

# 9 Disability services

## 9.1 Introduction

This chapter presents a national picture of services and assistance designed to enable people with a disability to participate in a full community life. People aged under 65 years are the primary focus; information on older people is contained in Chapter 8.

Following clarification of the concepts and definitions used, the various sections address in turn the prevalence of disability and the need for services; a profile of the services provided; and the outcomes for people with a disability.

### Disability and definitions

Disability is usually conceptualised as being multi-dimensional for the person involved. There may be effects on organs or body parts, for instance impairments in the mobility of joints or bones. There may be effects on certain activities, for instance lifting or gripping objects with the hand. There may be effects on a person's participation in a full community life; for instance, environmental modification or equipment may be needed so that the person is enabled to work in their usual employment.

To present data on disability and disability services it is necessary to classify or summarise people's needs and relate them to service data items and definitions. Classification necessitates balancing two important but sometimes countervailing requirements. On the one hand, it is important to try to use appropriate and acceptable terminology which acknowledges the full extent of people's experience. On the other hand, clear service and data definitions are needed so that it can be seen who is eligible for and receiving services. Inevitably, data definitions and quantitative data represent an uneasy compromise between the drive towards and the resistance to such simplification, classification or labelling.

Three dimensions of disability are recognised in the International Classification of Impairments, Disabilities and Handicaps (ICIDH), the 1980 definitions being set out in Box 9.1.

A new version of the ICIDH is now being drafted, to embrace developments in the field since 1980, and criticism of the first ICIDH. A range of countries, including Australia, is involved in the work with the World Health Organization, as well as organisations representing people with a disability. One of the major developments is the more specific recognition of the social construction of the third dimension of disability. It is being proposed that this third dimension be renamed 'participation', and that its definition recognise the critical role played by environmental or contextual factors in restricting full participation (Box 9.2).

Physical health and autonomy (including opportunities for worthwhile social participation) have been argued to be the two primary, universal prerequisites for human

### **Box 9.1: Definitions of the ICIDH 1980**

*The International Classification of Impairments, Disabilities and Handicaps (ICIDH), provides a conceptual framework for disability which is described in three dimensions—impairment, disability and handicap:*

**Impairment:** *In the context of health experience an impairment is any loss or abnormality of psychological, physiological or anatomical structure or function.*

**Disability:** *In the context of health experience a disability is any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being.*

**Handicap:** *In the context of health experience a handicap is a disadvantage for a given individual, resulting from an impairment or a disability, that limits or prevents the fulfilment of a role that is normal (depending on age, sex, and social and cultural factors) for that individual.*

*Impairment is considered to occur at the level of organ or system function. Disability is concerned with functional performance or activity, affecting the whole person.*

*The third dimension—'handicap'—focuses on the person as a social being and reflects the interaction with and adaptation to the person's surroundings. The classification system for handicap is not hierarchical, but is constructed of a group of dimensions, with each dimension having an associated scaling factor to indicate impact on the individual's life.*

*Source: WHO 1980.*

### **Box 9.2: Definitions of the new draft ICIDH**

*In the context of health condition:*

**Impairment** *is a loss or abnormality in body structure or of a physiological or psychological function.*

**Activity** *is the nature and extent of functioning at the level of the person. Activities may be limited in nature, duration and quality.*

**Participation** *is the nature and extent of a person's involvement in life situations in relationship to impairments, activities, health conditions and contextual factors. Participation may be restricted in nature, duration and quality. Participation is considered within seven broad domains: personal maintenance; mobility; exchange of information; social relationships; education, work, leisure and spirituality; economic life; and civic and community life.*

**Context** *includes the features, aspects, attributes of, or objects, structures, human-made organisations, service provision, and agencies in, the physical, social and attitudinal environment in which people live and conduct their lives.*

*The draft ICIDH2 has been issued as a public document for field trial purposes. The final version is planned to be published in 1999.*

*Source: WHO 1997.*

wellbeing (Doyal & Gough 1991). The evolving ICIDH concepts—impairment, activity (limitation) and participation—can thus be situated in a broader framework for universal needs and wellbeing.

These definitions and terminology are therefore in a state of flux. In this chapter, the words of the new draft ICIDH will generally be used, except when referring specifically to some existing data sources which define and contain data items such as 'handicap'.

## **Data sources and developments**

The data sources used in this chapter include population survey data and a range of administrative sources, as well as some smaller scale studies. Interpreting data from these sources requires recognition that variation may occur because of:

- differences in definition and classification;
- different methods of collecting data—for instance, surveys, service or clinical collections; and
- differences in reporting methods—for instance, self-reported data may give different results from 'professional assessments' which may in turn differ from professional to professional.

There is a healthy debate in the disability field in Australia about appropriate terms, definitions and classifications, and about the usefulness of the various sources of data. There is also strong interest in moving towards greater consistency in terms and definitions, so that different data sources can be related to each other and provide a more coherent national picture of services for people with a disability. Relevant national and international data developments will therefore be highlighted at various points in the chapter.

## **Data and chapter framework**

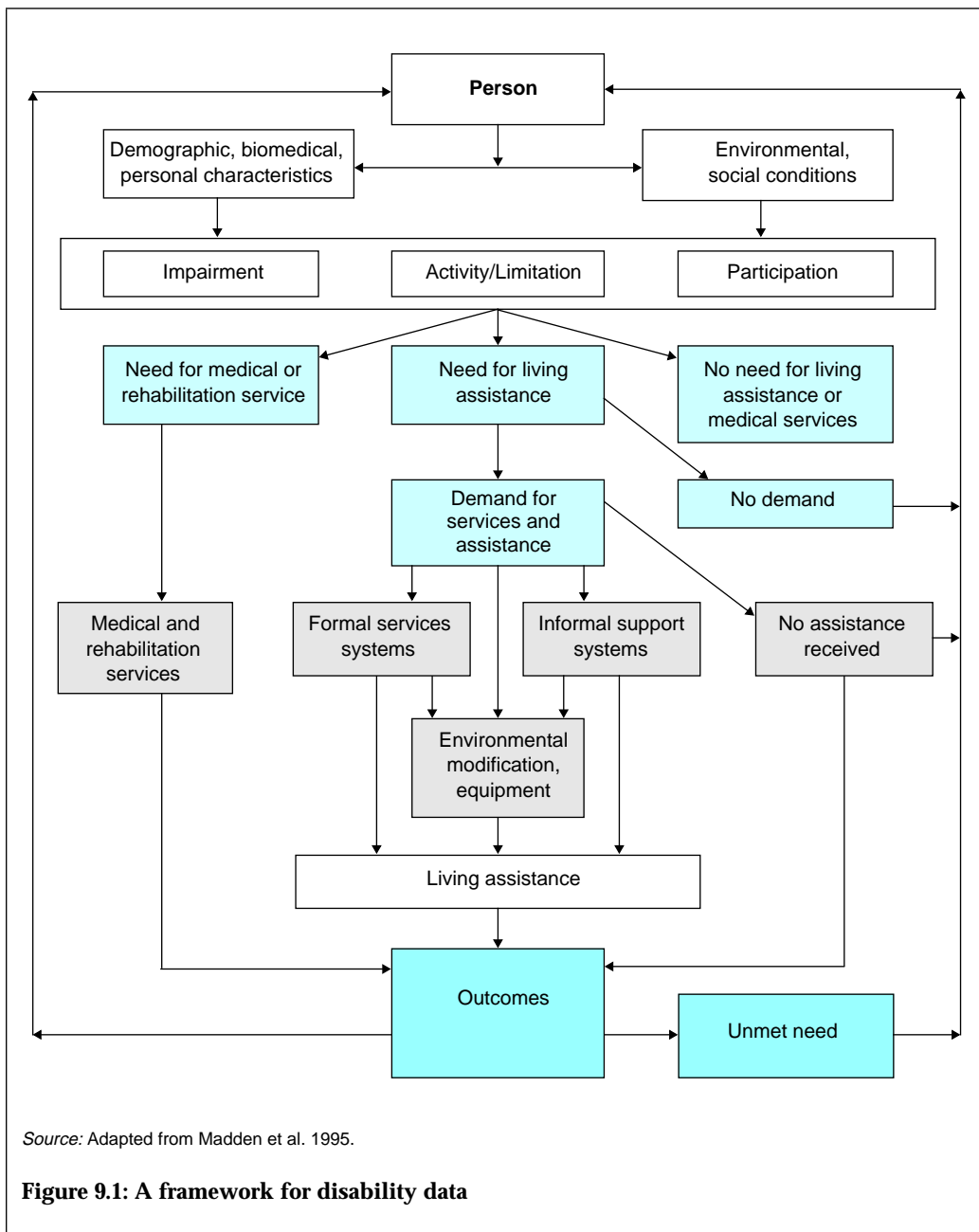
Environmental or social conditions may combine with individual biomedical, demographic and other factors to create effects on functional abilities and participation outcomes. Needs may arise for health or rehabilitation services, or for disability services or other support (providing 'living assistance'). A need may then translate into a demand for services or assistance. A framework for this approach, together with the three-dimensional conceptualisation of disability, is illustrated in Figure 9.1.

Services of relevance to people with a disability may address needs in any of the three dimensions: impairments, activities and activity limitations, or participation. Generally, it is health-related services which address the first dimension—impairment—and health or rehabilitation services which address the second dimension—activity limitation.

Those services and assistance which primarily address the third dimension of disability—participation—are the subject of this chapter.<sup>1</sup> Such services and assistance may come in various forms: formal services, including specific disability support services, income support or relevant mainstream services; equipment, long-term

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1 Such services may also affect impairments and activity limitations. Similarly, health services may have an effect on participation, but this is not usually their primary purpose and such an effect is often achieved by an intermediate effect on impairment or disability.



treatment or environmental modifications; or informal support. Outcomes from these services may include increased or more satisfying participation but may also include unmet needs. These outcomes, including unmet needs, affect the person and feed back into the overall description of their situation.

Section 9.2 summarises relevant population data and presents some estimates of the demand for services. Section 9.3 provides data on services: income support, disability support, generic services, and informal support. Significant policy and administrative developments in the field, affecting the form of services provided, are outlined. Section 9.4 describes progress on monitoring service outcomes, and presents information on outcomes for people with a disability, drawing particularly on the notion that the goal of disability services is to enhance people's participation in the full range of community life.

## 9.2 Prevalence of disability and need for services

This section outlines the main available data on disability in the Australian population: overall prevalence, the occurrence of particular disability groupings and of multiple disabilities, and changes in prevalence in recent years. The absence of data on disability among Indigenous peoples is discussed, reasons identified and methods to make progress suggested. The section concludes by drawing some inferences about the need for services.

### Disability in the Australian population

The most recent national Australian population survey on disability was the 1993 Survey of Disability, Ageing and Carers; the next is scheduled for 1998. Results of the 1993 survey have been published in a range of material since 1993 (ABS 1993a; AIHW 1995; Gibson et al. 1996; Madden et al. 1996); this section concentrates on outlining some key features of the survey results.

#### Prevalence

The 1993 ABS survey defined 'disability' as the presence of one or more of 15 'restrictions, limitations or impairments' identified by survey respondents (Box 9.3).

According to this definition, there were 3,176,700 people in Australia reporting disability in 1993.<sup>2</sup> Of these, 2,031,900 were aged under 65, of whom 925,700 (45.6%) were female, and 1,106,200 (54.4%) male (Table 9.1).

In designing the survey, the ABS attempted as far as possible to use the definitions of the 1980 ICIDH, and collected data on 'handicap' as well as on 'disability'. 'Handicap'

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2 Strictly, people did not 'report' disability and handicap in the ABS survey. They reported activity limitations, restrictions or impairments, from which they were classified as having a disability or handicap. The term 'report' is used, nevertheless, both for brevity and to emphasise the self-reported nature of the data. Prevalence estimation from population surveys depends on the reliability of self-reported data. There is little evidence that any one data source is intrinsically more 'reliable' than another, but rather that definitions, survey questions, assessment instruments, personal perspectives and collection methods can all affect estimates, and care must be taken that the data are suitable to the purpose of their application. Comparability of self-reported results in non-homogeneous communities is considered to be promoted by the use of ADL-based instruments with precise specification of severity categories (Mathers 1996).

### **Box 9.3: Areas of limitation, restriction or impairment identified by the ABS**

*Affirmative responses to any of the following categories 'screen' the person into the ABS survey, where the limitation, restriction or impairment has lasted or was likely to last for 6 months or more:*

- *loss of sight, not corrected by glasses or contact lenses*
- *loss of hearing*
- *speech difficulties in native languages*
- *blackouts, fits, or loss of consciousness*
- *slowness at learning or understanding*
- *incomplete use of arms or fingers*
- *difficulty gripping or holding small objects*
- *incomplete use of feet or legs*
- *treatment for nerves or an emotional condition*
- *restriction in physical activities or in doing physical work*
- *disfigurement or deformity*
- *long-term effects of head injury, stroke or any other brain damage*
- *a mental illness requiring help or supervision*
- *treatment or medication for a long-term condition or ailment, person still restricted*
- *any other long-term condition resulting in a restriction*

*This list thus creates the implicit definition of disability for the survey. In ICIDH 1980 terms, the ABS notion of disability ranges over impairment, disability and even handicap and health condition.*

was identified where a person, because of their disability, had a limitation or restriction in performing certain tasks associated with self-care, mobility, verbal communication, schooling or employment.<sup>3</sup> In 1993 there were 1,519,000 people aged under 65 years who reported handicap (9.7% of the population in that age group). A total of 368,300 (or 2.4% of the population aged 5 to 64) reported 'severe or profound handicap', meaning that they always or sometimes needed personal assistance or supervision with activities of daily living (self-care, mobility or verbal communication) (Table 9.1; AIHW 1995:245).

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<sup>3</sup> Throughout this chapter, the word 'handicap' will be used only in the context of the ABS surveys and the 1980 ICIDH; the word is becoming less common in Australia and, for some people, unacceptable.

**Table 9.1: People aged 0–64 years with a disability, by disability status, severity of handicap,<sup>(a)</sup> and sex, 1993<sup>(b)</sup>**

	Profound	Severe	Moderate	Mild	Not determined <sup>(c)</sup>	Total with handicap	Disability, no handicap	Total with disability
<b>Number ('000)</b>								
Males	82.5	99.8	136.0	291.9	199.8	809.9	296.3	1,106.2
Females	74.8	111.2	121.4	262.6	139.2	709.1	216.6	925.7
<b>Persons</b>	<b>157.3</b>	<b>211.0</b>	<b>257.3</b>	<b>554.5</b>	<b>338.9</b>	<b>1,519.0</b>	<b>512.9</b>	<b>2,031.9</b>
<b>Percentage<sup>(d)</sup></b>								
Males	1.0	1.3	1.7	3.7	2.5	10.3	3.8	14.0
Females	1.0	1.4	1.6	3.4	1.8	9.2	2.8	12.0
<b>Persons</b>	<b>1.0</b>	<b>1.4</b>	<b>1.7</b>	<b>3.6</b>	<b>2.2</b>	<b>9.7</b>	<b>3.3</b>	<b>13.0</b>

(a) Severity of handicap was not determined for children aged 0–4 years with a disability. Some totals include people aged 5–64 only.

(b) Estimates of 1,900 or less have a relative standard error (RSE) of 50% or more. Estimates of 8,000 or less have an RSE of 25% or more. These estimates should be interpreted accordingly.

(c) This group comprises all children aged 0–4 years with a disability and people who had a schooling or employment limitation only.

(d) Percentage of the Australian population of that sex and age group.

Source: AIHW 1995:246, 395, 396.

### Disability groupings

A common form of terminology in Australia refers to disability groupings, such as 'intellectual disability', when what is usually meant is disability related to intellectual impairment. 'Physical disability' may similarly be related to physical impairment but also to more complex impairments such as quadriplegia (which is generally categorised as physical disability because the effects on the body are primarily physical and the relevant organisations use this term). This common terminology, while not clearly defined, and not based on a one-dimensional classification, is generally understood and is adopted by the major disability organisations in Australia.

Table 9.2 attempts to relate available data to the major disability groupings. Most disabilities arose from main disabling conditions that were likely to be related to physical disabilities; 9.0% of people aged 0–64 years reported such primary conditions. The next most frequent in this age group were disabling conditions affecting sensory abilities (2.2%) and intellectual abilities (1.6%). These data do not indicate the overall prevalence of these conditions, since they count each person only once, according to the main disabling condition.

The disabling condition is, of course, only one aspect of the person's experience; the presence of severe or profound handicap (in ABS terms) illustrates another dimension. People with a psychiatric or nervous system condition, or head or brain injury, as a main disabling condition, were the most likely to report associated severe or profound handicap; those with diseases of the ear, or circulatory or respiratory conditions, were the least likely to report a severe or profound handicap (Table 9.3).

People with physical disabilities were more likely to report handicap in self-care, and less likely to report handicap with communication, than were people with other disabilities. Mobility and employment handicaps were quite frequent across all disability groups.

**Table 9.2: People with a disability, by primary disabling condition and by sex and age, as a percentage of the Australian population of that sex and age, 1993<sup>(a)</sup>**

Disability group	Males				Females				Persons			
	0-64	65+	All ages	Total ('000)	0-64	65+	All ages	Total ('000)	0-64	65+	All ages	Total ('000)
<b>Psychiatric<sup>(b)</sup></b>	<b>0.2</b>	<b>1.3</b>	<b>0.4</b>	<b>31.1</b>	<b>0.2</b>	<b>2.0</b>	<b>0.4</b>	<b>39.4</b>	<b>0.2</b>	<b>1.7</b>	<b>0.4</b>	<b>70.5</b>
<b>Intellectual &amp; 'Other mental'<sup>(c)</sup></b>	<b>1.5</b>	<b>1.2</b>	<b>1.5</b>	<b>129.5</b>	<b>1.7</b>	<b>2.0</b>	<b>1.7</b>	<b>153.5</b>	<b>1.6</b>	<b>1.7</b>	<b>1.6</b>	<b>283.0</b>
<b>Sensory</b>	<b>2.8</b>	<b>13.6</b>	<b>3.9</b>	<b>339.4</b>	<b>1.6</b>	<b>9.2</b>	<b>2.6</b>	<b>232.5</b>	<b>2.2</b>	<b>11.1</b>	<b>3.2</b>	<b>571.9</b>
Diseases of the eye	0.5	2.1	0.7	57.1	0.3	3.7	0.7	64.9	0.4	3.0	0.7	122.0
Diseases of the ear	2.3	11.5	3.2	282.3	1.4	5.5	1.9	167.6	1.8	8.1	2.6	450.0
<b>Physical</b>	<b>9.5</b>	<b>42.0</b>	<b>12.7</b>	<b>1,119.4</b>	<b>8.5</b>	<b>41.0</b>	<b>12.8</b>	<b>1,131.9</b>	<b>9.0</b>	<b>41.5</b>	<b>12.8</b>	<b>2,251.3</b>
Nervous system diseases	0.8	2.3	1.0	86.9	0.8	2.4	1.0	90.1	0.8	2.4	1.0	177.0
Circulatory diseases	0.9	9.1	1.7	150.6	0.5	7.2	1.4	126.1	0.7	8.0	1.6	276.7
Respiratory diseases	1.3	4.7	1.7	148.3	1.5	2.6	1.6	142.1	1.4	3.5	1.6	290.4
Arthritis	1.3	10.2	2.2	191.9	1.6	16.0	3.5	312.4	1.5	13.5	2.9	504.3
Other musculoskeletal disorders	2.0	4.0	2.2	190.3	1.6	3.6	1.9	168.7	1.8	3.8	2.0	359.0
Head injury/stroke/any other brain damage	0.3	1.0	0.4	33.1	0.2	1.0	0.3	26.5	0.3	1.0	0.3	59.6
All other diseases and conditions <sup>(d)</sup>	2.8	10.7	3.6	318.3	2.2	8.1	3.0	266.1	2.5	9.2	3.3	584.4
<b>Total (%) of population</b>	<b>14.0</b>	<b>58.1</b>	<b>18.4</b>	<b>..</b>	<b>12.0</b>	<b>54.3</b>	<b>17.6</b>	<b>..</b>	<b>13.0</b>	<b>55.9</b>	<b>18.0</b>	<b>..</b>
<b>Total<sup>(e)</sup> ('000)</b>	<b>1,106.2</b>	<b>513.2</b>	<b>..</b>	<b>1,619.3</b>	<b>925.7</b>	<b>631.7</b>	<b>..</b>	<b>1,557.4</b>	<b>2,031.9</b>	<b>1,144.8</b>	<b>..</b>	<b>3,176.7</b>

(a) Estimates of 1,900 or less have a relative standard error (RSE) of 50% or more. Estimates of 8,000 or less have an RSE of 25% or more. These estimates should be interpreted accordingly.

