



# 8 Disability and disability services

## 8.1 Introduction

This chapter presents an overview of disability in Australia and services for people with a disability.

Disability is conceptualised as multidimensional, relating to the body functions and structures of people, the activities they do, the life areas in which they participate, and factors in their environment which affect these experiences (Box 8.1, Figure 8.1). Increasingly, disability is recognised as something that affects most people in the population, to varying degrees and at varying life stages; it can be measured along a continuum and estimates vary with the particular definition used.

Services of relevance to people with a disability may seek to ameliorate disadvantage associated with any of these components of disability, including the environmental factors. This chapter focuses chiefly on people aged under 65 years,<sup>1</sup> and on services and assistance directed primarily towards their activities and participation in various areas of life:

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

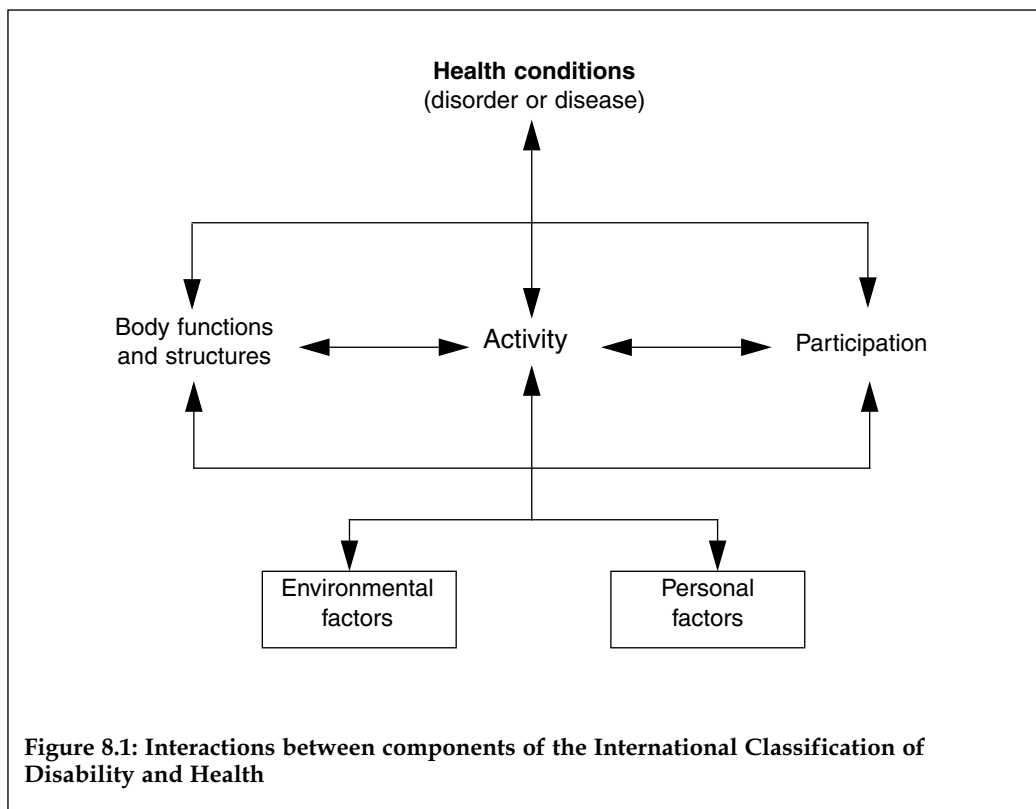
Section 8.2 outlines recent developments in the disability field, including data developments. Section 8.3 gives an overview of disability in the Australian population, and the need for services and assistance. Section 8.4 supplies data on services and assistance provided. Section 8.5 discusses outcomes for people with disability, with a special focus, in this edition, on people with communication restrictions. Section 8.6 concludes the chapter.

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1 People who have acquired a disability before reaching 65 years of age, are generally regarded as the responsibility of the disability services sector. People who acquire disabilities at older ages are generally the responsibility of the health or aged care services sector.

## 8.2 Recent developments

The disability field is strongly influenced by philosophical ideas about human society and how it functions, by the theory and practice of human service provision including access to generic services by people with disabilities, by economic trends and funding patterns and practices, and by demographic change in the population. This section briefly explores some recent developments affecting the disability services field.



