce net benefits. While the DDA should be amended to allow standards to be developed for all areas of the Act, they should not be able to alter the fundamental scope of the Act.*

*The unjustifiable hardship defence should be strengthened and extended to all areas of the Act. It should also apply to all standards.*

*An explicit duty to make 'reasonable adjustments' should be included in the DDA.*

- *It should cover all areas of the Act.*
- *It should exclude adjustments that would cause unjustifiable hardship.*
- *Its costs should be shared between affected organisations and government.*

*Source: Productivity Commission 2004a.*

Across Australia, disability services are delivered under the Commonwealth State/Territory Disability Agreement (CSTDA 2003). The 2002–07 Agreement has five key policy priorities which reflect this understanding, placing specialist disability services within the broad field of human services for all people:

- to strengthen access to generic services by people with disabilities;
- to strengthen across-government linkages;
- to strengthen individuals, families and carers;
- to improve long-term strategies to respond to, and manage demand for, specialist disability services; and
- to improve accountability, performance reporting and quality.

The Australian Government is now placing considerable emphasis on the need to develop and implement whole-of-government approaches: 'Most of the pressing problems of public policy do not respect organisational boundaries. Nor do most citizens' (Shergold 2004).

## **Income support and economic participation**

Reducing welfare dependence and increasing workforce participation was flagged as a priority of the Australian Government after its re-election in October 2004 (Howard 2004). Two of the complementary goals of welfare reform were to encourage workforce participation for people with disabilities, and to limit the growth in the number of people receiving the Disability Support Pension (DSP). For several years, change has been flagged and discussed in a series of reports (outlined in AIHW 2001:270–1, 2003a:333–6). The underlying philosophy is one of mutual obligation of government and citizens, and there has been consultation and debate over these years to attempt to balance and implement these obligations appropriately (see, for instance, Disability and Participation Alliance 2005). Employment retention, not just obtaining a job, is seen as an essential component of reform, especially by disability advocates (Diamond 2005).

It was announced in May 2005 Budget statements that, from 1 July 2006, people with disabilities who are new claimants of income support and are able to work between 15 and 29 hours per week within a 2-year period at award wages in the open labour market would receive an enhanced Newstart Allowance or Youth Allowance (rather than DSP) and be subject to part-time mutual obligation requirements. These people would be eligible for the Pensioner Concession Card, Pharmaceutical Allowance and Telephone Allowance (Dutton 2005). The planned changes to DSP were accompanied by extra employment services designed to promote workforce participation: disability open employment services, the Job Network, vocational rehabilitation and the Personal Support Program. These initiatives are being introduced at a time of population ageing and projected slowing in labour force growth (Andrews 2005). Efforts are being made by government to encourage employers to expand work opportunities for people with disabilities.

In its 2005 Budget submission, ACROD advocated the need for related initiatives, including removing the ceiling on employment assistance places in specialist disability services, increasing vocational training participation rates among people with



disabilities, and for Australian governments themselves to improve their record of employing people with disabilities (ACROD 2005). Australia's relatively poor performance in employing people with 'mental health disorders' has been pointed to by the Mental Health Council of Australia which has stated its intention to be 'a very active player' in the promised consultation process (MHCA 2005).

A national inquiry on employment and disability is due to report in November 2005 (HREOC 2005c). In launching its inquiry, HREOC pointed to the lower participation rates of people with disability, their higher unemployment rates, and lower earnings (see also Section 5.5).

## Advocacy and advice

A range of advocacy and 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:

- National Advisory Council on Disability and Carer Issues, which will meet for the first time in late 2005. This new body will provide the government with advice on issues affecting people with disability, carers and the caring process (FaCS 2005b). It replaces two former advisory groups, the National Disability Advisory Council and National Family Carers Voice.
- Australian Federation of Disability Organisations, which was established in November 2004. Its mission is 'to champion the rights of people with disability in Australia, and help them participate fully in Australian life' (AFDO 2005).
- ACROD, which describes itself as the national industry association for disability services, with a network of state, territory and national offices. Its areas of interest are indicated in its recent budget submission, covering topics such as: open and supported employment services and policies for government funding, regulation and support thereof; the need for benchmarks for the provision of disability services; the need for a 'properly resourced national equipment strategy'; and strategies to address disability and ageing (ACROD 2005).
- Association of Competitive Employment (ACE), which is the national peak body for open employment services for people with disabilities.

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

## National developments in disability support services

The 2002–07 CSTDA and the previous two agreements provide the national framework for the funding and provision of disability support services. The Australian Government is responsible for the planning, policy setting and management of employment services under this agreement, while the states and territories are responsible for all other disability support services. Advocacy, information and print disability services are considered shared responsibilities under the Agreement. The five key policy priorities under the CSTDA are listed previously in this chapter.

The third CSTDA introduced a schedule that specifies the annual production of performance indicators as part of the accountability measures for all governments, indicators relating to service access and expenditure. These were produced for the first time in 2002–03 and published in the National Disability Administrators' (NDA) first CSTDA Public Report (NDA 2004; see also AIHW 2004c). The second CSTDA Public Report, using 2003–04 data, was released in 2005 (NDA 2005).

The agreements commit the parties to work together to address key issues for people with a disability, including:

- flexibility between service provision by different levels of government;
- the situation of young people living in Australian Government-funded residential aged care facilities; and
- issues facing people with a disability who are ageing (FaCS 2005c).

The situation of younger people in residential aged care facilities was also given attention by a Senate Committee. Such accommodation was found 'unacceptable in most instances' and it was recommended that individual situations be assessed and alternative accommodation be provided (Senate Community Affairs Committee 2005).

The current CSTDA is a two-tiered arrangement of multilateral and bilateral agreements. The 2004–05 federal budget included a bilateral funding offer to all states and territories for additional respite for older carers. Under these bilateral agreements, carers aged 70 years or above who are caring for their son or daughter with a disability would be eligible for up to 4 weeks of respite per year, and carers aged between 65 and 69 years who need to spend time in hospital would be eligible for up to 2 weeks respite per year (FaCS 2004a).

Current state and territory government policy directions for disability support services vary somewhat between jurisdictions (NDA 2004; SCRCSSP 2005). Common areas of focus include:

- family-oriented approach to services—focusing on supporting young people with disabilities and their carers;
- supporting people with disabilities so that they can live in the community;
- provision of flexible services aimed at serving the needs of individuals (sometimes based on individualised funding packages), and the desire to move people out of inappropriate services (e.g. young people in aged care homes); and
- a review of disability legislation being undertaken in a number of states and territories.

In late 2004, responsibility for administration of open employment services operating under the CSTDA moved from the Department of Family and Community Services (FaCS) to the Department of Employment and Workplace Relations (DEWR). As a result, DEWR proposed that, from July 2005:

- open employment services will operate as a specialist network of services (separate from the mainstream Job Network);

- case-based funding will be fully implemented in these services – that is, higher levels of funding will be available for services taking on clients with the highest support needs; and
- Job Network member agencies will be able to register job seekers who receive the DSP (DEWR 2005a).

Consultations on the proposed operation of open employment services under DEWR were held in early 2005. DEWR reported strong support for the case-based funding model. Open employment services are still in a 'transition' period (DEWR 2005b).

The Australian Government's National Respite for Carers Program has resource centres in each capital city which are designed to act as a single point of contact for carers to obtain information and access to relevant services (see also Chapter 4). This program provides respite for carers of young people with a disability, when their needs are not being met by existing state/territory programs.

## Disability data developments and challenges

Disability data continue to improve. The National Aboriginal and Torres Strait Islander Social Survey 2002 has now provided information on Indigenous disability. The first full year of data from the redeveloped CSTDA NMDS collection provides a new benchmark collection on disability services for future reference. These enhanced sources, as well as new data from the 2003 Survey of Disability, Ageing and Carers, are reflected in this chapter.

Further developments are in train:

- A disability question in the Australian Census has been developed for 2006. This decision follows some years of representation by the disability sector and the AIHW, and of options testing by the ABS. The collection of basic disability information in the Census will enable small area data to be improved, for service planning purposes, information on subpopulations to be compiled, and disability information to be related to the rich array of other social data from the Census.
- The AIHW (as the Australian Collaborating Centre for the WHO Family of International Classifications) is continuing to work on the implementation of the ICF. A data capture tool has been developed to assist users to apply the classification – the Functioning and Related Health Outcomes Module (AIHW 2005a). The module reflects national data standards that already incorporate the ICF (AIHW 2005b). This tool is intended to support whole-of-government consistency in the identification and measurement of functioning and disability.
- There is considerable interest and activity in implementing the ICF in internationally comparable disability surveys. Both the AIHW and the ABS have been involved in the UN's Washington Group, as well as in UNESCAP work in 2004 on disability statistics in the Asia Pacific region.
- An Australian Forum on improving disability data and the use of the ICF, is planned for February 2006, with an Australian ICF User Guide (version 2) to be produced later in that year, both reflecting the vigorous interest in Australia in the use of the classification. The AIHW is promoting the use of the ICF in a wide range of fields, to improve the quality, relevance and consistency of disability information (see also Chapter 1).



- There is increasing adoption of national data standards, based on the ICF, in administrative data collections. The national disability services collection has for several years used the Activities and Participation dimension in a key data item on support needs. For the new national minimum data set for children's services, a relevant data item for disability has been developed which relates to national standards, thus enabling data comparisons with the relevant population survey.

All these developments will provide improved infrastructure for 'disability identification' in generic services, enabling access to and outcomes from these services to be monitored. Some of these initiatives are challenging, particularly when they involve bringing a newer and more holistic conceptualisation of disability into the sphere of health surveys and information systems (Madden et al. 2005), and into the plethora of assessment scales now used in human services fields in Australia. This very variability, however, makes greater consistency (or at least 'inter-operability') all the more an important goal.

The long-term vision is that, with more consistent approaches to disability data across the spectrum of human services, the resulting 'joined up' data will support whole-of-government approaches to the provision of services relevant to people with a disability.

### 5.3 Disability in the Australian population

This section presents an overview of disability in Australia, drawing on two new sources of population data. The 2003 Survey of Disability, Ageing and Carers is used to profile the population, by updating major analyses carried out since the last survey in 1998. The National Aboriginal and Torres Strait Islander Social Survey provides a first useful picture of disability among Indigenous Australians.

In 2003 there were an estimated 3,946,400 people with a disability – about 20% of the Australian population (Table 5.1).<sup>1</sup> Of these, 2,556,000 people were aged under 65 years, representing 14.8% of the population in that age range. 'Disability', as defined by the survey, is a mix of 17 impairments, activity limitations and participation restrictions identified in the survey screening questions (see Technical Appendix). These estimates cover a broad spectrum of disabilities, in terms of both the nature and extent of the effects on the person.

The extent to which these disabilities affect everyday life is indicated by the presence of a 'profound or severe core activity limitation'. In 2003, 6.3% of the population (1,238,600 people) experienced such limitations, meaning that they always or sometimes needed assistance with activities of self-care, mobility and communication.

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1. 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.

This total comprised 677,700 people aged under 65 (3.9% of the population aged under 65) and 560,900 aged 65 and over (22.5% of those 65 and over). Of children aged 0–14 years, 4.3% had profound or severe core activity limitations, compared to 2.2% of people aged 15–24 years; otherwise, the higher the age group, the greater the likelihood of such limitations. Disability and ageing will be discussed in more detail later in this section.

**Table 5.1: All persons by disability status and severity of core activity limitation, 2003**

Age group	Core activity limitation			Total with disability	Total population
	Profound	Severe	Total profound or severe		
	Number ('000)				
0–14	78.0	87.3	165.3	317.9	3,850.6
15–24	24.0	36.9	61.0	249.3	2,786.4
25–34	20.6	46.8	67.5	314.3	2,948.9
35–44	23.7	73.6	97.3	418.5	2,951.8
45–64	86.2	200.5	286.7	1,256.0	4,684.7
65+	359.6	201.3	560.9	1,390.4	2,496.8
<b>Total</b>	<b>592.2</b>	<b>646.4</b>	<b>1,238.6</b>	<b>3,946.4</b>	<b>19,719.3</b>
<b>Total &lt;65</b>	<b>232.6</b>	<b>445.1</b>	<b>677.7</b>	<b>2,556.0</b>	<b>17,222.5</b>
	Per cent <sup>(a)</sup>				
0–14	2.0	2.3	4.3	8.3	..
15–24	0.9	1.3	2.2	8.9	..
25–34	0.7	1.6	2.3	10.7	..
35–44	0.8	2.5	3.3	14.2	..
45–64	1.8	4.3	6.1	26.8	..
65+	14.4	8.1	22.5	55.7	..
<b>Total</b>	<b>3.0</b>	<b>3.3</b>	<b>6.3</b>	<b>20.0</b>	..
<b>Total &lt;65</b>	<b>1.4</b>	<b>2.6</b>	<b>3.9</b>	<b>14.8</b>	..

(a) Per cent of the Australian population of that age.

Note: See Technical Appendix for definitions of terms used to categorise 'disability status' in the survey.

Sources: Tables A5.1, A5.2; AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers confidentialised unit record file.

The nature of the disabilities experienced is sometimes described by terms such as 'intellectual' or 'physical' disability, and the AIHW has developed a series of estimates of these groups (see Box 5.3 for terms; and AIHW 2003b for methods and previous estimates). Prevalence estimates vary with the scope and level of disabilities under consideration. Four sets of estimates are accordingly provided, to support different applications and to illustrate the variation arising from the different bases of estimation (Table 5.2). The estimates based on 'main disabling condition' are used when people with multiple conditions are to be counted only once, but not when a full picture of all disabilities – personally or within the population – is needed (see Technical Appendix).

### **Box 5.3: Disability groups**

***Intellectual/learning disability** is associated with impairment of intellectual functions, with limitations in a range of daily activities and with restriction in participation in various life areas. Support may be needed throughout life, the level of support tending to be consistent over a period of time but may change in association with changes in life circumstances.*

***Psychiatric disability** is associated with clinically recognisable symptoms and behaviour patterns frequently associated with distress that may impair personal functioning in normal social activity. Impairments of global or specific mental functions may be experienced, with associated activity limitations and participation restrictions in various areas. Support needed may vary in range, and may be required with intermittent intensity during the course of the condition. Changes in level of support tend to be related to changes in the extent of impairment, or in the environment. Psychiatric disability may be associated with schizophrenia, affective disorders, anxiety disorders, addictive behaviours, personality disorders, stress, psychosis, depression and adjustment disorders.*

***Sensory/speech disability** is associated with impairment of the eye, ear and related structures and of speech, structures and functions. The extent of impairment and activity limitation may remain consistent for long periods. Activity limitations may occur in various areas, for instance communication and mobility. A specific range of environmental factors will affect the level of disability experienced by people in this grouping. Once in place, the level of support tends to be relatively consistent.*

***Physical/diverse disability** is associated with the presence of an impairment, which may have diverse effects within and among individuals, including effects on physical activities such as mobility. The range and extent of activity limitation and participation restriction will vary with the extent of impairment as well as with environmental factors. Environmental adjustments and support needs are related to areas of activity limitation and participation restriction, and may be required for long periods. Levels of support may vary with both life changes and extent of impairment. Included in this broad category is the subcategory **Acquired brain injury** which is used to describe multiple disabilities arising from damage to the brain acquired after birth. It can occur as a result of accidents, stroke, brain tumours, infection, poisoning, lack of oxygen, degenerative neurological disease, etc. Effects include deterioration in cognitive, physical, emotional or independent functioning.*

Sources: AIHW 2005b; NCSDC 2004.

Physical/diverse disabilities were the most prevalent, whichever of the four estimates is considered (Table 5.2). Based on consideration of all reported conditions, 2,043,400 people aged under 65 years reported one or more physical/diverse disabilities (12% of the population of that age). Of these, 1,995,300 also reported one or more activity limitations or participation restrictions (12% of the under 65 population) and, using the narrowest scope, 512,600 (3.0%) had a profound or severe core activity limitation.

One or more sensory/speech disabilities were reported by an estimated 728,300 people aged under 65 years in 2003 (or 4.2% of this age group), based on consideration of all reported conditions. Of these, 713,200 people (4.1%) also reported one or more activity limitations or participation restrictions, and 254,700 (1.5%) had a profound or severe activity limitation.

**Table 5.2: Estimates of main disability groups in Australia, 2003**

	Aged under 65		Aged 65+		All ages	
	Number ('000)	% of people aged <65	Number ('000)	% of people aged 65+	Number ('000)	% of total population
<b>All disabling conditions</b>						
Intellectual	436.2	2.5	152.5	6.1	588.7	3.0
Psychiatric	722.1	4.2	295.8	11.8	1,017.9	5.2
Sensory/speech	728.3	4.2	768.0	30.8	1,496.3	7.6
Acquired brain injury <sup>(a)</sup>	317.4	1.8	120.9	4.8	438.3	2.2
Physical/diverse	2,043.4	11.9	1,307.2	52.4	3,350.6	17.0
<i>All disabling conditions and activity limitations and participation restrictions</i>						
Intellectual	432.0	2.5	152.5	6.1	584.5	3.0
Psychiatric	720.0	4.2	295.8	11.8	1,015.8	5.2
Sensory/speech	713.2	4.1	768.0	30.8	1,481.2	7.5
Acquired brain injury <sup>(a)</sup>	311.8	1.8	120.9	4.8	432.7	2.2
Physical/diverse	1,995.3	11.6	1,307.2	52.4	3,302.6	16.7
<i>All disabling conditions and profound or severe core activity limitations</i>						
Intellectual	215.1	1.2	135.9	5.4	351.0	1.8
Psychiatric	277.7	1.6	215.1	8.6	492.8	2.5
Sensory/speech	254.7	1.5	325.1	13.0	579.8	2.9
Acquired brain injury <sup>(a)</sup>	99.9	0.6	57.5	2.3	157.5	0.8
Physical/diverse	512.6	3.0	538.5	21.6	1,051.1	5.3
<b>Main disabling condition</b>						
Intellectual	162.7	0.9	*3.0	*0.1	165.7	0.8
Psychiatric	326.0	1.9	106.2	4.3	432.2	2.2
Sensory/speech	247.1	1.4	165.2	6.6	412.3	2.1
Acquired brain injury <sup>(a)</sup>	27.3	0.2	**1.4	**0.1	28.7	0.1
Physical/diverse	1,792.8	10.4	1,114.6	44.6	2,907.4	14.7
<b>Total with a disability</b>	<b>2,556.0</b>	<b>14.8</b>	<b>1,390.4</b>	<b>55.7</b>	<b>3,946.4</b>	<b>20.0</b>
<b>Total population</b>	<b>17,222.5</b>	<b>..</b>	<b>2,496.8</b>	<b>..</b>	<b>19,719.3</b>	<b>..</b>

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

*Notes*

1. Estimates marked with \* have an associated relative standard error (RSE) of between 25% and 50% and should be interpreted accordingly.
2. Estimates marked with \*\* have an associated relative standard error (RSE) of greater than 50% and should be interpreted accordingly.

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

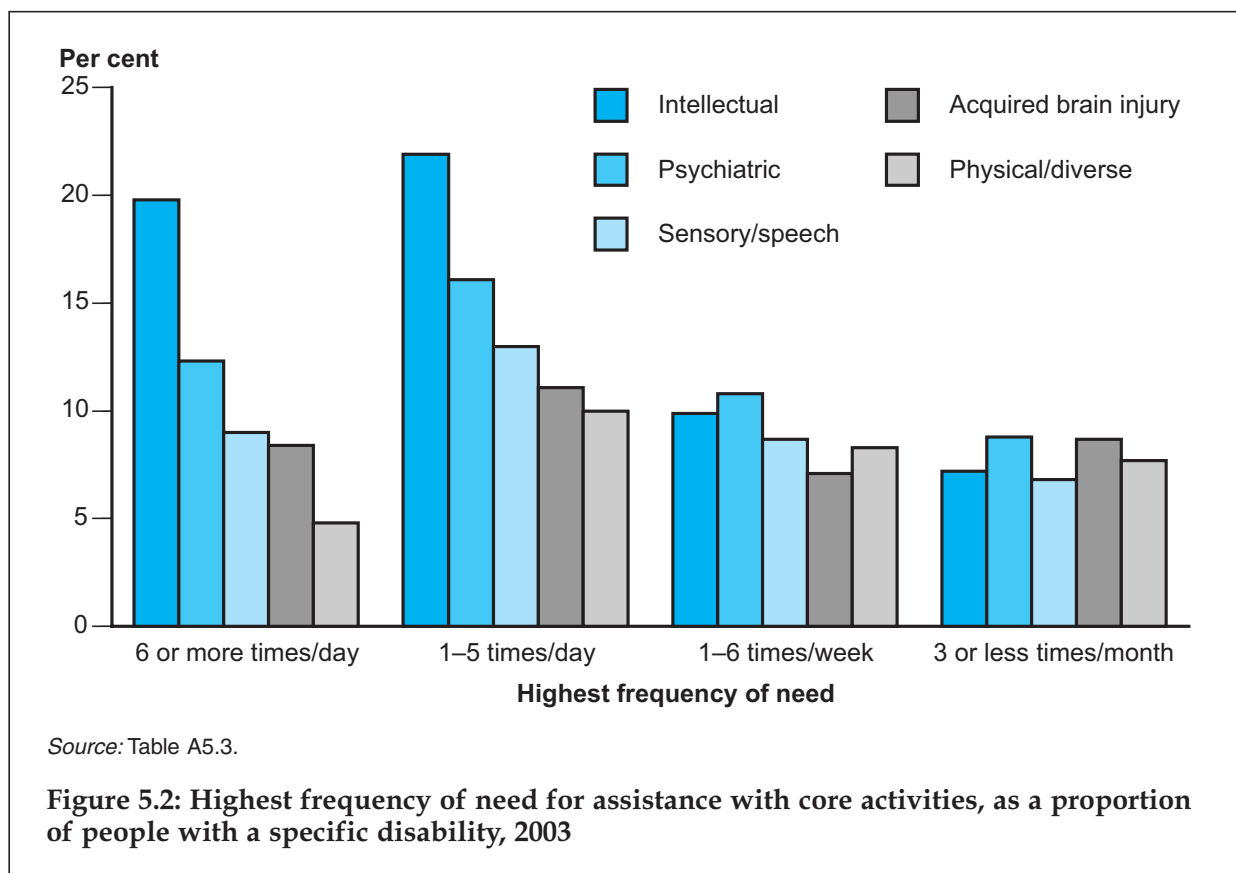
Similarly, focusing on 'all disabling conditions' estimates (Table 5.2):

- psychiatric disability was reported for an estimated 722,100 people aged under 65 (4.2% of the age group), of whom 720,000 (4.2%) had activity limitations or participation restrictions, and 277,700 (1.6%) had a profound or severe activity limitation;

- intellectual disability was reported by 436,200 people aged under 65 (2.5% of the age group), of whom 432,000 (2.5%) had activity limitations or participation restrictions, and 215,100 (1.2%) had a profound or severe activity limitation; and
- acquired brain injury was reported by 317,400 people aged under 65 (1.8% of the age group), of whom 311,800 (1.8%) had activity limitations or participation restrictions, and 99,900 (0.6%) had a profound or severe activity limitation associated with acquired brain injury.