(b) This group is the same as the group entitled 'Mental psychoses' in ABS publications.

(c) This group is the same as the group entitled 'Other mental disorders' in ABS publications and includes not only 'slow at learning or understanding things', but also some psychoses and depressions; the category excludes conditions such as Down Syndrome and infantile autism.

(d) ABS grouping of this category includes other physical diseases and conditions such as spina bifida, diabetes, neoplasms, and diseases of urinary system, genital organs and breast. However, it also includes Down Syndrome.

(e) Because only the main disabling condition is considered, each person is counted only once.

Source: AIHW 1995:243.

**Table 9.3: People aged under 65 years with a handicap, by area and severity of handicap and by main disabling condition, as a percentage of the Australian population with a handicap in each condition type, 1993<sup>(a)</sup>**

	Sensory				Physical							Total physical	Total
	Psych- iatric <sup>(b)</sup>	Intell- ectual & 'Other mental' <sup>(c)</sup>	Disease of eye	Disease of ear	Nervous system <sup>(d)</sup>	Circu- latory	Respir- atory	Arthritis	Other musculo- skeletal	Head or brain injury	All other diseases & cond- itions		
<b>Area of handicap</b>													
Self-care	32.0	23.4	16.8	5.9	50.5	19.5	21.1	44.2	45.8	41.7	34.9	37.5	32.9
Mobility	71.3	59.3	55.1	30.2	71.9	80.4	65.5	77.5	72.8	72.3	64.2	70.7	66.1
Communication	20.8	17.0	17.7	55.2	16.6	3.7	3.8	5.5	4.1	17.6	10.0	7.5	12.5
Schooling	0.5	30.2	10.8	16.5	11.3	2.1	17.4	0.7	2.1	6.2	9.0	6.8	10.5
Employment	84.7	48.9	60.3	48.2	68.1	75.7	40.6	68.4	80.1	71.5	63.8	66.7	63.3
<b>Severity of handicap</b>													
Profound	23.7	16.6	10.2	5.4	31.4	4.7	6.0	4.0	4.7	21.0	10.4	9.4	10.4
Severe	14.7	11.9	18.5	4.9	16.4	11.7	11.1	19.6	18.4	15.1	11.4	14.9	13.9
Moderate	18.5	14.4	4.9	5.5	10.1	13.2	9.7	22.3	25.2	17.7	20.3	18.8	16.9
Mild	21.1	25.9	34.4	54.4	21.6	53.0	45.5	41.9	35.1	27.7	34.1	37.2	36.5
Not determined <sup>(e)</sup>	21.9	31.2	32.0	29.9	20.5	17.4	27.7	12.2	16.6	18.6	23.7	19.8	22.3

(a) Area of handicap percentages for each group do not add to 100% since persons may have a handicap or limitation in more than one area.

(b) This group is the same as the group entitled 'Mental psychoses' in ABS publications.

(c) This group is the same as the group entitled 'Other mental disorders' in ABS publications and includes not only 'slow at learning or understanding things', but also some psychoses and depressions; the category excludes conditions such as Down Syndrome and infantile autism.

(d) This group includes people with motor neurone disease, ataxia, multiple sclerosis, quadriplegia and paraplegia. While these diagnoses may arise from a sensory impairment, they are generally perceived to be a physical disability.

(e) This group comprises all children aged 0–4 years with a disability and persons who had a schooling or employment limitation only.

Source: Table A9.2.

The AIHW is preparing a series of reports aimed at clarifying the definitions of these disability groupings and providing improved estimates of the size and profile of the groups. The first such report relates to intellectual disability.

### Intellectual disability: definition and estimation

The twin problems of defining intellectual disability and estimating its prevalence were the subject of a recent study (Wen 1997). Estimates in Australia ranged from 0.4% to 1.86% of the population, depending on the definition used, and the sampling and measurement methods of the different studies (Table 9.4). The generally accepted

**Table 9.4: Comparison of estimates of the prevalence of intellectual disability**

Prevalence Estimates (%)	Regions	Data sources and methods	Definitions
0.3–0.4	World	Agency records	Adapted definitions of AAMR/ICD-9 etc.
0.4–0.5	Australian States	Agency records	Adapted definitions of AAMR
0.42	Australia	1989–90 ABS national health survey (excluded people in institutions) Mental retardation/specific delays in development as a long-term condition	Adapted ICD-9 classifications
0.65	Australia	1993 ABS disability survey, 'intellectual' as a primary disabling condition, identified before age 18	Adapted ICIDH concepts and ICD-9 classifications, AIHW groupings
0.73	Australia	1993 ABS disability survey, 'intellectual' as a primary disabling condition	Adapted ICIDH concepts and ICD-9 classifications, AIHW groupings
0.99	Australia	1993 ABS disability survey, 'intellectual disability' including all relevant disabling conditions and disorders Need ongoing support in basic daily living activities	Adapted ICIDH concepts and ICD-9 classifications, AIHW groupings
1–1.5	World	Epidemiological studies	AAMR/ICD etc.
1.7	Australia	1993 ABS disability survey, based on screening question of 'slow at learning or understanding'	All people reporting positively to the screening question of 'slow at learning or understanding'
1.86	Australia	1993 ABS disability survey, 'intellectual disability' including all relevant disabling conditions and disorders	Adapted ICIDH concepts and ICD-9 classifications, AIHW groupings
3.0	United States	US President's Task Force and President's Panel on Mental Retardation	This 'theoretical prevalence' rate is an extrapolation from statistical models based on IQ scores

#### Notes

1. While the ABS disability survey was used for several of the Australian estimates, AIHW categorisations of 'intellectual disability' were used, rather than the 'Other mental disorders' category of ABS used in Tables 9.2 and 9.3. The AIHW category includes 'slow at learning', Down Syndrome, infantile autism, reading disorders, developmental delay and dyslexia.
2. AAMR is the American Association on Mental Retardation (see Luckasson et al. 1992).
3. ICD refers to the International Classification of Diseases (see WHO 1992).

Source: Wen 1997.

definitions of intellectual disability include not only aspects of impairment but also aspects of 'low general intellectual functioning' (similar to the ICIDH notion of disability or activity limitation), 'difficulties in adaptive behaviour' (similar to participation effects) and the need for support. A prevalence figure of 0.99% or 174,000 was suggested for use in Australia, to align the available data as well as possible with these elements of the definition.

### **Psychiatric disability and mental health**

It is important to distinguish between a medical diagnosis of a mental health problem and its effects on a person's functioning or participation in day-to-day life. These possibly multi-dimensional effects are frequently termed 'psychiatric disability'.

The first reliable national estimates of various mental health conditions should become available in late 1997 or early 1998, when the results of the first National Survey of Mental Health and Wellbeing become available (Box 9.4).

#### **Box 9.4: National Survey of Mental Health and Wellbeing**

*The survey is being conducted in 1997, and is a major undertaking under the National Mental Health Strategy, designed by leading experts in the mental health field in Australia in cooperation with the ABS.*

*The three principal questions addressed by the survey were:*

- *how many Australians have which mental health disorders?*
- *what disability is associated with these disorders?*
- *what is the pattern of service use by persons with and without mental health disorders?*

*The results of the survey will show the prevalence of mental health disorders, including alcohol dependence, cannabis dependence, anxiety disorders, major depression, and panic disorders. Comorbidity (patterns of multiple disorders) and associated factors including demographic and social factors will be analysed. Disability is to be indicated using a health-related measure derived from the SF-12 (Ware et al. 1995).*

Pending the results of this national survey, Australian Health Ministers (1992) have been using an estimate that, at any one time, some 3–4% of all Australians will experience 'severe mental disorders' and estimates of milder conditions can be higher. Other prevalence estimates are reviewed in Table 9.5.

Prevalence estimates of mental health disorders may differ because of differences in the definitions (severe or non-severe mental health problems, or disability-oriented definitions relating to social effects) and in collection approaches used (for instance, population survey versus clinical methods). The ABS disability survey screening questions may be sources of underestimation of psychiatric disability (Madden et al. 1995). Using all information from that survey (not just the screening questions but also the ICD-coded conditions), the Institute has derived a prevalence estimate for psychiatric disability of 2.8%. The ABS 1989–90 National Health Survey indicated that about 1.9% of Australians living in households experienced long-term mental disorders. It is

hoped that the new national mental health survey will enable refinement of these estimates.

**Table 9.5: Comparison of estimates of the prevalence of mental disorders**

Prevalence estimates (%)	Number of people	Sources and methods
0.4	70,500	1993 ABS disability survey, 'psychiatric' <sup>(a)</sup> as a <i>primary</i> disabling condition, (ABS groupings)
0.6	105,100	1993 ABS disability survey, 'psychiatric' <sup>(a)</sup> as one of <i>all</i> disabling conditions, (ABS groupings)
1.9	321,600	1989–90 ABS national health survey, 'mental disorder' as long-term medical condition. (The survey did not cover people in institutions.)
2.4	418,300	1993 ABS disability survey, based on positive responses to the survey screening questions about mental illness requiring assistance and treatment for nerves or emotional condition
2.8	494,400	1993 ABS disability survey, 'psychiatric' based on all information in the survey including positive responses to screening questions and all reported ICD-coded conditions
3–4	—	Australian Health Ministers (1992) National Mental Health Policy

(a) This group is the same as the group entitled 'Mental psychoses' in ABS publications.

Sources: AIHW analysis of ABS 1993 Survey of Disability, Ageing and Carers data; ABS 1991, 1992; Australian Health Ministers 1992; Madden et al. 1995.

### Multiple disabilities

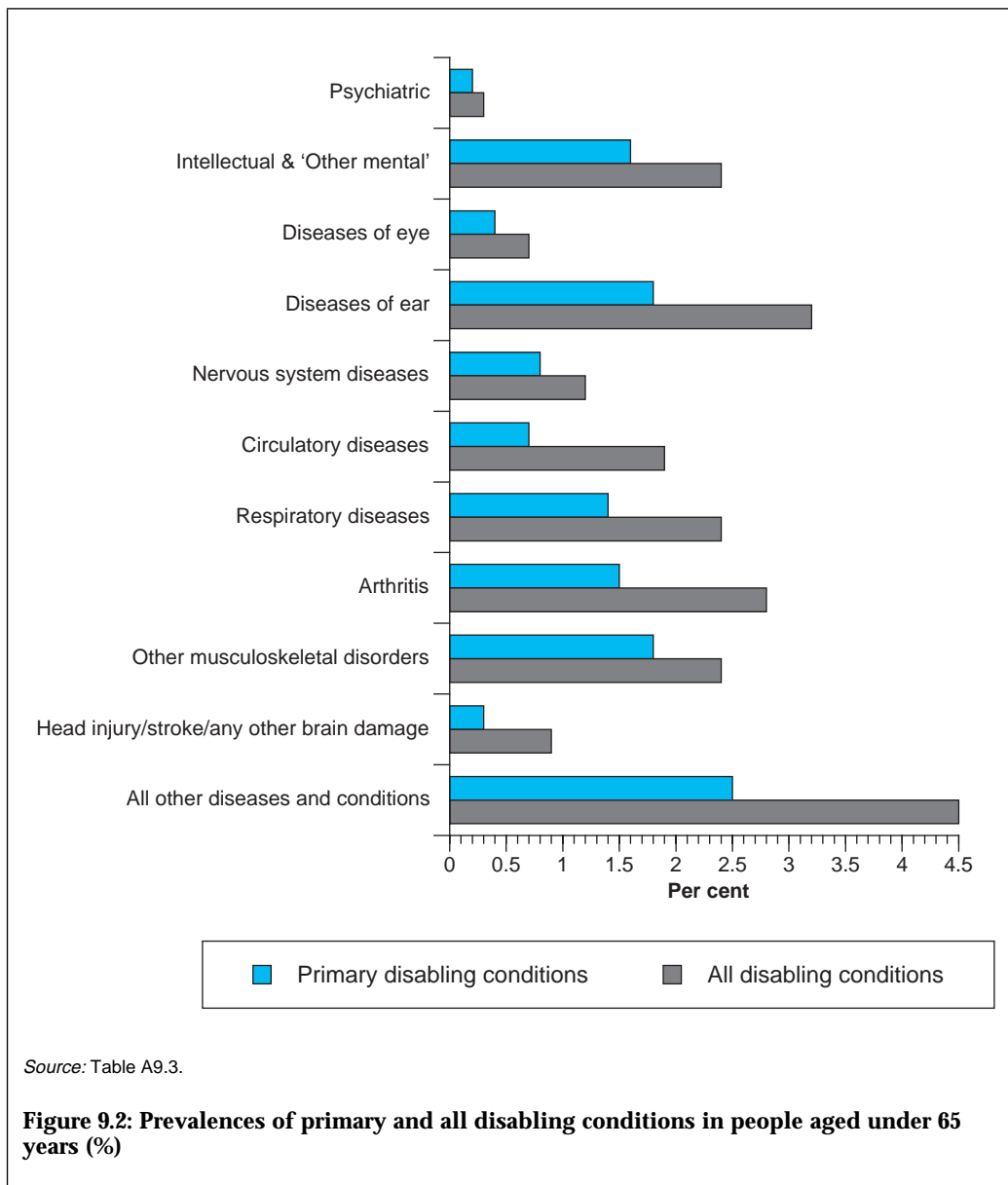
All conditions were reported in the ABS disability survey at higher rates than indicated by their presence as a primary disabling condition among people aged under 65 years (Figure 9.2).<sup>4</sup> Brain injury (for instance, from stroke or head injury) was frequently reported in combination with other conditions, but psychiatric conditions less commonly so.

The possibility of multiple disabilities or conditions complicates the estimation of prevalence at a national level. More significantly, the presence of multiple disabilities or conditions is also likely to be related to a more severe experience of disability for the individual. More than half the people reporting profound handicap in the ABS survey had a combination of impairments, while 74% of those with mild handicap had only one impairment type or other condition (ABS 1996a:5). The average number of areas of handicap reported by people with a severe handicap in 1993 was 2.10, compared with an overall average of 1.61 for all people with handicap (Table A9.1).

A recent review of data on intellectual disability (Wen 1997) revealed that people with intellectual disability frequently have a range of associated disabilities:

- Among people with an intellectual disability who lived in households and whose disabling conditions occurred before the age of 18 years, the most commonly associated

<sup>4</sup> The prevalence in this age group is lower than that in the population overall (Table 9.6).



impairments or disabilities were physical (37.6%), speech (26.2%) and psychiatric (19.3%) (Wen 1997).

- In a study of 2,412 people with intellectual disability receiving services in Queensland, 261 (11%) engaged in at least one form of aggressive behaviour; of these, some 80% engaged in three or more forms of aggression and two-thirds received medication for challenging behaviour (Sigafos et al. 1994).

- In a population survey of 24,498 children in Sweden, it was found that 64% of children with 'severe retardation' and 57% of children with 'mild retardation' were suffering from a psychiatric condition (Gillberg et al. 1986).
- In a study of 'mental retardation' in a Sydney region, 202 affected adults were randomly selected for medical examination (Beange & Taplin 1995). The authors found that:

the study group had significantly increased cardiovascular risk factors, rate of medical consultation, rate of hospitalisation, and mortality. The research sample has an average of 5.4 medical disorders per person, half of which had not been detected previously. We concluded that the provision of health care to adults with mental retardation needs to be improved.

The multiple needs of many people with intellectual disability are reflected in their high representation in ongoing support services (see Section 9.3 following).

### **Changes in prevalence**

The prevalence rates of disability and handicap reported in the ABS population surveys rose between 1981 and 1988, but tended to remain steady between 1988 and 1993 (Table 9.6). Age- and sex-standardised rates of disability and handicap followed a similar pattern. However age- and sex-standardised rates of severe and profound handicap remained fairly steady over the three surveys, at just over 4% of the total population, and 2.5% of the population aged 15–64. This finding is consistent with the possibility that:

- the main source of variation in the overall prevalence rates of severe and profound handicap has been the change in the age (and sex) structure of the population; and that
- people have interpreted the questions relating to assistance with activities of daily living in a similar way over the three surveys (see also AIHW 1995; Wen et al. 1995).

Factors other than demographic change could influence disability trends. Such factors could include injury experience, the epidemiology of disabling conditions, and changes in medical technology and practice. At this stage there is little definitive evidence of recent large-scale effects in Australia.

Analyses of trends in disability in Australia have been initiated in the health field, usually with the aim of examining overall trends in health status and addressing the question: are we living longer but sicker? Mathers (1995) suggested that the extension of life expectancy has been accompanied by an extension of years lived with disability, although this is usually 'mild or moderate' disability; years lived with severe disability do not appear to have been extended.

Little of national reliability is known about trends in the long-term effects of injury, including disability. However, mortality due to a number of significant causes, such as transport and road injuries, has decreased in recent years (Abraham et al. 1995; Alessandri et al. 1996; Bordeaux & Harrison 1996) so there may be some effects on disability prevalence (although it is not certain whether there would be related falls or rises in the prevalence of disability). The establishment of a spinal cord injury surveil-

**Table 9.6: Prevalence rates of disability and handicap, as a percentage of the Australian population, 1981, 1988, 1993<sup>(a)</sup> (%)**

Prevalence rates	Disability All ages	Handicap All ages	Severe handicap <sup>(b)</sup>			
			0–14	15–64	65+	All ages
<b>Reported rates</b>						
1981 actual data	13.2	8.6	1.6	2.4	17.0	3.8
1988 actual data	15.6	13.0	2.3	2.5	18.6	4.3
1993 data using 1988 categories	16.6	12.8	2.3	2.5	16.9	4.2
<b>Age-standardised rates</b>						
1981 data using 1993 age structure	14.1	9.3	1.6	2.4	17.8	4.2
1988 data using 1993 age structure	15.9	13.3	2.3	2.5	18.8	4.5
1993 data using 1993 age structure and 1988 categories	16.6	12.8	2.3	2.5	16.9	4.2

(a) These rates are estimates derived from surveys where people report their disability status from a list of conditions.

(b) Severe handicap rates for 1993 data refer to people with profound and severe handicaps.

Source: Wen et al. 1995.

lance system at the National Injury Surveillance Unit should improve the data available about the effects of this relatively uncommon but severe cause of disability.

Perinatal data on the incidence of congenital malformations may also shed light on factors affecting trends in disability prevalence. Recent information from the National Perinatal Statistics Unit suggests that rates of congenital malformation have been declining in the 1990s (Lancaster et al. 1997). This decline follows a recorded upward trend in the rate of major congenital malformations in the late 1980s, attributed to improving ascertainment by new birth defect registers in some States and Territories (Abraham et al. 1995).