### Human rights and ethics

Most policies in the disability field have, in recent decades, been underpinned by a human rights philosophy—encapsulated in the basic principle that people with disabilities should have the same opportunities to participate in society as do others (see, for example, AIHW 1993:266–79; UN 1994). The United Nations is now seeking input from member states to develop proposals for an international convention to promote and protect the rights of people with disabilities. In the Asia-Pacific region, the UN has fostered a ‘framework for action towards an inclusive, barrier-free and rights-based society for person with disabilities’ (ESCAP 2002).

International agreement on definitions and classifications of disability (Figure 8.1, Box 8.1) opens the way for these to contribute to clarity in the scope and terminology of such agreements. Indeed, the ICF is recognised as aligning with the existing UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities and

## Box 8.1: The International Classification of Functioning, Disability and Health (ICF)

*Functioning and disability are multidimensional concepts, relating to the body functions and structures of people, the activities they do, the life areas in which they participate, and the factors in their environment which affect these experiences. In the ICF, a person's functioning or disability is conceived as a dynamic interaction between health conditions and environmental and personal factors (WHO 2001:6).*

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

- **Body functions** are the physiological functions of body systems (including psychological functions).
- **Body structures** are anatomical parts of the body, such as organs, limbs and their components.
- **Impairments** are problems in body function and structure, such as significant deviation or loss.
- **Activity** is the execution of a task or action by an individual.
- **Participation** is involvement in a life situation.
- **Activity limitations** are difficulties an individual may have in executing activities.
- **Participation restrictions** are problems an individual may experience in involvement in life situations.

*Environmental factors make up the physical, social and attitudinal environment in which people live and conduct their lives. These are recorded as either facilitators or barriers (both on a 5-point scale) to indicate the effect they have on the person's functioning.*

*The ICF contains a hierarchy of classifications and codes for each of its main components: Body Functions and Structures, Activities and Participation, and Environmental Factors. Measures can be recorded against each of the neutral codes, to indicate the extent of 'problem' with any of these aspects of functioning. Environmental Factors can be recorded as being either barriers to or facilitators of a person's functioning.*

*The ICF was endorsed for international use by the World Health Assembly in May 2001. It is regarded by the World Health Organization as one of the two core international classifications for health and health-related information, the other being the International Classification of Diseases and Related Health Problems (ICD).*

*The potential value of using the ICF in Australia is that it:*

- *recognises the role of environmental factors in the creation of disability and the importance of participation as a desired outcome, as well as the relevance of underlying health conditions and their effects; and*
- *provides a framework within which a wide variety of information relevant to disability and functioning can be developed, assembled and related.*

Source: AIHW 2003d.

other rights formulations (Madden 2003; UN 1994; WHO 2001:5). The focus of the ICF on environment is seen as particularly relevant to its application in human rights initiatives (Bickenbach et al forthcoming).

The rapidly changing field of genetics is another area where scientific developments are stirring active ethical debate (Box 8.2).

## **Disability Discrimination Act**

The *Disability Discrimination Act 1992* (DDA) is one of the major national expressions of the human rights approach to disability, making discrimination on the grounds of disability unlawful, and providing a framework for the setting of access standards in significant fields (see Box 8.3 for an overview of recent progress on standards). Individual people may make complaints under the DDA, and standards can be set in order to achieve system-wide change. These standards are set after negotiation with industry to agree the nature and time scale of the changes to be effected. DDA standards have two major purposes: 'to set legislative deadlines for achieving equal access for people with disabilities in the areas covered by the DDA; and to provide more definite and certain benchmarks for accessibility and equality than is provided by the general anti-discrimination model' (HREOC 2003:1). While change is slow, the Act is credited with some positive shifts over the last 10 years— standards for accessible public transport, increased emphasis on 'universal' building design, voluntary industry standards in banking and finance, and a requirement that Telstra provide telephone typewriter services (TTYs) to hearing impaired people (Innes 2003). The Human Rights and Equal Opportunity Commission deals with complaints under the DDA (HREOC 2003).