Focusing only on the ‘main disabling condition’ of each person, 15% of the total population reported physical/diverse as the disability most affecting their daily life, as did 10% of people aged under 65. Among those aged under 65, 1.4% had a sensory/speech main disability, 1.9% psychiatric, 0.9% intellectual disability and 0.2% acquired brain injury.

There is some relationship between the nature of disability, as indicated by these disability groupings, and the extent of disability, as indicated by the frequency of need for assistance with the core activities (Figure 5.2). People with intellectual disability were the most likely to report needing assistance 6 or more times per day (20%), followed by people with psychiatric disability (12%). People reporting physical disabilities were the least likely to report needing such frequent assistance (4.8%). Similar differences among the disability groups held for people needing assistance 1–5 times per day. The differences became less marked when the highest frequency of assistance was less than daily.

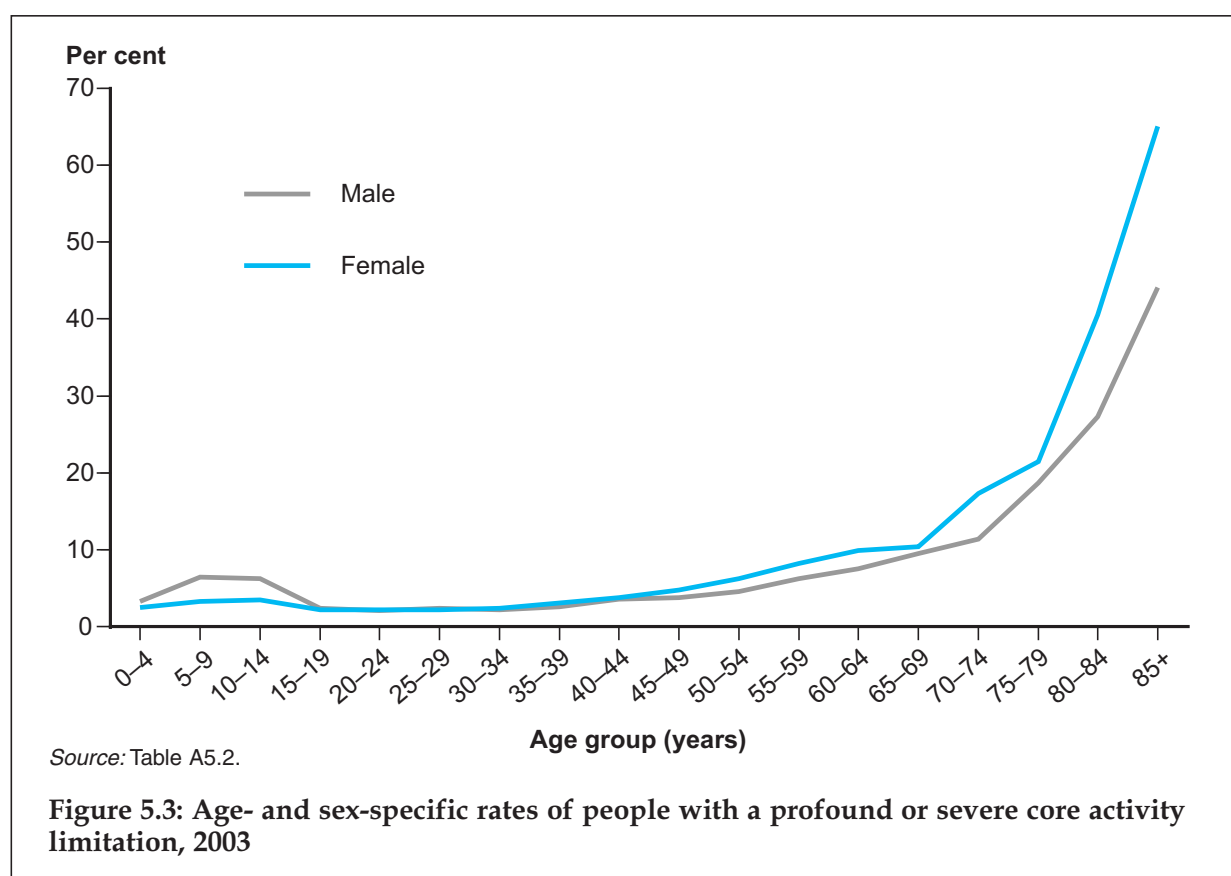




People with physical/diverse disabilities were the most likely to report needing no help at all (see Table A5.3) and those with intellectual disabilities the least likely. It was people aged 65+ with intellectual or psychiatric disabilities who were the most likely of all to need assistance 6+ times per day.

## Disability and ageing

The relationship between disability and age is not necessarily straightforward, even though at first glance it may seem so because of the general tendency for the likelihood of disability to increase with age (Figure 5.3). Here attention is focused on the age- and sex-specific rates of profound or severe core activity limitations. The graph reflects what happens to people during the life-cycle, their changing environments and the accumulation of risks they encounter.



The peak in early childhood and school years may reflect the environment of family, early intervention services and school, which may combine to identify a greater proportion of disabilities than at later ages. This pattern has been present in previous years, and these and other factors are discussed later in this section (under 'Children with a disability'; see also AIHW 2004a). The prevalence rate was lower among adolescents than children, and remained at a rate just under 2.5% among people in their 20s and early 30s.

From age 35, disability prevalence rates increased with age, as new risk factors for disability impacted on the population. For young adults, injury is a relatively high risk (see Chapter 2). Young adult males, in particular, may experience injuries such as spinal

cord and brain injuries that can lead to lifelong disability (AIHW NISU: Cripps 2004; AIHW NISU: O'Connor 2002). Working ages may see work-related injuries occur; these middle years are also the years of onset of musculoskeletal and other conditions such as arthritis and heart diseases associated with physical disabilities, as well as hearing and psychiatric disabilities (AIHW 2003b, 2004b). In the older age groups, more illnesses affecting human functioning become prevalent, including cardiovascular diseases, cancers and dementia, and the rates of vision, hearing and movement-related disabilities are higher. (Sex differences at older ages are discussed in Chapter 4, and in childhood under 'Children with a disability' in this chapter.)

The patterns of age at onset of disability are illustrated in Table 5.3. Among people of all ages reporting intellectual disabilities, 94% reported an age at onset of 14 years or younger. Psychiatric disabilities and acquired brain injury were most likely to have started at ages 15–44 years (50% and 56% respectively). The onset of physical disabilities was more evenly spread across the life-cycle; while most likely to start in the age range 15–44 years (39% did so), this was the most likely of the disability groups to have an age of onset 65 years or above. Each of the groupings is quite broad and there is variation within them. For instance, speech disabilities have a likely earlier age of onset than vision disabilities – in 1998, about 87% of people with speech as a main disabling condition first experienced the condition at age 0–4 years, compared with 15% for those with vision disorders (AIHW 2003b:71). (See Box 5.4 on the need for caution when interpreting age-at-onset data.)

**Table 5.3: People of all ages with a disability living in households: age at onset of main disabling condition by disability groups (based on main disabling condition), 2003**

	Age at onset of main condition					Total
	0–14	15–44	45–64	65+	Not known	
	<b>Number ('000)</b>					
Intellectual	152.1	*5.1	**0.2	**0.9	*3.7	162.0
Psychiatric	107.4	183.4	50.0	16.8	6.6	364.0
Sensory/speech	137.7	108.1	86.5	64.1	8.7	405.0
Acquired brain injury <sup>(a)</sup>	*9.0	15.3	*2.9	—	—	27.2
Physical/diverse	385.2	1,103.2	844.7	448.6	28.6	2810.3
<b>Total</b>	<b>791.3</b>	<b>1,415.1</b>	<b>984.3</b>	<b>530.4</b>	<b>47.5</b>	<b>3,768.5</b>
	<b>Per cent</b>					
Intellectual	93.9	*3.1	**0.1	**0.5	*2.3	100.0
Psychiatric	29.5	50.4	13.7	4.6	1.8	100.0
Sensory/speech	34.0	26.7	21.3	15.8	2.1	100.0
Acquired brain injury <sup>(a)</sup>	*33.1	56.3	10.5	—	—	100.0
Physical/diverse	13.7	39.3	30.1	16.0	1.0	100.0
<b>Total</b>	<b>21.0</b>	<b>37.5</b>	<b>26.1</b>	<b>14.1</b>	<b>1.3</b>	<b>100.0</b>

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

*Notes*

1. Estimates marked with \* have an associated relative standard error (RSE) of between 25% and 50% and should be interpreted accordingly.
2. Estimates marked with \*\* have an associated relative standard error (RSE) of greater than 50% and should be interpreted accordingly.

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

While it is well known that the overall population is ageing, there is also evidence that people with early-onset disabilities are living longer than previously (AIHW 2000a; see Chapter 4 for discussion of ageing more generally). A Western Australian study (Leonard et al. 2004:25), based on linked data sets for that state, found that:

Average life expectancy for affected persons has greatly increased over the past 50 years, such that a person with moderate intellectual disability is expected to live to at least 67 years of age, and people with mild intellectual disability should, on average, live to 74 years of age ... For people with Down syndrome ... average survival is now 59 years.

#### **Box 5.4: Interpreting data on age at onset**

*Survey information about 'age when accident happened/onset of main disabling condition' is used as a proxy measure to indicate 'age of onset of disability,' and this information was not collected among people living in cared accommodation. Therefore some data limitations need to be considered. For instance, the exclusion of people in cared accommodation affects comparisons among condition groups, possibly associated with underestimates of some disabilities in the older age groups. The analysis in Table 5.3 relates to 'main' conditions only. (This information was collected for main disabling condition only.) A person with an early-onset condition who has learned to cope with that condition might find a recently acquired condition more disabling and report this as the main condition.*

*Comparisons of ages of onset among people of different current ages are not attempted, as the survey data are cross-sectional – essentially a snapshot at a point in time. This means that for each age group, there is a limited range of possible ages of onset – for instance, a person aged under 45 cannot have a disability reported to have begun at age 50.*

*The reported patterns of onset partly reflect current age structures of the population. The high proportion of people reporting onset before age 65 relates to the high proportion of people with a disability who were aged under 65 in 2003 (65% – Table 5.1 – 2,556,000 of 3,946,400).*

The relationship between disability and ageing thus has several facets. The picture for people aged 45–64 years with a disability is of particular interest. These are people who are approaching the years when they may need aged care, or to make a transition from disability services to aged care services. The great majority of these people had a physical disability in 2003 (82%, based on the main condition reported) and, for most, this had commenced in adult years (only 7.4% had an age of onset under 15 years; see Table A5.4). In contrast, the relatively small proportion of people in the 45–64 years age group reporting a main condition associated with intellectual disability (0.5%) were very likely (78%) to report the age of onset as being 14 years or under.

People in older age groups needed more frequent assistance than younger people, and with more core activities. People aged 65+ years, with a disability, were much more likely to report needing assistance 6+ times per day than younger people, and this held across all disability groups (see Table A5.3). Most notably, 48% of people aged 65+ with intellectual disability reported needing assistance 6+ times per day, compared to 10% of

those aged under 65. Of those with psychiatric disability, 29% reported needing assistance 6+ times per day, compared to 5% of those aged under 65. There was no indication that people aged 45–64 years had more frequent needs for assistance than those aged under 45 years and, in fact, there were higher proportions needing no help with any core activities.

Among people with profound or severe core activity limitations, almost 40% of those aged 65+ years needed assistance with two or three of the core activities, compared to 38% of those aged 0–44 years and 35% of those aged 45–64 years (Table 5.4). Older people also had higher numbers of health conditions associated with disability (see Figure 5.5).

**Table 5.4: People with a profound or severe core activity limitation living in households: number of activities with which assistance needed, by age, 2003**

	0–44 years		45–64 years		Total <65 years		65+ years	
	Number ('000)	Per cent	Number ('000)	Per cent	Number ('000)	Per cent	Number ('000)	Per cent
At least one of ten daily activities <sup>(a)</sup>	376.2	97.8	273.4	98.8	649.5	98.2	405.1	99.6
One core activity	223.2	58.0	174.9	63.2	398.0	60.2	238.4	58.6
Two core activities	94.8	24.6	91.1	32.9	185.9	28.1	141.3	34.7
Three core activities	51.7	13.4	*5.9	*2.1	57.6	8.7	20.8	5.1
Total with two or three core activities	146.5	38.1	97.0	35.0	243.5	36.8	162.1	39.8
<b>Total profound or severe</b>	<b>384.7</b>		<b>276.7</b>		<b>661.4</b>		<b>406.9</b>	

(a) Daily activities include three core activities (self-care, mobility and communication) plus cognition or emotion, health care, housework, property maintenance, paperwork, meal preparation and transport.

Note: Estimates marked with \* have an associated relative standard error (RSE) of between 25% and 50% and should be interpreted accordingly.

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

## Disability trends 1981–2003

As the population grows and ages and as life expectancy increases, there will be more people in Australia at older ages and more people with disabilities, but there is no evidence that the age-standardised rates of severe disability are rising (ABS 2004a; AIHW 2000a, 2003a). The evidence from the five population disability surveys since 1981 is that:

- the reported age-standardised rates of 'severe disability' in Australia were fairly stable between 1981 and 1993;
- there was an increase in rates from 1993 to 1998, mainly attributed, after considerable analysis, to changes in the survey methodology, questions and administration, and population ageing;
- the 2003 survey maintained the 1998 survey questions and methods, and the results confirmed the previous, stable rates of 'severe disability'. The age-standardised rates for profound or severe core activity limitations were 6.4% in 1998 and 6.3% in 2003; and
- overall, then, it has been concluded that there was no change in rates for profound or severe core activity limitations between 1981 and 2003. The rise in reported rates in 1998 is attributable to survey methodology changes rather than population changes.

Even though underlying age-specific prevalence rates appear relatively stable, population growth and population ageing are associated with an increase in the number of people with a disability. Between 1998 and 2003, the number of people with a profound or severe core activity limitation increased by 9.6%, from 1,135,900 to 1,244,500 (ABS 1999, 2004a). With population ageing, the increase in the number of older people (aged 65 and over) with a disability could be associated with an increase in the overall number of people with multiple health conditions and people needing more frequent assistance with daily activities (because of the association of these with age – see Tables A5.3, A5.6; AIHW 2004b).

## Children with a disability

There are distinctive patterns of disability in childhood years which deserve special attention. The AIHW compiled a report on the topic in 2004 (AIHW 2004a). Some key findings from this report are updated here.

In 2003, children aged under 15 years had higher rates of profound or severe core activity limitation (4.3%) than people in the next age group (2.2% of 15–24 year olds; see Table 5.1). Congenital conditions, present since birth, do not simply disappear when people reach 19 years of age, and the downturn observed in Figure 5.3 could be related to a number of factors. These could include: successful interventions in childhood that have increased the level of functioning; the person moving to more inclusive or accepting environments than school; or a reduction in the person's own propensity to report difficulties with daily activities (in comparison, say, with parents' responses on the child's behalf in previous years).

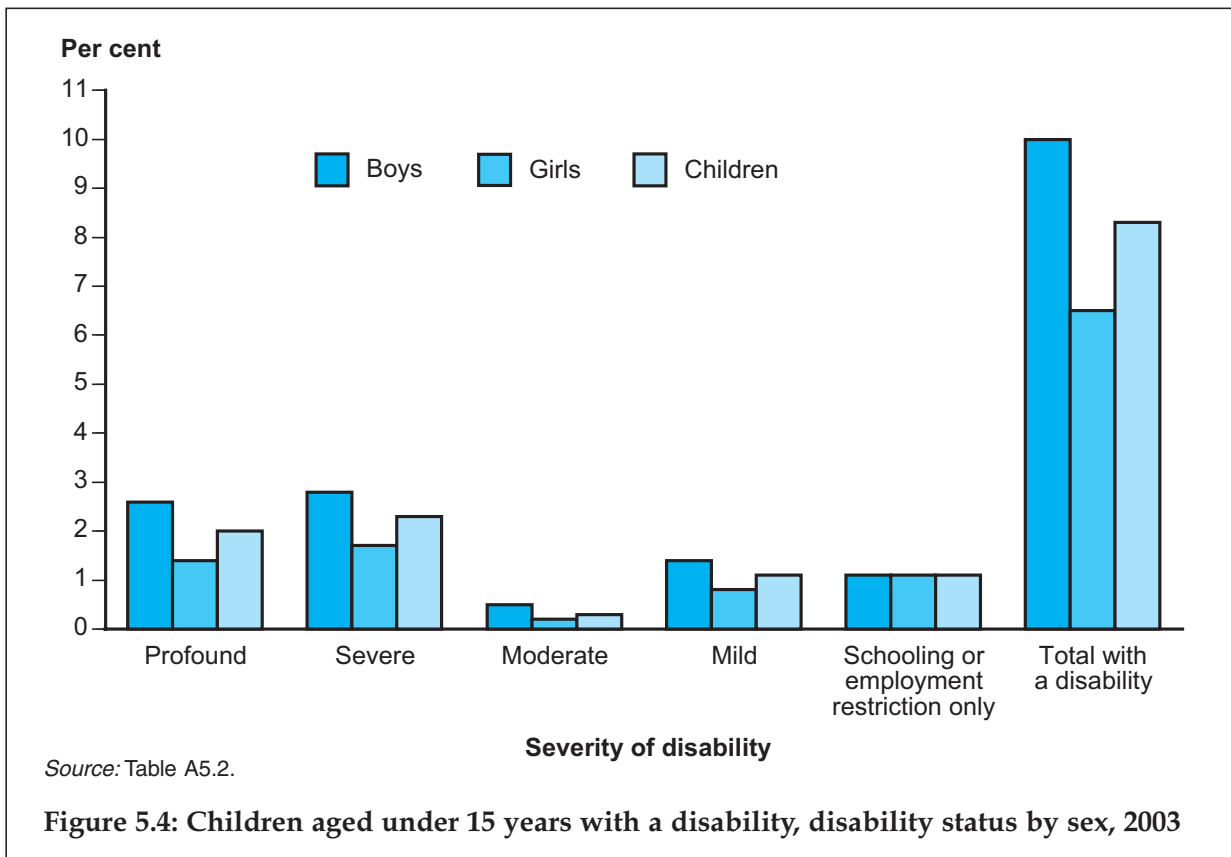
It is possible that the environment of family, early intervention services and school may combine in the early years to identify a greater proportion of disabilities than at later ages. It may also be that 'communication' as a core activity has a particular influence on profound or severe core activity limitation rates in childhood – in 1998, children with disabilities were far more likely to report profound or severe core activity limitations involving communication than did other people with disabilities (AIHW 2004a:17–18).

Another possible factor in this pattern, but one on which the evidence is not clear, is that prevalence rates of related conditions may have risen in recent years. For instance, Attention Deficit Hyperactivity Disorder (ADHD) and autism are conditions where numbers are reportedly rising; some researchers attribute this mainly to changing diagnostic methods and increased awareness of the conditions (AIHW 2004a:37–40).

In 2003, 10% of boys, and 6.5% of girls aged under 15 years had a disability (Figure 5.4; Tables A5.2, A5.5). There were age and sex differences in both prevalence rates and severity:

- Higher disability rates for boys also held across all age groups – for instance, of boys aged 5–9 years, 12% reported disability and 2.9% reported 'profound' core activity limitations; the figures for girls aged 5–9 years were 6.4% and 1.5% respectively.
- Boys were more likely than girls to report disability in all 'severity' categories; 2.6% of boys and 1.4% of girls reported 'profound' disability. While the rates for boys were higher in most age and severity groups, the pattern was not universal.
- The higher rates for boys held, in a fairly consistent pattern, across all disability groups.