Perinatal deaths due to congenital malformations declined from 35.9 per 10,000 births in 1973 to 17.5 per 10,000 births in 1994 (Lancaster et al. 1997). The perinatal death rate for anencephalus showed the most pronounced decline but there were also substantial falls for spina bifida, hydrocephalus and congenital heart defects. Perinatal death rates due to chromosomal abnormalities increased in the same period, from 2.2 per 10,000 births in 1973 to 3.9 per 10,000 in 1994. Infant deaths and deaths of children aged 1–14 years because of congenital malformations also declined between 1980 and 1994.

Rates of congenital malformation in live births showed a decline for anencephalus from 5.1 per 10,000 births in 1985 to 1.7 in 1994; and for spina bifida from 7.1 per 10,000 births in 1987 to 2.9 in 1994.

There was no clear trend in the national rate for hydrocephalus in births between 1985 and 1994. The national rate of Down Syndrome was relatively constant at around 12.8 per 10,000 births in the same period. For all these four conditions, the number of induced abortions performed before 20 weeks gestation increased over similar reporting periods.

Decisions about what constitutes appropriate medical treatment, and the difficult and sensitive debates surrounding pregnancy terminations, are perhaps particularly

difficult and sensitive for people with a disability. Some people fear that the available and projected combination of medical technology, genetic and other pregnancy testing, and abortion, are tending to create an idealised concept of a 'normal' human being (Ralph 1995). Ralph argues that these factors, combined with efforts to measure 'quality of life' for economic reasons (for instance, to prioritise resource allocation), can subtly undermine the notion of equal rights to life, creating pressure for people with a disability to justify their right to life, and their right to social acceptance and support in achieving a fully participative life.

Monitoring trends in these contentious areas of medical practice is, therefore, an important part of monitoring and understanding trends in disability.

### **Disability among Indigenous peoples**

There has been little progress since the publication of *Australia's Welfare 1995* in establishing national prevalence estimates for disability among Aboriginal and Torres Strait Islander peoples. The problems lie in definition and conceptualisation, as well as in survey sampling methods.

The National Aboriginal and Torres Strait Islander Survey results showed 2.8% of people aged 25–44 and 1% of those aged 15–24 reporting severe or profound handicap in 1994 (ABS 1995b). While these results appeared similar to those for the general population, reported in the Disability, Ageing and Carers Survey (Table 9.1; AIHW 1995:246), the two surveys were not considered strictly comparable.

Rather, it could be expected that rates of disability among Indigenous people would be higher than those of the general population, because of their higher rates of disabling conditions. For instance, Indigenous people experience higher rates of injury, and respiratory and circulatory disease—all often associated with disability (ABS & AIHW 1997). A study in a New South Wales region, using ABS definitions, found rates of severe handicap about 2.4 times higher than the total population (Thomson & Snow 1994). Subsequent studies of service use are consistent with this finding; Aboriginal and Torres Strait Islander people in the Northern Territory were twice as likely to be users of disability support services (Black & Eckerman 1997) and made greater use of Home and Community Care (HACC) services at younger ages (Jenkins 1995).

The difficulty in obtaining better data on disability among Indigenous people is threefold:

- the National Aboriginal and Torres Strait Islander Survey had an adequate sample size on which to base reliable estimates but, because it covered a wide range of material, there was little detail on disability, and it was not considered strictly comparable to other disability data;
- the Disability, Ageing and Carers Survey had adequate detail on disability but inadequate sampling of Indigenous people for reliable estimates; and
- there is not wide confidence that concepts of disability used in either of these ABS surveys are adequately developed for use in Indigenous communities.

If population surveys are to establish useful prevalence estimates, cooperative work is needed, involving Indigenous people, to develop an acceptable conceptualisation of Indigenous disability, including testing the socially and environmentally constructed

notion of participation. It is hoped that a first step in addressing this issue will be taken during the Australian testing of the ICIDH revision. The two technical issues identified above, relating to survey design, must also be addressed.

Efforts are being made to promote the use of standard 'Indigenous identifiers' in service data collections, for instance in two relatively new collections, involving the AIHW, relating to disability support services (see Section 9.3). Using such data to evaluate service access by, and adequacy for, Indigenous people will only be possible if there is ongoing effort to improve corresponding population data on disability among Indigenous peoples.

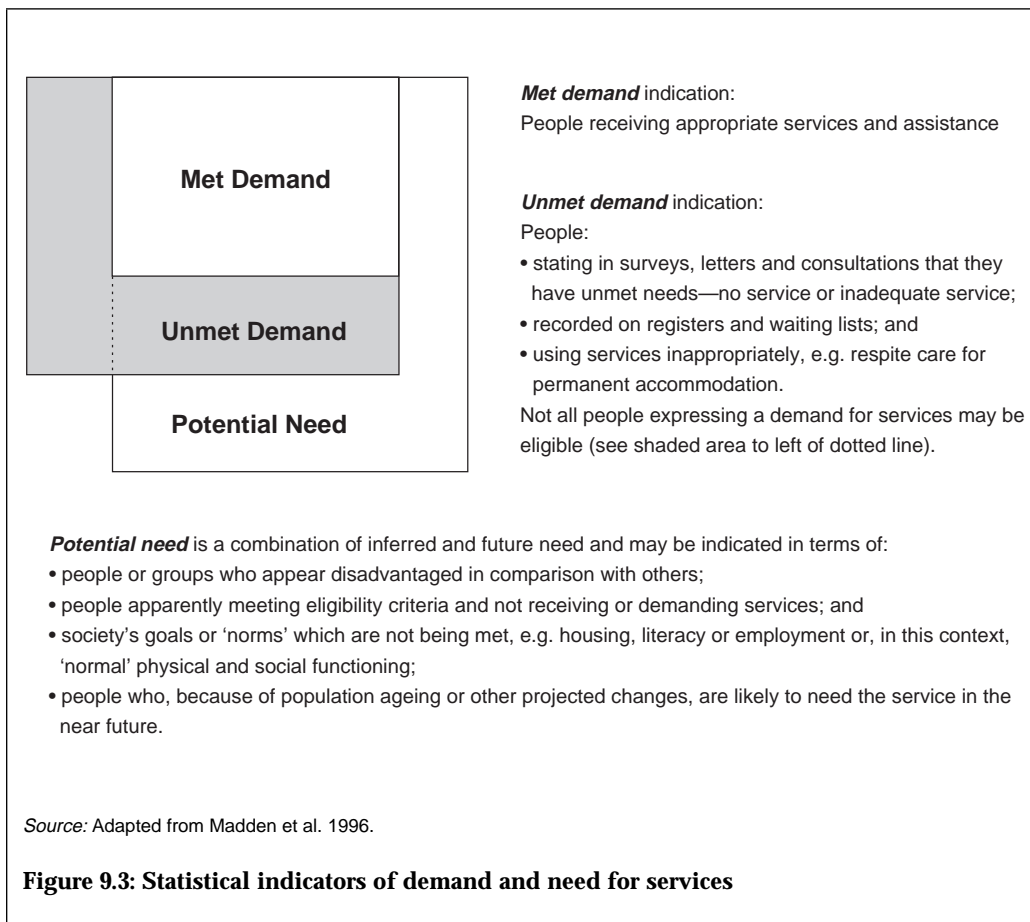
### **Need and demand for services**

Needs and demands for services or assistance may be indicated by statistical data in a number of different ways. Figure 9.3 illustrates the relationships between met demand, unmet demand and potential need and suggests approaches to the statistical indication of each.

The demand for disability support services in Australia was the subject of a study by the AIHW in 1995–96 (Madden et al. 1996), one of six commissioned to inform the national evaluation of the Commonwealth/State Disability Agreement (CSDA). The importance of the Institute's study was recognised by the principal consultant evaluating the Agreement (Yeatman 1996:33). Unmet demand was conceptualised as in Figure 9.3. People's stated unmet need for formal services, accompanied by evidence of their having tried unsuccessfully to obtain such services, was used to indicate unmet demand.

A principal finding of the study was that there were an estimated 13,500 people, aged 5–64 years, with severe or profound handicap (in ABS terms), who expressed need for more formal support services of the kind provided as accommodation, accommodation support and respite care services under the Agreement, and who were not receiving them because the service was unavailable or could not be arranged (shaded figures, rounded, in Table 9.7). The figure of 13,500 represented approximately 64% of the estimated number of service recipients at the time. This estimate was considered conservative (Yeatman 1996:33), because of the focus on particular areas of need (those in Areas 2 and 3 in Table 9.7 were excluded) and because of the exclusion of all but a few reasons for not receiving the services. The study examined a range of other sources, and concluded that CSDA services for people needing ongoing support were being provided in a broader climate of unmet demand for housing and accommodation for people with a disability (Madden et al. 1996:43–47).

There is a double impact arising both from the ageing of the population with disability and the ageing of carers (a significant 'potential need' in terms of Figure 9.3). The population aged 45–64 years with severe or profound handicap was projected to increase by 18.9% between 1995 and 2001—the fastest growing age group (Table 9.8). Consequently, there are likely to be increasing numbers of older people making the transition from disability services concentrating on working age people, to aged care services suitable for people with a disability (see also Chapters 3 and 8 for further discussion of factors relating to ageing and carers).



Because of the significance of the 40+ age group among recipients of the Disability Support Pension (Table 9.12 following), the high projected growth in this age group will have an impact on the demand for social security assistance. A recent study of the demand for training and employment assistance provided under the Disability Reform Package estimated that demand at 60,000 places compared with a current supply of 27,000 places (Coopers & Lybrand 1997). Groups identified as having higher unmet demands were younger people (who were more motivated to train and find work), people with high support needs, and people with psychiatric disability.

The ageing of carers presages further pressure on services. Among people with the need for ongoing support in self-care, mobility or verbal communication ('severe or profound handicap' in ABS terms), there were 7,700 whose principal carer was a parent aged 65 years or more (AIHW 1995:293).

Further refinement of the approach used by the Institute for the demand study will be possible as the ABS population survey, already a valuable information source, itself becomes further refined. 'Severity of handicap', for instance, as presently measured in the ABS surveys, concentrates on the need for assistance with activities of daily living

**Table 9.7: People aged 5 years and over with a profound or severe handicap in households, by reason for no or not enough formal help and by area of unmet need,<sup>(a)</sup> 1993<sup>(b)</sup> ('000)**

Reason for no/not enough help received <sup>(c)</sup>	Age 5–64			Age 65+			Total all ages		
	Area 1	Area 2	Area 3	Area 1	Area 2	Area 3	Area 1	Area 2	Area 3
Did not know of a service	4.6	9.3	2.0	5.5	10.5	2.8	10.1	19.7	4.8
Need not important enough	20.0	10.9	4.2	12.3	3.2	1.5	32.3	14.1	5.7
Would not ask/pride	14.9	10.6	0.5	10.3	9.6	1.1	25.2	20.2	1.5
No service available	8.0	4.9	1.6	4.3	3.4	0.3	12.4	8.3	2.0
Unable to arrange service	5.4	2.0	1.2	2.5	6.1	0.4	7.8	8.1	1.6
Other	17.1	8.0	2.0	13.2	12.4	1.3	30.3	20.3	3.3
<b>Total</b>	<b>70.0</b>	<b>45.8</b>	<b>11.4</b>	<b>48.1</b>	<b>45.0</b>	<b>7.3</b>	<b>118.1</b>	<b>90.7</b>	<b>18.7</b>

(a) Unmet need was defined as having reported at least one reason for no formal help or not enough formal help being received.

(b) Estimates of 1,900 or less have an RSE of 50% or more. Estimates of 8,000 or less have an RSE of 25% or more. These estimates should be interpreted accordingly.

(c) To preserve the 'conservative' approach to analysis, people's reasons for not receiving enough formal help were allocated in the order shown. There is thus, if anything, a bias away from being allocated to the two shaded groups.

Note: People's unmet needs were allocated to:

- Area 1 if they had unmet needs for regular assistance with self-care, mobility or verbal communication (and possibly in Areas 2 or 3);
- Area 2 if they had unmet needs for regular assistance in any of health care, home help, home maintenance or meal preparation (and possibly in Area 3 but none in Area 1);
- Area 3 if they had unmet needs for regular assistance in personal affairs or transport (and none in Areas 1 or 2).

Source: Madden et al. 1996.

**Table 9.8: Projected population<sup>(a)</sup> of persons with a profound or severe handicap, by age group, 1993, 1995, 2001 ('000)**

Age group	Number with profound or severe handicap			% change 1995–2001
	1993 <sup>(b)</sup>	1995	2001	
5–14	62.3	63.1	65.2	3.3
15–19	16.9	16.4	17.2	4.8
20–29	44.0	43.9	43.0	-2.2
30–44	96.2	97.9	102.5	4.7
45–64	148.7	157.6	187.4	18.9
65+	352.8	381.8	446.2	16.9
Total 5–64	368.3	378.9	415.2	9.6
Total 15–64	305.9	315.8	350.1	10.8
<b>Total</b>	<b>721.0</b>	<b>760.8</b>	<b>861.5</b>	<b>13.2</b>

(a) Population projections (series A and B) as at 30 June.

(b) 1993 data from ABS 1993 Survey of Disability, Ageing and Carers.

Sources: AIHW analysis of ABS 1993 Survey of Disability, Ageing and Carers data. First published in Madden et al. 1996.

(self-care, mobility and verbal communication). Information on a fuller range of needs for living assistance should be available from the 1998 ABS survey.

The ABS is also investigating the possible development of a question on disability for the 2001 Census. This is a challenging issue because of the need to develop a highly succinct question which nevertheless is consistent with the much more detailed series of questions asked in the disability surveys. The advantages of such a question, if satisfactorily developed, would include more reliable estimates of disability prevalence: in small areas—of great interest to planning departments; and among small population groups, including Indigenous peoples (see also Madden & Hogan forthcoming).

### 9.3 Disability services and assistance

Formal services of relevance to people with a disability may be broadly categorised as:

- disability-specific income support;
- disability support services; and
- generic services, some of which may contain components targeted specifically at people with a disability.

Table 9.9 outlines the scope of formal services in these categories, and the role of government and non-government sectors in their funding and/or delivery.

This section provides data on each of these three broad service categories. Care and assistance are frequently provided outside the formal care system, so some data on informal care and assistance are also included.

#### Recent developments

Since the Institute's last biennial report (AIHW 1995), there has been a number of developments in disability services. There are renegotiations between Commonwealth and State Governments, and changes in the roles of government and non-government service providers (both for-profit and not-for-profit), and between the formal service system and the informal assistance provided generally by families. It is against this backdrop that the most recent available national data on disability services are presented later in this section.

#### Reduced government role in service delivery

Most Australian governments are seeking to reduce their role in direct service provision, and to become funders and/or purchasers of services, with an involvement in standards setting, quality assurance, planning and policy development. This direction is as strong in the field of disability services as in other community services.

The creation of a new Commonwealth services delivery agency represented a major change in the way government services are to be delivered and a major step in the purchaser/provider split in the delivery of welfare services. New funding models for employment support services for people with a disability are being planned by the Commonwealth, based on clients' needs and service outcomes. Commonwealth 1996–97 budget initiatives also included the corporatisation of the Commonwealth Rehabilitation Service and the Australian Government Health Service.

Similar developments are underway in most States and Territories. In New South Wales, for instance, the purchaser/provider split has been institutionalised by the

**Table 9.9: Formal services relevant to people with a disability, by broad service category and by sector role (in funding and/or provision)**

	<b>Commonwealth role</b>	<b>State role</b>	<b>Local government role</b>	<b>Non-government role</b>
<b>Income support</b>	Income security programs of DSS, DVA and DHFS	Injury compensation schemes and related services	Rate concessions	Emergency relief (non-specific)
	Concessions, fringe benefits	Concessions, fringe benefits		Disability insurance Superannuation
<b>Disability support services</b>	Employment and other services under CSDA, including funding to States	Accommodation and other support services under CSDA and State schemes	HACC services	CSDA services and HACC services
	HACC services	HACC services		Other support services, including information and advocacy
	Nursing homes and hostels (funding)	Nursing homes and hostels (funding and provision)		Nursing homes and hostels (funding and provision)
	Commonwealth Rehabilitation Service Australian Hearing Service	Various equipment schemes		
<b>Relevant generic services</b>	Employment programs, including disability-specific	Education, both special and integrated	Physical access, parking	Emergency relief (non-specific)
	Public housing and crisis accommodation, including disability-specific	Public housing, including disability-specific		
	Child care services, including disability-specific	Child care services, including disability-specific	Child care services (provision and coordination)	Child care services (provision)
	Health services (funding)	Health services (funding and provision)		
	Other (e.g. sport, library and information)	Other (e.g. sport, library and information)	Other (e.g. sport, library)	
		Transport, including disability-specific		

*Note:* No distinction is made between for-profit and not-for-profit sectors.

*Source:* Adapted from AIHW 1995:259.

creation of a new Ageing and Disability Department, separate from the Department of Community Services which is responsible for direct delivery of some services for people with a disability. A whole-of-government Disability Policy Framework has been developed to promote a holistic approach to service delivery, addressing the diverse

needs of people with a disability (NSW Government 1997). In Victoria, changes have been introduced in relation to consumer-focused funding, unit cost funding, the expansion of the non-government sector, and new resource allocation methods. In Queensland, a Disability Directions Committee is developing a whole-of-government approach to planning for people with disabilities, with a focus on community-based living, individual 'packages of support', and the expansion of the non-government sector. In South Australia, Options Coordination agencies provide a single entry point to the service system for people with disabilities, with the aim of ensuring consistent determination of eligibility, assessment of need and allocation of resources for the purchase of various services. Local Area Coordination in Western Australia fulfils a similar role.

### **Renegotiation and resourcing of Commonwealth–State arrangements**

The first Commonwealth/State Disability Agreement (CSDA) set out the types of disability support services to be provided or funded by Commonwealth, State and Territory Governments. An independent review of the Agreement was carried out (Yeatman 1996) before the negotiation of a new Agreement began. Renegotiation of the Agreement has continued beyond the expiry date (30 June 1997), with interim funding in place until February 1998.

### **National performance indicators**

In February 1994 the Council of Australian Governments agreed that 'in clarifying the roles and responsibilities of Governments in the delivery of services, the overriding objective should be to improve outcomes for clients and value for money for taxpayers' (quoted in SCRCSSP 1995:2). A process of 'performance monitoring' was begun. In 1996 a working group was established to begin work on performance indicators for disability services. The working group comprises representatives of all Australian jurisdictions, the Industry Commission (which coordinates the work) and the AIHW. (Further discussion of this work appears in Section 9.4 below and, more generally, in Chapter 1.)

### **National Disability Advisory Council**

In August 1996, the Minister for Family Services announced the establishment of the National Disability Advisory Council (replacing the Australian Disability Consultative Council). In February 1997, the council confirmed its commitment to the review of the National Disability Advocacy program, continuing the Commonwealth Disability Strategy, and to the ongoing development of standards under the Disability Discrimination Act.

### **Disability Discrimination Act Standards development**

The development of standards under the Disability Discrimination Act (DDA) has been progressing in five key areas: building codes; employment; public transport; information; and communication. The National Disability Advisory Council has made a commitment to this work, with members involved on the following working groups: DDA Standards, Public Transport and the Building Access Technical Committee.

### **Carers**

The importance of family or voluntary care of people with a disability was recognised in both the 1996–97 and 1997–98 Commonwealth budgets. Funding was announced in the 1996–97 Federal Budget for the establishment of a national Respite for Carers

program, enabling new initiatives such as carer resource centres and emergency respite services to be introduced (DHFS 1996b). In the 1997–98 Budget, a Carers Package brought in extensions of the Carer Payment to people providing constant care for a child under 16 years with profound disabilities. The adoption of Child Disability Tables was also announced, as a measure designed to simplify and codify eligibility for the Child Disability Allowance, and to target assistance more effectively (Newman 1997). The payment rate for the Domiciliary Nursing Care Benefit was increased, and three payments—the Carer Pension (new in 1997), the Domiciliary Nursing Care Benefit and the Child Disability Allowance—were brought into alignment (DHFS 1997).