The Commonwealth Government launched a new Commonwealth Disability Strategy, in recognition of its own legislative responsibilities to ensure that 'people with disabilities have the same access to buildings, services, information, employment, education, sport and recreational activities as everyone else in the community' (Commonwealth of Australia 2000). The strategy encourages Commonwealth agencies to prepare action plans and provides a performance framework for reporting on progress.

An inquiry into the DDA was announced in February 2003, to examine its effectiveness in achieving its stated goals of eliminating discrimination, ensuring equality of people with disabilities before the law, and promoting recognition and acceptance of the rights of people with disabilities. The review is also considering the extent to which the DDA restricts competition, and is to quantify the costs and benefits of the DDA approach and examine mechanisms for improving efficiency and 'minimising compliance costs and paper burden on small business' (Productivity Commission 2003a:6).

## **Income support and employment**

Both nationally and internationally, there are efforts to understand the rising numbers of people receiving disability-related income support, and to clarify the relationship between, on the one hand, measures to support people with a disability in their search for work and in employment once obtained and, on the other, the features of programs that provide income support to replace or supplement earnings otherwise unavailable

## **Box 8.2: Genetics and ethics**

*The rapid development of genetic science and technology continues to focus attention on ethical issues of fundamental significance to the disability field. An increasing number of tests for genetic diseases are becoming available as a result of the human genome project and other advances in genetics. These enable an embryo to be screened for one or more genetic disorders during early pregnancy with the option of abortion if any are found. Pre-implantation genetic diagnosis (PGD) is also becoming more common. This involves the creation of embryos using in-vitro fertilisation (IVF) techniques that are then tested for particular genetic disorders. Embryos without the disorder can be transferred to the mother's womb and embryos with the abnormality allowed to succumb.*

*Some disability rights activists argue that the trend towards preventing the birth of children with genetic impairments is based on misinformation about the lives of people with a disability as well as a lack of support for families with such children (e.g. Newell 2002). They ask the fundamental question as to whether disability represents an element of the diversity of humanity rather than a negative characteristic that should be eliminated. On the other hand, the use of PGD has raised the possibility that parents with a disability may wish to have a child with the same disability, for example deaf parents may choose to have deaf children. The ethics of such a choice are under debate. One viewpoint argues that it would be unethical to deliberately have a child with a disability; another suggests that certain disabilities could be in the long-term interests of the child as they will share the same experiences as their affected parents (Human Fertilisation and Embryology Authority and Advisory Committee on Genetic Testing 1999).*

*In Australia, these issues have been highlighted by the recent controversy over the use of embryonic stem cells in scientific research. After considerable community debate, the Commonwealth parliament passed the Research Involving Human Embryos Act at the end of 2002. Under this Act, researchers are able to get approval to use surplus embryos from Australian IVF clinics, but cannot create embryos specifically for research. Some disability advocates have welcomed this legislation believing that embryonic stem cell research will lead to the development of cures for conditions such as spinal cord injuries, motor neurone disease, Parkinson's disease and multiple sclerosis. Others argue that this focus on 'miracle cures' is a diversion from the real day-to-day needs of people with disabilities and the resources required for these to be met. They see it as a return to the 'disability as tragedy' mentality that inhibits the acceptance of people with disabilities as valued community members with worthwhile lives.*

*Recently, IVF itself has been found to be associated with an increase in disability. A study of Western Australian children born between 1993 and 1997 found that infants conceived by IVF had twice the risk of a major birth defect, diagnosed by 1 year of age, as naturally conceived infants (Hansen et al. 2002). The reasons for this difference are not known.*

*Advances in genetic testing also have widespread implications for the privacy and confidentiality of an individual's genetic information and fairness in its use by such bodies as insurers, employers, courts, schools, adoption agencies and the military. The Australian Law Reform Commission and the Australian Health Ethics Committee have conducted an*

*(continued)*

### **Box 8.2 (continued): Genetics and ethics**

*inquiry into the ethics of human genetic samples and information. The aims of the inquiry were to see how best to protect privacy, to protect against unfair discrimination and to ensure the highest ethical standards in research and practice (ALRC & NHMRC 2003).*