## Disability among Aboriginal and Torres Strait Islander peoples

Data on disability among Aboriginal and Torres Strait Islander people have been inadequate, but national statistics have recently been significantly improved. The National Aboriginal and Torres Strait Islander Social Survey (ABS 2004b) has overcome a number of the challenges previously identified for this field, although the question of Indigenous conceptualisation of disability still remains for discussion (e.g. AIHW 1999:224).

In 2002, 102,900 (37%) of Aboriginal or Torres Strait Islander people aged 15 years and over had a disability or a long-term health condition (Table 5.5). Of these, 21,800 (or 8% of the population aged 15 years and over) had a profound or severe core activity limitation, meaning that they always or sometimes needed assistance with activities of everyday living (self-care, mobility and communication). These estimates are not strictly comparable with those for the general population presented previously in this section (e.g. Table 5.1). There were fewer survey screening questions in remote areas, probably leading to under-enumeration of physical and psychiatric disabilities in these areas and in the overall estimates (which use common criteria for both remote and non-remote areas) (ABS & AIHW 2005).

The disability status of Indigenous people can be compared to that of non-Indigenous people in the General Social Survey, using broader criteria, for non-remote areas (ABS & AIHW 2005). The Indigenous to non-Indigenous age-standardised rate ratio for people aged 18 years and over with a profound or severe core activity limitation is calculated to be 2.1 (2.5 for males, 1.8 for females).

This means that, if the Indigenous and non-Indigenous populations had the same age structure as the total Australian population, the number of Indigenous people in non-remote areas with profound or severe core activity limitation would be 2.1 times the corresponding number of non-Indigenous people. If the broader criteria used in non-remote areas had been used in remote areas, it is likely that the prevalence estimates for remote areas would be higher, as would the rate ratios. In general terms, then, it can be said that Aboriginal and Torres Strait Islander people have severe disability rates at least 2.1 times those of other Australians.

**Table 5.5: Aboriginal and Torres Strait Islander people aged 15 or over by disability status, Australia, 2002**

Age group	Profound/severe core activity limitation		Disability/limitation (nfd)		Total with disability or long-term health condition		Has no disability or long-term health condition		Total	
	No. ('000)	Per cent	No. ('000)	Per cent	No. ('000)	Per cent	No. ('000)	Per cent	No. ('000)	Per cent
<b>Males</b>										
15–24	*1.6	4.0	7.2	17.6	8.9	21.6	32.3	78.4	41.2	100.0
25–34	2.3	6.9	7.7	22.9	10.0	29.8	23.5	70.2	33.4	100.0
35–44	1.4	5.2	8.8	32.2	10.2	37.4	17.1	62.6	27.4	100.0
45–54	1.9	10.4	8.0	43.5	9.9	53.9	8.5	46.1	18.5	100.0
55–64	1.1	12.0	5.2	59.1	6.3	71.1	2.6	28.9	8.9	100.0
65+	1.7	28.7	2.8	48.0	4.5	76.7	1.4	23.3	5.9	100.0
<i>Total</i>	<i>10.0</i>	<i>7.4</i>	<i>39.8</i>	<i>29.5</i>	<i>49.8</i>	<i>36.9</i>	<i>85.4</i>	<i>63.1</i>	<i>135.2</i>	<i>100.0</i>
<b>Females</b>										
15–24	*1.5	3.6	8.4	20.3	9.9	23.9	31.6	76.1	41.5	100.0
25–34	1.9	5.0	8.7	23.2	10.6	28.2	27.0	71.8	37.7	100.0
35–44	2.7	8.9	9.1	29.9	11.8	38.9	18.6	61.1	30.4	100.0
45–54	2.8	14.1	6.3	31.5	9.1	45.6	10.8	54.4	19.9	100.0
55–64	1.3	12.7	5.5	52.6	6.8	65.3	3.6	34.7	10.4	100.0
65+	1.6	22.3	3.3	46.6	4.8	68.8	2.2	31.2	7.0	100.0
<i>Total</i>	<i>11.8</i>	<i>8.0</i>	<i>41.3</i>	<i>28.1</i>	<i>53.1</i>	<i>36.1</i>	<i>93.9</i>	<i>63.9</i>	<i>147.0</i>	<i>100.0</i>
<b>Persons</b>										
15–24	3.1	3.8	15.7	19.0	18.8	22.7	63.9	77.3	82.7	100.0
25–34	4.2	5.9	16.4	23.1	20.6	29.0	50.5	71.0	71.1	100.0
35–44	4.1	7.2	17.9	31.0	22.0	38.2	35.7	61.8	57.8	100.0
45–54	4.7	12.3	14.3	37.3	19.0	49.6	19.4	50.4	38.4	100.0
55–64	2.4	12.4	10.7	55.6	13.1	68.0	6.2	32.0	19.3	100.0
65+	3.2	25.2	6.1	47.2	9.3	72.4	3.6	27.6	12.9	100.0
<b>Total</b>	<b>21.8</b>	<b>7.7</b>	<b>81.1</b>	<b>28.7</b>	<b>102.9</b>	<b>36.5</b>	<b>179.3</b>	<b>63.5</b>	<b>282.2</b>	<b>100.0</b>

*Notes*

1. 'Total with disability or long term health condition' is the sum of persons with 'profound/severe core activity limitation' and persons with 'disability/limitation nfd'.
2. Common criteria were used to identify persons with a disability in both non-remote and remote areas. This means that people with a psychological disability cannot be explicitly identified and some people with physical disability will not be included.
3. Estimates marked with \* have an associated relative standard error (RSE) of between 25% and 50% and should be interpreted accordingly.

Source: ABS & AIHW 2005.

Among Aboriginal and Torres Strait Islander people aged 18–64 years, those with a disability or long-term health condition had completed fewer years of school on average than other people. In non-remote areas, 52% of Indigenous people with a disability or long-term health condition had completed only Year 9 or below, compared with 28% of people without a disability or long-term health condition. In remote areas, the corresponding proportions were 64% and 43% (Table 5.6). Indigenous people in remote areas with a profound or severe core activity limitation were the least likely to have progressed beyond Year 9, with 71% educated to this level or below. People with no disability were about twice as likely as others to have completed Year 12, in both remote and non-remote areas.

**Table 5.6: Aboriginal and Torres Strait Islander people aged 18–64 years or over by highest year of school completed by remoteness and disability status (per cent), 2002**

Highest year of school completed	Non-remote area				Remote area			
	Profound or severe core activity limitation	Total with a disability or long-term health condition	No disability or long-term health condition	Total	Profound or severe core activity limitation	Total with a disability or long-term health condition	No disability or long-term health condition	Total
Completed Year 12	*12.1	11.8	25.6	20.3	*6.2	8.3	17.0	13.7
Completed Year 10 or 11	33.4	36.0	46.9	42.8	*23.3	28.2	39.7	35.3
Completed Year 9 or below <sup>(a)</sup>	54.5	52.2	27.5	37.0	70.5	63.5	43.3	50.9
<b>Total</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>
<b>Total (number)<sup>(b)</sup></b>	<b>14,000</b>	<b>69,300</b>	<b>111,600</b>	<b>180,900</b>	<b>6,700</b>	<b>26,100</b>	<b>42,900</b>	<b>69,100</b>

(a) Includes persons who never attended school.

(b) Excludes persons who were still at school.

#### Notes

1. Common criteria were used to identify persons with a disability in both non-remote and remote areas. This means that people with a psychological disability cannot be explicitly identified and some people with physical disability will not be included.
2. Estimates marked with \* have an associated relative standard error (RSE) of between 25% and 50% and should be interpreted accordingly.

Source: ABS & AIHW 2005.

Aboriginal and Torres Strait Islander people with a disability or long-term health condition were much less likely to be employed, especially full-time, and less likely to be in the labour force than those without a disability or long-term health condition (Table 5.7). This was true for both men and women. People with a profound or severe core activity limitation were the least likely to be employed, with only 30% of men and 23% of women being employed either full-time or part-time, compared with 70% of men and 49% of women with no disability or long-term health condition. Most people with a profound or severe core activity limitation were not in the labour force (56% of men and 72% of women).

Employment is not the only area of further disadvantage experienced by Aboriginal and Torres Strait Islander people with disabilities. In 2002, they also experienced lower income levels and were more likely to have been removed from their natural families (ABS & AIHW 2005). The reasons for these multiple disadvantages may be related to age and geography, as well as to other complex social factors. Nevertheless, it is clear that Aboriginal and Torres Strait Islander people with disabilities were more likely to be

experiencing a range of other social disadvantages than other Indigenous people, themselves generally disadvantaged when compared with other Australians.

Social participation is a notable exception to this pattern. Some 61% of Aboriginal and Torres Strait Islander people aged 15 years and over in non-remote areas, and 87% in remote areas, had attended a cultural event in the 12 months before the survey; 90% had been involved in social activities in the previous 3 months (ABS & AIHW 2005). People with varying levels of disability were equally involved in these activities.

**Table 5.7: Indigenous persons aged 18–64 years, labour force status by disability status and sex, 2002 (per cent)**

	Males				Females			
	Profound or severe core activity limitation	Disability or long-term health condition	No disability or long-term health condition	Total	Profound or severe core activity limitation	Disability or long-term health condition	No disability or long-term health condition	Total
Employed full-time	*10.8	25.0	45.9	38.2	*4.2	12.6	21.9	18.5
Employed part-time	*19.0	19.3	23.8	22.2	18.2	18.8	27.5	24.4
<i>Total employed</i>	<i>29.8</i>	<i>44.4</i>	<i>69.8</i>	<i>60.5</i>	<i>22.5</i>	<i>31.5</i>	<i>49.4</i>	<i>43.0</i>
Total unemployed	*14.3	15.5	16.3	16.0	*5.5	10.2	10.4	10.3
Not in the labour force	56.0	40.1	13.9	23.5	72.0	58.3	40.2	46.7
<b>Total</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>
<b>Total (number)</b>	<b>7,700</b>	<b>41,600</b>	<b>71,700</b>	<b>113,400</b>	<b>9,800</b>	<b>44,900</b>	<b>80,300</b>	<b>125,200</b>

*Notes*

1. Common criteria were used to identify persons with a disability in both non-remote and remote areas. This means that people with a psychological disability cannot be explicitly identified and some people with physical disability will not be included.
2. Estimates marked with \* have an associated relative standard error (RSE) of between 25% and 50% and should be interpreted accordingly.

Source: ABS & AIHW 2005.

## Disability, related health conditions and other factors

Disability and its components (i.e. impairments, activity limitations and participation restrictions) are related to health conditions, environmental factors and personal factors (see Figure 5.1).

The presence of multiple health conditions tends to be associated with more ‘severe’ disability (Figure 5.5; Table A5.6). In 2003, the average number of conditions for people in the general population was 0.9, for people with a disability 3.1, and for people with a profound core activity limitation 4.1. Older age groups (65+ years) had higher average numbers of health conditions, across all categories of disability status.

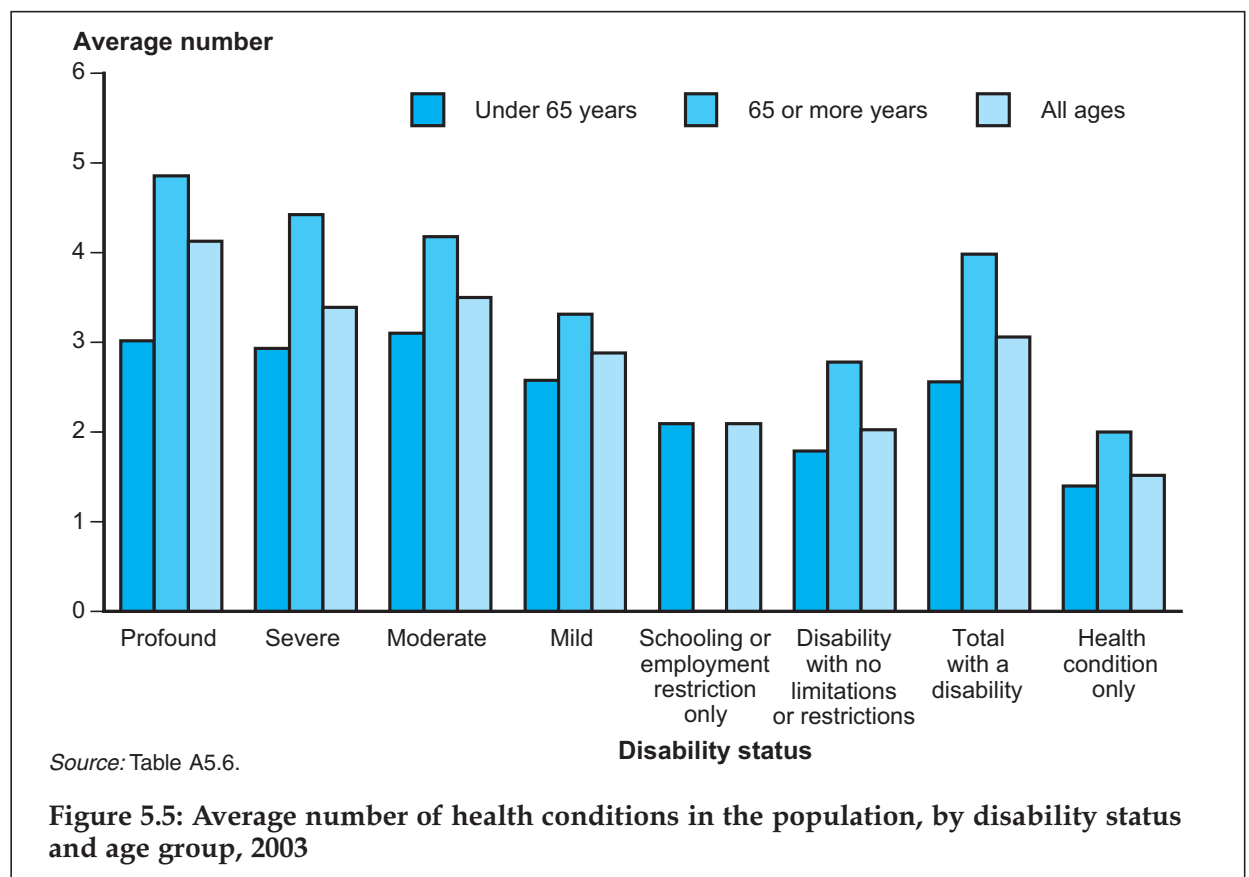
The relationship between health conditions and disability can be looked at in a number of ways. One way is by examining health conditions most likely to be associated with profound or severe core activity limitation. The 15 health conditions (of those recorded in the disability survey) most likely to be associated with profound or severe core activity limitations are shown in Figure 5.6. Of people aged under 65 with autism in

2003, 82% reported such limitations in 2003, as did 79% of those with paralysis, 67% of those with speech-related conditions and 64% of those with cerebral palsy (Figure 5.6). Dementia (98%) led the list of top five conditions for people aged 65 years and over with a profound or severe core activity limitation, followed by 89% of those with paralysis, 87% of those with speech-related conditions, 79% with Parkinson's disease and 76% with schizophrenia. Most of these conditions are highly related to age.

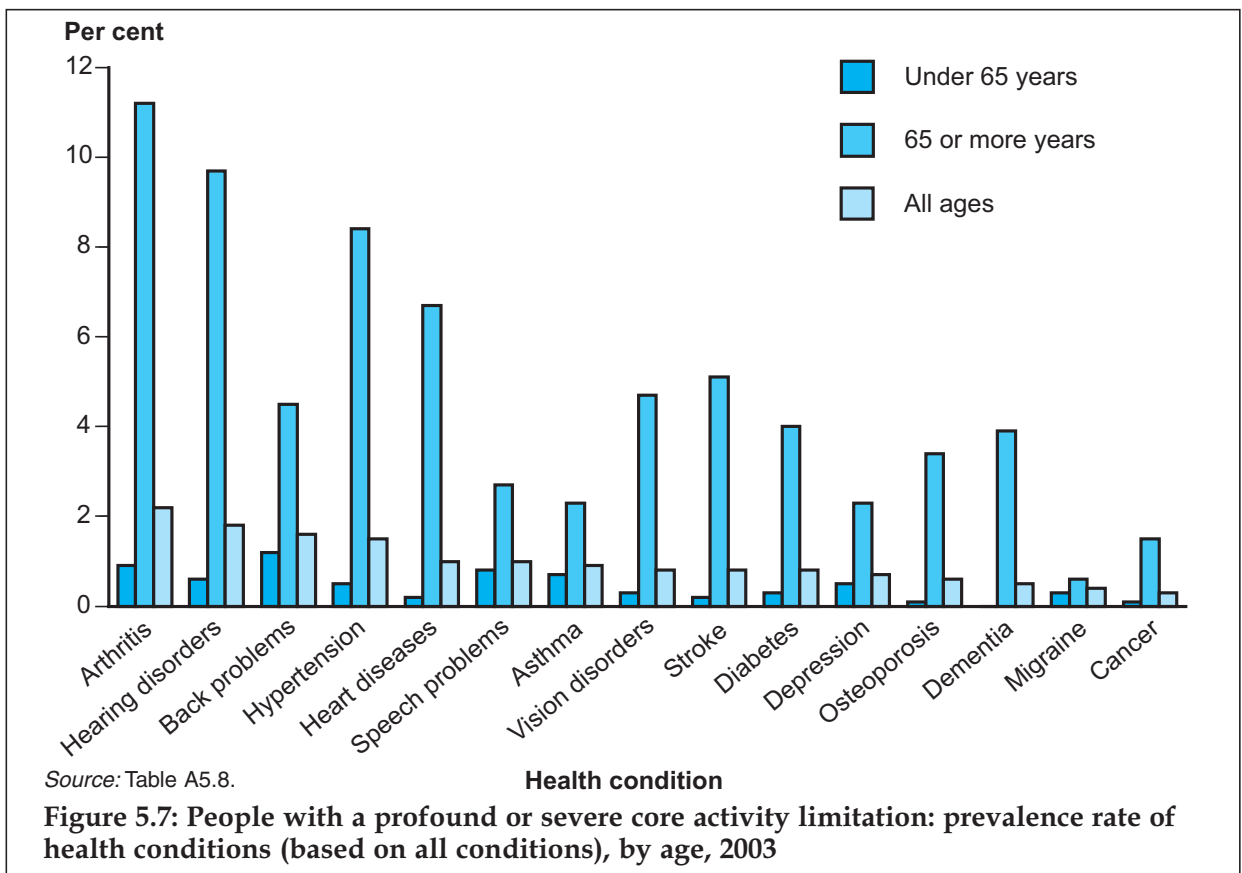
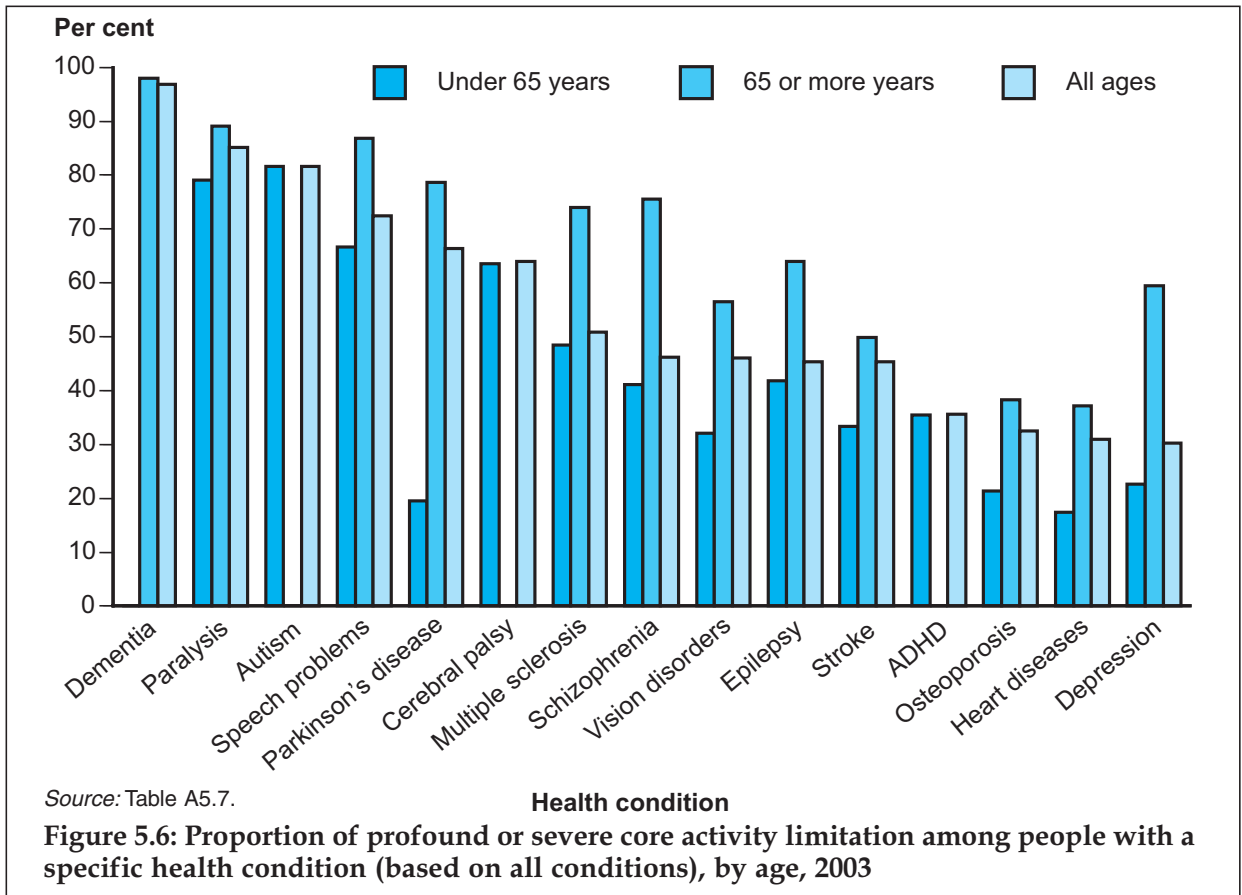
Another way of looking at the relationship between disability and health conditions is to ask the question: when looking at profound or severe core activity limitation in the population, which are the most common associated diseases or conditions? Here, a different picture emerges, related to the prevalence of the health conditions themselves.