### **National data development**

There have been calls in a number of major reports for greater consistency in concepts and definitions underpinning national data on disability services (AIHW 1993; Baume & Kay 1995; Office of Disability 1994; Senate Standing Committee 1992; Yeatman 1996). The Institute in 1996 established a Disability Data Reference and Advisory Group to advise it as it works to achieve this goal. The group comprises government and non-government representatives as well as independent experts, and has established a program of work on both national and international developments, including the development of nationally consistent data definitions and the revision of the ICIDH (Madden & Hogan forthcoming).

The significant changes occurring in service structures, previously outlined, bring new challenges for agencies responsible for data collection and analysis. Continuing cooperation between national statistical agencies, the new policy and monitoring departments and the service departments should ensure that relevant information on disability service use and outcomes continues to develop. On a broader front, the Institute is also working to develop a national community services data dictionary (see Chapter 1).

## **Income support**

### **Commonwealth programs**

The Commonwealth Government, with its responsibility for social security, is the main source of income support services provided by Australian governments. Major disability-related payments made by the Commonwealth covered an average of 783,700 people in 1995–96, with outlays totalling \$5.8 billion, or 14% of total outlays in the social security portfolio (DSS 1996a).

The most common payment for people with a disability is the Disability Support Pension (DSP), with almost half a million recipients in 1995–96 (Table 9.10). Eligibility for this pension is based on a minimum level of impairment and the inability to work full-time in open employment at full award wages, or be retrained for work, within 2 years. Men aged under 65 years and women under 60.5 years are eligible. Rent Assistance was paid to 127,087 or 25.4% of DSP recipients (DSS 1996b). Sickness Allowance is paid to people of work-force age who are temporarily unable to work because of a medical condition.

The Child Disability Allowance is paid to the parents of children with disabilities in recognition of the extra costs, including carers' loss of income, required to bring up a child needing substantial daily care at home. Carers receiving the Domiciliary Nursing Care Benefit provide care at home for people who would be eligible for entry to a nursing home.

**Table 9.10: Commonwealth disability-related income support payments, by number of recipients and by expenditure on payments and total outlays, 1995–96**

	Recipients as at June 1996	Expenditure (\$m) 1995–96	Department
Disability Support Pension	499,235	4,036.0	DSS
Child Disability Allowance	101,084	213.7	DSS
Mobility Allowance	24,985	34.1	DSS
Rehabilitation Allowance	17	.. (a)	DSS
Sickness Allowance	33,215	354.0	DSS
Wife Pension (DSP) <sup>(b)</sup>	107,803	800.3 (c)	DSS
Carer Pension (DSP) <sup>(b)</sup>	13,483	182.1	DSS
Carer Pension (other) <sup>(b)</sup>	2,054	.. (d)	DSS
Domiciliary Nursing Care Benefit	42,047 (e)	59.0	DHFS
Continence Aids Assistance Program	10,732	n.a.	DHFS
Veterans' Service Pension	337,823	2,609.5	DVA
Veterans' Disability Pension	159,178	1,720.2 (f)	DVA

(a) Included under expenditure for Disability Support Pension (DSP) and Wife Pension.

(b) Wives or carers of people receiving Disability Support Pension or Age Pension or any other form of payment.

(c) These figures are for total Wife Pension, not just DSP.

(d) Included under expenditure for Carer Pension (DSP).

(e) 42,525 people with disabilities were cared for by these carers of whom 15,110 were aged under 60 years, and 26,304 of whom were aged under 70 years.

(f) This figure includes expenditure on 93,456 War Widow/ers Pensions.

*Note:* Expenditure does not include running costs. Only program costs are included.

*Sources:* DSS recipient numbers come from DSS (1996b) and expenditure numbers come from DSS (1996a). DHFS figures are from DHFS (1996a).

People receiving the Veterans' Service Pension are generally aged 60 years or over if male, or 55 and over if female, although younger people may receive the payment if they are permanently incapacitated for work. People receiving the Veterans' Disability Pension and War Widow/ers Pension included about 24% and 7%, respectively, who were aged under 65.

Outlays of \$5 million were made by the Department of Social Security (DSS) in 1995–96 on postal concessions for blind people.

The vast majority of DSP recipients are aged 40 years or more (77% of males and 70% of females). Recipients of disability-related income security payments are much more likely to be male than female (Table 9.11), the sex distribution being very different from the population estimates outlined in Section 9.2. The predominance of males in the DSP figures has been attributed to: the effect of the combined income test for couples; high unemployment among older men; and industrial injury (AIHW 1993:296). Because social security data provide one of the few national sources of data available at regional level, there has been a temptation for planning departments to use them as input to planning processes; these sex differences must be kept in mind if the DSS data are used for regional planning (see also AIHW 1993:295 for further discussion).

While there is some evidence of greater prevalence of intellectual disability among males in childhood (Wen 1997), it is not adequate to explain the fact that the number of

**Table 9.11: Recipients of disability-related income support payments, by sex and age group, December 1996**

	Age group (years)								Total
	<16	16-19	20-29	30-39	40-49	50-59	60-64	65+	
<b>Males</b>									
Disability Support Pension	—	6,685	26,504	45,222	63,660	111,809	89,266	2,024	345,170
Child Disability Allowance	66,229	1,150	13	—	—	—	—	—	67,392
Rehabilitation Allowance	—	—	2	2	1	1	—	—	6
Sickness Allowance	1	621	3,319	3,452	2,933	2,368	469	—	13,163
Carer Pension <sup>(a)</sup>	3	78	587	1,795	3,224	4,808	2,603	259	13,357
<i>Total</i>	<i>66,233</i>	<i>8,534</i>	<i>30,425</i>	<i>50,471</i>	<i>69,818</i>	<i>118,986</i>	<i>92,338</i>	<i>2,283</i>	<i>439,088</i>
<b>Females</b>									
Disability Support Pension	—	4,879	18,573	26,552	42,693	70,412	3,325	179	166,613
Child Disability Allowance	35,065	748	4	—	—	—	—	—	35,817
Rehabilitation Allowance	—	—	—	2	—	1	—	—	3
Sickness Allowance	—	417	1,878	1,426	1,864	1,223	17	—	6,825
Carer Pension <sup>(a)</sup>	1	160	831	1,735	4,777	5,957	373	148	13,982
<i>Total</i>	<i>35,066</i>	<i>6,204</i>	<i>21,286</i>	<i>29,715</i>	<i>49,334</i>	<i>77,593</i>	<i>3,715</i>	<i>327</i>	<i>223,240</i>
<b>Persons</b>									
Disability Support Pension	—	11,564	45,077	71,774	106,353	182,221	92,591	2,203	511,783
Child Disability Allowance	101,294	1,898	17	—	—	—	—	—	103,209
Rehabilitation Allowance	—	—	2	4	1	2	—	—	9
Sickness Allowance	1	1,038	5,197	4,878	4,797	3,591	486	—	19,988
Carer Pension <sup>(a)</sup>	4	238	1,418	3,530	8,001	10,765	2,976	407	27,339
<b>Total</b>	<b>101,299</b>	<b>14,738</b>	<b>51,711</b>	<b>80,186</b>	<b>119,152</b>	<b>196,579</b>	<b>96,053</b>	<b>2,610</b>	<b>662,328</b>

(a) These figures are for all carer pensions, of which only approximately 50% relate to DSP recipients (DSS 1996b).

Note: Mobility Allowance figures are: Males=14,575, Females=11,066 and Total=25,641.

Source: DSS unpublished data.

males, for whom the Child Disability Allowance is received, is almost double the number of females.

Changes in recent years to social security arrangements are reflected in Table 9.12. As a result of the Disability Reform Package, introduced in late 1991, the Disability Support Pension and Sickness Allowance replaced other payments, principally the Invalid Pension and Sickness Benefit.

The increase in numbers of DSP recipients since its introduction has been attributed to demographic changes, such as the ageing of the working age population and the

**Table 9.12: Recipients of disability-related income support payments, June, 1988–96**

	1988	1989	1990	1991	1992	1993	1994	1995	1996
Disability Support Pension <sup>(a)</sup>	..	..	..	..	378,558	406,572	436,234	464,430	499,235
Invalid Pension	296,913	307,795	306,713	334,234	..	..	..	..	..
Shelt. Employment Allowance	10,669	10,435	10,124	10,148	..	..	..	..	..
Rehabilitation Allowance	2,143	2,063	2,211	3,574	1,939	579	153	34	17
Sickness Allowance	..	..	..	..	44,172	46,579	47,132	47,311	33,215
Sickness Benefit	75,189	79,001	79,195	71,399	..	..	..	..	..
<b>Total</b>	<b>384,925</b>	<b>399,290</b>	<b>409,480</b>	<b>421,670</b>	<b>424,700</b>	<b>452,540</b>	<b>482,280</b>	<b>511,775</b>	<b>532,467</b>

(a) Disability Support Pension replaced Invalid Pension, Sheltered Employment Allowance and Rehabilitation Allowance from November 1991 as part of the Disability Reform Package.

Sources: DSS 1996b for all numbers other than Sheltered Employment Allowance; Disability Task Force 1995:110.

associated increase in the prevalence of disability, as well as sustained high unemployment (DSS 1996a:102). The entry of the 'baby boomer' bulge into the high incidence rate (age 50+ years) has been estimated to contribute significantly to a projection of 80,000 annual new grants by the year 2006 (Coopers & Lybrand 1997).

The numbers of recipients of the Child Disability Allowance have also risen, from 78,798 in 1993–94 to 101,084 in 1995–96 (AIHW 1995; Table 9.10). This increase has been attributed to greater general awareness of the allowance, particularly as a result of outreach advertising by the DSS, and to networking of the parents of children with particular medical conditions, for instance, asthma (DSS 1996a).

### Other income support

Significant income replacement programs are provided by State and Territory compensation schemes for work- and some transport-related injuries. These schemes vary among different jurisdictions. They depend on insurance contributions from employers and vehicle users, and usually provide payments related to previous earnings, as well as generally emphasising prevention and rehabilitation.

New forms of insurance or 'pre-funding' for long-term care for older people, or younger people with a disability, have been suggested and costed. These may be needed as a more significant part of the overall system as the population ages, and 'free' access to long-term care services may be limited (Walsh & De Ravin 1995).

Many States and Territories provide a range of concessions for people with a disability; for instance, transport concession and taxi schemes, rates, rent rebates, subsidies for technical aids or home modifications. A common 'gateway' for access to these concessions is possession of a pensioner concession card from the Department of Social Security. It is not generally possible to obtain data on these programs specific to people under 65 years who have a disability.

Concessions (including tax concessions), fringe benefits and subsidies provide other forms of income support, and come from a variety of sources, such as government business enterprises, water, gas and electricity authorities, health authorities, local government and the Australian Tax Office.

## Disability support services provided under the Commonwealth/ State Disability Agreement

The Commonwealth/State Disability Agreement (CSDA) 1991 sets out responsibilities for the provision of disability support services by Australian governments. Broadly, the Commonwealth takes responsibility for employment services, with the States and Territories assuming responsibility for accommodation and other support services. Both levels of government retain some responsibility for advocacy and research. Governments share responsibility for funding and planning CSDA services, and agree to share information about services. Although there is no set age limit for eligibility, these services are largely directed to people aged under 65 years.

All jurisdictions, in cooperation with the Institute, have agreed on a Minimum Data Set (MDS) as a basis for a national data collection on CSDA services and their clients. Features of the collection need to be kept in mind when interpreting the 1996 data (Box 9.5).

### Service types and funding

Funding totalling \$1,264 million was recorded, by Australian governments, as being provided in 1995–96 to disability support services under the CSDA (Table 9.13). Accommodation services received the most government funding: a total of \$728 million, or approximately 58% of CSDA funding. Community support, community access and respite services received a total of \$331 million, and employment support services \$169 million.

**Table 9.13: CSDA funding of services provided by Australian governments, by type of service, and State and Territory, 1995–96 (\$m)**

Type of service	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Total
Accommodation support	273.45	177.32	76.45	83.78	87.14	24.47	—	5.74	728.35
<i>Per cent of State total</i>	<i>61.6</i>	<i>51.9</i>	<i>56.3</i>	<i>56.8</i>	<i>63.0</i>	<i>57.8</i>	<i>—</i>	<i>57.6</i>	
Community support; community access; and respite	112.22	111.48	28.74	37.55	25.68	12.67	—	2.34	330.69
<i>Per cent of State total</i>	<i>25.3</i>	<i>32.6</i>	<i>21.2</i>	<i>25.5</i>	<i>18.6</i>	<i>29.9</i>	<i>—</i>	<i>23.5</i>	
Employment support	51.50	45.55	24.07	23.55	15.44	3.88	3.69	1.47	169.16
<i>Per cent of State total</i>	<i>11.6</i>	<i>13.3</i>	<i>17.7</i>	<i>16.0</i>	<i>11.2</i>	<i>9.2</i>	<i>21.3</i>	<i>14.8</i>	
Service type other/not stated	6.66	7.37	6.51	2.60	9.96	1.30	0.67	0.41	35.47
<b>Total</b>	<b>443.84</b>	<b>341.72</b>	<b>135.76</b>	<b>147.48</b>	<b>138.21</b>	<b>42.33</b>	<b>4.36</b>	<b>9.96</b>	<b>1,263.67</b>

#### Notes

1. Data for the Australian Capital Territory were not collected for 1996.
2. Advocacy, Information/referral; combined advocacy/information, and print disability/alternative formats of communication services are included in 'Service type other/not stated'.

Source: Black et al. forthcoming.

### **Box 9.5: The 1996 CSDA Minimum Data Set collection**

*Most jurisdictions collect the data on forms on an agreed 'snapshot day'—a form for each service type at each outlet, and one for each person receiving that service type at that outlet. Client forms may double count clients, in so far as one person may receive more than one service on the snapshot day.*

*Services are provided under the CSDA in six broad categories:*

- *accommodation support—ranges through institutional accommodation (disability-specific) and related services, group homes, and in-home support*
- *community support—includes a wide range of services, such as advocacy and information services, therapy and early childhood intervention, counselling, support groups, brokerage and case planning services*
- *community access—includes continuing education, independent living training, post-school options (assisting the transition from school to the work force)*
- *respite services, either centre-based or home-based*
- *employment services, including open employment and supported employment services*
- *other support, including research and development and the funding of peak bodies.*

*There is some variation among jurisdictions in what services are considered to fall under the CSDA. For instance, psychiatric disability services and early childhood intervention services are particularly 'grey' areas and are not included as CSDA services in all jurisdictions. The provision of community-based support services under other programs may also vary, and affect interstate comparisons.*

*The collection is still developing. In 1996, features to be aware of were:*

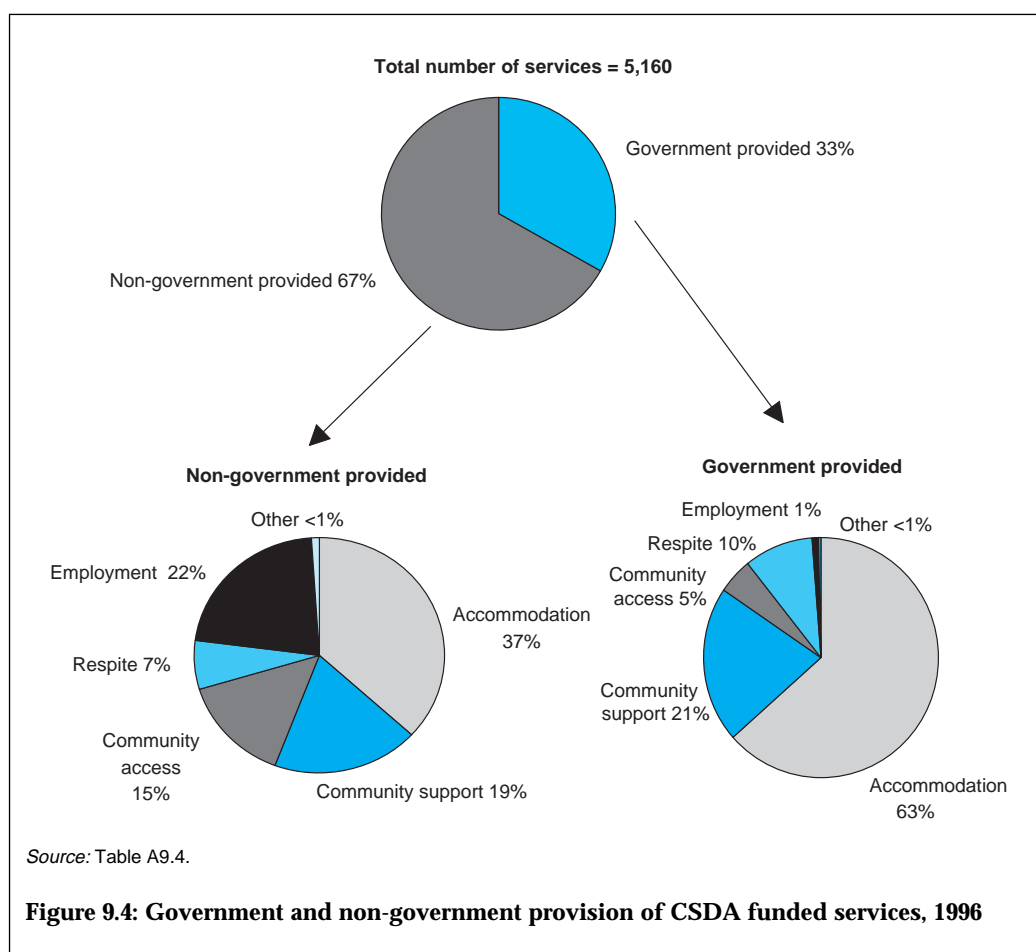
- *Western Australia extracted MDS data from an ongoing database relating to services and clients (an option now under consideration by other jurisdictions); in some tables, therefore, WA data are counted on a different basis from other jurisdictions.*
- *The Commonwealth did not collect client data from business services (supported employment services); client data for open employment services were extracted from an ongoing database managed by the AIHW.*
- *The Australian Capital Territory did not participate in the 1996 CSDA MDS collection.*
- *Response rates improved in 1996; in 1995 only four jurisdictions had response rates over 90%, whereas in 1996 all did—most over 95%; Victoria's response rate in 1995, for instance, was only 80%, whereas in 1996 it was over 95%.*

*The data set and its ongoing development are described in more detail in: AIHW (1995); Black & Madden (1995); Black & Eckerman (1997); Black et al. (forthcoming).*

States spending more than 58% of the total funding on accommodation services were New South Wales and South Australia (62% and 63%, respectively), perhaps reflecting an historical focus on institutional accommodation, and the possibly wider range of services (e.g. health-related services) offered in older, larger institutions. Victoria spent a

relatively lower amount on this service type (approximately 52%). Correspondingly, New South Wales and South Australia spent a smaller proportion on community support, community access and respite services (25% and 19%, respectively) and Victoria relatively more (33%).

The number of services reported in the 1996 CSDA MDS collection was 5,160. The apparent increase from 1995 (when 4,219 reported in the collection) may be largely due to the inclusion of Western Australia services in 1996, improved response rates for the collection, and a continued move to an outlet level collection. Of the 5,160 services reported, the majority (67%) were provided by non-government organisations. Governments provided 33% of services, heavily concentrated in their traditional area of accommodation services (Figure 9.4).