*The inquiry set out to find ‘a sensible path that meets twin goals: to foster innovations in genetic research and practice that serve humanitarian ends and to provide sufficient reassurance to the community that such innovations will be subject to proper ethical scrutiny and legal control’ (ALRC 2002:2) and has made a large number of recommendations. It has proposed that a careful mix of strategies is required – stronger ethical oversight, stronger regulations, industry codes, education campaigns, an independent expert advisory body, and revised privacy and discrimination laws. It is recommended that employers should be able to collect and use an employee’s genetic information only where this is reasonable and relevant within the terms of anti-discrimination and occupational health and safety legislation, and that a person should not be denied employment on the basis of predictive genetic information. One recommendation is that the Commonwealth Disability Discrimination Act 1992 should be amended to ensure that it covers unlawful discrimination based on a person’s real or perceived genetic status.*

or inadequate. As part of its welfare reforms, the Commonwealth released a consultation paper ‘*Building a Simpler System To Help Jobless Families and Individuals*’. The paper canvasses various options for change, including a ‘broader path to reform’ with an income support system that ‘might provide standard rates of income support and income and assets test, with additional assistance for particular needs (such as the costs of disability and participation) and more flexible participation requirements for a greater number of people’ (FaCS 2002d:11).

A recent study by the OECD of related policies and experiences in 20 member countries, including Australia, found that:

- disability benefit recipiency rates are high and increasing in many countries and rates of cessation from disability benefits are generally low;
- ‘mental and psychological problems are responsible for between one quarter and one-third of the disability benefit recipiency levels’ and for much of the increase in these levels (OECD 2003:10); almost one in three current and new Australian recipients in 1999 were classified with ‘mental illness’ (according to ‘stock’ and ‘inflow’ figures; OECD 2003:86); and
- age profiles revealed a tendency for benefits to be concentrated among people over age 50, and for vocational rehabilitation and training, and supported employment programs, to be directed more towards younger age groups.

The policy conclusions suggested an approach to reshape disability policy based on ‘a framework of mutual obligations’ (OECD 2003:155).

In Australia in recent years, the Commonwealth Department of Family and Community Services has been engaged in a range of reforms designed to encourage and support people with disabilities to find and retain employment. Case-based funding for

## **Box 8.3: Recent progress in implementing the Disability Discrimination Act**

### ***Disability Standards for Accessible Public Transport***

*The Disability Standards for Accessible Public Transport were approved by both Houses of Parliament and commenced on 23 October 2002. The standards establish minimum accessibility requirements to be met by providers and operators of public transport conveyances, infrastructure and premises. The standards take into account the range of disabilities covered by the DDA and apply to the full range of public transport conveyances, premises and infrastructure, with some limited exceptions. There is a compliance timetable that allows for incremental compliance with the relevant requirements over 30 years, with milestones at the fifth, tenth, fifteenth, twentieth and thirtieth years.*

*The Disability Discrimination Act 1992 (DDA) was amended to allow the Human Rights and Equal Opportunity Commission to grant exemptions to disability standards in relation to public transport in appropriate circumstances. These amendments to the DDA commenced on 19 August 2002.*

### ***Disability Standard for Access to Premises***

*The Building Access Policy Committee is currently developing a draft standard, to be included in the Building Code of Australia. The Australian Building Codes Board, which is a member of the committee, released a Directions Report in December 2001, seeking feedback on proposals. Public information sessions were conducted in all capital cities in February and March 2002. Further public comment will be sought on the draft standard once it is released.*

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

*Draft standards were released for consultation in 2000. The Department of Education Science and Training has since been working with stakeholders to finalise the draft standards and a Regulation Impact Statement for further consideration by the Ministerial Council on Education, Employment, Training and Youth Affairs.*

*Source: Information provided by Civil Justice Division, Attorney-General's Department, 2003.*

disability employment assistance is being introduced and evaluated, so as to fund agencies in relation to the support needs of people with disabilities seeking or being supported in work (FaCS 2002a). Measures to assist business services to achieve quality assurance certification, and remain viable while supporting people with 'low productive capacity', were announced in the 2003 Commonwealth budget (FaCS 2003a). The certification procedure requires all disability-funded agencies to achieve independent certification against the 12 national Disability Service Standards by the end of 2004 (FaCS 2002e). (See Section 8.4 for data on income support, and use of specialist and generic employment services.)