The leading conditions associated with profound or severe core activity limitations among people aged under 65 in 2003 were back problems and arthritis—1.2% of people of this age reported back problems and a profound or severe core activity limitation, and 0.9% reported arthritis and a profound or severe core activity limitation (Figure 5.7; Table A5.8). For the population of all ages, arthritis, hearing, and back problems led the list. Conditions such as ADHD, autism and dementia, while highly likely to be related to profound or severe core activity limitations, were less common as they were generally less prevalent (Figure 5.7; Table A5.8, and AIHW 2004b).

It is not suggested that these conditions and diseases explain or 'account for' most disability in the population. The ICF model does not suggest direct causal relationships, but rather acknowledges that a health condition is one of several important factors in the creation of disability (see Figure 5.1).







Further analyses have been conducted to examine the relationships between disability, environmental and personal factors as well as health conditions, and how these relationships vary with different measures of 'severity' of disability. Findings from these analyses are summarised in Box 5.5.

### **Box 5.5: Disability, health conditions and other factors, 1998 – multivariate analyses**

*Multivariate analyses – conducted to investigate the interrelationships between disability, health conditions, and environmental and personal factors – did not reveal key, simple indicators of disability severity from among all the factors it was possible to consider. Rather, they confirmed the complexity of relationships between disability severity, health conditions, and personal and environmental factors.*

*Personal factors (demographic characteristics, such as age and sex, and socioeconomic factors such as education and employment) and environmental factors (such as informal care and use of equipment) were found to be strongly related to severity of disability. The further variability in these relationships, according to specific health conditions, suggests that health conditions also play a complex and varying role in the creation of disability, although these effects are not simple to predict. The fact that a number of health conditions are very age-related (e.g. dementia and autism) further complicates the relationships. Overall, it appears likely that there are three-way interactions between the severity of disability, the environmental factors that may affect it, and the underlying long-term conditions associated with the disability.*

*The main results were reasonably similar for the severity measures examined: regularity of need for assistance with core activities (sometimes, always, never); frequency of need for assistance (daily, 3 times a day, etc.); and hours of informal care. This may not be surprising given the probable relationship between these measures.*

*The number of long-term conditions a person had was highly correlated with the severity of disability, however measured. This means that co-morbidity is very important in examining the relationships between particular conditions and the severity of disability.*

*The multivariate analyses also found that use of equipment, as one of the 12 personal and environmental factors under consideration, was associated with profound or severe core activity limitation.*

*Source: AIHW 2004b.*

## **Environmental factors: equipment**

Equipment is a key aspect of people's environment, and one which can significantly facilitate functioning. In 2003 a total of 1,886,200 people (48% of people with a disability) used equipment (Table 5.9).

For people aged under 65 years with a disability, the most commonly used equipment was 'medical aids' (used by 611,000 people or 24% of people with disability in this age group) and mobile or cordless phones (222,800 or 8.7%) (Table 5.8). Equipment of all kinds was likely to be used by people with profound activity limitations, especially equipment associated with the core activities – self-care, mobility and communication.

Medical aids were used by 29% of people with a profound core activity limitation; aids for showering/bathing were used by 19%; aids for toileting 12% and incontinence 11%; wheelchairs – manual by 9% and electric by 3%; and mobile or cordless phones by 16%.

**Table 5.8: Aids and equipment used by people aged under 65 years with a disability, by type of aid/equipment and disability status, 2003**

Aid/equipment used	Core activity restriction								Total with disability	
	Profound		Severe		Moderate		Mild			
	No. ('000)	Per cent	No. ('000)	Per cent	No. ('000)	Per cent	No. ('000)	Per cent	No. ('000)	Per cent
Eating aids	11.4	4.9	*5.6	*1.3	**0.2	**0.0	**1.3	**0.2	18.5	0.7
Showering/bathing aids	43.7	18.8	37.3	8.4	15.2	3.5	*3.7	*0.6	100.0	3.9
Toilet aids	27.3	11.7	12.0	2.7	7.9	1.8	**0.7	**0.1	47.8	1.9
Incontinence aids	24.7	10.6	*6.0	*1.4	6.2	1.4	*2.4	*0.4	39.3	1.5
Dressing aids	17.0	7.3	17.9	4.0	4.3	1.0	—	—	39.2	1.5
Electric wheelchair/scooter	*6.9	*3.0	*3.3	*0.7	—	—	**0.3	**0.1	10.5	0.4
Manual wheelchair	20.4	8.8	*3.3	*0.7	—	—	—	—	23.7	0.9
Cane	*5.5	*2.4	*7.6	*1.7	*4.0	*0.9	—	—	17.2	0.7
Crutches/walking stick	20.3	8.7	33.7	7.6	12.3	2.8	*7.0	*1.1	73.2	2.9
Walking frame	12.3	5.3	*4.6	*1.0	**1.9	**0.4	—	—	18.8	0.7
Seating/bedding aids	18.3	7.9	21.2	4.8	*6.7	*1.5	**1.4	**0.2	47.6	1.9
Other mobility aids	10.1	4.3	*5.6	*1.3	**0.8	**0.2	*3.6	*0.6	20.1	0.8
Reading/writing aids	13.3	5.7	11.3	2.5	*2.8	*0.6	*8.5	*1.4	35.9	1.4
Speech aids	*5.3	*2.3	*2.5	*0.6	**0.4	**0.1	—	—	*8.2	*0.3
Mobile/cordless phone	37.9	16.3	95.9	21.5	45.4	10.4	29.9	4.8	222.8	8.7
Fax machine	**1.4	**0.6	*9.3	*2.1	*4.0	*0.9	**2.1	**0.3	19.6	0.8
Meal preparation aids	*8.3	*3.6	15.9	3.6	*4.9	*1.1	**0.4	**0.1	32.2	1.3
Medical aids	68.2	29.3	153.9	34.6	142.2	32.6	126.1	20.1	611.0	23.9
<b>Total</b>	<b>232.6</b>	<b>..</b>	<b>445.1</b>	<b>..</b>	<b>436.5</b>	<b>..</b>	<b>626.7</b>	<b>..</b>	<b>2,556.0</b>	<b>..</b>

*Notes*

1. Aids or equipment used are those needed because of disabling conditions.
2. Reading/writing and speech aids include both low and high technology aids.
3. Totals are not the sum of the components because more than one aid or piece of equipment may be used by each person, or because people with schooling or employment restriction only are not presented but included in total with disability.
4. Estimates marked with \* have an associated relative standard error (RSE) of between 25% and 50% and should be interpreted accordingly.
5. Estimates marked with \*\* have an associated relative standard error (RSE) of greater than 50% and should be interpreted accordingly.

Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers.

Table 5.9: Aids and equipment used, by type of aid/equipment and age group (people with a disability), 2003

	0–14 years		15–29 years		30–44 years		45–64 years		65+ years		All ages	
	No. ('000)	Per cent	No ('000)	Per cent	No ('000)	Per cent	No. ('000)	Per cent	No. ('000)	Per cent	No. ('000)	Per cent
Self-care	24.8	16.8	19.7	11.5	45.4	14.1	154.8	17.8	785.2	32.7	1,030.0	26.3
Mobility	11.6	7.8	12.9	7.5	43.8	13.7	145.9	16.8	699.5	29.1	913.7	23.4
Communication	39.2	26.6	41.6	24.3	67.6	21.0	148.8	17.1	175.9	7.3	473.2	12.1
Hearing	10.2	6.9	11.7	6.8	14.6	4.5	72.7	8.4	344.3	14.3	453.4	11.6
Meal preparation	*2.5	*1.7	*4.2	*2.4	*8.2	*2.6	17.3	2.0	28.0	1.2	60.2	1.5
Medical	59.4	40.2	81.3	47.4	141.5	44.1	328.9	37.9	371.3	15.4	982.3	25.1
<b>Total aids used</b>	<b>147.6</b>	<b>100.0</b>	<b>171.4</b>	<b>100.0</b>	<b>321.2</b>	<b>100.0</b>	<b>868.3</b>	<b>100.0</b>	<b>2,404.1</b>	<b>100.0</b>	<b>3,912.7</b>	<b>100.0</b>
Number of users	104.8	71.0	125.5	73.2	207.1	64.5	525.5	60.5	923.4	38.4	1,886.2	48.2
Average number of aids	1.4		1.4		1.6		1.7		2.6		2.1	

*Notes*

1. Estimates marked with \* have an associated relative standard error (RSE) of between 25% and 50% and should be interpreted accordingly.
2. Estimates marked with \*\* have an associated relative standard error (RSE) of greater than 50% and should be interpreted accordingly.

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

The patterns of use of equipment varied somewhat with age (Table 5.8), as might be expected, given the age variations in disability groups and frequency of need for assistance (see also Tables 5.2, A5.3; AIHW 2004b). Medical aids were commonly used in all age groups and:

- Children made frequent use of communication aids (27% of all aids used by children aged under 15 with a disability) and self-care aids (17%).
- People aged 15–29 years (and 30–44 years) with a disability also made frequent use of these aids—24% (and 21%) were communication aids and 12% (and 14%) were self-care aids.
- The pattern changed for people aged 45–64 years, with self-care aids (18%), mobility aids (17%) and communication aids (17%) being the most commonly used apart from medical aids.
- People aged 65 years and over most commonly used self-care aids (33%) and mobility aids (29%).
- People aged 45 years and over reported the highest average number of types of aids used (1.7 for those aged 45–64 years and 2.6 for those aged 65+).

## 5.4 Services and assistance

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

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

Most assistance received by people aged under 65 with a disability is provided by family and friends, and these carers are briefly profiled in this section.

### Income support

#### Australian Government payments and allowances

The Australian Government is the main source of income support for people with a disability and for their carers (Box 5.6).

In 2004, the Disability Support Pension (DSP) was the most common payment for people with a disability, with close to 697,000 recipients and accounting for almost \$7.5 billion expenditure in 2003–04 (Tables 5.10, 5.11). The Australian Government Department of Veterans' Affairs Disability Pension was received by over 154,000 veterans at a cost of \$1.3 billion. Payments to carers accounted for nearly \$1.9 billion. Carer Allowance (Child and Adult) payments were received by close to 300,000 recipients in June 2004 (96,153 Carer Allowance Child and 201,454 Carer Allowance Adult) and accounted for \$965 million expenditure. Carer Payment was received by over 84,000 recipients at a cost of \$921 million.



## **Box 5.6: Australian Government disability-related payments and allowances**

**Disability Support Pension (DSP)** is a means-tested income support payment for people aged at least 16 years but under Age Pension (AP) age (at date of claim lodgement), who have a physical, intellectual or psychiatric impairment and an overall impairment rating of at least 20 points on the impairment tables. Eligibility criteria until 30 June 2006 are that, as a result of the impairment, recipients must have an inability to work 30 hours per week at full award wages in open employment, and be unable to undertake educational or vocational training which would equip them for work, within the next 2 years of their life. People of the same age who are permanently blind are also eligible for DSP. Except for permanently blind people, payments are income- and assets-tested, combined tests being applied for people with a spouse/partner. Changes to apply from 1 July 2006 were described earlier in this chapter.

**Mobility Allowance** is a non-means-tested income supplement, paid to people aged 16 years or over with a disability to help with transport costs to employment, vocational training, voluntary work or any combination of these activities, or job search, who are unable to use public transport without substantial assistance. It is also payable to recipients of Newstart Allowance and Youth Allowance.

**Sickness Allowance** is paid to people over 21 years of age but under Age Pension age who are temporarily incapacitated for work or full-time study because of disability, illness or injury and who have a job or full-time study to return to. It is not payable to Youth Allowance recipients who become incapacitated for study.

**Carer Allowance (Child/Adult)** is an income supplement payment available to people who provide daily care and attention in a private home to a person who has a disability or severe medical condition or who is frail aged. The Child Disability Assessment Tool and the Adult Disability Assessment Tool are used to assess eligibility. Up until September 2004 an eligibility requirement was that the care recipient and carer must live together in the same private residence (for Carer Allowance Child) or care must be provided in the home of the carer or care recipient (Carer Allowance Adult). Carer Allowance is free of income and assets tests and may be paid in addition to Carer Payment or other payments.

**Carer Payment (DSP/AP/other)** is an income support payment for people whose caring responsibilities prevent them from substantial workforce participation. The recipient must be providing constant care, permanently or for an extended period of time, to: a person (aged 16 or over) who has a severe physical, intellectual or psychiatric disability that qualifies the carer under the Adult Disability Assessment Tool; or to a child (aged under 16 years) with a profound disability; or to two or more children with disabilities. Carer Payment cannot be received as well as another income support payment, and the person being cared for must be receiving a social security pension or payment (e.g. DSP, AP) or satisfy specific income and assets tests. The recipient is not required to live with or adjacent to the person being cared for, but must be providing constant care in a private home.

**Wife Pension (DSP/AP)** is paid to female partners of DSP or Age Pension recipients who were on these payments as at 30 June 1995. Since 1 July 1995, this payment has been closed to new applicants.

*Newstart Allowance (incapacitated) and Youth Allowance (incapacitated) provide an exemption from 'activity test requirements' available to people – 21 years or more or under 21 years, respectively – who, due to a medical condition, illness or injury, are temporarily unable to work or, in the case of Youth Allowance, to study.*

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

*Contenance Aids Assistance Scheme provides assistance to people who have permanent and ongoing incontinence as a result of a neurological condition or severe impairment who are aged 16–64 years, or 65+ years and working in paid employment at least 8 hours per week. The aim of the program is to help eligible clients to meet the costs of continence aids.*

**Table 5.10: Australian Government disability-related payments and allowances, recipients and expenditure (all ages), 2003–04**

	<b>Recipients as at June 2004</b>	<b>Administered expenses 2003–04 (\$m)</b>
Disability Support Pension	696,742	7,492.5
Mobility Allowance	47,402	82.2
Sickness Allowance <sup>(a)</sup>	8,478	85.4
Carer Allowance (Child/Adult) <sup>(b)</sup>	297,607	965.4 <sup>(c)</sup>
Carer Payment (DSP/AP/other)	84,082	921.0
Wife Pension (DSP)	33,183	326.1
Newstart Allowance (incap.)	51,171	n.a. <sup>(d)</sup>
Youth Allowance (incap.)	3,861	n.a. <sup>(d)</sup>
Contenance Aids Assistance Scheme	18,173	10.15
Disability Pension (DVA)	154,602	1,289

(a) From July 2002 FaCS 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: 17,464 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.

Sources: DVA 2004; FaCS unpublished data.

For the last decade, there has been an upward trend in the numbers of DSP recipients (Table 5.11; AIHW 2003a:351–2). Several factors have been suggested for these increases—labour market conditions for older workers, changes to eligibility criteria and benefit levels, as well as growth in and ageing of the population. There has also been a steady rise in the numbers of people receiving a reduced rate of DSP, reflecting other sources of income, including employment-derived; however, fewer than 10% of DSP recipients in 2002 and 2003 had earnings from paid employment (FaCS 2002b, 2003). The increase in these numbers is generally commensurate with growth in DSP numbers overall.

Table 5.11: All recipients of disability-related payments and allowances, June 1995 – June 2004

	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004
Disability Support Pension (all)	464,430	499,235	527,514	553,336	577,682	602,280	623,926	658,915	673,334	696,742
DSP (maximum rate)	398,964	421,301	449,934	463,577	484,662	501,304	515,839	552,583	563,023	n.a.
DSP (reduced rate)	65,466	77,934	77,580	89,759	93,020	100,976	108,087	106,332	110,311	n.a.
Mobility Allowance	22,851	24,985	26,595	28,975	31,001	35,154	37,574	41,997	44,562	47,402
Sickness Allowance <sup>(a)</sup>	47,311	33,215	15,759	16,285	11,181	10,733	10,942	9,522	8,755	8,478
Carer Allowance (Child) <sup>(b)</sup>	78,898	90,644	95,520	90,830	100,452	116,955	111,691	115,404	119,003	96,153
Carer Allowance (Adult) <sup>(c)</sup>	38,408	42,047	44,103	45,675	51,857	84,104	123,350	153,863	180,606	201,454
Carer Payment (DSP) <sup>(d)</sup>	10,633	13,483	15,735	18,556	21,392	24,500	28,171	34,963	75,937	84,082
Carer Payment (AP)	8,324	9,500	10,954	11,740	13,407	15,346	18,097	20,227	n.a. <sup>(d)</sup>	n.a. <sup>(d)</sup>
Carer Payment (other)	1,141	2,054	2,869	3,683	5,271	7,704	10,922	12,070	n.a. <sup>(d)</sup>	n.a. <sup>(d)</sup>
Wife Pension (DSP)	121,839	107,803	91,307	79,892	68,523	59,934	51,225	44,238	37,880	33,183
Wife Pension (AP)	39,611	41,125	36,577	36,233	32,196	31,362	26,476	23,730	20,230	19,646
Newstart Allowance (incapacitated)	n.a.	n.a.	n.a.	48,792	59,670	68,016	76,850	76,882	54,243	51,171
Youth Allowance (incapacitated)	n.a.	n.a.	n.a.	n.a.	3,929	5,883	5,959	5,792	3,941	3,861
Disability Pension (DVA)	157,298	159,079	160,145	161,829	162,810	162,730	162,505	159,425	157,865	154,602

(a) From July 2002 FaCS 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 these counts are those who receive Carer Allowance (Child) Health Care Card only (only applies to data from 1999 on).

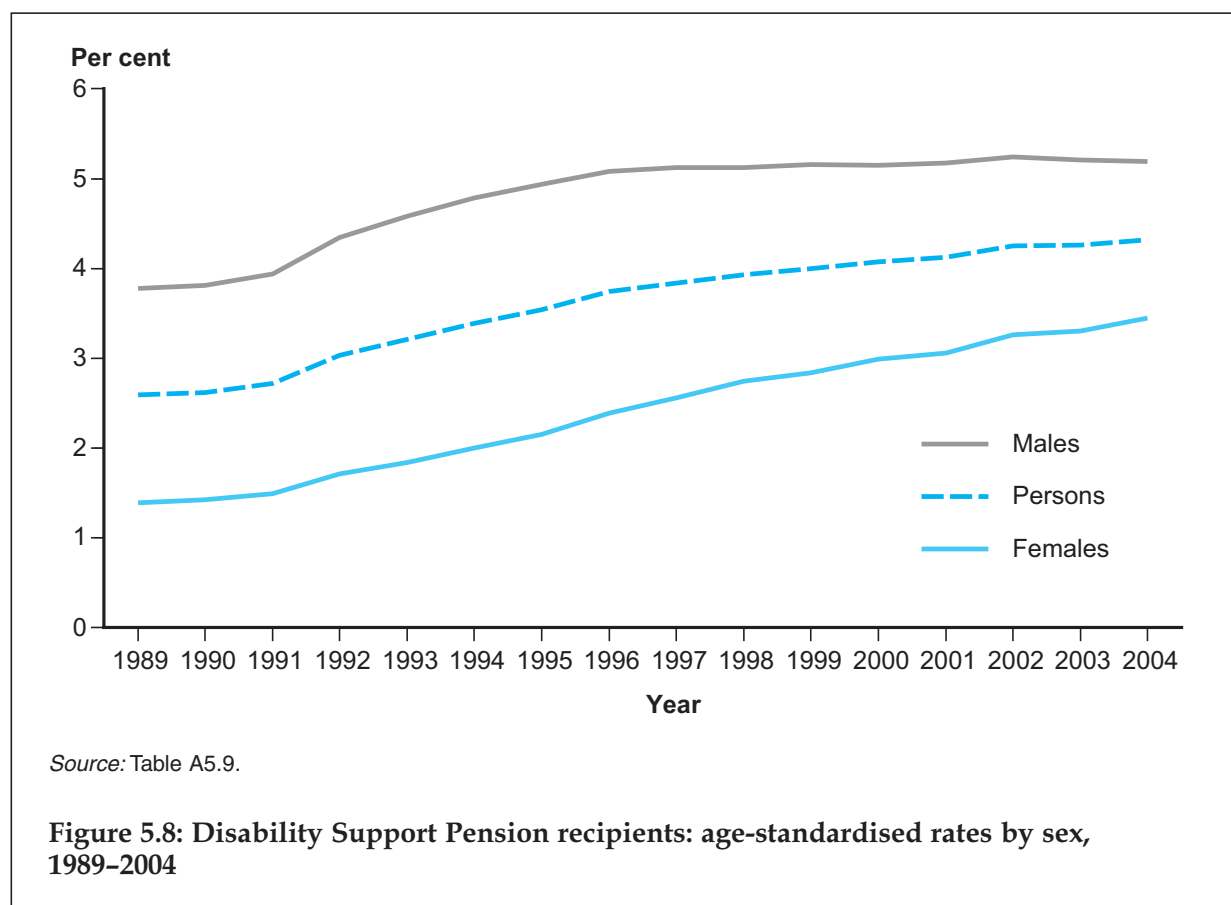
(c) From 2001 includes those who receive both Carer Allowance (Adult) and Carer Allowance (Child) and those not coded by type of payment.