**Figure 9.4: Government and non-government provision of CSDA funded services, 1996**

### CSDA client numbers

The number of clients receiving services on the selected snapshot day is similar (although slightly lower) to that reported for a typical operating day (Table 9.14). Annual figures show greater variation, illustrating the different nature, intensity and

**Table 9.14: Recipients of CSDA funded services, by provider and time period, 1996**

Type of service	Government provided			Non-government provided		
	Snapshot day	Estimate for a typical day	Annual estimate for 1995–96	Snapshot day	Estimate for a typical day	Annual estimate for 1995–96
Accommodation support	8,447	8,605	12,082	10,241	10,813	28,604
Community support	5,898	6,830	58,502	5,526	7,760	76,334
Community access	2,816	2,942	6,643	8,639	9,846	58,351
Respite	666	690	9,126	1,150	1,787	16,849
Employment	n.a.	n.a.	n.a.	15,712	n.a.	n.a.

*Notes*

1. An individual may be counted more than once if more than one service type was accessed on the snapshot day.
2. Data for Western Australia cover a 12-month period and have been adjusted for identified multiple service use.
3. Data for the Australian Capital Territory were not collected for 1996.
4. Data for service types: Advocacy; Info./referral; Combined advocacy/info.; Print disability/alt. formats of communication; Service evaluation/training; Peak bodies; Research/development; and Other were not collected.
5. Data for the Commonwealth were not collected, except via the NIMS system for open employment services. Hence data for employment services are not generally available, apart from a snapshot day estimate for open employment services (see also Table 9.15).
6. Snapshot day data may not agree with data in Tables 9.15 to 9.18 and A9.5, mainly because for some service recipients no detailed recipient data was completed.
7. Estimates for typical day and the full year are provided by service providers.

Source: Black et al. forthcoming, Table 1.1.

turnover of the different service types. Community support and respite services exhibited the greatest variation between a typical operating day and estimated annual numbers, presumably indicating a high level of turnover during the year and the likelihood that many of these services are not provided daily. Accommodation services in the non-government sector appeared to have higher turnover than accommodation services in the government sector.

Overall, there were more clients in the non-government sector than the government sector, for all service types.

Of the 68,488 CSDA clients recorded as having received services on the snapshot day in 1996, 18,977 or 28% were receiving accommodation services (Table 9.15). Again, this illustrates the intensity of these services, which receive some 58% of CSDA funding (Table 9.13). The absence of Western Australia snapshot day figures for 1996 makes the national figure for community support services unreliable. While it appears that about half the clients overall received community support services (such as advocacy and information services, therapy, early childhood intervention, counselling, other support, and case planning services), this number was affected mainly by the figures for Western Australia which were annual and reflect the high turnover noted in Table 9.14. As the Commonwealth data relate only to open employment services, and Australian Capital Territory data were not available, analysis at national level is limited.

The majority (39,569 or 58%) of service recipients were male. The age distributions for males and females followed a similar pattern, the most common ages for both being 20–34 years. There were relatively fewer clients at the beginning and end of the eligible

age range: some 14% were aged 0–14 years and 16% aged 45–69 years (Figure 9.5; Table A9.5).

**Table 9.15: Recipients of CSDA funded services, by type of service and by State and Territory, 1996**

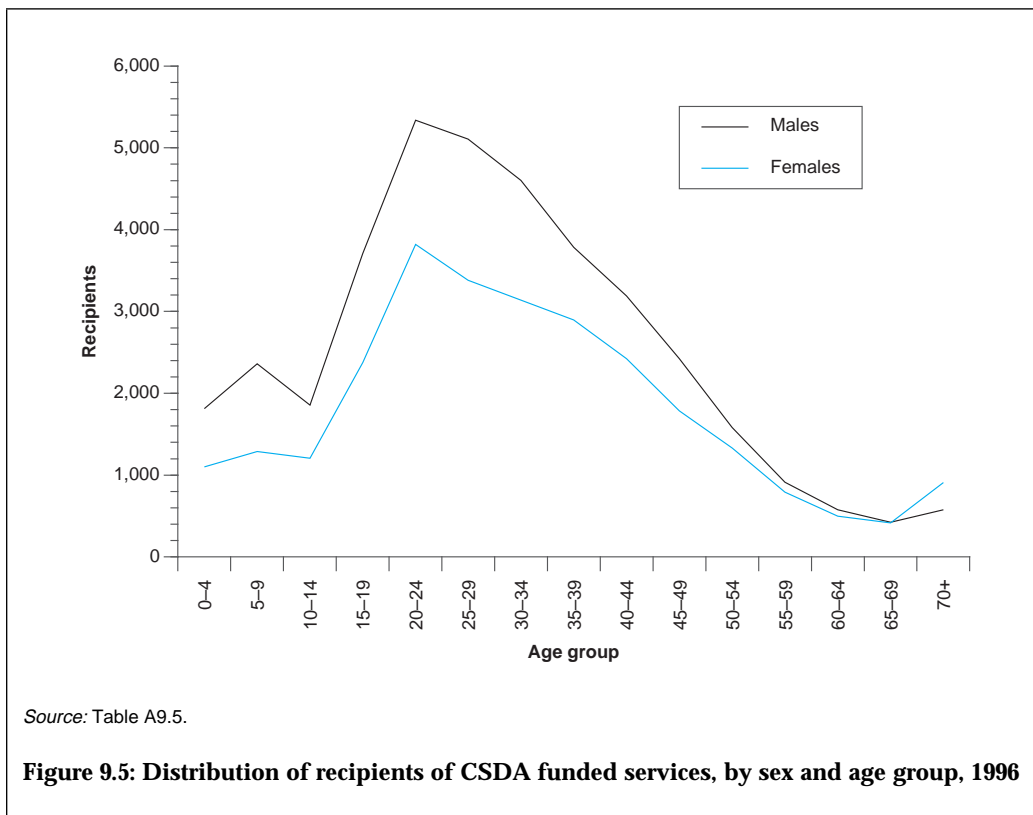
Type of service	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Total
Institutions/large residential/hostels	2,701	1,584	687	920	1,042	283	—	0	7,217
Group homes	2,286	2,204	1,453	727	523	267	—	101	7,561
In-home accommodation support	880	1,452	887	684	383	70	—	42	4,398
<i>Total accommodation support</i>	<i>5,867</i>	<i>5,240</i>	<i>3,027</i>	<i>2,132</i>	<i>1,948</i>	<i>620</i>	<i>—</i>	<i>143</i>	<i>18,977</i>
Community support and Respite	1,208	1,436	596	6,462	688	109	—	50	10,549
Community access and Recreation/holiday programs	3,081	5,704	1,335	6,458	750	593	—	64	17,985
Health-related community support	2,439	1,582	1,516	5,696	333	122	—	6	11,694
<i>Total community support; community access; and respite</i>	<i>6,728</i>	<i>8,722</i>	<i>3,447</i>	<i>13,404</i>	<i>1,771</i>	<i>824</i>	<i>—</i>	<i>120</i>	<i>35,016</i>
Competitive Employment Training and Placement	3,013	3,596	2,718	1,531	189	231	0	88	11,366
Individual Supported Job	1,155	1,249	612	111	388	26	0	0	3,541
Supported employment <sup>(a)</sup>	8	160	218	183	15	13	49	0	646
Sheltered employment <sup>(a)</sup>	0	0	17	76	66	0	0	0	159
<i>Total employment support</i>	<i>4,176</i>	<i>5,005</i>	<i>3,565</i>	<i>1,901</i>	<i>658</i>	<i>270</i>	<i>49</i>	<i>88</i>	<i>15,712</i>
Service type other/not stated	0	155	0	159	0	0	0	0	314
<b>Total</b>	<b>16,771</b>	<b>19,122</b>	<b>10,039</b>	<b>16,065</b>	<b>4,377</b>	<b>1,714</b>	<b>49</b>	<b>351</b>	<b>68,488</b>

(a) Data for Commonwealth were not collected, except for those in the NIMS collection. There were a small number of recipients recorded in the NIMS open employment collection whose service provider was coded as either a supported employment or sheltered employment service. Data on supported or sheltered employment services are otherwise unavailable.

*Notes*

1. An individual may be counted more than once if more than one service type was accessed on the snapshot day.
2. Data for Western Australia cover a 12-month period and have been adjusted for identified multiple service use; this has resulted in totals and subtotals differing from component numbers.
3. Data for the Australian Capital Territory were not collected for 1996.
4. Data for service types: Advocacy; Info./referral; Combined advocacy/info.; Print disability/alt. formats of communication; Service evaluation/training; Peak bodies; Research/development; and Other were not collected.
5. Some service type groupings used here are broader than are available for States and Territories other than Western Australia. 'Community support' means Family/individual case practice/management, Counselling: individual/ family/ group, Brokerage/direct funding, Mutual support/self-help groups and Community support: other/not stated. 'Health-related community support' means Early childhood intervention, Therapy, Behaviour/specialist intervention and Resource teams/regional teams. Some other service type groups may be similarly split.

Source: Black et al. forthcoming.



### CSDA client characteristics

The majority of people receiving CSDA services in 1996 had an intellectual disability as their primary disability (39,687 or 57.9%—see Table 9.16). Next most common was physical disability (9,264 or 13.5%), followed by psychiatric disability (6,277 or 9.2%).

Some 72% of clients of CSDA services were reported to need continual, frequent or occasional support in activities of daily living (self-care, mobility or communication)—a severe or profound handicap in ABS terms. Clients with psychiatric disability were the least likely to need such intensive support with these activities, 36% requiring no assistance. Respondents (usually service providers) often did not know the extent of this type of support needed by people receiving services for developmental delay or specific learning disabilities; this perhaps suggests the specialist, short-session nature of these services and/or relatively low levels of need for assistance with these activities.

Recognising that disability support services are designed to provide assistance in a far greater range of activities than self-care, mobility and communication, the CSDA MDS collection was expanded in 1996 to include clients' needs for assistance with: home living, social skills, self-direction, managing emotions, learning, working, other daily activities. Table 9.17 presents some results for CSDA clients overall, and for two of the primary disability groupings—intellectual disability and psychiatric disability—believed to be poorly served by the previous focus of the data on activities of daily living.

**Table 9.16: Recipients of CSDA funded services, by primary disability group and frequency of need for assistance in activities of daily living, 1996**

Primary disability group	Need for assistance												Total	
	Never		Occasional		Frequent		Continual		Not applicable/ not known		Not stated			
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%
Developmental delay	26	1.5	126	7.5	315	18.7	781	46.4	429	25.5	7	0.4	1,684	100.0
Intellectual	4,724	11.9	8,270	20.8	8,182	20.6	14,213	35.8	4,246	10.7	52	0.1	39,687	100.0
Specific learning/PDD	52	10.9	100	21.0	58	12.2	69	14.5	198	41.5	0	0.0	477	100.0
Autism	26	2.4	124	11.5	224	20.7	635	58.7	72	6.7	1	0.1	1,082	100.0
Physical	891	9.6	1,582	17.1	1,466	15.8	4,285	46.3	1,035	11.2	5	0.1	9,264	100.0
Acquired brain injury	328	16.0	502	24.5	430	21.0	749	36.5	36	1.8	6	0.3	2,051	100.0
Deaf and blind	6	4.4	12	8.8	30	21.9	80	58.4	9	6.6	0	0.0	137	100.0
Vision	243	13.1	854	45.9	358	19.2	301	16.2	101	5.4	4	0.2	1,861	100.0
Hearing	192	17.2	341	30.6	257	23.0	246	22.1	77	6.9	2	0.2	1,115	100.0
Speech	14	5.5	57	22.4	74	29.0	89	34.9	21	8.2	0	0.0	255	100.0
Psychiatric	2,256	35.9	1,427	22.7	1,063	16.9	447	7.1	1,076	17.1	8	0.1	6,277	100.0
Neurological	250	14.0	381	21.3	299	16.7	810	45.4	43	2.4	3	0.2	1,786	100.0
Not stated	68	2.4	73	2.6	58	2.1	186	6.6	2,346	83.4	81	2.9	2,812	100.0
<b>Total</b>	<b>9,076</b>	<b>13.2</b>	<b>13,849</b>	<b>20.2</b>	<b>12,814</b>	<b>18.7</b>	<b>22,891</b>	<b>33.4</b>	<b>9,689</b>	<b>14.1</b>	<b>169</b>	<b>&lt;0.05</b>	<b>68,488</b>	<b>100.0</b>

*Notes*

1. An individual may be counted more than once if more than one service type was accessed on the snapshot day.
2. Data for Western Australia cover a 12-month period and have been adjusted for identified multiple service use.
3. Data for the Australian Capital Territory were not collected for 1996.
4. Data for service types: Advocacy; Info./referral; Combined advocacy/info.; Print disability/alt. formats of communication; Service evaluation/training; Peak bodies; Research/development; and Other were not collected.
5. Data for the Commonwealth were not collected, except for those in the NIMS collection.
6. Specific learning/PDD and autism are included with intellectual disability in data for recipients of CSDA services funded by the Commonwealth.
7. Frequency of need for assistance in activities of daily living is the most frequent need for support with self-care, mobility or communication for each recipient.

Source: Black et al. forthcoming.

**Table 9.17: Recipients of CSDA services, by frequency of need for support in social or emotional areas, by primary disability group, 1996**

Area of support need	Never		Occasional		Frequent		Continual		Not applicable		Not stated/not known		Total	
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%
<b>Intellectual disability</b>														
Social skills	1,250	3.9	5,728	18.1	6,983	22.0	12,418	39.1	504	1.6	4,848	15.3	31,731	100.0
Managing emotion	582	2.3	5,952	24.0	5,724	23.1	10,987	44.3	298	1.2	1,242	5.0	24,785	100.0
Learning	482	1.6	3,730	12.6	6,447	21.8	13,212	44.7	970	3.3	4,736	16.0	29,577	100.0
Working	1,269	4.3	2,687	9.1	3,029	10.2	7,884	26.7	9,689	32.8	5,019	17.0	29,577	100.0
Home living	639	2.0	3,378	10.6	6,203	19.5	14,087	44.4	2,326	7.3	5,098	16.1	31,731	100.0
Self-direction	511	1.7	4,120	13.9	6,996	23.7	12,579	42.5	820	2.8	4,551	15.4	29,577	100.0
Other day activity	1,004	3.2	4,740	14.9	6,361	20.0	12,953	40.8	1,469	4.6	5,204	16.4	31,731	100.0
<b>Psychiatric disability</b>														
Social skills	348	11.1	852	27.2	597	19.1	262	8.4	30	1.0	1,042	33.3	3,131	100.0
Managing emotion	153	8.0	709	37.2	639	33.5	322	16.9	22	1.2	60	3.1	1,905	100.0
Learning	425	13.6	802	25.6	469	15.0	202	6.5	136	4.3	1,097	35.0	3,131	100.0
Working	280	8.9	446	14.2	353	11.3	242	7.7	657	21.0	1,153	36.8	3,131	100.0
Home living	423	13.5	670	21.4	523	16.7	329	10.5	131	4.2	1,055	33.7	3,131	100.0
Self-direction	211	6.7	871	27.8	654	20.9	326	10.4	23	0.7	1,046	33.4	3,131	100.0
Other day activity	280	0.4	818	26.1	607	19.4	286	9.1	75	2.4	1,065	34.0	3,131	100.0
<b>All primary disability groups</b>														
Social skills	4,190	8.0	9,407	17.9	9,741	18.5	16,700	31.7	2,010	3.8	10,635	20.2	52,683	100.0
Managing emotion	2,174	5.6	9,643	25.0	8,402	21.8	14,684	38.1	1,638	4.3	1,978	5.1	38,519	100.0
Learning	2,772	5.5	6,768	13.5	9,262	18.4	18,399	36.6	2,393	4.8	10,654	21.2	50,248	100.0
Working	2,581	5.1	3,778	7.5	3,905	7.8	9,994	19.9	18,841	37.5	11,149	22.2	50,248	100.0
Home living	1,811	3.4	5,224	9.9	8,246	15.7	19,755	37.5	6,817	12.9	10,830	20.6	52,683	100.0
Self-direction	2,735	5.4	7,745	15.4	10,117	20.1	17,159	34.1	2,178	4.3	10,314	20.5	50,248	100.0
Other day activity	2,409	4.6	7,891	15.0	9,146	17.4	17,863	33.9	4,283	8.1	11,091	21.1	52,683	100.0

**Notes**

1. An individual may be counted more than once if more than one service type was accessed on the snapshot day.
2. Data for Western Australia cover a 12-month period and have been adjusted for identified multiple service use.
3. Data for the Australian Capital Territory were not collected for 1996. Data for the Commonwealth were not collected.
4. Data for service types: Advocacy; Info./referral; Combined advocacy/info.; Print disability/alt. formats of communication; Service evaluation/training; Peak bodies; Research/development; and Other were not collected.
5. Data on learning, working and self-direction for recipients of CSDA directly provided 'Intellectual Disability Services' funded by Queensland were not collected. Data for Western Australia on managing emotion were not collected. The consequences are that there are different total populations for some of the support areas measured.
6. There is a high proportion of clients for whom the need for social and emotional support was not known—over 30% for most of these areas of need for people with psychiatric disability as their primary disability, and over 20% overall (all disabilities) for most areas of need. This may occur either because agencies do not regard the information as essential in providing the services, and/or may not have had the information available in this form for this first time it was collected.

Source: Black et al. forthcoming.

Clients with an intellectual disability as their primary disability reported generally high support needs in these 'social and emotional' areas. Very few reported never needing support, and a high proportion (usually 40% or more) reported the need for continual assistance in these areas. This pattern is consistent with other data, reported in Section 9.2, suggesting the high and multiple needs of this group.

People with psychiatric disability as their primary disability reported more specialised needs. While they were quite likely to report no need for assistance with activities of daily living (36%—see Table 9.16), they were much less likely to report no need for assistance with the 'social and emotional' areas reported in Table 9.17. Relatively few, however, reported the need for continual assistance.

On the 1996 snapshot day, 1,567 CSDA service recipients identified themselves as of Aboriginal or Torres Strait Islander origin (Table 9.18). This figure represented 2.3% of the number of clients on that day, commensurate with their overall representation in the population (1.7% of the Australian population overall, but 1.9% of the population aged under 65 years—ABS 1995b). Their service use could be expected to be higher because of likely higher overall disability prevalence (see Section 9.2). In fact, in 1995 in the

**Table 9.18: Recipients of CSDA funded services, by primary disability group and Indigenous origin, 1996**

Primary disability group	Not Indigenous		Indigenous		Not known/ not stated		Total	
	No.	%	No.	%	No.	%	No.	%
Developmental delay	1,576	2.8	42	2.7	66	0.7	1,684	2.4
Intellectual	33,054	57.8	890	56.8	5,743	58.8	39,687	57.9
Specific learning/PDD	393	0.7	14	0.9	70	0.7	477	0.7
Autism	1,027	1.8	13	0.8	42	0.4	1,082	1.6
Physical	7,988	14.0	272	17.4	1,004	10.3	9,264	13.5
Acquired brain injury	1,900	3.3	71	4.5	80	0.8	2,051	3.0
Deaf and blind	117	0.2	8	0.5	12	0.1	137	0.2
Vision	1,672	2.9	27	1.7	162	1.7	1,861	2.7
Hearing	1,017	1.8	41	2.6	57	0.6	1,115	1.6
Speech	227	0.4	8	0.5	20	0.2	255	0.4
Psychiatric	5,791	10.1	113	7.2	373	3.8	6,277	9.2
Neurological	1,659	2.9	56	3.6	71	0.7	1,786	2.6
Not stated	739	1.3	12	0.8	2,061	21.1	2,812	4.1
<b>Total</b>	<b>57,160</b>	<b>100.0</b>	<b>1,567</b>	<b>100.0</b>	<b>9,761</b>	<b>100.0</b>	<b>68,488</b>	<b>100.0</b>

*Notes*

1. An individual may be counted more than once if more than one service type was accessed on the snapshot day.
2. Data for Western Australia cover a 12-month period and have been adjusted for identified multiple service use.
3. Data for the Australian Capital Territory were not collected for 1996.
4. Data for service types: Advocacy; Info./referral; Combined advocacy/info.; Print disability/alt. formats of communication; Service evaluation/training; Peak bodies; Research/development; and Other were not collected.
5. Data for the Commonwealth were not collected, except for those in the NIMS collection.
6. Specific learning/PDD and autism are included with intellectual disability in data for the Australian Capital Territory and the Commonwealth.