## National developments in disability support services

The second Commonwealth/State Disability Agreement (CSDA) was in place from 1997–98, and was due to expire in June 2002. The term was extended to allow for ongoing negotiations over a new Agreement. The extended negotiations over the new Commonwealth State/Territory Disability Agreement (CSTDA) focused, in their later stages, on funding issues, in the context of an awareness of unmet need for disability support services and the need for indexation in the light of population growth and service cost increases (see Section 8.5; AIHW 2002b; SPRC 2002). The new Agreement was signed in 2003 and will terminate on 30 June 2007.

The preamble of the new CSTDA was developed jointly by National Disability Administrators and the National Disability Advisory Council, with input from state-based disability advisory bodies. It describes a shared vision based in a rights framework, with governments agreeing to ‘work cooperatively to build inclusive communities where people with a disability, their families and carers are valued and are equal participants in all aspects of life’, and recognising that ‘people with a disability have rights equal with other members of the Australian community, and should be enabled to exercise these rights’ (CSTDA 2003). It acknowledges the principles and objectives of the *Commonwealth Disability Services Act 1986*, the *Disability Discrimination Act*, and complementary state and territory legislation (for an historical overview, see AIHW 1993:266–79).

Five key policy priorities were agreed, to:

- strengthen access to generic services by people with disabilities;
- strengthen across government linkages;<sup>2</sup>
- strengthen individuals, families and carers;
- improve accountability, performance reporting and quality; and
- improve long-term strategies to respond to, and manage demand for, specialist disability services.

A new feature of the agreement is the performance reporting framework which, according to principles set out in the schedules to the agreement, will ‘provide the basis for a publicly available report to demonstrate achievements in the delivery of specialist disability services and national progress in implementing agreed national policy priorities’ (CSTDA 2003). The framework will rely chiefly on data from the new CSTDA National Minimum Data Set, developed by the National Disability Administrators in partnership with the AIHW (Box 8.4).

Current features of government policies in disability support services are consistent with those outlined in the last biennial report—deinstitutionalisation, the search for flexible community-based services, breaking down service ‘stovepipes’, clearer

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2 Bilateral agreement between the Commonwealth and each of the states and territories is being negotiated and will aim to improve the interface between employment services and community access services.



### **Box 8.4: Redevelopment of the CSTDA NMDS**

*Since 1994, the CSDA Minimum Data Set (MDS) 'snapshot' collections have provided information about services delivered under the CSDA and the people receiving those services.*

*In 1999, in recognition of the changing information needs in the disability services field, the National Disability Administrators and the AIHW began a process to review and redevelop the CSDA MDS and related data collections. The redevelopment was undertaken over 2 years and the collection was fully implemented nationally in October 2002. In anticipation of the signing of the CSTDA, the redeveloped collection is now referred to as the Commonwealth State/Territory Disability Agreement National Minimum Data Set (CSTDA NMDS).*

*The process of redevelopment focused strongly on asking policy makers and other stakeholders about their main information needs. As well as government departments responsible for CSTDA-funded services, CSTDA service providers, consumers, non-government organisations, carers, peak organisations and others interested in the disability services field were given the opportunity to comment on, participate in and test the redeveloped collection (see AIHW 2003b for further information on the redevelopment).*

*The most significant change in the redeveloped collection is that, for most service types, service providers are required to provide information about all service users (referred to as 'consumers' in the snapshot collections). A small number of new data items have been introduced, including items on primary carers, in recognition of the mutual support among people with disabilities, carers and formal services, and the fact that the importance of ageing carers in particular is now recognised in program goal statements.*

contractual funding arrangements, and a concern with population ageing and growth in demand (AIHW 2001a:271-3). Portability, both within states and across state boundaries, is also recognised as an important goal. Ongoing efforts towards regionalisation or localisation of services, and associated community consultation mechanisms, are occurring in a number of Australian jurisdictions, for instance Queensland, Northern Territory and New South Wales, as well as in Victoria and Western Australia which have had longer standing regional structures and processes.

## **Advocacy and advice**

Disability policy in Australia is strongly influenced by organisations representing people with disabilities and non-government organisations providing services in the sector.