(d) Carer Payment figures split by DSP, AP and other are unavailable for 2003 and 2004; hence totals for Carer Payment (DSP) in 2003 and 2004 are the sum of these components.

Sources: AIHW 2003a; DVA 2003, 2004; FaCS 2001 and FaCS unpublished data.

Several other payments and allowances experienced upward trends in recipient numbers between 1995 and 2004 (Table 5.11). The number of people receiving the Carer Allowance (Adult) continued its steep rise since 2000 (from 84,104 in 2000 to 201,454 in 2004). Similarly, there was a noticeable increase in the number of people receiving Carer Payment, almost twofold over the same period. Several reasons have been suggested for these trends, including demographic changes (e.g. the ageing of the population and associated rise in the number of people with a disability); greater awareness of these payments; reduction in access to other forms of income support (e.g. wife and widow pensions); and the increase in the number of people with disabilities and medical conditions being cared for at home (FaCS 2002b, 2003, 2004c). The Wife Pension (DSP/AP) continued its downward trend since the payment was closed to new applicants in 1995. (See Chapter 4 for further discussion of recent Carer Payment and Carer Allowance data.)

Not all the rise in DSP recipient numbers can be attributed to population growth and ageing, since age-adjusted rates rose over the period 1989–2004 (Figure 5.8; Table A5.9). Male rates have levelled off in recent years (to about 5.2% of the male population aged 16+ years). Male recipients aged 50–64 years – the age group with the highest proportion of the population receiving DSP – accounted for this slowing of growth from 1996; rates for younger age groups have continued a gradual upward trend.



Female rates have continued to rise, although more slowly and, in 2004, about 3.5% of the female population aged 16+ years received the DSP. As with men aged under 50 years, the proportion of women under 60 years receiving DSP gradually increased over the period, approximately doubling in all age groups since 1990. The age group 60–64 years was where the large changes occurred: the rate grew from 0.2% in 1995 to 8.4% in 2004. The increases in female rates overall could be related to a number of factors, including the closure in 1995 of the Wife Pension to new recipients. The increase in the age group 60–64 years may reflect adjustments to the eligibility ages for Age Pension (60 years to 1995, 62 years in 2002 and due to be 65 years, as for men, by 2014). Trends in female rates could also be affected by changes in the sex relativities of labour force participation and earnings, and how these might affect the partners' combined assets test and, in turn, DSP receipt.

In June 1989, 26% of DSP recipients (80,510 of 307,795) were women compared to 40% in June 2004 (277,913 of 696,742).

## **Concessions**

The Australian Government provides a range of concession cards to eligible people with a disability and their carers. These cards entitle the holder to various concessions on specific national, state and territory, and local government services, as well as some private sector concessions. The core areas agreed by state and territory governments are energy consumption, water and sewerage, municipal rates and transport (including public transport, motor vehicle registration and licence fees). Other concession areas vary across the country, for instance ambulance travel for isolated patients, glasses, dental care, taxi subsidies, and so on.

A Companion Card scheme currently operates in Victoria and will be introduced in Western Australia during 2005 (Disability Services Commission 2005; Victorian Government 2005). This enables an eligible person with a disability to attend particular events and venues with their carer for the price of a single ticket. The card is for people with a significant permanent disability, who always need a companion to provide attendant care type support (see Chapter 8 for more information on concessions and their costs).

## **Personal injury compensation schemes**

Personal injury compensation schemes are significant sources of income and ongoing support for people with a disability. Schemes, mainly for work- and transport-related injury, operate under specific legislation in each state and territory. National data are few.

The Productivity Commission, in its 2004 review of workers compensation and occupational health and safety, pointed to 'a total economic cost in excess of \$31 billion annually [due to] work-related fatalities, injuries and illnesses' (Productivity Commission 2004b:XXII). The review called for greater national consistency in approaches to workers compensation. It also pointed to the counter-productive aspects of fault-based systems, where compensation is related to the ability to establish fault rather than need.



## 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 a 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 (see Section 5.2 for more details on this Agreement).

The main CSTDA service groups are:

- accommodation support services – providing accommodation, or support to enable a person with a disability to remain in existing accommodation or move to more appropriate accommodation;
- community support services – providing the support needed for a person with a disability to live in a non-institutional setting;
- community access services – providing opportunities for people with a disability to gain social independence;
- respite services – providing a short-term and time-limited break for families and other voluntary caregivers of people with a disability; and
- employment services – providing employment assistance to people with a disability in obtaining and/or retaining paid employment through open employment or supported employment services. Note that people with disabilities also have access to generic employment services (see below).

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 national collation and analysis on an annual basis. The NMDS underwent a major redevelopment process during 1999–2002, to better capture the full extent of service usage throughout a year and to include some new items. Before the redeveloped collection was implemented in October 2002, data were collected on a 'snapshot' day – that is, a single day of the year. Data presented here are from the 2003–04 data collection, which is the first full year of data from the redeveloped collection, and represents a new benchmark for future analysis.

Expenditure (by all governments) on disability support services during 2003–04 totalled \$3.28 billion (Table 5.12). Over half this expenditure was used to fund accommodation support services (\$1,638 million). A further \$390 million was spent on community access services, \$352 million on community support, and \$301 million on employment services. Respite services received \$185 million in funding, while \$282 million went towards administration costs. (See also Table 8.11 for funding sources for disability services.)

**Table 5.12: Expenditure on disability support services by Australian, state and territory governments, by service group and administration expenditure, 2003–04 (\$ million)**

Service group	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	AustGovt	Aust.
Accommodation support	602.75	481.46	200.02	148.69	119.13	50.34	25.05	11.02	—	1,638.46
Community support	82.67	125.59	46.13	47.11	25.55	7.92	8.11	8.81	—	351.89
Community access	116.71	157.07	58.09	20.75	14.02	12.16	3.10	2.20	5.58 <sup>(a)</sup>	389.68
Respite	65.51	41.24	34.02	19.00	10.81	5.16	4.02	1.28	4.43 <sup>(a)</sup>	185.47
Employment	—	—	—	—	—	—	—	—	301.28	301.28
Advocacy, information and print disability	7.52	6.39	5.21	1.89	2.18	1.76	0.73	0.12	13.22	39.02
Other support	5.57	33.69	7.83	8.17	10.73	1.01	1.97	0.07	26.07	95.11
<i>Subtotal</i>	<i>880.73</i>	<i>845.44</i>	<i>351.30</i>	<i>245.61</i>	<i>182.42</i>	<i>78.35</i>	<i>42.98</i>	<i>23.50</i>	<i>350.58</i>	<i>3,000.91</i>
Administration	111.61	75.37	30.55	14.13	12.85	4.31	4.52	0.99	27.95	282.28
<b>Total</b>	<b>992.33</b>	<b>920.81</b>	<b>381.85</b>	<b>259.74</b>	<b>195.26</b>	<b>82.66</b>	<b>47.50</b>	<b>24.49</b>	<b>378.54</b>	<b>3,283.18</b>

(a) Australian Government-funded community access and respite services are not funded under the CSTDA. They are funded under the Disability Services Act Discretionary Fund.  
Notes

1. Data presented in this table are from *Report on Government Services 2005* (SCRSSP 2005), for all jurisdictions except Queensland. Queensland data are inclusive of CSTDA-funded specialist psychiatric disability services which are excluded from SCRSSP reporting.
2. Total expenditure on services quoted from SCRSSP 2005 includes actual payroll tax for NSW, Victoria (in part), Tasmania and the NT.

## CSTDA service users

A total of 187,806 service users accessed CSTDA-funded services during 2003–04 (Table 5.13; AIHW 2005c). The most widely accessed service group was community support (used by 42% of service users), followed by employment (34%) and community access (25%). Employment services were used by 64,281 service users, including 43,042 using open employment, 18,637 supported employment, and 4,100 dual open and supported employment services. Accommodation support services were accessed by 33,175 service users (18%), with 5,303 of these people using institutional accommodation. The proportion of recipients of accommodation support services using 'community-based' services (that is, accommodation other than institutions and hostels) rose from 60% on the 1995 snapshot day to 73% in 2001 and 2002 (AIHW 2001; SCRCSSP 2002, 2003). These trends are not comparable with 2003–04 data because full financial year data are now collected.

**Table 5.13: Users of CSTDA-funded services, service group by state and territory, 2003–04**

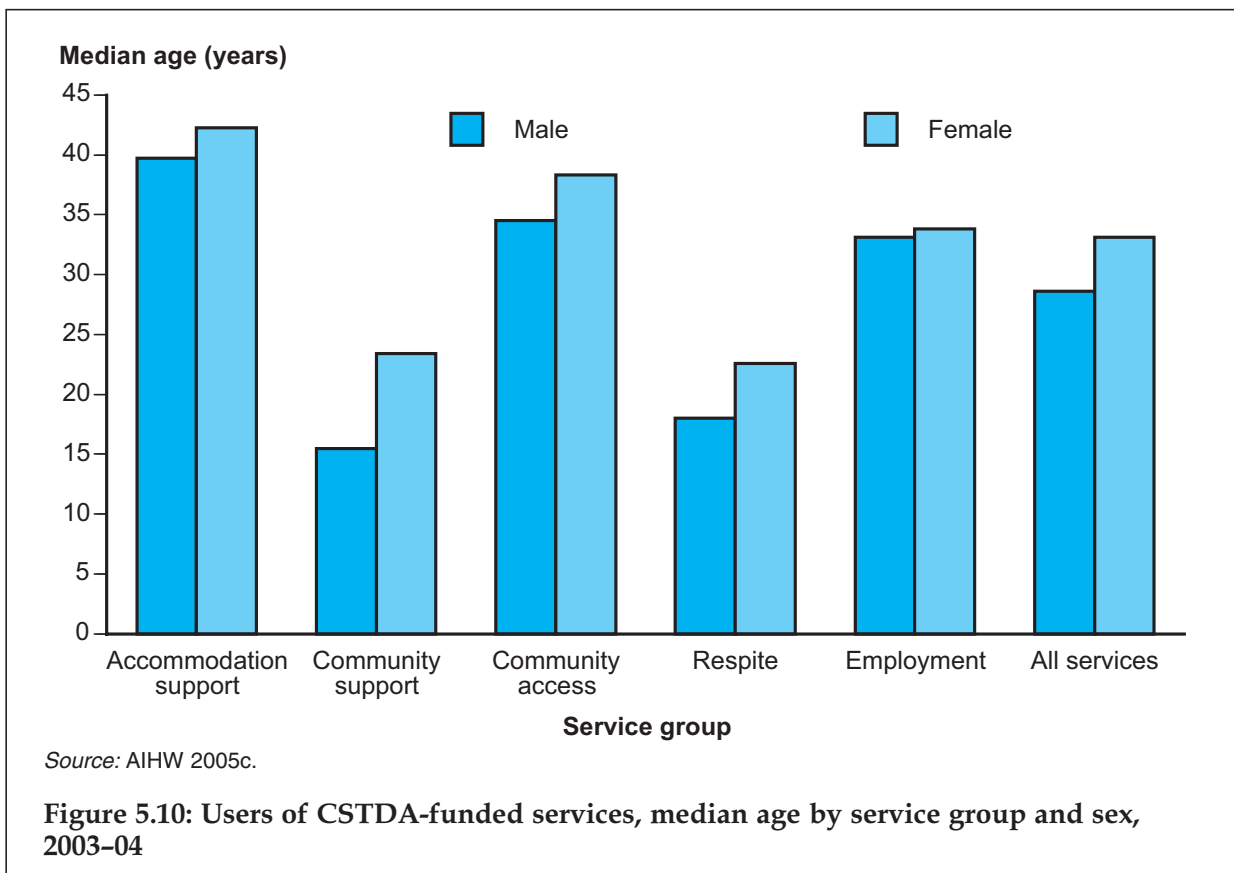
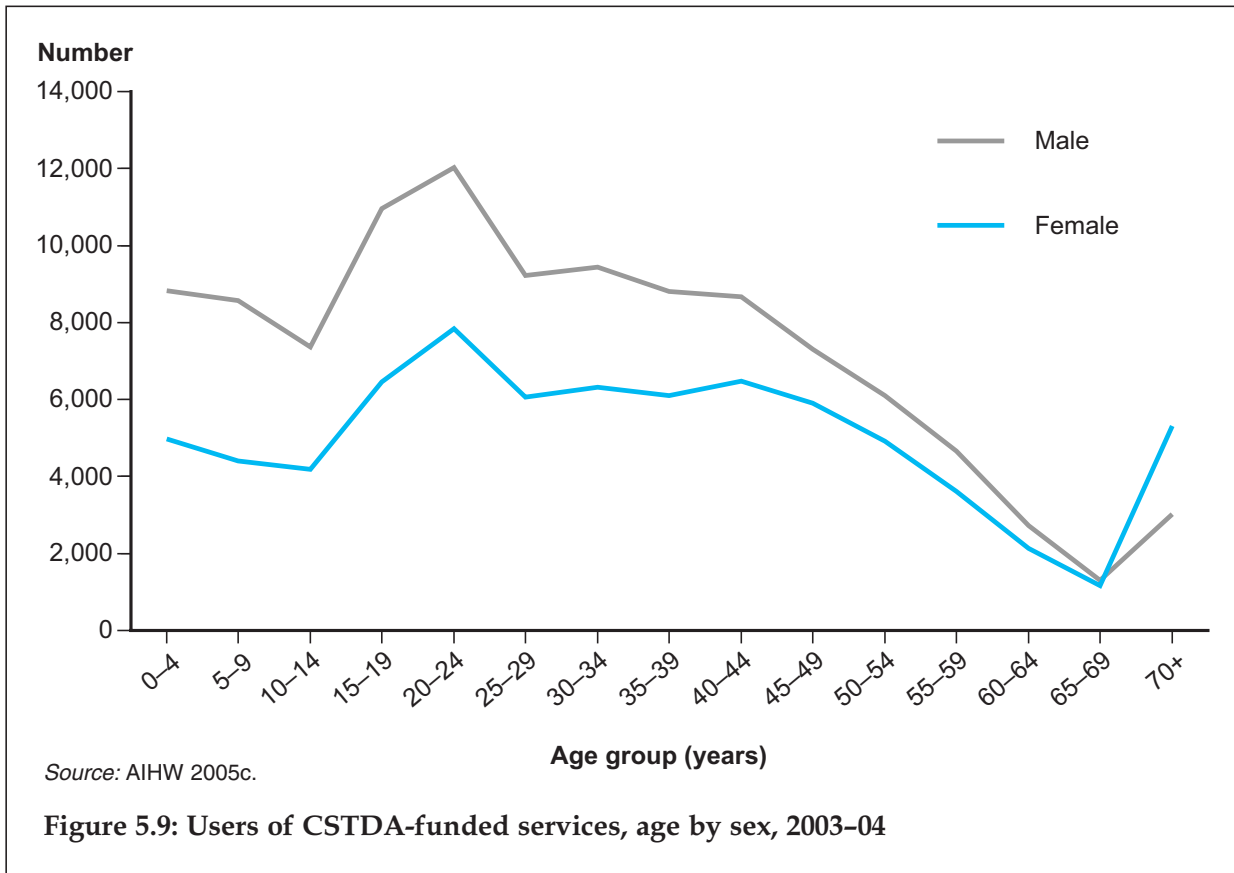
Service group	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Total	%
Accommodation support	6,440	12,989	4,933	3,136	4,069	1,069	334	212	33,175	17.7
Institutions/residentials/hostels	1,824	942	935	518	866	218	0	0	5,303	..
Group homes	3,345	4,490	903	1,092	674	460	200	146	11,308	..
Other accommodation types	1,440	7,768	3,228	1,576	2,635	420	136	71	17,271	..
Community support	18,013	28,485	8,564	11,138	9,916	2,173	188	509	78,847	42.0
Community access	6,483	18,441	5,354	10,354	4,827	1,493	419	286	47,636	25.4
Respite	4,153	8,607	3,306	2,464	1,390	238	255	155	20,547	10.9
Employment	19,003	18,283	12,036	6,217	5,911	1,667	898	410	64,281	34.2
Open employment	11,915	12,480	9,831	3,939	3,098	861	704	304	43,042	..
Supported employment	6,695	4,454	2,058	1,946	2,780	532	82	117	18,637	..
Open and supported employment	854	1,786	319	491	211	302	122	15	4,100	..
<b>Total service users</b>	<b>43,619</b>	<b>68,238</b>	<b>26,352</b>	<b>22,896</b>	<b>19,099</b>	<b>5,197</b>	<b>1,638</b>	<b>1,258</b>	<b>187,806</b>	<b>..</b>
<b>Total per cent</b>	<b>23.2</b>	<b>36.3</b>	<b>14.0</b>	<b>12.2</b>	<b>10.2</b>	<b>2.8</b>	<b>0.9</b>	<b>0.7</b>	<b>..</b>	<b>..</b>

### 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 twelve month period from 1 July 2003 to 30 June 2004. Service type totals may not be the sum of components since individuals may have accessed more than one service type during the 12-month period. Totals for Australia may not be the sum of the components since individuals may have accessed services in more than one state or territory during the twelve month period.
2. Victorian data are reported to be significantly understated; errors in the 'date of last service received' as well as a lower than expected response rates have led to under-counting of service users in the current year.

Source: AIHW 2005c.

Around three-fifths of service users in 2003–04 were male (110,177 or 59%) (AIHW 2005c). There was a higher number of males in all 5-year age groups except for those aged 70 years or more (Figure 5.9). The number of service users was highest for the 20–24 age group, for both sexes. Female service users had a higher median age than males, across all service groups (Figure 5.10). The difference in median age was greatest for users of community support services (23.4 years for females, 15.5 years for males), and smallest for employment services (33.8 years for females, 33.1 years for males).



A total of 6,524 service users (3.5%) were identified as being of Aboriginal or Torres Strait Islander origin (Table 5.14)—this represents a higher proportion than in the overall population (2.4%; ABS 2004c). Indigenous service users were present in larger proportions for respite (5.2%), community support (4.6%) and accommodation support (3.8%) services, but in smaller proportions for employment (2.6%) and community access (2.8%) services (AIHW 2005c).

Indigenous service users were more likely to report intellectual (43%) or physical (18%) disability as their primary disability type than non-Indigenous service users (40% and 13% respectively) (Table 5.14). On the other hand, non-Indigenous service users were more likely to report neurological (6%) or psychiatric (9%) disability than Indigenous service users (4% and 6% respectively).

**Table 5.14: Users of CSTDA-funded services, primary disability group by Indigenous status, 2003–04**

Primary disability group	Indigenous		Non-Indigenous		Not stated/ not collected		Total	
	No.	%	No.	%	No.	%	No.	%
Intellectual	2,785	42.7	65,225	39.9	3,691	20.6	71,701	38.2
Specific learning/ADD	213	3.3	5,160	3.2	326	1.8	5,699	3.0
Autism	237	3.6	7,747	4.7	265	1.5	8,249	4.4
Physical	1,146	17.6	21,902	13.4	1,737	9.7	24,785	13.2
Acquired brain injury	438	6.7	7,182	4.4	297	1.7	7,917	4.2
Neurological	259	4.0	9,396	5.8	426	2.4	10,081	5.4
Deafblind	33	0.5	465	0.3	14	0.1	512	0.3
Vision	136	2.1	5,794	3.5	3,315	18.5	9,245	4.9
Hearing	176	2.7	4,863	3.0	401	2.2	5,440	2.9
Speech	63	1.0	1,173	0.7	67	0.4	1,303	0.7
Psychiatric	406	6.2	14,225	8.7	928	5.2	15,559	8.3
Developmental delay	261	4.0	8,884	5.4	583	3.3	9,728	5.2
Not stated/not collected	371	5.7	11,384	7.0	5,832	32.6	17,587	9.4
<b>Total</b>	<b>6,524</b>	<b>100.0</b>	<b>163,400</b>	<b>100.0</b>	<b>17,882</b>	<b>100.0</b>	<b>187,806</b>	<b>100.0</b>

*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.
2. In tables the term 'Indigenous' refers to service users who identified as Aboriginal and/or Torres Strait Islander people. 'Non-Indigenous' refers to service users who reported not being Aboriginal or Torres Strait Islander people.
3. 'Not stated/not collected' includes both service users accessing only 3.02 services for whom Indigenous and primary disability data were not collected and other service users with no response.

Source: AIHW 2005c.

Individualised funding involves the application of funding to a particular service outlet/s which the service user (or their carer/advocate) has chosen as relevant to his or her needs. Such funding is allocated to individual service users on the basis of a needs assessment, funding application, or similar process (AIHW 2004d). In 2003–04, around 17% of service users reported that they received individualised funding (Table 5.15). Those in respite (24%) and employment (22%) services were most likely to report receiving such funding.