Source: Black et al. forthcoming, Table 3.7.

Northern Territory, where the identification was more complete, service use by Indigenous people appeared to be about twice the rate expected on the basis of their representation in the population (Black & Eckerman 1997).

Physical and hearing disabilities, and acquired brain injury, were more common among Indigenous clients than the overall client population. This pattern appears consistent with patterns of Indigenous morbidity, including relatively high rates of injury and hearing disorders (Section 9.2; ABS & AIHW 1997; Thomson & Snow 1994). Some caution is needed in interpreting these data, as there is a very large number (9,761) of people for whom Indigenous status was not recorded.

### **Open employment services**

Open employment services prepare and support people with a disability to work in the open labour market. Since 1995, data on these services have been collected via a system developed for and with service providers wishing to improve and share management information and to collate national data (see Box 9.6 for details of the systems development). Some client and service data are included in Tables 9.13–9.18 presented above.

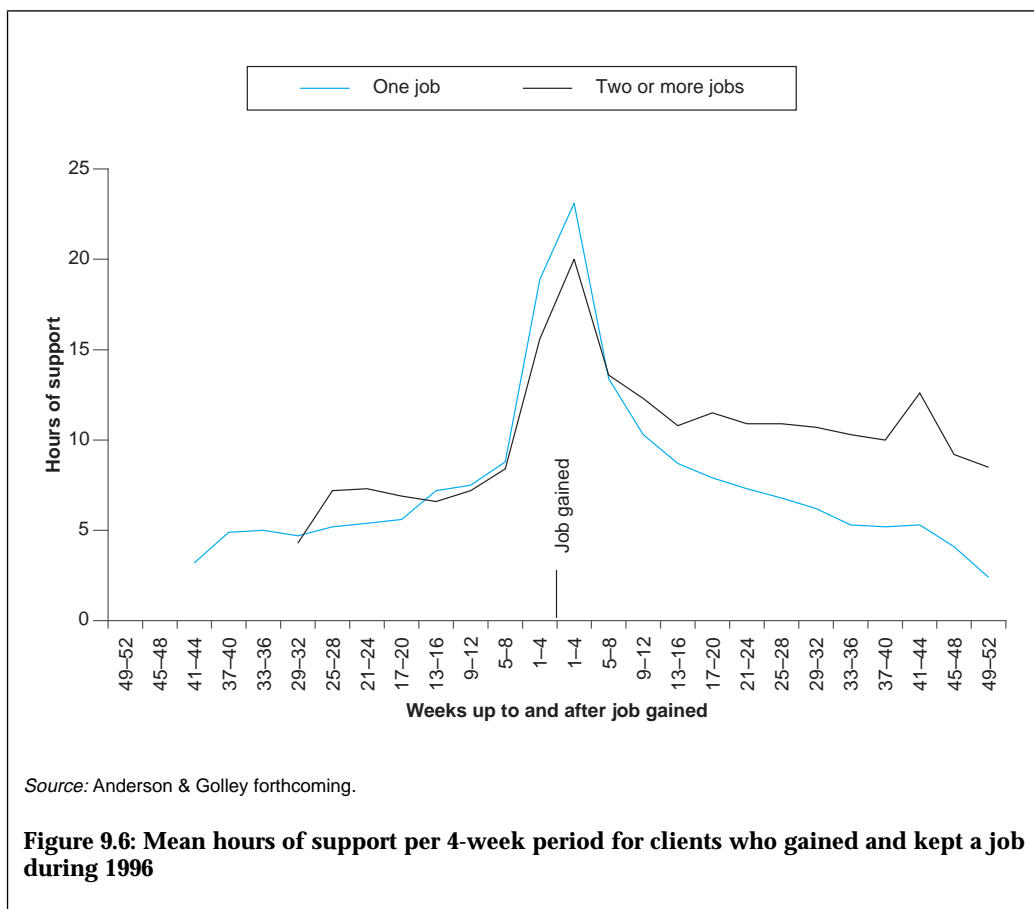
In 1996 22,170 clients were recorded as having received some support during the year. Of these clients, 64% were male and the majority (59%) were aged under 30 years (Anderson & Golley forthcoming). The most common primary disability reported was intellectual/learning disability (50%).

About two-thirds (65%) of all support hours were given to people with an intellectual/learning disability; these were the largest disability group but also had the highest mean support per client—74 hours during 1996.

#### **Box 9.6: Data development for open employment services**

*The development and implementation of the information management system for open employment services were funded by the Commonwealth Department of Health and Family Services. The Institute became involved during the implementation phase and is now manager of the system, working in cooperation with an independent provider representative (the Industry Development Manager) and the Department in the ongoing use and development of the system. Front-end software captures data for the agencies' use and transmission to the Institute for central collation.*

*Both data sets or collections relating to CSDA services—the CSDA MDS collection and the system for open employment services—are relatively new and provide national data not available until the last 2 years. The data now available have relied on considerable effort and cooperation among all concerned—government departments around Australia, non-government agencies, people using services, and the Institute. Proposals for ongoing data improvement are under consideration, and are needed to ensure that high-quality, consistent national data can be collated annually. The CSDA MDS, as a data set, can be collected by different jurisdictions in various ways, although many now use standard national forms developed by the Institute. As each jurisdiction implements changes to the way administrative data are collected, there is the option to integrate the collection of MDS data with collection of a wider set of data needed for the jurisdiction's own purposes. Administrative changes flowing from a new CSDA may necessitate further development.*



People who had jobs during the year (workers) received more support than other clients (2.0 versus 0.9 hours per week). There were peaks of support around the time a job was gained (Figure 9.6). Workers who had only one job during 1996, and retained it at the end of the year, received levels of support which tended to decline the longer they stayed in the job.

### Other relevant services

A range of other services of a more generic nature are relevant to people with a disability (see Table 9.9).

Standards drafted under the Disability Discrimination Act are designed to ensure greater general accessibility of mainstream services. Progress on several fronts has occurred, coordinated by the Commonwealth Attorney-General's Department:

- Transport: a national proposal has been developed, which is now going through the COAG 'regulatory impact statement' process; a draft standard is expected by the end of 1998.

- Access to public premises: a regulation document, proposing changes to building codes, was released in 1997 for public comment.
- Employment: draft standards have been prepared, and are now being redrafted after wide consultation.
- Education: a discussion paper is scheduled for release in 1997.
- Access to Commonwealth information: a discussion paper was released in 1996 and is being redrafted for further consultation.

The remainder of this section provides information on more of these generic or mainstream services of relevance to people with a disability: services designed primarily for older people, and education and employment services. Some data on informal care are also presented.

### Services focused on aged care

A number of programs designed primarily to provide aged care are also available to people aged under 65 years who have a disability.

In 1993–94 (the last year for which data were available), there were 7,462 Home and Community Care (HACC) clients aged under 65 (Table 9.19). This figure represented about 17.9% of the total number of HACC clients at the time.

Nationally, home help was the most used service among HACC clients aged under 65, but there was considerable variation among the States and Territories, with high levels of home nursing use in Queensland, Western Australia and Tasmania. Home respite and centre day care services were also frequently used, as were home paramedical,

**Table 9.19: HACC clients aged under 65 years, by type of service and by State and Territory, 1993–94 (%)**

Type of service	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Australia
Home help	54.4	58.0	50.1	29.0	20.6	67.1	43.1	50.1	47.4
Home nursing	27.3	25.3	57.5	59.7	37.2 <sup>(a)</sup>	56.6	39.5	33.9	36.6
Home paramedical	6.1	16.4	10.6	4.2	42.2 <sup>(a)</sup>	11.6	6.5	20.6	15.3
Centre paramedical	6.8	<sup>(b)</sup>	13.4	5.7	9.5	5.0	8.3	20.1	7.0
Home respite	23.3	25.0	14.6	2.6	8.5	24.0	21.4	15.7	18.3
Centre day care	20.5	15.3	31.2	6.8	11.1	18.2	9.1	9.9	16.8
Home meals	12.9	12.0	11.1	3.9	3.2	9.1	8.7	28.7	10.7
Centre meals	3.0	<sup>(c)</sup>	12.3	2.1	3.2	3.9	2.2	16.2	4.0
Home maintenance	18.2	16.5	10.5	4.0	6.2	19.3	20.3	19.3	14.1
Transport	46.9	n.a.	31.1	7.4	13.4	28.2	30.8	35.0	24.2
<b>Total clients</b>	<b>2,206</b>	<b>1,651</b>	<b>808</b>	<b>618</b>	<b>1,161</b>	<b>362</b>	<b>276</b>	<b>383</b>	<b>7,465</b>

(a) For South Australia the home nursing category is deflated and the home paramedical category inflated, because what is recorded as home nursing in other States is often recorded as home paramedical in South Australia.

(b) Included with home paramedical.

(c) Included with home meals.

#### Notes

1. The database used in this analysis was the HSH, HACC User Characteristics Survey 1993–94. For further information on these data and interstate comparisons, see Mathur (1996). HACC data refer to a 4-week sample period.
2. Persons may receive more than one service type.

home maintenance and transport. There was considerable variation in the use of transport services: 46.9% of clients in New South Wales compared with a national average of 24.2% and the lowest rate, 7.4%, in Western Australia.

Age and sex profiles of respite and non-respite clients for four main aged care service types are presented in Table A9.6. The programs themselves are described in Chapter 8. The table shows that:

- HACC clients aged under 65 were more likely to be respite clients than permanent clients; and
- in all aged care service categories, and in all age groups, clients were more likely to be female than male; male clients were, however, more likely to be younger (that is, aged under 65 or under 60) than were female clients.

### Education and training

In 1996 over 80,000 students with disabilities were recorded as attending school (Table 9.20). This figure compares with some 211,000 people with a disability reported in the population aged 5–14 years in 1993 (AIHW 1995:244). Over half (42,278) the students recorded were attending government primary schools, and a further 24,385 were attending government secondary schools. Only 1,699 were recorded as attending special schools.

At 31 March 1997 there were 1,861 trainees and apprentices, or about 1% of all trainees and apprentices, recorded as having a disability (Table 9.21).

University students are asked on enrolment if they have a disability, impairment or long-term condition which may affect their studies. In 1996 there were 11,587 or 1.8% of all students who answered yes to this question (DEETYA unpublished data). The Commonwealth Department of Employment, Education, Training and Youth Affairs

**Table 9.20: Students with disabilities in government and non-government schools, by State or Territory,<sup>(a)</sup> 1996**

	Government		Non-government			Total
	Primary	Secondary	Regular primary	Regular secondary	Special	
New South Wales	13,028.0	7,555.0	3,166.2	1,891.2	896.9	26,537.3
Victoria	6,974.0	6,268.0	1,678.0	867.2	454.3	16,241.5
Queensland	6,028.5	2,686.0	1,306.0	732.8	101.8	10,855.1
Western Australia	3,858.0	1,857.2	744.4	358.0	75.3	6,892.9
South Australia	7,764.6	4,064.9	630.3	385.3	155.9	13,001.0
Tasmania	2,177.3	954.0	109.6	68.2	15.0	3,324.1
Australian Capital Territory	983.0	576.0	96.6	105.2	0.0 <sup>(b)</sup>	1,760.8
Northern Territory	1,465.0	424.0	168.0	67.0	0.0 <sup>(b)</sup>	2,124.0
<b>Total</b>	<b>42,278.4</b>	<b>24,385.1</b>	<b>7,899.1</b>	<b>4,474.9</b>	<b>1,699.2</b>	<b>80,736.7</b>

(a) Figures are full-time equivalents and hence enrolled student numbers are higher.

(b) No non-government special schools in this State/Territory.

Source: Unpublished DEETYA data from the 1996 Non-government Schools Census and from data provided by State/Territory Governments.

**Table 9.21: Trainees and apprentices, by sex and disability status, by State/Territory, 31 March 1997**

	With a disability		Without a disability		Not specified <sup>(a)</sup>		Total
	Males	Females	Males	Females	Males	Females	
New South Wales	311	89	2,696	1,020	36,810	8,633	49,559
Victoria <sup>(b)</sup>	0	0	0	0	33,315	7,960	41,275
Queensland	880	183	24,525	6,931	0	0	32,519
Western Australia	142	36	4,801	1,492	3,216	777	10,464
South Australia	129	20	13,873	2,744	0	0	16,766
Tasmania	23	3	3,407	1,102	0	0	4,535
Australian Capital Territory	11	4	1,911	897	0	0	2,823
Northern Territory	23	7	56	23	1,495	409	2,013
<b>Total</b>	<b>1,519</b>	<b>342</b>	<b>51,269</b>	<b>14,209</b>	<b>74,836</b>	<b>17,779</b>	<b>159,954</b>

(a) In these cases, a question regarding disability was either not asked on the contract of training, or was asked but not recorded on the State training authority database or was not answered by the apprentice or trainee.

(b) Victoria did not provide information on persons with disabilities.

Source: National Centre for Vocational Education Research Limited unpublished data.

(DEETYA) provides some specific-purpose funding to schools and universities to assist in the provision of education to people with disabilities.

### Employment assistance

Labour market assistance is available to people with disabilities through mainstream employment programs as well as through the specialised support services discussed earlier. Until March 1998 DEETYA will administer labour market assistance for people registered as unemployed, largely through the Commonwealth Employment Service. There are two main categories of people with a disability accessing this type of assistance: those who are designated as Disability Reform Package clients (DRP) through the Disability Panel arrangements administered jointly by DEETYA, DSS and the Commonwealth Department of Health and Family Services (DHFS), and those who have self-identified with no formal assessment. A range of assistance is offered, including employer incentives, training for employment, and job seeker preparation and support.

In 1995–96 DEETYA labour market programs assisted a total of 389,401 males, 19% of whom had a disability, and 236,852 females, 13% of whom had a disability. Males aged 45–59 and females 30–44 years were the groups most likely to be recorded as having a disability (Table A9.7).

From May 1998, most labour market assistance administered by DEETYA will be 'cashed out' to fund employment services in the new employment services market.

### Informal care

People with a disability receive significant assistance from family and friends. Of people living in a household, reporting handicap and receiving assistance in 1993, 91.9% received some assistance from family and friends and 39.8% received formal services, with 31.7% receiving both informal assistance and formal services. Even people with a severe or profound handicap living in households relied predominantly on family and friends for assistance. For 81.9% of people with profound or severe

handicap reporting the need for help, the main provider of assistance with self-care activities was an informal carer usually resident in the same household (AIHW 1995:289–91).

The caring role affects the lives of those who undertake it. Carers interviewed during the 1993 ABS survey reported experiencing frequent sleep interruptions, and social effects such as losing touch with their friends, strain on family relationships, and effects on their ability to go out (ABS 1995a). Overall, the effects fell mostly on women aged 30 and over, consistent with their predominance as principal carers of people of any age (Madden et al. 1996). It is estimated that, in 1993:

- 33,000 people, mainly aged 30 and over, gave up work to take on a caring role;
- 110,800 people stated that the caring role had brought them closer to the person involved; this compared with 88,200 who reported that there was a strain placed on the relationship; and
- 61,700 reported less income, 80,800 reported extra expenses and over 100,000 reported difficulty in meeting living expenses (Table 9.22).

**Table 9.22: Usual resident principal carers,<sup>(a)</sup> by effect of caring role and by age group, 1993<sup>(b)</sup> ('000)**

Effect of caring role	Age group of principal carers					Total	% female
	<30	30–44	45–54	55–64	65+		
<b>Whether left work</b>							
Not applicable	31.5	82.5	56.1	46.0	72.9	288.9	67.9
Yes	2.1	10.6	8.6	7.8	4.0	33.0	72.1
No	3.2	9.5	14.6	14.4	19.5	61.2	46.8
<b>Effect on relationship</b>							
Not applicable	1.1	3.0	2.1	4.6	7.3	18.2	55.6
No change	15.8	40.1	30.4	28.0	51.6	166.0	59.4
Brought you closer	12.2	34.2	23.9	17.0	23.5	110.8	64.7
Placed a strain on relationship	7.7	25.2	22.8	18.5	14.0	88.2	77.5
<b>Effect on financial situation</b>							
Not applicable	0.6	2.3	3.7	4.5	7.3	18.3	55.6
No change	19.0	34.9	26.8	26.9	53.4	161.0	60.2
A minor change	5.7	19.7	13.2	10.5	12.4	61.5	71.5
Income is less	2.1	20.0	18.9	15.7	4.9	61.7	73.4
Extra expenses	9.5	25.6	16.7	10.6	18.4	80.8	64.9
<b>Difficulty in meeting living costs</b>							
Not applicable	25.2	56.5	42.8	41.1	72.7	238.3	62.7
Yes	9.0	35.4	24.0	18.7	13.1	100.2	71.6
No	2.6	10.6	12.5	8.3	10.6	44.7	61.9

(a) Principal carers of people with severe or profound handicap in households.

(b) Estimates of 1,900 or less have an RSE of 50% or more. Estimates of 8,000 or less have an RSE of 25% or more. These estimates should be interpreted accordingly.

Source: AIHW analysis of ABS 1993 Survey of Disability, Ageing and Carers data; first published in Madden et al. 1996.

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

What distinguishes the carer of a person with a disability from many other carers is that it is often a lifelong commitment, rather than a life cycle commitment connected to extreme youth or extreme age. Parent carers of people with a severe or profound handicap in 1993 had, on average, been caring for longer periods of time than other family, including spouses (Table 9.23). Of parent carers, only 20% had been caring for the person for fewer than 5 years, compared with 43% of spouse carers and 53% of other family carers.

It is estimated that, of the 7,700 parents aged 65 years and over who were principal carers, almost half had been caring for a person with a severe or profound handicap for over 30 years (Madden et al. 1996:67).

**Table 9.23: Usual resident principal carers,<sup>(a)</sup> by years in caring role, by age group and by relationship to recipient, 1993<sup>(b)</sup>**

Years in caring role	Relationship of carer to recipient									
	Spouse		Parent		Other family		Friend		Total	
	('000)	%	('000)	%	('000)	%	('000)	%	('000)	%
<b>All carers</b>										
Less than 1 year	16.9	7.4	1.7	2.0	7.0	10.8	1.9	23.8	27.4	7.2
1–4	80.7	35.6	15.3	18.3	27.0	41.7	3.8	47.8	126.8	33.1
5–9	62.2	27.4	29.8	35.7	16.7	25.9	1.6	19.7	110.3	28.8
10–14	36.7	16.2	13.7	16.3	9.7	15.0	0.7	8.7	60.7	15.8
15–19	11.4	5.0	6.6	7.8	1.8	2.8	—	—	19.8	5.2
20+	19.0	8.4	16.5	19.8	2.5	3.9	—	—	38.1	9.9
<b>Total</b>	<b>226.9</b>	<b>100.0</b>	<b>83.6</b>	<b>100.0</b>	<b>64.7</b>	<b>100.0</b>	<b>8.0</b>	<b>100.0</b>	<b>383.1</b>	<b>100.0</b>
<b>Age group of carers</b>										
15–24	3.7	1.6	0.6	0.7	11.1	17.2	0.7	8.1	16.1	4.2
25–64	140.3	61.8	75.3	90.0	48.6	75.1	6.7	82.0	270.6	70.6
65+	82.9	36.6	7.7	9.2	5.0	7.7	0.8	9.8	96.4	25.2
<b>Total</b>	<b>226.9</b>	<b>100.0</b>	<b>83.6</b>	<b>100.0</b>	<b>64.7</b>	<b>100.0</b>	<b>8.0</b>	<b>100.0</b>	<b>383.1</b>	<b>100.0</b>

(a) Principal carers of people with severe or profound handicap in households.