The National Disability Advisory Council, appointed by the Commonwealth Minister for Family and Community Services, provides 'consumer focused advice on matters referred by the Minister', encourages consultation between the Commonwealth Government and consumers, carers and disability service providers, and may also seek references from the Minister on matters it considers need investigation (FaCS 2003a). The topics of the council's working groups indicate the scope of its interests: the CSTDA; employment; deinstitutionalisation, community housing and accommodation;

welfare reform and income support; health care; the ageing/disability interface; education and training; rights and access. This national body has state counterparts with which it consults on national issues.

Jointly chaired by the National Disability Advisory Council chair and a commissioner of the Aboriginal and Torres Strait Islander Commission, an interim National Indigenous Disability Network has been formed and has begun meeting.

An Australian Federation of Disability Organisations is in the process of being formed. In January 2001, new funding arrangements for disability peak organisations funded through FaCS were announced, and eight of these organisations were given the task of developing the new Federation (NEDA 2003).

ACROD describes itself as the national industry association for disability services. Its national office takes a particular interest in national policies affecting people with disabilities, including the negotiation of the CSTDA, the issue of unmet need for disability support services, and Commonwealth policies on income support and employment services for people with disabilities (ACROD 2003). Its state and territory offices focus on their own jurisdiction's issues and responsibilities. ACROD has, in the last year, launched a new magazine, *disparity*, containing a wide range of articles about aspects of disability philosophy and policy.

## Insurance—who pays for disability?

Insurance has been in the public policy spotlight in recent years, with financial difficulties being experienced by public liability and medical indemnity insurers. Most recently, an inquiry has been announced into national workers compensation and occupational health and safety (OHS) frameworks, reflecting the need for a consistent national approach to scope, definitions and benefits structures, and concern that 'the coverage of employees under workers' compensation and OHS programmes appears to have declined due to changes in the composition of the workforce and working arrangements' (Productivity Commission 2003b:2).

Much of the publicity surrounding the discussions of insurance has focused on the financial difficulties of insurers, of professionals such as doctors, of employers and of community organisations facing rising costs that threaten areas of their activity. A third (229) of respondents to an Australian Council of Social Science survey of community service organisations reported difficulty in obtaining insurance cover in the 2001–02 financial year. Of these, 162 (71%) said the difficulty was due to the increased cost of cover and 90 (29%) said they had been refused cover (ACOSS 2003:22).

However, these personal injury compensation and insurance schemes exist to compensate and support the victims of accidental and, in some cases, catastrophic injury. The varying scope and benefits of the different insurance schemes, and the gaps left between them, have caused discussion to be reopened about basic questions concerning community responsibility for sharing the costs of disability (e.g. Blair 2003). The plethora of systems across Australia results in wide variations in support available for people with similar needs, depending on how their disability arose.

## Medical indemnity and national data

A Medical Indemnity Forum was held in April 2002 to discuss the problems of rising medical indemnity costs and the financial viability of medical indemnity insurers. A number of initiatives arose out of the forum.

In general, the largest single component of very large damages awards in medical indemnity claims is for future care costs. Ministers agreed that urgent work was needed to develop proposals for providing more efficient access to compensation. A group was established, under the auspices of the Australian Health Ministers' Advisory Council (AHMAC), to undertake a 'long term care project', with the aim of developing a workable model to provide an equitable and effective way of managing the long-term care needs and costs for people catastrophically injured in adverse medical events.

Health ministers also decided that a 'national database for medical negligence claims' should be established, to assist in determining future medical indemnity strategies. The absence of a national database to date has made it difficult to analyse trends in the number, nature and cost of medical indemnity claims. A working group was convened under the auspices of AHMAC, and the AIHW was subsequently commissioned to work with the group to further develop proposals for a national medical indemnity collection for the public sector. The data collection commenced on 1 January 2003.

## Conceptual and data development

The AIHW has continued its disability data development work program, advised by its broadly based advisory group, the Advisory Committee on Australian and International Disability Data. The aim of this work program is to provide data infrastructure, including disability definitions and concepts, to enable relevant and consistent disability data to be collected in Australian population and service collections, both specialist and generic. Two main achievements since the last biennial report are the completion of the Australian ICF User Guide and the inclusion of related data elements in the National Community Services Data Dictionary (AIHW 2003d, 2003e).