**Table 5.15: Users of CSTDA-funded services, individual funding status by service group, 2003–04**

Service group	Has individualised funding		Does not have individualised funding		Not known		Not stated/not collected		Total	
	No.	%	No.	%	No.	%	No.	%	No.	%
Accommodation support	6,992	21.1	22,621	68.2	1,824	5.5	1,738	5.2	33,175	100.0
Community support	12,988	16.5	53,041	67.3	5,834	7.4	6,984	8.9	78,847	100.0
Community access	10,040	21.1	31,228	65.6	2,574	5.4	3,794	8.0	47,636	100.0
Respite	4,893	23.8	13,592	66.2	1,256	6.1	806	3.9	20,547	100.0
Employment	13,812	21.5	50,469	78.5	0	—	0	—	64,281	100.0
<b>Total</b>	<b>31,193</b>	<b>16.6</b>	<b>135,496</b>	<b>72.1</b>	<b>9,190</b>	<b>4.9</b>	<b>11,927</b>	<b>6.4</b>	<b>187,806</b>	<b>100.0</b>

*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. Total for all service groups may not be the sum of components since individuals may have accessed services from more than one service group over the twelve month period. Service user data were not collected for all CSTDA service types.
2. Case Based Funding is currently being implemented within employment services. Once fully implemented, 100% of employment service users will be funded under this mechanism.
3. 'Not stated/not collected' includes both service users accessing only 3.02 services for whom individualised funding data were not collected and other service users with no response.

Source: AIHW 2005c.

The availability of full year data makes analysis of multiple service usage more meaningful than with previous snapshot day collections. It is now possible to examine the full range of CSTDA-funded services accessed over an entire year. During 2003–04, a total of 42,326 service users (23%) accessed services from two or more CSTDA-funded service groups (Table 5.16). The most common combination of service groups was accommodation support and community access, followed by community support and community access.

In 2003–04, a total of 78,360 service users (42%) indicated that they had an informal carer—defined as 'a person such as a family member, who provides care and assistance on a regular and sustained basis' (Table 5.17; AIHW 2005c). A further 38% indicated that they did not have such a carer, while this information was not reported for around 20% of service users—2003–04 was the first time this data item was collected over a full year; therefore this missing rate is expected to improve in future collections.

Service users aged under 15 years were most likely to report having a carer (79%), followed by those aged 15–24 years (48%). One-fifth (20%) of service users aged 65 years or more reported that they had a carer. Of the 78,360 service users with a carer, 53,012 (68%) indicated that the carer was a 'primary' carer—defined as someone who assists with activities of daily living, including self-care, mobility and communication (AIHW 2005c). When considering these findings, it should be recognised that the roles of parent and carer are often difficult to distinguish, particularly in the case of children—many parents consider themselves also carers if they are providing more care than would be typical of the care provided to a child of the same age without a disability.

**Table 5.16: Users of CSTDA-funded services, service group combinations most commonly received, 2003–04**

Service groups used	Number	Per cent of service users using two or more services	Per cent of all service users
<b>Five most common combinations</b>			
Accommodation and community access	14,013	33.1	7.5
Community support and community access	13,484	31.9	7.2
Accommodation and community support	10,710	25.3	5.7
Community support and respite	8,993	21.2	4.8
Accommodation and employment	5,640	13.3	3.0
<b>Other combinations</b>			
Three or more services involving above combinations	11,994	28.3	6.4
All other combinations	7,198	17.0	3.8
<b>Total</b>	<b>42,326</b>	<b>100.0</b>	<b>22.5</b>

*Notes*

1. Service user numbers reflect use of any of five service groups: accommodation support, community support, community access, respite and employment.
2. Service users with three, four or five service groups are included under all relevant combinations. Thus, numbers in a column may not add up to the total.
3. 'All other combinations' includes three two-way combinations for service users of respite services other than with accommodation, the combination of community support and employment, and other three-, four- and five-way combinations of service groups.

Source: AIHW 2005c.

**Table 5.17: Users of CSTDA-funded services, existence of an informal carer by service user age group, 2003–04**

Age group of service user (years)	Has an informal carer		Does not have an informal carer		Not stated/not collected		Total	
	No.	%	No.	%	No.	%	No.	%
0–14	26,117	79.4	1,550	4.7	5,217	15.9	32,884	100.0
15–24	17,950	48.1	13,491	36.2	5,868	15.7	37,309	100.0
25–44	21,771	35.6	30,981	50.7	8,356	13.7	61,108	100.0
45–64	10,343	27.7	21,221	56.8	5,815	15.6	37,379	100.0
65+	2,131	19.8	4,873	45.3	3,762	34.9	10,766	100.0
Not stated	48	0.6	22	0.3	8,290	99.2	8,360	100.0
<b>Total</b>	<b>78,360</b>	<b>41.7</b>	<b>72,138</b>	<b>38.4</b>	<b>37,308</b>	<b>19.9</b>	<b>187,806</b>	<b>100.0</b>

*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 twelve month period.
2. 'Not stated/not collected' includes both service users accessing only 3.02 services for whom informal carer data were not collected and other service users with no response.

Source: AIHW 2005c.

Most service users with a carer reported that the carer was their mother (69%) (Table 5.18). This was by far the most common relationship reported – fathers were the next most common (6%), followed by wife/female partner, husband/male partner and other female relative (all around 5%). Carers in the age group 25–44 were more likely than

other age groups to be the mother of a service user (83%). Of those carers aged under 15 years, 64% reported they were the daughter (33%) or son (31%) of the service user. Of the 6,472 carers aged 65 years and over, 3,959 were mothers (61%), 749 fathers (12%), 543 a husband/male partner (8%) and 446 a wife/female partner (7%).

**Table 5.18: CSTDA-funded service users with an informal carer, relationship of carer to service user by age group of carer, 2003-04**

Relationship of carer to service user	Age group of carer (years)					Not stated/ not collected	Total
	0-14	15-24	25-44	45-64	65+		
	<b>Number</b>						
Wife/female partner	0	36	830	1,312	446	1,065	3,689
Husband/male partner	0	31	850	1,474	543	635	3,533
Mother	0	709	24,156	13,685	3,959	11,241	53,750
Father	0	10	1,048	1,582	749	1,511	4,900
Daughter	33	118	238	234	17	100	740
Son	31	87	122	103	8	77	428
Daughter-in-law	0	1	8	16	1	7	33
Son-in-law	0	0	1	3	0	1	5
Other female relative	7	67	652	1,431	461	1,011	3,629
Other male relative	1	21	248	381	81	360	1,092
Friend/neighbour—female	0	17	248	426	81	566	1,338
Friend/neighbour—male	0	8	119	124	47	341	639
Not stated/not collected	27	29	491	328	79	3,630	4,584
<b>Total</b>	<b>99</b>	<b>1,134</b>	<b>29,011</b>	<b>21,099</b>	<b>6,472</b>	<b>20,545</b>	<b>78,360</b>
	<b>Per cent</b>						
Wife/female partner	—	3.2	2.9	6.2	6.9	5.2	4.7
Husband/male partner	—	2.7	2.9	7.0	8.4	3.1	4.5
Mother	—	62.5	83.3	64.9	61.2	54.7	68.6
Father	—	0.9	3.6	7.5	11.6	7.4	6.3
Daughter	33.3	10.4	0.8	1.1	0.3	0.5	0.9
Son	31.3	7.7	0.4	0.5	0.1	0.4	0.5
Daughter-in-law	—	0.1	0.0	0.1	0.0	0.0	0.0
Son-in-law	—	—	0.0	0.0	—	0.0	0.0
Other female relative	7.1	5.9	2.2	6.8	7.1	4.9	4.6
Other male relative	1.0	1.9	0.9	1.8	1.3	1.8	1.4
Friend/neighbour—female	—	1.5	0.9	2.0	1.3	2.8	1.7
Friend/neighbour—male	—	0.7	0.4	0.6	0.7	1.7	0.8
Not stated/not collected	27.3	2.6	1.7	1.6	1.2	17.7	5.8
<b>Total</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>

*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 twelve month period.
2. 'Not stated/not collected' includes both service users accessing only 3.02 services for whom informal carer data were not collected and other service users with no response.

Source: AIHW 2005c.

## Other disability-specific services

### Home and Community Care

The Home and Community Care (HACC) program provides a range of community care services, targeting frail and older people with disabilities, as well as younger people with disabilities and their carers. During 2003–04, there were 170,100 HACC clients under the age of 65 years (24% of the total 707,200). The most commonly used services by these clients were assessment, case management and case planning/ review (40%); nursing (25%); and domestic assistance (20%). These younger clients used 1.8 services over the year, on average, compared with 2.1 for those 65 years and over (see Table 4.12). See Chapter 4 for detailed discussion of the HACC program.

### Aged care

There were 6,240 clients aged under 65 years in permanent residential aged care as at 30 June 2004, representing 4.3% of all residents. Of these clients, 987 (16%) were aged under 50 years. There were also 1,935 people under the age of 65 years who accessed Community Aged Care Packages (7% of all CACP recipients) (see Tables 4.18, 4.19).

### Rehabilitation, hearing services and equipment

CRS Australia provides vocational rehabilitation services to people with a disability, injury or health condition to gain or maintain employment. It also offers independent living and counselling services. All CRS services are free to people receiving income support payments from Centrelink (CRS Australia 2005).

During 2003–04, CRS assisted a total of 41,354 customers (16,819 existing and 24,535 new customers). Of the new customers supported, the most commonly reported primary disability type was physical (58%), followed by psychiatric disability (28%). Of the 23,587 customers who exited a CRS rehabilitation program during 2003–04, 8,874 (38%) achieved a 'durable' employment outcome – that is, they were employed for 13 weeks or more (FaCS 2004b).

Australian Hearing is the sole government-funded provider of hearing services to eligible recipients – primarily people under the age of 21 years, age pensioners, sickness allowance recipients and some veterans. During 2003–04, it provided 335,638 services, including 280,065 to pensioners and veterans, and 45,993 people under the age of 21. Around half of Australian Hearing clients were aged 80 years and over, while over a third were less than 10 years old (Australian Hearing 2004). 'Eligible recipients' aged 21 years or more can access free assessment, rehabilitation and aid fitting services by applying for a voucher. During 2003–04, the Office of Hearing Services issued 178,413 vouchers (DoHA 2005).

Equipment services in Australia are somewhat fragmented, being provided by a mosaic of services, generally through the health or veterans systems or the non-government sector (see e.g. AIHW: Bricknell 2003) No national data on these various programs are compiled. Some indication of the importance of equipment is provided by the population data in Tables 5.8 and 5.9.

## Relevant generic services

### Health

There is growing interest in the question of access to health services by people with disabilities, and how adequate and effective this access is. Various authors have raised a range of concerns about the health outcomes of people with disabilities; their access to services; the quality of services received, including problems in communication between health professionals and people with disabilities; health professionals' inadequate knowledge of health conditions of people with disabilities, including patterns of dual diagnoses such as mental health and intellectual disability; the adequacy of medical records; and the appropriateness of services provided (see AIHW 2003a:368–9; Leonard et al 2004).

Similar issues were raised in a health forum in 2004 (HREOC 2004):

- the problem of 'diagnostic overshadowing' when 'a person's symptoms or condition is wrongly attributed to their disability rather than a separate medical condition';
- the need for improved education and training of health professionals and related non-medical staff;
- the need for medical professions to ensure sexually active people with disabilities are respected and given the 'appropriate information and support to protect themselves';
- the need for Medicare schedules to recognise that some people with disabilities require longer consultations to ensure the required communication takes place;
- the need for Auslan services;
- affordability of equipment;
- medication labelling and instructions – various formats are needed; and
- the need for trials of new drugs to include a wider range of people, including people with disabilities.

Improved screening methods of people with intellectual disabilities are being trialled in Queensland (University of Queensland 2005). Results so far indicate that previously missed health problems included hearing and sight, that immunisations needed updating, and weight problems needed attention.

### Education and training

Students with a disability may attend either 'special' schools or mainstream schools, sometimes with special educational assistance. Enrolment in special education services, in both special and mainstream schools, is dependent on satisfying specified criteria stipulated by the government of the state or territory in which a student is enrolled. There is significant variation across jurisdictions in the criteria used to identify a student with a disability. For example, criteria relating to social or emotional impairment exist in some jurisdictions, such as New South Wales, but not in others, such as the Australian Capital Territory (SCRCSSP 2005). A Senate Committee inquiry into the education of students with disabilities highlighted the need for nationally agreed definitions of disabilities, as well as recommending further inquiry into the transition of such students from school to further study, employment and lifelong learning (Commonwealth of Australia 2002).



Table 5.19: Students with disabilities attending government and non-government schools, 2004 (FTE)<sup>(a)</sup>

	NSW <sup>(b)</sup>	Vic	Qld	WA <sup>(c)</sup>	SA	Tas	ACT	NT	Total
<b>Government schools<sup>(d)</sup></b>									
Mainstream	29,066	13,964	12,120	9,495	11,536	2,769	1,316	4,210	84,476
Special	3,981	7,180	2,612	735	996	184	287	195	16,170
<i>Total</i>	<i>33,047</i>	<i>21,144</i>	<i>14,732</i>	<i>10,230</i>	<i>12,532</i>	<i>2,953</i>	<i>1,603</i>	<i>4,405</i>	<i>100,646</i>
Percentage attending mainstream schools	88.0	66.0	82.3	92.8	92.1	93.8	82.1	95.6	83.9
Percentage of all government school students	4.4	3.9	3.3	4.1	7.4	4.7	4.5	12.0	4.4
<b>Non-government schools<sup>(e)</sup></b>									
Mainstream	8,986	5,727	2,700	1,546	2,391	304	300	181	22,135
Special	1,245	506	143	34	137	16	0	0	2,081
<i>Total</i>	<i>10,231</i>	<i>6,233</i>	<i>2,843</i>	<i>1,580</i>	<i>2,528</i>	<i>320</i>	<i>300</i>	<i>181</i>	<i>24,216</i>
Percentage attending mainstream schools	87.8	91.9	95.0	97.8	94.6	95.0	100.0	100.0	91.4
Percentage of all non-government school students	2.8	2.2	1.4	1.5	3.0	1.5	1.2	2.1	2.2
<b>Total students with disabilities</b>	<b>43,278</b>	<b>27,377</b>	<b>17,575</b>	<b>11,810</b>	<b>15,060</b>	<b>3,273</b>	<b>1,903</b>	<b>4,586</b>	<b>124,862</b>
Total all students ('000)	1,108.6	826.4	648.0	358.6	252.0	83.8	59.9	45.4	3,382.7
Percentage of all school students	3.9	3.3	2.7	3.3	6.0	3.9	3.2	10.1	3.7

(a) FTE 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.

(b) Data for government mainstream schools in NSW include students with disabilities in regular classes (16,600 students) and special classes (12,466). Only students with disabilities in regular classes were reported in 2002.

(c) Data for government special schools in WA include education support schools and education support centres.

(d) Data for government schools in NSW include students at kindergarten level; in Vic, exclude kindergarten level and early special education facilities; in Qld, exclude kindergarten level and may include early special education facilities depending on where they are based; in WA, include kindergarten or pre-primary level; in SA, exclude preschools; in Tas, include kindergarten level but exclude early special education facilities; in NT, include preschools; and in the ACT include kindergarten or pre-primary level.

(e) Data for non-government schools include students at kindergarten level.

Sources: DEST 2004 Non-government Schools Census, unpublished data; and data provided to AIHW by state and territory education authorities.

In 2004, there were 124,862 school students with disabilities—100,646 attending government schools, of whom 84% were in mainstream schools, and 24,216 attending non-government schools, of whom 91% were in mainstream schools (Table 5.19). Variation between jurisdictions in the proportion of students attending mainstream schools in the government sector was marked—from 66% in Victoria to 96% in the Northern Territory. In the non-government sector, the proportion of students attending mainstream schools varied from 88% in New South Wales to 100% in the Australian Capital Territory and the Northern Territory. This variation may reflect differences between jurisdictions in terms of enrolment integration policies as well as the availability of special schools.

Students with disabilities as a proportion of all students attending government and non-government schools ranged from 3% in Queensland to 10% in the Northern Territory. In all jurisdictions, the proportion of students with disabilities was greater in government schools than in non-government schools; nationally, the proportion of students with disabilities was twice as high in government schools (4%) as in non-government schools (2%).

National statistics on students with disabilities attending higher education have been collected since 1996. Since that time, the number has increased from 11,656 (1.9% of all students) to 24,593 (3.7%) in 2004 (DEST 2005b). It is important to note that these students identified through self-report.

The number of students in Vocational Education and Training (VET) reporting a disability has steadily increased, from 53,475 in 1998 (3.5% of all students) to 91,439 in 2003 (5.3%) (NCVER 2005). A number of factors have contributed to the apparent growth in participation levels, including the addition of new disability groups to the original definition, improved methods of identifying people with a disability, and greater and more coordinated efforts to improve access and participation for these people. Physical disabilities were the most common form of disability reported in 2003 (20%), followed by medical (17%), visual (15%), learning (14%) and hearing-related disabilities (12%). The majority (86%) of students with a reported disability had a single disability. Over the period 2001–04 the proportion of VET graduates with a disability who were employed after training increased from 45% to 51%, while the proportion who were unemployed after training declined from 21% to 16% (NCVER 2005). Despite these improvements, the proportion of graduates with a disability employed after training remained lower than graduates without a disability in 2004 (51% compared with 77%) and the proportion unemployed was higher than for those without a disability (16% compared with 11%).

## **Employment assistance**

Centrelink provides an assessment and referral service for job seekers with a disability. Job seekers are assessed to determine the level of assistance required by an individual seeking employment. Disability Employment Indicators may also be used for further assessment if a person indicates that they have a disability that may affect their ability to work; this instrument is used to gauge the type and level of support a person will require in their employment. Depending on the level of support these measures indicate a person will need, Centrelink refers them to the Job Network, or a specialist disability employment service (see CSTDA service user information above), or a vocational rehabilitation program delivered by CRS Australia.

People with disabilities thus have access to mainstream employment services through DEWR's Job Network. DEWR has several processes in place to assist people with

disabilities seeking mainstream employment. The Active Participation Model, introduced in July 2003, was designed to improve access to job seekers with a disability through individualised support. Included in this assistance is access to a Job Seeker Account, which allows individuals to receive additional assistance to meet their specific needs, such as training and equipment. There is also a range of specialist Job Network providers who address the needs of specific disability groups, such as people with hearing or vision impairments or mental health issues. The Employer Incentive Strategy is designed to encourage employers to provide opportunities for people with disabilities; during 2003–04 this incentive assisted 6,280 people through the supported wage system (3,425), wage subsidies (2,580) and workplace modifications (275) (DEWR 2004a).

During 2003–04, 27,160 people with disabilities commenced the Job Placements program (5.2% of the total 518,008 people in this program), and a further 46,728 people with disabilities commenced Intensive Support (7.6% of the total) (DEWR 2004a).

A person is said to have achieved a ‘positive outcome’ in a Job Network program if they are employed, in training, or in education 3 months after completion of the program. Of the 4,452 job seekers with a disability who exited the Job Placements program between 1 July 2003 and 30 June 2004, 59% achieved a positive outcome, compared with 74% of all job seekers (Table 5.20). Of the 18,984 job seekers with a disability exiting customised Intensive Support, 46% achieved a positive outcome, compared with 53% of all job seekers exiting this type of support. There were a further 2,907 job seekers with a disability who exited intensive job search training support—53% of these achieved a positive outcome, compared with 63% of all job seekers who exited this type of support.

**Table 5.20: Job seekers exiting Job Network programs and proportion achieving positive outcomes, 2003–04**

	Job seekers with a disability		All job seekers	
	Number of exits	Positive outcomes	Number of exits	Positive outcomes
Job Placements	4,452	59.2%	121,815	74.4%
Intensive Support: customised assistance	18,984	45.8%	185,126	53.0%
Intensive Support: job search training	2,907	52.9%	133,136	63.1%

*Note:* numbers include those people who exited Job Network services between 1 July 2003 and 30 June 2004, and outcomes achieved 3 months after their exit date (up to 30 September 2004).

*Source:* DEWR 2004b.

## Housing and accommodation assistance

At 30 June 2004, there were 99 community housing organisations funded under the Commonwealth State Housing Agreement (CSHA) with specifically targeted assistance to people with a disability. Just over 5,000 households living in CSHA community housing contained a person with a disability, representing 21% of all households assisted (AIHW 2005d).

Forty-two percent of public housing tenants aged 15–64 years reported a disability in 2003, compared with 17% of people in all housing tenure types. At 30 June 2004, 27% of public housing tenants and 17% of SOMIH tenants reported that their main source of household income was DSP (see Tables 6.6, 6.15 and 6.16).

People accessing services from the Supported Accommodation Assistance Program (SAAP) were considered part of the 'disability' client group if they received DSP or DVA disability pension; were referred from or to a psychiatric unit; or requested or received disability-specific services (AIHW: Murdoch 2005). During 2002–03, of the total 97,600 SAAP clients, 24,900 (26%) were in the SAAP 'disability' client group<sup>2</sup>. These 'disability' clients had an average of 1.80 support periods, compared with 1.67 for all other clients. People in this client group were more likely than other SAAP clients to be male (58% compared with 38%), and were on average 7 years older (mean age of 36.8 years compared with 29.8 years for other SAAP clients). See Chapter 7 for more discussion of the SAAP program.