(b) Estimates of 1,900 or less have an RSE of 50% or more. Estimates of 8,000 or less have an RSE of 25% or more. These estimates should be interpreted accordingly.

Source: AIHW analysis of ABS 1993 Survey of Disability, Ageing and Carers data; first published in Madden et al. 1996.

## 9.4 Outcomes

In the last 2 years there has been progress in the development of national outcome measures for disability services. This section first describes progress in the development of service-specific outcome indicators, and provides data for some services and programs. Then the development of over-arching goals for clients of services is outlined

and data presented, indicating outcomes for people with a disability in terms of their participation in various spheres of community life.

## **Service outcomes**

### **Disability services standards**

On 1 March 1993, a set of eight national and three Commonwealth-specific disability services standards came into effect. The eight national standards relate to: service access; individual needs; decision-making and choice; privacy, dignity and confidentiality; participation and integration; valued status; complaints and disputes; and service management. The three Commonwealth-specific standards relate to: employment conditions; employment support; and employment skills development. Some States have added their own additional standards (for instance, for family relationships and for the protection of human rights) to reflect the objectives and principles of their State legislation.

All jurisdictions provide and fund services in accordance with their own disability services legislation, and the national standards. In most jurisdictions, funded services undergo a regular assessment, in terms set out under a service agreement, with the standards included as a component. Some jurisdictions, such as the Commonwealth, also provide a formal opportunity to consumers to provide their views on the services' achievements against the standards.

### **Framework for performance indicators**

Outcome-related performance indicators have been defined as 'a statistic or other unit of information which reflects, directly or indirectly, the performance of a health or welfare intervention, facility, service or system in contributing to optimal well-being in its target population' (Armstrong 1995). In practice, this causal relationship is usually hard to establish in the field of human services, even in small-scale studies with complex designs.

Specific service outcomes often include aspects such as effectiveness, access, quality, appropriateness and efficiency. Work done under the auspices of the Council of Australian Governments included the development of a framework of performance indicators for disability services. This framework comprised efficiency indicators (inputs per output unit) and a range of effectiveness indicators designed to indicate quality, access and participation outcomes (SCRCSSP 1997, Chapter 8). Much of the emphasis in that report was on interstate comparison of service performance.

### **Quality**

Quality of care has received criticism from inquiries established by governments, as well as being the subject of public concern following specific incidents, such as the fire in Kew Cottages in Victoria in 1996, in which nine people with a disability lost their lives.

The NSW Community Services Commission, for instance, reported in 1996 on the recruitment, screening and appointment practices of three State departments responsible for operating or funding residential care services, including services for people with a disability (Community Services Commission 1996). They found that the balance

of present practices weighted the rights of employees and potential employees too heavily in comparison with the rights of vulnerable residents of institutions. Their report made a series of recommendations aimed at: breaking down the isolation of institutions; subjecting potential employees to greater scrutiny; improving their training, pay and career paths; and improving complaints procedures. Another report, into a specific New South Wales institution, had documented breaches of the residents' civil and human rights and principles of acknowledged good practice in relation to behaviour management for people with intellectual disabilities (Community Services Commission 1995:10).

An audit report on large residential centres for people with a disability in New South Wales reviewed their performance in ten practice areas, basing the review on the legislation and the national standards. The report indicated that 'practices in both government and non-government centres fail to protect adequately the human and legal rights, safety and dignity of residents' (Audit Office 1997). The report acknowledges the costs of remedying the situation.

A national study into the abuse of adults with an intellectual disability in residential services based its findings on information from staff, residents and families (Conway et al. 1996). There was considerable evidence of verbal, sexual and physical abuse, including abuse under the guise of 'behaviour management'. Again, recommendations related to training, the development of appropriate policies and procedures, and the provision of necessary resources.

Quality is also an issue in 'mainstream' services such as education. A report based on the views of 784 people, responding to advertisements and invitations (a non-random sample), found many instances of discrimination in terms of difficulties with enrolment, differential application of discipline policies, and failure to address bullying or harassment (National Children's & Youth Law Centre 1997:6):

Attitudes have moved a long way in the last decade, but continuing improvement in the situation for students with a disability will require a renewed emphasis on ensuring equitable access to education. Many respondents reported that the negative attitudes of both staff and students were still a major problem.

Similarly, changes in criminal justice and police procedures have been recommended by the NSW Law Reform Commission. They found that 'people with an intellectual disability are over-represented in the criminal justice system as both victims and offenders'. The Commission's report cites evidence that people with an intellectual disability make up at least 12–13% of the State's prison population (NSW Law Reform Commission 1996:xvii, 25).

These reports collectively reveal a gap between: the standards set in legislation and 'best practice' documents; the experiences of service recipients; and the resources which Australian society is willing to find for the purposes of providing services in accordance with the standards set.

### **Access**

Comprehensive data are not available to indicate the level of availability of services for people with a disability who need them. One of the few national studies on the subject

(Madden et al. 1996) examined the level of unmet demand for disability support services funded or provided under the CSDA and found:

- an estimated 13,500 people in 1993, needing ongoing support in daily living activities and reporting unmet needs for accommodation support or respite services, who could not obtain these services because they were unavailable or could not be arranged (see also Section 9.2);
- a double impact likely to affect service availability in the near future—the ageing of carers and the ageing of people with a disability (a projected 19% growth in the number of people with severe or profound handicap and aged 45–64 years, between 1995 and 2001).

### Outcome indicators for open employment services

Service-specific outcome indicators are also developing in the disability field. Open employment services for people with a disability have been described in Section 9.3 and some client data provided. Some data on outcomes have also been developed.

Of 22,170 clients in 1996, 11,284 had a job at some time during the year ('workers'). Significantly, the number of workers increased by 2,083 or 31% during the year (Anderson & Golley forthcoming)—a positive outcome measure for this group of services (Table 9.24).

**Table 9.24: Job history of workers with a disability, during 1996**

Job history	With one job during 1996		With more than one job during 1996		All workers	
	No.	%	No.	%	No.	%
Job retained	4,119	36.5	1,268	11.2	5,387	47.7
Job lost	948	8.4	285	2.5	1,233	10.9
Job gained and retained	2,676	23.7	640	5.7	3,316	29.4
Job gained and lost	1,136	10.1	212	1.9	1,348	12.0
<b>Total</b>	<b>8,879</b>	<b>78.7</b>	<b>2,405</b>	<b>21.3</b>	<b>11,284</b>	<b>100.0</b>

*Source:* Anderson & Golley forthcoming.

Of all workers, 48% had a job at both the beginning and end of 1996 (termed 'job retained') and 29% gained a job during 1996 and remained in employment at the end of the year ('job gained and retained'). A further 11% were employed at the beginning of the year but not at the end ('job lost'), and the remaining 12% had work at some time during 1996 but started and finished the year unemployed ('job gained and lost').

In order to conduct a more detailed analysis of outcomes, four sets of outcome measures were developed by the Institute: time in work, mean wage, number of jobs per worker, and number of weeks to obtain a job (Table 9.25).

Among workers with a disability:

- it took an average of 27.4 weeks to get a job (for those who had not had one previously);

**Table 9.25: Workers with a disability, by weeks to get job, time in work, hours of work and income earned, and by job history, 1996<sup>(a)</sup>**

Job history	No. of workers	Mean jobs/worker	Mean weeks to get job <sup>(b)</sup>	Mean time in work		Mean hours of work		Income earned from jobs (\$)		
				Wks	% <sup>(c)</sup>	Per work week	Per week <sup>(d)</sup>	Per hour	Per work week	Per week <sup>(d)</sup>
Job retained	5,387	1.36	—	46.6	97.4	26.6	25.9	9.11	239	232
Job lost	1,233	1.30	—	20.3	43.1	24.9	11.1	9.15	222	97
Job gained and retained	3,316	1.26	27.6	25.1	60.7	23.7	14.8	9.31	213	131
Job gained and lost	1,348	1.20	27.0	11.9	27.7	24.0	6.9	9.46	222	63
<b>Total</b>	<b>11,284</b>	<b>1.30</b>	<b>27.4</b>	<b>33.2</b>	<b>72.3</b>	<b>25.3</b>	<b>18.8</b>	<b>9.22</b>	<b>227</b>	<b>167</b>

(a) Clients who had a job during 1996, not including work experience.

(b) Mean time receiving support before commencement of first or only job for workers who had not had a job previously.

(c) Percentage of the support period.

(d) Per week of the support period.

Source: Anderson & Golley forthcoming.

- an average of 33.2 weeks were spent with work (72.3% of the year or of the period of support if less than 1 year);
- the average time worked per week was 25.3 hours; and
- the average hourly rate of pay was \$9.22, the average weekly pay was \$227 per week of work and \$167 averaged over the year.

In order to explore the interrelationships among these measures of job experience and other factors describing agencies and their clients, multivariate regressions were carried out. Client factors which appeared to be related to one or more of the measures included: sex, age, Indigenous status, primary disability type, presence of another disability, living arrangements, and the need for continual assistance with activities of daily living (Anderson & Wisener 1996). These interrelationships were found to be complex, and could not be simplified to a simple predictive model of factors likely to lead to successful job experience.

These findings also illustrate how restrictive it is to require that an outcome be attributable to a specific intervention.

### Outcomes for people with a disability: participation

One of the obstacles to devising national effectiveness measures has been the lack of generally agreed, measurable goals in the disability services field. It was therefore a significant milestone when disability administrators from all jurisdictions developed and agreed national goals for disability services in 1996:

Governments strive to enhance the quality of life experienced by people with a disability through assisting them to live as valued and participating members of the community. (SCRCSSP 1997:389)

The measurement of 'quality of life' is the topic of much research and debate, and measurement for people with a disability is perhaps particularly complex (see, for example, AIHW 1995:295–6; Cummins 1993; Parmenter 1996). The debate in relation to

people with a disability crystallises around several key issues: what is the purpose of measurement; what aspects of life are examined; who makes the judgements about quality of life—the person involved or an ‘expert’ from any of a number of disciplines; and by what method or scale is the measurement done. If gains in quality of life are used to determine access to services, the fact that expert views may differ from individual views is of more than academic interest.

The administrators’ statement simplifies the problem by operationalising the concept to mean life ‘as valued and participating members of the community’. This statement is of even greater significance when placed beside the work being done internationally in revising the ICIDH (see Section 9.2). The new draft third dimension of this classification system is named ‘Participation’ and is constructed in relation to a holistic framework of domains of human experience and activity. This convergence of national and international concepts—around the notion of participation—opens the way to meaningful outcome measurement.

In order to contribute to this monitoring of overall personal outcomes for people with a disability, this section presents new analyses of data indicating the degree to which people with a disability are participating in a range of valued human undertakings or roles.

Underlying the analysis is the assumption that, if the goal of participation is being achieved, the patterns of participation for people with a disability will be similar to those of the rest of the population. Services are, of course, only one of a range of influences on these outcomes for people.

Crucial to the analysis has been the availability of good population data from the Australian Bureau of Statistics, not only from the specialised Disability, Ageing and Carers Survey, but also from other social surveys which identify people with a disability and enable comparison of aspects of their lives with those of the rest of the population.

The analysis is framed as far as possible in the holistic domains of participation suggested in the public draft ‘Beta’ version of the revised ICIDH (Box 9.2):

- in the domain of personal care and maintenance, data are presented on living arrangements as well as self-care;
- in the domain of education, work, leisure and spirituality, data are presented on school attendance, employment and time use;
- data on income and expenditure are used to indicate participation in the area of economic life; and
- data on mobility and verbal communication are relevant to the domains of mobility and social relationships.

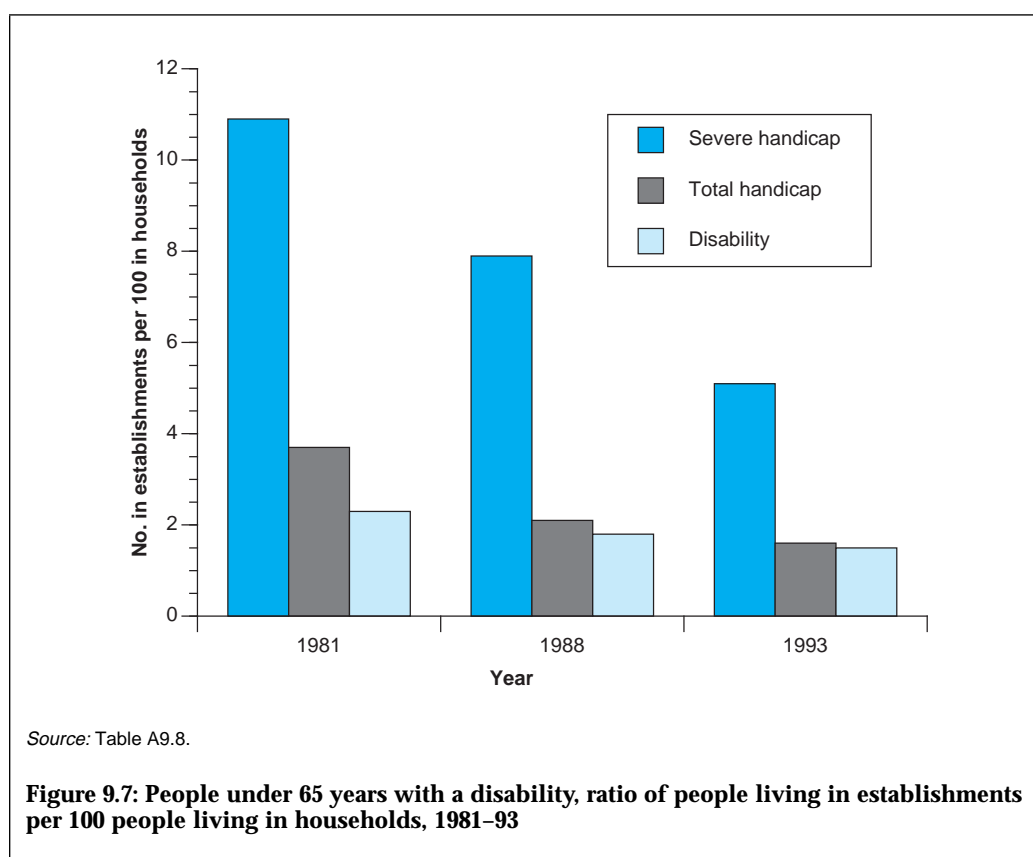
At this stage no data are presented in the domain of civic and community life.

### **Type of residence and living arrangements**

Living in community settings is an important goal of people with a disability, and de-institutionalisation has also been a goal of most governments responsible for the accommodation of people with a disability (see, for instance, AIHW 1993:270–9).

Available data provide evidence that de-institutionalisation has been occurring. The 1981, 1988 and 1993 ABS disability surveys indicate that the percentage of people with

'severe handicap', or any disability, who live in households has risen (Table A9.8). This trend is even clearer when the ratio of people in 'establishments' to people in households is calculated (Figure 9.7). In 1981 there were, on average, 10.9 people aged under 65 years with severe handicap living in establishments for every 100 living in households. By 1993 this ratio had been more than halved, to 5.1 for every 100.



The majority of people with severe handicap aged under 65 years were living with relatives in 1993 (Table A9.8). Most of the change since 1981 has been an increase in the proportion living with relatives; people who at one time were living in institutions are tending to live with relatives rather than in other arrangements. These two findings show clearly the importance of programs to support carers and the stability of living and caring arrangements.

### Income and expenditure

Some income and expenditure comparisons are made possible using data from the ABS Household Expenditure Survey (Table 9.26). The survey identifies households in which a person with a disability lives. Households can also be categorised by the age of the 'reference person', who is the household member whose characteristics seem most likely to be associated with changes in household expenditure.

**Table 9.26: Average weekly income and expenditure of household with or without people with disability or handicap, by age of household reference person,<sup>(a)</sup> 1993–94 (\$)**

Household income and expenditure	Age of household reference person								All households
	Under 65		65+		Under 65		65+		
	Whether household has persons with handicap <sup>(b)</sup>				Whether household has persons with disability <sup>(b)</sup>				
	Yes	No	Yes	No	Yes	No	Yes	No	
<b>Average weekly income (\$)</b>									
Weekly income	656	827	371	343	709	860	356	335	724
Weekly income from government cash benefits	151	70	221	185	119	58	201	177	99
<b>Average weekly expenditure (\$)</b>									
Current housing costs	70	99	40	38	81	104	39	40	85
Fuel and power	18	18	14	12	18	18	13	12	17
Food and non-alcoholic beverages	110	122	75	71	115	123	73	70	111
Alcoholic beverages	17	19	9	10	18	20	10	10	17
Tobacco	12	10	5	4	13	9	4	5	9
Clothing and footwear	30	38	19	18	33	40	17	19	34
Household furnishings and equipment	43	44	21	22	41	45	22	21	40
Household services and operation	31	34	23	22	31	35	23	21	32
Medical care and health expenses	33	28	24	20	31	28	22	18	27
Transport	98	106	41	46	96	109	44	47	94
Recreation	86	88	40	44	85	90	46	38	79
Personal care	11	12	7	8	12	13	8	7	11
Miscellaneous goods and services	43	53	19	20	46	55	20	21	46
<b>Total commodity and service expenditure (\$)</b>	<b>601</b>	<b>672</b>	<b>338</b>	<b>336</b>	<b>618</b>	<b>688</b>	<b>340</b>	<b>329</b>	<b>602</b>

(a) The reference person is the household member whose characteristics seem most likely to be associated with changes in household expenditure, e.g. in couple households, the reference person is the partner with the highest income; in one-parent households, that parent is the reference person; and in lone-person households, that person is the reference person (ABS 1996b).

(b) The definitions of disability and handicap used in the 1993–94 Household Expenditure Survey do not exactly correspond to those in the Survey of Disability, Ageing and Carers 1993.

*Note:* The interpretation of these data requires some care, because the number of people in the household vary.

*Source:* AIHW analysis of the ABS 1993–94 Household Expenditure Survey (unit record file).

For households where the reference person was aged under 65 years and there was a person with a disability or handicap:

- average weekly income in 1993–94 was \$656, compared to \$827 for households with no such person;

- households where there was a person with a handicap derived relatively more income (\$151) from government cash benefits than did households with a person with a disability (\$119) or households with no persons with a disability (\$58); this suggests some effective targeting of income support services;
- fuel and power expenditure was the same as other households;
- all other items of expenditure were lower, except for medical care and health expenses, and tobacco.

These indications are consistent with a recent study of the non-discretionary costs faced by people with a disability, involving interviews with over 1,000 Disability Support Pension recipients, 100 of whom completed a 2-week costs diary (Thomas 1997). It was estimated that some 80% of these additional costs related to transport, prescriptions, personal care goods and health practitioners.

### **Time use**

People with a handicap reported somewhat different overall patterns of activity, compared with the rest of the population, in the 1992 nationwide Time Use Survey (Table 9.27).

People aged 15–64 with a severe handicap spent relatively more time on personal care (including sleeping) and passive leisure, and less time on labour force and educational activities, when compared with people in the same age range with no disability. Males with severe handicap also spent relatively less time on social activities and more time on domestic activities than other males.