## Unpaid care

The provision of unpaid care is not only a vital part of Australian family life, but a critically important complement to formal services. Trends in deinstitutionalisation and non-institutionalisation mean that greater numbers and proportions of people with severe disabilities now live in the community, frequently with families (AIHW 2001; AIHW: Madden et al. 1999; AIHW: Wen & Madden 1998). Outcomes for people with disabilities and the wellbeing of Australian families are thus strongly affected by the adequacy and quality of in-home support.

In 2003, Australians aged less than 65 years who needed help with self-care, mobility or communication received most of the assistance they needed from family and friends – 65% received informal assistance only, 26% received both formal and informal assistance, 3% received formal assistance only and 6% had no provider of assistance (Table 5.21). People needing assistance with communication were likely (63%) to be receiving a mix of formal and informal assistance. The picture was slightly different for the 'non-core activities' listed – 43% of people received informal assistance only with these activities, 51% both informal and formal assistance, 4% formal service only, and 2% had no assistance.

'Primary carers' are those who provide the most ongoing assistance with core activities (self-care, mobility, communication). In 2003, primary carers (ABS 2004a):

- were mainly female (71%);
- cited a range of reasons for their caring role, the most common being 'family responsibility' (58% of primary carers), the belief that they could provide better care (39%), and 'emotional obligation' (35%);
- had a lower labour force participation rate (39%) than people who were not carers (68%); and
- spent long hours caring – 37% of primary carers spent on average 40 hours or more per week providing care; 18% spent 20–39 hours per week.

Previous analyses of Australian survey data have pointed more generally to the reasons for and effects of caring (AIHW 2000a, 2002). 'For some, the primary caring role imposes considerable burden, but it is a role that people take on out of a sense of responsibility and the desire to provide the best possible care' (AIHW 2003a:114). A review of literature

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2. This number may be an underestimate because some data items used to estimate the SAAP 'disability' group were not collected by all SAAP agencies (see AIHW: Murdoch 2005 for details).

dealing with carers' quality of life, while recording some positive findings, such as better relationships and understanding, concluded that 'caregivers of people with severe disability are at extreme risk of being highly stressed, clinically depressed, and with subjective quality of life that is way below normal' (Cummins 2001:97).

In 2003 there were 202,000 primary carers of people aged under 65, living with the main recipient of their care (Table 5.22). They were most likely to be a parent caring for a son or daughter (89,400 or 44%) or someone caring for a spouse or partner (88,600 also 44%).

**Table 5.21: People aged under 65 years with a profound or severe core activity limitation living in households: type of assistance received, activity in which help is needed, 2003**

Activity with which help needed	Type of provider				Total
	No provider	Informal only	Formal only	Informal and formal	
	Number ('000)				
Self-care	30.5	253.9	*9.0	25.2	318.6
Mobility	22.6	339.9	11.3	92.9	466.6
Communication	*4.0	48.5	*6.4	98.4	157.3
<b>Total core activity<sup>(a)</sup></b>	<b>40.9</b>	<b>415.9</b>	<b>18.1</b>	<b>166.6</b>	<b>641.5</b>
Cognition or emotion	10.8	133.8	19.1	153.0	316.8
Health care	14.7	160.7	37.5	92.5	305.4
Housework	*9.1	211.6	14.6	24.3	259.6
Property maintenance	*8.6	197.2	22.9	49.9	278.5
Paperwork	*5.8	103.4	*7.7	*9.6	126.6
Meal preparation	*2.4	103.8	*4.8	*5.2	116.2
Transport	*9.4	225.1	13.3	20.6	268.3
<b>Total non-core activity<sup>(b)</sup></b>	<b>*9.1</b>	<b>237.6</b>	<b>24.6</b>	<b>282.9</b>	<b>554.2</b>
	Per cent				
Self-care	9.6	79.7	*2.8	7.9	100.0
Mobility	4.8	72.8	2.4	19.9	100.0
Communication	*2.6	30.8	*4.1	62.5	100.0
<b>Total core activity<sup>(a)</sup></b>	<b>6.4</b>	<b>64.8</b>	<b>2.8</b>	<b>26.0</b>	<b>100.0</b>
Cognition or emotion	3.4	42.3	6.0	48.3	100.0
Health care	4.8	52.6	12.3	30.3	100.0
Housework	*3.5	81.5	5.6	9.4	100.0
Property maintenance	*3.1	70.8	8.2	17.9	100.0
Paperwork	*4.6	81.7	*6.1	*7.6	100.0
Meal preparation	*2.1	89.3	*4.1	*4.4	100.0
Transport	*3.5	83.9	5.0	7.7	100.0
<b>Total non-core activity<sup>(b)</sup></b>	<b>*1.6</b>	<b>42.9</b>	<b>4.4</b>	<b>51.0</b>	<b>100.0</b>

(a) Includes people who need help with at least one core activity.

(b) Includes people who need help with at least one core activity and one or more non-core activities.

*Note:* Estimates marked with \* have an associated relative standard error (RSE) of between 25% and 50% and should be interpreted accordingly.

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



Table 5.22: Primary carers of people aged under 65 years: years in caring role and age group, by relationship to main recipient of care, 2003

	Partner		Parent		Son or daughter		Other		Total	
	No. ('000)	Per cent	No. ('000)	Per cent	No. ('000)	Per cent	No. ('000)	Per cent	No. ('000)	Per cent
<b>Years in caring role</b>										
Does not know	*3.1	*3.5	**0.7	**0.7	**0.5	**4.1	—	—	*4.2	*2.1
Less than 1 year	*4.5	*5.1	*2.9	*3.3	**0.4	**3.3	**0.5	**3.8	*8.3	*4.1
1–4 years	29.2	33.0	19.3	21.5	*6.0	*50.4	*5.7	*47.6	60.2	29.8
5–9 years	23.5	26.5	22.7	25.4	*2.7	*22.6	*2.6	*21.6	51.5	25.5
10–14 years	14.2	16.0	20.3	22.7	**0.7	**5.5	**0.2	**2.1	35.4	17.5
15–19 years	*6.4	*7.2	*8.6	*9.7	—	—	**1.5	**12.2	16.5	8.2
20 or more years	*7.7	*8.7	14.9	16.7	**1.7	**14.1	**1.6	**12.9	25.9	12.8
<b>Total</b>	<b>88.6</b>	<b>100.0</b>	<b>89.4</b>	<b>100.0</b>	<b>11.9</b>	<b>100.0</b>	<b>12.1</b>	<b>100.0</b>	<b>202.0</b>	<b>100.0</b>
<b>Age group of carer</b>										
15–24	*3.4	*3.8	*3.0	*3.4	*8.2	*68.6	—	—	14.6	7.2
25–44	22.6	25.5	51.6	57.7	*2.9	*24.2	*3.9	*32.5	81.0	40.1
45–64	54.5	61.5	30.7	34.3	—	—	*6.0	*49.9	91.1	45.1
65+	*8.2	*9.2	*4.1	*4.6	**0.9	**7.2	**2.1	**17.6	15.3	7.6
<b>Total</b>	<b>88.6</b>	<b>100.0</b>	<b>89.4</b>	<b>100.0</b>	<b>11.9</b>	<b>100.0</b>	<b>12.1</b>	<b>100.0</b>	<b>202.0</b>	<b>100.0</b>

*Notes*

1. Table includes primary carers aged 15 years or more living in households with the main recipient of care.
2. The estimates of disability are based on the confidentialised unit record file (CURF) of the ABS 2003 Survey of Disability, Ageing and Carers (SDAC). To protect the confidentiality of survey respondents, some children's records have been dropped 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. The estimates from the CURF are used throughout the chapter for internal consistency.
3. Estimates marked with \* have an associated relative standard error (RSE) of between 25% and 50% and should be interpreted accordingly.
4. Estimates marked with \*\* have an associated relative standard error (RSE) of greater than 50% and should be interpreted accordingly.

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



The majority of parent carers were in the 25–44 age range (58%); and 34% were aged 45–64 years. An estimated 4,100 were aged 65 years and over; a total of 6,400 primary parent carers were aged 65+ (ABS 2004a:52). Care had been provided by parents over a much longer time span than by others—23% had cared for their son or daughter for 10–14 years (compared to 16% for spouse carers), 10% for 15–19 years (compared to 7%) and 17% for 20 or more years (compared to 9% for spouse carers).

People with profound or severe core activity limitations aged under 65 years were, then, located in an environment of assistance provided chiefly by family and friends, with a further ingredient of formal assistance to them and their carers. How well did this mix work for the carers?

- Some 20% of carers living with a person aged under 65 reported the need for further assistance—12% received some assistance but needed more, while 8% needed assistance and received none; 35% received assistance and needed no more while 45% did not need assistance (Table 5.23).
- Most carers (63%) reported that there was another person providing regular assistance with caring tasks, but 29% said there was not.
- Respite services played a limited role in their lives. The majority of primary carers (76%) said that they had never received respite and did not want it. However, 8% of primary carers had never received respite and needed it. For those who had used respite, there was incomplete reach of the service—3% of primary carers had received a formal respite service in the previous 3 months and did not need further assistance; 5% had received such respite but needed more; 4% did not receive such respite but needed it. Overall, then, some 18% of primary carers of people with severe/profound core activity limitations needed more respite provided by formal services.

More information on the care of older Australians is provided in Chapter 4. The total imputed value of unpaid care is discussed and estimated in Chapter 8.

## 5.5 Outcomes

Participation is a widely recognised goal of people with disabilities, an explicit goal of disability programs, and hence a key criterion for judging outcomes for people with disabilities within Australian society (see Sections 5.2 and 5.4). A discussion of participation by people with disabilities in Australian society is the primary focus of this section, following a brief overview of some service-related outcomes.

### Service-related outcomes

#### Accessibility

Access to services is an important indicator of service or program outcomes. Access to generic services such as health, education and employment is indicated in Section 5.4, although there is room for data improvement.

Access to disability support services provided under the CSTDA is indicated in Table 5.24. CSTDA services are targeted at people needing ongoing assistance with self-care, mobility and communication. The ‘potential population’ for these services is

calculated from population disability survey estimates of these numbers, further applying an Indigenous factor to allow for higher rates of disability in that group and a labour force factor for employment services. Respite potential population figures allow for family arrangements (AIHW 2005c). It is not suggested that every person needing ongoing assistance needs a formal service. The 'potential population' estimates were constructed for comparative purposes, to provide indications of relative need, for interstate comparisons and trend analyses.

**Table 5.23: Primary carers of people aged under 65 years, by carers age group and assistance needed, 2003**

	15–64 years		65+ years		Total 15+ years	
	No. ('000)	Per cent	No. ('000)	Per cent	No. ('000)	Per cent
<b>Need for and receipt of assistance</b>						
Receives assistance and:						
does not need further assistance	64.1	34.3	6.0	39.0	70.0	34.7
needs further assistance	22.6	12.1	2.1	13.7	24.7	12.2
Does not receive assistance and:						
needs assistance	15.3	8.2	1.0	6.9	16.4	8.1
does not need assistance	84.7	45.4	6.2	40.5	90.9	45.0
<b>Total</b>	<b>186.7</b>	<b>100.0</b>	<b>15.3</b>	<b>100.0</b>	<b>202.0</b>	<b>100.0</b>
<b>Availability of fall-back carer</b>						
Available	120.5	64.5	6.8	44.5	127.3	63.0
Not available	50.5	27.1	7.1	46.2	57.6	28.5
Don't know if available	15.7	8.4	1.4	9.3	17.1	8.5
<b>Total</b>	<b>186.7</b>	<b>100.0</b>	<b>15.3</b>	<b>100.0</b>	<b>202.0</b>	<b>100.0</b>
<b>Need for and receipt of respite care</b>						
Received in the last 3 months and:						
does not need further care	*6.2	*3.3	**0.2	**1.5	*6.5	*3.2
needs further care	10.4	5.6	**0.5	**3.5	10.9	5.4
None received in the last 3 months and:						
does not need care	*6.7	*3.6	**0.7	**4.7	*7.4	*3.7
needs care	*7.0	*3.8	**0.9	**5.6	*7.9	*3.9
Never received respite care and:						
does not need or want care	139.7	74.8	12.9	84.6	152.6	75.5
needs care	16.7	8.9	—	—	16.7	8.3
<b>Total</b>	<b>186.7</b>	<b>100.0</b>	<b>15.3</b>	<b>100.0</b>	<b>202.0</b>	<b>100.0</b>

*Notes*

1. Includes primary carers aged 15 years or more living in households with the main recipient of care.
2. Estimates marked with \* have an associated relative standard error (RSE) of between 25% and 50% and should be interpreted accordingly.
3. Estimates marked with \*\* have an associated relative standard error (RSE) of greater than 50% and should be interpreted accordingly.

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

Employment services reach relatively more of their potential target group (196 service users per 1,000 potential population), and accommodation support services the fewest of the major service categories (48 service users per 1,000 potential population – Table 5.24).

This basic indicator takes no account of the different levels of service provided – for instance accommodation support services, in some cases, provide a high level of support over many hours – nor the presence of complementary informal care, possibly more likely for people needing accommodation support than employment support.

CSTDA services are not entitlement services nor do they, as do some aged care services, have a planning ratio (see Chapter 4 and AIHW 2002:214–16). Unmet need in 2001 for specialist disability services was reported by the AIHW as: 12,500 people needing accommodation and respite services, 8,200 places for community access services, and 5,400 people needing employment support (AIHW 2002). These estimates have not been updated. This report and others have pointed to the unmet need for relevant equipment and the fragmentation of national supply mechanisms (AIHW: Bricknell 2003). ‘Managing demand’ remains one of the five key policy priorities under the CSTDA, advocacy groups continue to point to ongoing unmet need for disability support services, and the figures in Table 5.23 suggest that informal carers need further assistance from formal services.

**Table 5.24: CSTDA-funded service users and ‘potential populations’ for selected service groups, 2003–04**

Service group	Service users, 2003–04	Potential population (June 2003)	Service users per 1,000 potential population
Accommodation support	33,175	687,710	48.2
Community support	78,847	687,710	114.7
Community access	47,636	687,710	69.3
Respite	20,547	213,298	96.3
Employment	64,281	328,677	195.6

*Notes*

1. The potential population for accommodation support and community access is the number of people aged under 65 years, with profound or severe core activity limitation, multiplied by an Indigenous factor.
2. The potential population for respite is the number of people aged under 65 years, with profound or severe core activity limitation and a primary carer, multiplied by an Indigenous factor.
3. The potential population for employment services is the number of people aged 15–64 years with profound or severe core activity limitation, multiplied by both an Indigenous factor and the labour force participation rate.
4. Numbers of people with profound or severe core activity limitation are AIHW estimates derived using the ABS 2003 Survey of Disability, Ageing and Carers data.
5. The Indigenous factor was calculated using weighted population data for all people and multiplying the data for Indigenous Australians by two and adding the data for non-Indigenous Australians. Hence Indigenous Australians are weighted at two and non-Indigenous Australians at one.

Source: AIHW 2005c.

## **CSTDA quality and outcome indicators**

It is possible to monitor the achievement of explicit program goals believed to relate to service quality and outcomes for people. Deinstitutionalisation, for instance, has been a goal in the disability services field for some years, and the proportion of people receiving ‘community-based’ accommodation support services (receiving support while in accommodation other than institutions and hostels) has risen since 1995 (Section 5.4). Disability services under the CSTDA are required to meet nationally agreed standards (DHS 1993; FaCS 2005d).

There was considerable discussion of the need to have better outcome and quality indicators during the CSTDA NMDS redevelopment process (AIHW 2003c). While service quality has been promoted by the creation of service standards and the establishment of monitoring processes, no feasible way of collecting meaningful national data reflecting 'quality' was identified or agreed. An outcome framework suitable for the CSTDA is described in the redevelopment report; it was anticipated that the framework could be used to plan for and to record client outcomes. Nevertheless it was recognised that the recording of client outcomes by service providers, for accountability purposes, in a field such as the disability field, is of questionable validity. 'Client satisfaction' and similar concepts can, in theory, provide information about service quality and client outcomes. In practice, consumer satisfaction surveys have achieved poor response rates and yielded limited new meaningful information (E-QUAL and Donovan Research 2000). Thus a feasible way of improving indicators of service quality and client outcomes in the CSTDA NMDS collection has yet to be developed.

## Participation as a whole-of-government outcome

In previous editions of *Australia's Welfare*, outcomes for people with a disability have been described using the framework of the International Classification of Functioning, Disability and Health (ICF); this is the approach used here. Participation, according to the ICF, is recorded in nine broad life areas in which all people, irrespective of disability, can expect to participate. In reflecting a 'whole person' and whole-of-life approach to participation, the ICF underpins a whole-of-government perspective for reviewing outcomes for people with disabilities.

The section provides a summary picture of participation in Australian society by people with disabilities. Population survey data are applied to the international standard framework of the ICF.

The outcome measures presented here are population measures. That is, they indicate a 'status' measure, but the cause cannot be attributed to any specific services or other factors. Further, they do not include outcomes for all people affected by disability, for instance the carer outcomes illustrated in Section 5.4. Nevertheless the data in this section are relevant outcome indicators for whole-of-government approaches to service provision to people with a disability.

## Overview of participation

Measures now in national data standards are used here (where relevant data are available) to indicate outcomes in each of the nine ICF life areas or domains in which all people expect to participate – the difficulty experienced, assistance needed, the extent of participation, and satisfaction with participation. The analyses also illustrate gaps and further areas for improvement in this important ABS survey.

## Extent of participation

The extent to which people with disabilities participate in the various life domains of the ICF is best indicated by comparison of their participation with that of the general population; this is in line with the underlying rights philosophy (see Section 5.2).

Such comparisons were included in *Australia's Welfare 1999* and *2001*. Overall, it was found in these analyses that people with disabilities were participating in many areas of Australian life, although often not to the same extent as the overall population. They were more likely to be living in the community than in previous years, but they tended to report lower levels of health, and they tended to have lower incomes than the general population, although the receipt of government pensions and allowances helped mitigate these income differentials. These comparative analyses will be updated in the future.

## **Difficulty and assistance with activities, and satisfaction with participation**

An overview of eight of the nine ICF life areas (domains) is presented in Table 5.25, indicating difficulty and assistance with activities, and satisfaction with participation, for people with disabilities. This is not a complete picture, as explained in Box 5.7, where possible improvements to source data are identified, and future updates of previous analyses foreshadowed.

Of the 2,556,000 people with disabilities aged under 65 years in Australia in 2003, difficulty was most often reported in the survey areas of:

- employment – 1,536,700 people;
- interpersonal interactions and relationships – 1,068,000 people;
- property maintenance – 852,600 people;
- transport (public and private) – 823,900 people;
- mobility (including public transport) – 821,700 people; and
- health care – 772,600 people.

In terms of the broad ICF domains, mobility and 'major life areas' were the two where there were large numbers of people with disabilities experiencing difficulties.

When the focus is on people who need assistance, the most frequent areas reported in the survey were:

- employment – 726,000 people;
- transport (public and private) – 667,100 people;
- property maintenance – 658,600 people; and
- interpersonal interactions and relationships – 635,800 people.

The broad life areas (ICF domains) in which the need for assistance was most often reported were therefore mobility, domestic life, interpersonal interactions and relationships and 'major life areas'.

Satisfaction with participation, as indicated by the likelihood of receiving the assistance needed, was lowest in the life areas of interpersonal interactions and relationships (38% not receiving the help needed – either 'none at all' or 'not enough'); communication (33%); and domestic life (with around 26% of people not receiving the help needed in housework and domestic relationships).



### **Box 5.7: Areas for improving and updating information on participation by people with disabilities**

*Table 5.25 extracts as much relevant information as possible from the ABS 2003 SDAC survey on the 9 participation domains of the ICF. Data on 8 of the 9 participation domains are presented; later tables provide some information on the 9th domain – community, social and civic life – as well as more detail on the ‘major life areas’ of employment and education.*

*Two areas of improvement in the disability survey are desirable: more complete coverage of the 9 ICF domains for activities and participation; and more information ‘measuring’ activities and participation in these 9 areas. Of the 9 life areas, several, such as self-care, mobility and communication, are covered well and others, such as learning and applying knowledge, are scarcely touched on. Others are mixed with and cannot be disentangled from unrelated ideas; for instance, the ‘cognition and emotion’ area of the survey includes relationships, feelings and decision making – mixing details from ‘interpersonal interactions and relationships’ and ‘general tasks and demands’ in the ICF.*

*Ideally, to be able to report fully in terms of Australian data standards, it would be possible to report on each of these ICF life areas according to the national data standards (see AIHW 2005b; NCSDC 2004) – that is, for each area, to have data on difficulty and assistance with activities, on the extent of participation in comparison with the rest of the Australian population, and on people’s satisfaction with participation.*

*Table 5.25 focuses on difficulty and the need for assistance. ‘Extent’ of participation has been reported on in previous editions of Australia’s Welfare, where relevant population data enable comparisons of the experience of people with disability and the rest of the population (e.g. in relation to housing and time use); these comparisons will be updated in future editions as new population data become available. ‘Satisfaction’ is defined in the national data standards in terms of the duration, frequency, manner and outcome of the participation, with the issue of ‘choice’ also recognised. Data are not available nationally. The closest we can come to ‘satisfaction’ with current survey data is ‘reported unmet need for assistance’ in each life area.*

*Finally, there is the considerable challenge of measuring the effect of environmental factors on outcomes.*

*The ABS is committed to using international standards and will be reviewing the content of the survey in the lead-up to the next disability survey in 2009.*

In the areas of employment and education, the provision of assistance is indicated differently from other areas of the survey. A schooling or employment restriction may indicate one of a range of difficulties or needs for assistance: these include being unable to work or attend school; being restricted in the type of work or hours that can be worked; needing special arrangements at work; attending a special class at school; and experiencing difficulty with schooling or employment. Of people with schooling restrictions, some 69% received some kind of support or special arrangement (such as a signing interpreter, disability support person, special equipment, special access or transport arrangements). Only 18% of those with employment restrictions received similar support or special arrangements.



**Table 5.25: People aged under 65 with a disability living in households: activities by whether has difficulty, assistance needed, assistance received, and extent to which need for assistance met, 2003**

ICF Activities and participation domains <sup>(a)</sup>	ABS 2003 disability survey activity and participation areas	Total with difficulty or needing help <sup>(b)</sup>		Extent to which need for assistance met (% of total needing help)			Support and arrangements received
		No. ('000)	Need help <sup>(c)</sup> No. ('000)	Fully	Partly	Not at all	
Learning and applying knowledge	Learning and understanding	413.1	n.a.	n.a.	n.a.	n.a.	(d)
General tasks and demands	Paperwork	280.6	223.1	78.9	14.7	6.3	..
	Decision making or thinking through problems <sup>(e)</sup>	(e)	333.3	(e)	(e)	(e)	..
Communication	Communication	198.2	157.3	67.2	30.2	2.6	..
	Speech	181.8	n.a.	n.a.	n.a.	n.a.	..
Mobility	Mobility (including public transport)	821.7	466.6	82.3	12.8	4.8	..
	Public and private transport	823.9	667.1	n.a.	n.a.	n.a.	..
	Private transport <sup>(f)</sup>	502.6	426.9	82.3	9.9	7.7	..
Self-care	Self-care	613.6	318.6	86.3	4.1	9.6	..
	Health care	772.6	496.6	80.3	13.1	6.6	..
Domestic life	Housework	693.1	477.5	74.0	19.4	6.6	..
	Property maintenance	852.6	658.6	73.6	20.3	6.1	..
	Meal preparation	179.4	143.6	86.7	10.8	2.5	..
Interpersonal interactions and relationships	Cognition and emotion <sup>(e)</sup>	1,068.0	635.8	61.8	33.0	5.2	..
	Making or maintaining relationships <sup>(e)</sup>	(e)	313.6	(e)	(e)	(e)	..
	Coping with feelings or emotions <sup>(e)</sup>	(e)	473.1	(e)	(e)	(e)	..
<b>% of total with a restriction</b>							
Major life areas	Schooling	256.9	132.2	(d)	(d)	(d)	68.7
	Employment	1,536.7	726.0	(g)	(g)	(g)	18.1

(a) The ICF domains also include community, social and civic life (See Table 5.26).

(b) For schooling and employment, this category refers to total with a schooling restriction or an employment restriction.

(c) For schooling and employment, this category refers to total with a profound or severe schooling restriction or employment restriction.

(d) See support and special arrangements for people with a schooling restriction. These include special equipment (including computer), special tuition, special assessment procedure, a counsellor or disability support person, special access or transport arrangements and other support.

(e) The 'Cognition and emotion' area of the survey includes making or maintaining relationships, coping with feelings or emotions and decision making or thinking through problems. In ICF terms, this grouping mixes 3 chapters across 2 dimensions (body function and activities).

(f) Private transport refers to going to places away from the usual place of residence. Need for help or difficulty are defined for this activity as the need to be driven and difficulty going to places without help or supervision.

(g) See support and special arrangements for people with an employment restriction. These include special leave arrangements, a special support person to assist/train on the job, help from someone at work, special equipment, modifying buildings/fittings, special/free transport or parking, training/retraining, allocating different duties and other support.

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

There are no data in the disability survey on the area of 'economic life' (e.g. economic self-sufficiency, engaging in transactions). Analyses of more economically focused surveys may yield more useful information. As might be expected from their experience in the labour market, households whose members include people with disabilities have been found to be more likely to have low incomes and to experience financial hardship than others. Saunders (2005) found that 9.4% of households with at least one adult with a disability, and 12.3% of households with no adults but at least one child with a disability, had incomes below the 50% median income benchmark (see Chapter 2 for data on this benchmark). These figures compared to 7.4% of other households. There were even greater differentials on five indicators of hardship: financial hardship, restricted participation, severe financial stress, expressed need and lack of support.

## Community, social and civic life

'Community, social and civic life' is the 9th ICF domain for activities and participation. The available survey data relevant to this domain are structured differently from the data in Table 5.25, and are summarised in Table 5.26.

**Table 5.26: People aged 5–64 years with a disability living in households: community participation, by disability status and age, 2003 (per cent)**

	Profound core activity limitation		Severe core activity limitation		Total with disability	
	5–44 years	45–64 years	5–44 years	45–64 years	5–44 years	45–64 years
<b>Community participation</b>						
<b>At home in the last 3 months</b>						
Visits from family/friends	84.7	86.3	92.9	88.7	90.7	89.2
Telephone calls with family/friends	68.3	87.6	86.1	90.4	88.8	92.3
Craftwork for/with other people	15.0	15.8	19.3	12.5	19.2	14.1
Church/special community activities	*6.9	*5.3	9.8	6.2	7.1	7.3
Voluntary work (including advocacy)	*2.2	*3.5	8.1	9.0	6.3	9.3
None of the above	9.6	*4.4	*2.9	*4.1	2.6	3.2
<b>Total population ('000)</b>	<b>118.8</b>	<b>77.6</b>	<b>230.2</b>	<b>199.1</b>	<b>1,239.2</b>	<b>1,244.9</b>
<b>Away from home in the last three months</b>						
Visited family/friends	79.4	70.8	91.4	84.9	89.6	87.0
Went to a restaurant or club	44.1	33.5	57.4	55.1	63.0	62.0
Attended church activities	18.0	14.4	20.0	20.3	18.9	20.3
Voluntary work (including advocacy)	9.1	*8.5	14.8	15.9	16.8	18.9
Organised performing arts activities	*8.2	**2.5	9.1	*3.9	7.6	4.6
Organised art/craft group activities	*6.1	*4.2	8.7	6.9	8.2	7.6
Other special interest group activities	18.1	*7.5	16.3	14.8	17.1	14.8
None of the above	8.7	15.4	*4.1	10.3	4.2	6.5
Does not leave home	*4.0	*3.5	—	*0.3	*0.5	*0.4
<b>Total population ('000)</b>	<b>118.8</b>	<b>77.6</b>	<b>230.2</b>	<b>199.1</b>	<b>1,239.2</b>	<b>1,244.9</b>

### Notes

1. Estimates marked with \* have an associated relative standard error (RSE) of between 25% and 50% and should be interpreted accordingly.
2. Estimates marked with \*\* have an associated relative standard error (RSE) of greater than 50% and should be interpreted accordingly.

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

Many people with a disability, including those with a profound or severe core activity limitation, had participated in social events and community activities in the 3 months preceding the 2003 Survey of Disability Ageing and Carers (Table 5.26). The predominant activities for all disability groups and all age groups were visits from and to family and friends, telephone calls with family and friends, and visits to restaurants and clubs. Thus, in 2003, not only did family and friends provide most of the assistance needed by people with disabilities, they were also the main focus of these people's social lives.

People with profound core activity limitations were less likely than other people with disabilities to have participated in these social activities. For instance, 79% of those aged 5–44 and 71% of those aged 45–64 had visited family and friends away from home in the previous 3 months, compared to 90% (and 87%) of people with disability in the same age groups. They were also the age groups most likely to respond that they had not participated in any of the listed social activities at home (9.6% and 4.4% respectively for the two age groups) or away from home (8.7% and 15.4%). Of people with a profound core activity limitation, 4.0% of people aged 5–44, and 3.5% of those aged 45–64, reported that they 'do not leave home'.

## Major life areas: a focus on employment and education

### Participation in education

People aged 15–64 years with a disability, in particular with a profound or severe limitation, had participated less in the education system than had people with no disability. In 2003, 69% (and 58%) of people with profound (or severe) core activity limitation had 'no non-school qualification', compared with 48% of people with no disability (ABS 2004a:22). Only 21% (and 26%) of people with a profound (or severe) limitation had completed Year 12, in contrast to 49% of people with no disability.

The inclusion of students with a disability in mainstream education is a generally accepted policy in Australian school systems. Previous analysis illustrated the effectiveness of these policies:<sup>3</sup> rising percentages of people aged 5–20 years in school and reporting a disability between 1981 and 1998; and rising percentages of people with disabilities (including severe disabilities) in the school population, in mainstream schools in special classes and in mainstream schools in ordinary classes (AIHW 2001:313). The increase in the percentage of people aged 5–20 attending school (and those not attending) among people with a disability was partly associated with the increase in reported disability prevalence among the population of that age.

In 2003, attendance rates for people aged 5–20 years with profound (91%) or severe (85%) limitations were higher than for people with a disability overall (79%) (Table 5.27). This is possibly because, of people who were not attending school, those with 'moderate' core activity limitation were more likely to have finished school (89%), compared to those with profound limitations, who were likely to be prevented by their

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3. The disability survey data on education among people with a disability are not directly comparable to the collections of education departments (see Table 5.19). Some students reported in the survey as having a disability were not recognised by the education departments.

Table 5.27: Percentage of school-aged people (aged 5–20 years) with a disability living in households, by school attendance and type of school and class, by disability status, 2003 (per cent)

	Core activity limitation				Schooling restriction only	Total with specific restrictions	Disability without restriction	Total with a disability
	Profound	Severe	Moderate	Mild				
<b>Attending school</b>								
Ordinary school class	38.5	59.9	76.9	67.8				
Ordinary school (special class)	23.3	30.9	23.1	28.2	33.7	28.8	—	25.1
Special school	38.3	*9.2	—	*4.1	—	12.4	—	10.8
<i>Total</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>
<b>Total ('000)</b>	<b>65.0</b>	<b>82.4</b>	<b>15.6</b>	<b>58.0</b>	<b>60.6</b>	<b>281.6</b>	<b>40.9</b>	<b>322.5</b>
<b>Not attending school</b>								
Reason for not attending:								
Condition prevents attendance	*41.0	*18.3	—	**10.7	18.4	16.1	—	12.1
Too young	—	*17.2	**11.4	**7.9	—	*7.7	**2.2	*6.3
Finished school	*59.0	*64.5	*88.6	81.3	81.6	76.2	97.8	81.6
<i>Total</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>
<b>Total ('000)</b>	<b>*6.5</b>	<b>14.4</b>	<b>*8.1</b>	<b>18.6</b>	<b>15.4</b>	<b>63.0</b>	<b>20.9</b>	<b>83.9</b>
<b>Total all school-aged people ('000)</b>	<b>71.6</b>	<b>96.8</b>	<b>23.6</b>	<b>76.6</b>	<b>76.0</b>	<b>344.6</b>	<b>61.8</b>	<b>406.4</b>
<b>Per cent attending school</b>	<b>90.8</b>	<b>85.1</b>	<b>66.1</b>	<b>75.7</b>	<b>79.7</b>	<b>81.7</b>	<b>66.2</b>	<b>79.4</b>

*Notes*

1. Estimates marked with \* have an associated relative standard error (RSE) of between 25% and 50% and should be interpreted accordingly.
2. Estimates marked with \*\* have an associated relative standard error (RSE) of greater than 50% and should be interpreted accordingly.

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

Table 5.28: People aged 15–64 years living in households, by labour force status and by disability status, 2003

	Core activity limitation				Schooling or employment restriction only	Total with specific restrictions	Total with a disability	Total without a disability	Total
	Profound	Severe	Moderate	Mild					
<b>Unemployment rate</b>	<b>Per cent</b>								
Males	**8.5	*10.1	*7.2	9.0	14.3	10.3	8.7	4.8	5.3
Females	**24.6	*9.0	*8.1	*6.3	14.3	9.3	8.2	5.2	5.6
Persons	*13.9	9.5	7.6	7.7	14.3	9.8	8.5	5.0	5.4
<b>Participation rate</b>									
Males	22.1	38.5	56.3	53.1	73.1	53.4	59.3	89.0	84.0
Females	*9.4	33.9	40.3	48.1	61.8	42.1	47.0	72.3	68.1
Persons	15.2	36.0	48.0	50.6	68.4	47.8	53.3	80.6	76.1
<b>Total in labour force</b>	<b>Number ('000)</b>								
Males	14.3	62.6	114.2	156.6	146.1	493.9	671.8	4,968.8	5,640.7
Females	7.1	65.4	89.0	138.8	87.3	387.7	511.1	4,009.5	4,520.5
Persons	21.4	128.0	203.3	295.4	233.4	881.6	1,182.9	8,978.3	10,161.2
<b>Total</b>									
Males	64.6	162.6	202.8	295.2	199.9	925.0	1,133.1	5,584.1	6,717.2
Females	76.3	193.0	220.7	288.7	141.3	920.0	1,086.9	5,549.1	6,636.0
Persons	140.9	355.6	423.5	583.9	341.2	1,845.0	2,220.0	11,133.2	13,353.2

*Notes*

1. Estimates marked with \* have an associated relative standard error (RSE) of between 25% and 50% and should be interpreted accordingly.
2. Estimates marked with \*\* have an associated relative standard error (RSE) of greater than 50% and should be interpreted accordingly.

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

condition from attending (41%). Of the 79% of people with disabilities aged 5–20 years who were attending school in 2003, 64% were in ordinary classes, 25% were in special classes in ordinary schools, and 11% were in special schools. People with profound core activity limitations were the most likely to be in special schools in 2003 (38%).

## Employment and labour force participation

In 2003, people aged 15–64 years with a disability had a lower level of involvement in the paid workforce than the rest of the population: a participation rate of 53%, compared with 81% for people without disability (Table 5.28). Participation rates for people with profound and severe core activity limitations were even lower – 15% and 36% respectively. Women’s rates were lower than men’s across all disability levels.

Unemployment rates must be interpreted in the context of these lower participation rates, for both men and women. The unemployment rate for males participating in the labour force and having a disability was 8.7% – higher than that for men with no disability (4.8%) or for men generally (5.3% as measured in this survey<sup>4</sup>). The unemployment rate for women with a disability was 8.2%, higher than that for women generally (5.6%). Women with profound core activity limitations had very high unemployment rates – 25%.

People with disabilities who were employed worked in a quite similar array of industries and occupations as other employed people. They were as likely to be ‘managers and administrators’ or professionals (8.4% and 18.4%) as others (8.1% and 19.2%) but slightly more likely to be ‘intermediate production and transport workers’ or labourers (10.6% and 10.9%) than others (7.7% and 7.9%) (ABS 2004a:27). They were more likely to be employed in government (including administration and defence), education, and health and community services (a total of 25.2%) than others (21.8%).

## 5.6 Summary and conclusion

Disability services are being delivered in a context of ongoing change. Population changes are significant: the Australian population overall is growing and ageing, and so is the population of people with disabilities. Differences between ‘older Australians’ and ‘ageing people with disabilities’ are not always clear-cut, and there is an acknowledged need to blend aged care and disability services more seamlessly and to improve intergovernmental linkages. Unpaid carers remain the main providers of assistance to people with disabilities and they and the service system together face these population pressures. Transitions to ‘retirement’ are seen to be needed, for both people with disabilities and for family carers, in addition to earlier life transitions, notably from school to work. Specialist disability services are looking to a flexible, individually focused model of service provision – and this, in turn, brings the challenge of accurate assessment of needs related to individualised, portable funding. Planning and funding for specialist service programs take place in a wider context of generic services of importance to people

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4. The 2003 disability survey used a less rigorous definition of unemployment than the standard: thus, while the figures quoted here enable comparisons, they do not match exactly the ABS labour force data of the time.



with disabilities. Demand management is on the agenda of both government and non-government funders and providers. Other programs and funding policies – such as those provided by insurance systems, where assistance is provided on the basis of fault as well as need – add to the mix. Beyond the service context are changes in the fields of science, technology and genetics which pose ethical dilemmas as well as the possibility of providing enabling equipment that could expand people’s opportunities. The consensual foundation of the field overall is that of human rights, and the need to create enabling environments so that people with disabilities can participate in every area of society.

This chapter, and the AIHW’s work in this field, attempt to provide statistics which inform people interested in disability, and those attempting to meet the challenges of this changing context. Ongoing improvements to national data, outlined in Section 5.2, are essential infrastructure for the overall system. Not least of these is the implementation of the ICF into more of the relevant data collections, to provide more consistent and ‘joined up’ data, so as to support ‘whole person’, whole-of-government policies.

## Population

In 2003 there were 3.9 million people with a disability in Australia—20% of the population. The majority, 2.6 million, were aged under 65 years and, of these, 677,700 people (3.9% of people aged under 65) had a profound or severe core activity limitation, meaning that they needed assistance with self-care, mobility or communication. The age-standardised rates of these more severe disabilities have not changed significantly in over 20 years. Nevertheless, because of population growth and ageing, the actual number of people with these disabilities is rising.

Equipment of all kinds was likely to be used by people with profound activity limitations, especially equipment associated with the core activities—self-care, mobility and communication.

For the first time it has been possible to include national data on disability among Aboriginal and Torres Strait Islander people, who had severe disability rates more than double those of other Australians in 2002.

## Services and assistance

The largest income support programs in 2003–04 were:

- Disability Support Pension, with almost 697,000 recipients in June 2004 and expenses of close to \$7.5 billion in 2003–04;
- Carer Allowance (Child/Adult), with 297,600 recipients and \$965 million expenses, and Carer Payment (DSP/AP/other) with 84,100 recipients and \$921 million expenses; and
- Disability Pension (DVA), with almost 155,000 recipients in June 2004 and \$1,289 million expenses.

Some but not all of the growth in DSP recipient numbers over recent years can be attributed to population growth and ageing. While male age-adjusted rates of DSP receipt have levelled off in recent years, female rates have not.

Disability support services under the CSTDA were provided to 187,806 service users during 2003–04. The most widely accessed service group was community support (used by 42% of service users), followed by employment (34%) and community access (25%). Accommodation support services were accessed by 33,175 service users (18%), with 5,303 of these people using institutional accommodation. Government expenditure on disability support services during 2003–04 totalled \$3.28 billion. Over half this expenditure was used to fund accommodation support services (\$1,638 million).

Employment services reached relatively more of their potential target group (196 service users per 1,000 ‘potential population’), and accommodation support services the fewest of the major service categories presented (48 per 1,000). Unmet need for disability support services remains on the agenda of advocacy groups, as does managing demand for disability administrators.

A total of 6,524 CSTDA service users (3.5%) were identified as being of Aboriginal or Torres Strait Islander origin, or both. While this represents a higher proportion than in the overall population (2.4%), it is less than might be expected given their rates of disability, now estimated to be more than double those of other Australians.

Many CSTDA service users rely on informal carers (although the data on carers are still improving in coverage). Of these, 6,472 carers were aged 65 years and over: 3,959 were mothers of the service user (61%), 749 fathers (12%), 543 a husband/male partner (8%) and 446 a wife/female partner (7%).

During 2003–04, there were 170,100 HACC clients under the age of 65 years (24% of the total 707,200). There were also 6,240 clients aged under 65 years in permanent residential aged care facilities as at 30 June 2004—representing 4.3% of all residents in receipt of these services.

The available data on rehabilitation and hearing services, and on generic services such as education, employment and housing, are reported here, but there are none on the increasingly important area of equipment services. The health of people with disabilities, and the adequacy of health services for them, remain areas of concern.

Unpaid care remains the mainstay of the support system for people with disabilities. In 2003 there were 202,000 primary carers of people aged under 65, living with the main recipient of care (primary carers are the main providers of assistance with self-care, mobility and/or communication). They were most likely to be caring for a son or daughter (44%), or spouse or partner (44%). Some 20% of carers reported the need for further assistance themselves, and 18% needed more respite provided by formal services.

## **Outcomes—and data enhancements needed**

A summary picture of participation in Australian society by people with disabilities is provided, with reference to the nine ICF ‘activities and participation’ life areas in which all people, irrespective of disability, expect to participate. Indicators are sought to ‘measure’ activity and participation in these life areas, reflecting national data standards.

Previous analyses have shown that people with disabilities are participating actively in all areas of Australian life, although not always to the same extent as other Australians. This new analysis confirms these findings and sheds light on some of the reasons why

this may be so. Very large numbers of people experienced difficulties in key areas such as mobility, interpersonal relationships and the 'major life areas' such as employment. The areas in which the need for assistance was most often reported were mobility, domestic life, interpersonal interactions and relationships, and employment.

These analyses, and the data gaps found in doing them, illustrate the benefits of using the ICF framework. It enables us to draw on various useful sources of data to compile a coherent summary picture. It also shows clearly the distance we still have to go before national data will really support a whole-of-government evaluation of the status of people with disabilities in Australian society. (Some specific directions for data are outlined in Sections 5.2 and 5.5.)

While Australia is relatively rich in information on people with disability and the specialist services they use, data on environmental factors (including equipment) and generic services (including health) are inadequate. Future enhancement may be needed to the national disability survey, to include more complete information on participation and environmental factors, using the ICF framework. The identification of people with disabilities in generic service collections, and greater consistency across disability and aged care services data, would promote understanding of person-centred outcomes and whole-of-government policy monitoring.

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