The presence of severe handicap appeared to be related to larger male–female differences in some areas (education and social activities) and to smaller differences in others (domestic activities). For instance, females with no disability spent 7.7% of the day on social activities, and males 6.6%; with severe handicap, females still spent 7.3% of their day on social activities but males spent only 4.1%. In contrast, males and females with severe handicap spent more of the day on domestic activities than did those with no disability, and male–female differences were larger among those with no disability.

### **Employment**

Overall, among working age people with a handicap, unemployment rates have worsened considerably since 1988 (Table 9.28). While unemployment rates for the total population, calculated from the ABS disability survey, rose from 8.2% in 1988 to 12.7% in 1993,<sup>5</sup> those for people with a handicap rose in the same period from 12.0% to 19.2%. The change may be partly related to rising participation rates of people with ‘mild’ handicap or ‘employment limitation only’; participation rates for people with a handicap rose from 40.2% in 1981 to 47.6% in 1993. This change may signify a greater propensity for these people to look for work, or a greater propensity for people to report difficulty and to be included in the ‘handicap’ category.

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5 Estimates from ABS labour force surveys in 1993 were as follows: the unemployment rate was 10.9%, with the average for males 11.5% and for females 10.1%; the participation rate for males was 73.8% and for females 51.8% (ABS 1993c).

**Table 9.27: Percentage of day spent on activity groups: people aged 5–64, by sex and by disability status,<sup>(a)</sup> 1992**

	Severe handicap			Disability without severe handicap			No disability			Total persons		
	Males	Females	Persons	Males	Females	Persons	Males	Females	Persons	Males	Females	Persons
Labour force and household												
Labour force	8.3	3.4	5.5	16.2	5.9	11.7	22.4	11.1	16.7	21.0	10.2	15.7
Household	12.3	20.8	17.1	12.3	21.1	16.1	8.9	20.0	14.5	9.5	20.1	14.8
Domestic activities	8.7	13.1	11.1	8.3	14.3	10.9	5.7	12.0	8.9	6.3	12.4	9.3
Child care/minding	0.9	3.5	2.4	1.0	2.5	1.6	1.1	4.2	2.7	1.1	3.9	2.5
Purchasing	2.7	4.2	3.6	3.0	4.3	3.6	2.1	3.8	2.9	2.2	3.9	3.0
<i>Total labour force and household</i>	<i>20.6</i>	<i>24.2</i>	<i>22.6</i>	<i>28.5</i>	<i>27.0</i>	<i>27.8</i>	<i>31.3</i>	<i>31.1</i>	<i>31.2</i>	<i>30.6</i>	<i>30.4</i>	<i>30.5</i>
Total personal	50.8	45.8	48.0	43.6	45.3	44.3	42.0	42.7	42.3	42.4	43.1	42.8
Total education	3.9	0.5	2.0	1.0	1.1	1.1	3.0	2.6	2.8	2.6	2.3	2.5
Total community	1.1	1.8	1.5	2.5	2.3	2.4	1.5	1.7	1.6	1.7	1.8	1.7
Social and leisure												
Social activities	4.1	7.3	5.9	6.3	7.5	6.8	6.6	7.7	7.2	6.5	7.7	7.1
Active leisure	2.9	3.8	3.4	3.0	2.9	3.0	4.0	3.0	3.5	3.8	3.0	3.4
Passive leisure	16.5	16.4	16.4	14.9	13.7	14.4	11.5	11.2	11.4	12.2	11.7	12.0
<i>Total social and leisure</i>	<i>23.5</i>	<i>27.5</i>	<i>25.8</i>	<i>24.2</i>	<i>24.2</i>	<i>24.2</i>	<i>22.1</i>	<i>21.9</i>	<i>22.0</i>	<i>22.6</i>	<i>22.3</i>	<i>22.4</i>
Undescribed	—	0.2	0.1	0.2	0.1	0.1	0.1	0.1	0.1	0.1	0.1	0.1
<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>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>

(a) The definitions of disability and handicap in the ABS 1992 Time Use Survey do not exactly correspond to those in the Survey of Disability, Ageing and Carers 1993.

Source: ABS 1992 Time Use Survey unpublished data.

**Table 9.28: Percentage of people aged 15–64 years in households, by unemployment and labour force participation rates and by disability status, 1981, 1988, 1993<sup>(a)</sup>**

	Year	Handicap				Total with a handicap	Disability without handicap	Total with a disability	No disability	Total with & without a disability
		Severe	Moderate	Mild	Not determined <sup>(b)</sup>					
<b>Unemployment rate<sup>(c)</sup></b>										
Males	1981	6.7	7.4	8.7	20.2	10.2	4.8	7.0	—	—
	1988	7.8	10.8	8.0	17.7	11.4	6.9	10.1	6.7	7.0
	1993	18.1	14.7	22.5	21.2	20.0	14.9	18.1	11.9	12.5
Females	1981	13.4	12.6	16.2	21.9	15.6	12.2	13.8	—	—
	1988	14.8	9.5	12.1	17.5	13.2	14.9	13.6	9.7	10.0
	1993	19.0	18.3	19.4	15.6	18.0	17.2	17.7	12.4	12.8
Persons	1981	9.5	8.9	11.1	20.8	12.0	7.0	9.1	—	—
	1988	11.3	10.3	9.5	17.7	12.0	9.4	11.3	7.9	8.2
	1993	18.5	16.1	21.2	19.3	19.2	15.6	18.0	12.1	12.7
<b>Participation rate</b>										
Males	1981	37.4	55.2	56.8	51.6	49.8	89.9	67.5	—	—
	1988	37.9	49.7	62.2	68.4	55.3	88.3	61.9	89.8	85.9
	1993	34.8	47.7	54.7	70.9	53.2	84.4	61.4	88.1	84.1
Females	1981	24.3	32.8	34.1	28.9	29.3	50.9	38.0	—	—
	1988	31.5	33.8	41.7	45.9	37.6	56.4	40.7	62.7	60.1
	1993	25.4	39.2	44.9	57.4	40.9	56.7	44.7	65.4	62.9
Persons	1981	30.7	45.9	46.7	40.6	40.2	73.2	54.2	—	—
	1988	34.4	42.6	52.7	59.3	47.1	75.3	52.2	76.2	73.2
	1993	30.0	43.9	50.1	65.5	47.6	72.8	53.9	76.7	73.6

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

(b) This group comprises all people who had a schooling or employment limitation only.

(c) For details of employment status by disability status, see Table A9.9.

Sources: ABS unpublished data; AIHW analysis of ABS 1993 Survey of Disability, Ageing and Carers confidentialised unit record file.

However, the situation is rather more bleak for people with severe handicap. Their participation rates did not rise over the period, remaining at around 30% or just over for the three surveys, while their unemployment rates rose from 11.3% in 1988 to 18.5% in 1993 (compared with a rise in the overall unemployment rates from 8.2% in 1988 to 12.7% in 1993).

Male and female rates of unemployment among those with severe handicap (or any handicap) have become closer, but only because male rates have risen to or exceeded female rates, rather than because of any improvement in female rates.

### **Education**

The inclusion of students with a disability into mainstream education is now accepted policy in most States and Territories. A perspective on trends in school education is given by the self-reported school attendance data from the ABS disability surveys (Table 9.29). Overall, there was a higher percentage of people aged 5–20 years, with a handicap, in schools in 1993 than in 1981. Students with handicaps of all severities were more likely to be attending special classes in ordinary schools in 1993 than in 1981. Evidence on overall attendance at special schools, or in ordinary classes at ordinary schools, was more equivocal—an apparent rise in 1988 and then a fall in 1993. Students with a severe handicap were more likely in 1993 to be attending ordinary schools than they were in 1981, the increase being higher for special classes than for ordinary (mainstream) classes.

The rising percentage of people attending school (and of those not attending school) and reporting handicap mirrors the overall increase in the proportion of the population reporting handicap. Most (91.2%) of those not attending school in 1993 were in fact in the 15–20 age range, and approximately one-third of these were aged 20 (AIHW analysis of ABS 1993 disability survey).

An analysis of longer term trends, using a wider variety of data sources, provides confirmation of the trend away from special schools (Dempsey & Foreman 1995). The authors found a drop in the numbers recorded as attending special schools Australia-wide, from approximately 25,200 in 1976 to under 18,000 in 1993. The authors also found that, although males and females appeared equally likely to be attending special schools, males were much more likely than females to attend special classes (support classes) within ordinary schools. School placement in a regular class in 1993 was more likely to occur for people with only one disabling condition; 90.5% of students with only one disability, and 70.8% of students with two or more disabilities, were in regular classes.

### **Self-care, mobility and communication**

It has been established that participation restriction in the areas of self-care, mobility and verbal communication, if indicated in terms of need for assistance, has remained fairly stable over the years of the three ABS disability surveys (Table 9.6). An estimated 13,500 people with severe or profound handicap (i.e. always or sometimes needs assistance with self-care, mobility or verbal communication) were unable to obtain that assistance in 1993 because services were unavailable or could not be arranged (Table 9.7). A greater number did not receive the needed assistance for other reasons, giving a total, for all reasons combined, of approximately 70,000 people who did not receive the services they said they needed.

**Table 9.29: Percentage of school-aged people (aged 5–20 years), by school attendance and type of school and class, by disability status, 1981, 1988, 1993<sup>(a)</sup>**

Type of school/class	Severe	Moderate	Mild	Schooling limitation only	Total with a handicap	Disability without handicap	Total with a disability
<b>Ordinary school class</b>							
1981	0.5	0.2	0.2	0.5	1.5	1.6	3.1
1988	0.7	0.5	0.9	0.9	3.0	1.0	4.0
1993	0.8	0.2	0.5	0.8	2.3	1.2	3.6
<b>Ordinary school (special class)</b>							
1981	0.2	0.1	0.0	0.3	0.6	0.0	0.6
1988	0.3	0.1	0.1	0.3	0.8	0.0	0.8
1993	0.6	0.1	0.1	0.5	1.4	0.0	1.4
<b>Special school</b>							
1981	0.3	0.0	0.0	0.1	0.4	0.0	0.4
1988	0.4	0.0	0.0	0.1	0.5	0.0	0.5
1993	0.3	0.0	0.0	0.0	0.3	0.0	0.3
<b>Total attending school</b>							
1981	1.0	0.3	0.3	0.9	2.5	1.6	4.1
1988	1.4	0.6	0.9	1.2	4.2	1.0	5.2
1993	1.7	0.4	0.6	1.3	4.0	1.3	5.3
<b>Not attending school</b>							
1981	0.2	0.1	0.1	0.1	0.6	0.9	1.6
1988	0.3	0.2	0.3	0.3	1.1	0.4	1.5
1993 <sup>(b)</sup>	0.5	0.1	0.3	0.3	1.2	0.5	1.7
<b>Total</b>							
1981	1.2	0.4	0.4	1.0	3.1	2.6	5.7
1988	1.7	0.8	1.3	1.6	5.3	1.3	6.7
1993	2.2	0.5	0.9	1.6	5.2	1.7	6.9

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

(b) Included with 1,379 people who reported 'do not know' about the type of school attending.

Sources: ABS unpublished data; AIHW analysis of ABS 1993 Survey of Disability, Ageing and Carers confidentialised unit record file.

## 9.5 Summary

Disability services are generally directed towards enhancing people's participation in a range of community activities, although they may also affect other dimensions of disability (for instance, impairments at organ level, and activity limitations, affecting the whole person).

## **Prevalence of disability**

In 1993 an estimated 1,519,000 people aged under 65 years reported a limitation or restriction in performing certain tasks associated with self-care, mobility, verbal communication, schooling or employment (9.7% of the population in that age group). A total of 368,300 (or 2.6% of the population aged 5–64 in 1993) reported that they always or sometimes needed personal assistance or supervision with activities of daily living (self-care, mobility or verbal communication)—that is, they had a ‘severe or profound handicap’. This group is of special significance when considering the need for disability support services designed to provide living assistance, to enable people with a disability to participate as fully as possible in society. The age- and sex-standardised rate of severe or profound handicap (approximately 2.5% of the 5–64 age group) has been fairly constant over the 12 years of national population surveys on disability.

Work has begun on reviewing the definitions and prevalence estimates of some of the major disability groupings referred to in the disability field, starting with intellectual disability. Intellectual disability is usually defined in terms of ‘low general intellectual functioning’, and also of ‘difficulties in adaptive behaviour’. Prevalence estimates of intellectual disability have ranged between 0.4% and 1.86% of the population, depending on the definition used, and on the sampling and measurement methods. As a result of a review of the major definitions and estimates, a prevalence figure of 0.99% or 174,000 is suggested for use in Australia. People with intellectual disability frequently have a range of associated disabilities and needs, and this is reflected in their high representation in ongoing support services.

There is little reliable national data on disability among Indigenous people. Further work is recommended, as a priority, to address the conceptual issues appropriately, and to overcome the very real sampling problems in national population surveys.

## **Unmet demand for services**

In 1993, an estimated 13,500 people with a severe or profound handicap reported an unmet demand for formal services of the type provided as accommodation support or respite services under the CSDA. A further, double impact is likely to increase pressure on services and the social security system in the near future—the ageing of carers (an estimated 7,700 people with severe or profound handicap had a principal carer aged 65 or more); and the ageing of people with a disability (a projected 19% growth in the number of people with severe or profound handicap and aged 45–64 years, between 1995 and 2001). There is also unmet demand for the training and employment assistance provided under the Disability Reform Package—an estimated demand of 60,000 places, compared with the current supply of 27,000 places.

## **Services**

Formal services for people with a disability include: disability-specific income support; disability support services; and generic services. Data on informal care and assistance provide an important and complementary perspective.

## **Income support**

Major disability-related payments made by the Commonwealth totalled \$5.8 billion in 1995–96. Over \$4 billion of these outlays were paid to the almost half-million recipients

of the Disability Support Pension. There have been significant increases over the last decade in the numbers of recipients of the Disability Support Pension.

### **Disability support services provided under the CSDA**

Support services provided under the Commonwealth/State Disability Agreement (CSDA) include accommodation and accommodation support, community support services, employment support services and respite services. These services—an increasingly varied mix—reach a more targeted group of people, who require ongoing support.

A total of \$1,264 million was provided by Australian governments in 1995–96 for the funding of these services: \$728 million (approximately 58%) was provided to non-government and government services for accommodation services; \$331 million for community support, community access and respite services; and \$169 million for employment support services.

On the snapshot day of the national collection, some 68,488 clients accessed CSDA services, with larger numbers accessing the services over the whole year, especially for service types with a large client turnover. Overall, there were more clients in the non-government sector than the government sector, for all service types.

Disability support services are targeted at people with a need for ongoing support, and these needs are reflected in the data. Some 72% of CSDA clients were reported to need continual, frequent or occasional help with activities of daily living (self-care, mobility and/or communication). Support and assistance may also be needed in social and emotional areas. The great majority of clients needed continual, frequent or occasional support in managing emotions (85%), learning (69%) and self-direction (70%).

### **Other services relevant to people with a disability**

Improved access to generic services is being worked towards in a number of ways. Under the Disability Discrimination Act, standards relating to transport, access to premises, employment, education and information are being developed.

In 1996 there were 80,737 school students, and in 1997 1,861 trainees and apprentices, who reported disability in order to receive recognition and assistance within mainstream education and training services. Of the 389,401 males receiving mainstream labour market assistance in 1995–96, 18.9% reported a disability, as did 12.8% of the 236,852 females assisted.

Younger people with a disability also use services designed primarily for aged care purposes, sometimes because that is all that is available. In 1993–94 approximately 8,000 Home and Community Care clients (around 19% of the total) were aged under 65 years. Over 2,000 younger people with a disability were using other aged care services, including nursing homes and hostels.

### **Informal care**

People with a disability receive significant assistance from family and friends. For example, for 82% of those with a severe or profound handicap who reported the need for help in 1993, the main provider of assistance with self-care activities was an informal carer usually resident in the same household. Caring for a person with a

disability is likely to be a long-term commitment. Parent carers of people with a severe or profound handicap in 1993 had, on average, been caring for longer periods of time than other family members. It is estimated that, of some 7,700 parents aged 65 years or more who were principal carers in 1993, almost half had been caring for the person with severe or profound handicap for over 30 years.

### **Recent developments**

Governments have decided to take a reduced role in direct service provision, seeking instead to become purchasers of services involved in standard setting, planning and policy development. The Commonwealth/State Disability Agreement is currently being renegotiated.

## **Outcomes**

### **Service outcomes**

Disability service standards are in place in all Australian jurisdictions. Qualitative reports have provided evidence of the need for improvements in the quality of specific accommodation services, institutions, and schools. These reports reveal a gap between the standards set in legislation and national standards, and the resources which Australian society is willing to find for the purposes of providing services in accordance with the standards set.

Access to disability support services is also an issue, with the finding that there were an estimated 13,500 people in 1993 with unmet demand for the types of services provided as accommodation, accommodation support and respite under the CSDA. With the ageing of the population and the ageing of carers, this unmet demand is not likely to lessen in the next decade.

The efficacy of open employment services for people with a disability is suggested by the finding that, among their clients, the number of workers increased by 31% during 1996. The time spent to gain a job, the duration of jobs, and the rates of pay were also examined as key outcome indicators. These outcomes appeared to be related to a range of client factors including sex, age, Indigenous status, primary disability type, presence of another disability, living arrangements, and the extent of need for assistance with activities of daily living. It is an important finding that these interrelationships were complex, and could not be simplified to derive a simple, predictive model of factors likely to lead to successful job experience.

### **Outcomes for people**

'Participation' has been adopted as a key goal of disability services nationally, and as a major dimension of the international conceptualisation of disability. Overall, people with a disability were found to be participating in every sphere of Australian life examined, but not as fully as people without disability. Households in which they lived had lower income levels in 1993–94 and correspondingly lower expenditure levels (except on medical and health expenses); the effects of these income differences are mitigated by government benefits. People with a disability spent more time on passive leisure activities and personal care, and less on labour force activities and education, than others in the population. Their experience of rising unemployment in recent years has been worse than that of the general population.

A fairly constant proportion of people (allowing for changes in the age and sex structure of the population), over a 12-year period, have reported the need for assistance with activities of daily living such as self-care, mobility and communication, although a large number were not receiving this assistance in 1993.

Trends in types of residence and living arrangements suggest that de-institutionalisation was a reality between the years 1981 and 1993. In 1981, there were on average 10.9 people aged under 65 years with a severe handicap living in establishments for every 100 living in households; by 1993, the ratio was 5.1. Much of this change is reflected in the higher numbers and proportions of people with a severe handicap living with relatives: in 1981, some 265,000 and by 1993, 324,000, (age-standardised expected numbers, showing an increase not attributable to changes in the age structure of the population). This finding highlights the complementary nature of informal and formal care, the importance of adequate provision of accommodation support and respite services, and the importance of monitoring the situation of carers.

### **The future**

Disability services in Australia, having evolved quite rapidly since the early 1980s, are continuing to change. Pressures for change have arisen from the expectations of people with disabilities, changing philosophies of service delivery, and ideas about the role of government, the non-government and private sectors, and the family.

The increasing policy focus on access to mainstream services, community-based support services and on recognition of carers is in line with the major changes in the lives of people with a disability outlined in this chapter. Overall, people with a disability are participating in many spheres of Australian society, although generally not as fully as other Australians. Over the last decade they have become more likely to be living in households, attending ordinary schools and seeking employment.

Evident in the service system are gaps between demand and provision, and between standards set and achieved. The growth in the population aged 40+ years, and the ageing of carers, will only increase pressure on services. These conflicting pressures will test the commitment of the Australian community to the stated policy goals for people with disabilities in Australia.

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