The User Guide is designed to promote the use of the ICF in Australia, by:

- providing information about the ICF to assist Australian understanding of its contents and usefulness;
- informing the user about current and emerging applications in Australia;
- providing advice about 'getting started' and using or applying the ICF; and
- promoting a consistent and constructive approach to using the ICF, particularly in those areas left to the user's discretion.

This work, in coming years, will focus on encouraging the use of the ICF and disability data definitions in the National Community Services Data Dictionary in a wider range of data collections, including those relating to the aged and community care, health services, housing and homelessness, and longitudinal data sets. In this context, a recent review of aged care dependency measures illustrated the value of the ICF as a 'Rosetta Stone' or common framework to help relate and evaluate similar measures within a common framework (T.B. Ustun pers. comm.; AIHW: Van Doeland & Benham 2003).

ICF concepts have been included in the CSTDA NMDS (see Box 8.4). The question on support needs incorporates both the ICF and national population survey concepts, to ensure that NMDS data can be related to national population data and also to some international data collections.

The Australian Bureau of Statistics is pilot testing a possible disability question for the 2006 population census. The advantages of successfully developing a useful question would be significant—in particular, being able to provide better information on disability among relatively small population groups, especially Indigenous Australians, and in small geographical areas for planning purposes. Approaches successfully used in other countries, for instance in the Canadian 2001 census, offer encouragement that a path forward can be found.

There are promising new initiatives to improve information on major disabilities. Notable among these is the proposed new National Cerebral Palsy Register, being developed with the aim of compiling data nationally on the ‘widely different origins and clinical manifestations ... best studied in subgroups’, with the research thus able to benefit from the compilation of a nationally consistent data set (Watson 2002).

## 8.3 Prevalence of disability and need for assistance

This section presents an overview of disability prevalence and need for assistance in the Australian population. Trends and recent changes in population patterns of disability prevalence are then analysed.

### Overview

Estimates of the prevalence of disability, and of various disability types and severities, are based on the ABS 1998 Survey of Disability, Ageing and Carers (ABS 1999).<sup>3</sup> The survey’s current terminology is set out in Box 3.5. Its concepts correspond reasonably well with the ICF (see Section 8.1) and in future years its terminology will align more closely; at present, the main variation is that ‘activity limitations’ in the ICF translate to ‘activity restrictions’ in the ABS survey.

In 1998, 3,610,300 people reported one or more of 17 impairments, limitations or restrictions which had lasted, or were likely to last, for at least 6 months and which restricted everyday activities<sup>4</sup> (AIHW 2001a:Tables 7.1, A7.1). Of these, 2,385,100 were aged under 65 (14.6% of the population of that age), and of them 2,048,700 people (12.5%) had at least one specific activity restriction.<sup>5</sup> Among these people, 655,000

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3 The 1998 survey provides the most recent available data. A new survey in the series is being conducted in 2003, and results are to be available in 2004.

4 The ABS 1998 disability survey equates this to ‘disability’ (ABS 1999).

5 The ABS 1998 survey collected information about ‘specific activity restrictions’, of which there are five categories: restrictions in the three ‘core’ activities of daily living (self-care, mobility and communication), and restrictions in schooling and employment.

(4.0%) of the population aged under 65, had a severe or profound core activity restriction, which means that they sometimes or always needed personal assistance or supervision with one or more of the core activities—self-care, mobility and communication. In the text of this chapter, ‘a severe or profound core activity restriction’ is generally abbreviated to ‘a severe or profound restriction’.

Of all people aged under 65, with a severe or profound restriction living in households, an estimated 264,300 (41.6%) needed assistance with more than one core activity, including 56,000 (8.8%) who needed help with all three (AIHW 2001a:Table 7.2).

### **Box 8.5: Disability groups**

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

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

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

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

Source: AIHW 2003e.

## Main disability groups

In Australia, disability groups, such as 'intellectual disability' and 'physical disability', provide a broad categorisation of disabilities based not only on underlying health conditions and impairments, but also on activity limitations and participation restrictions. These groupings are generally recognised in the disability field and in legislative and administrative contexts in Australia (AIHW 2003e). Descriptions of the groups to be discussed in this section are provided in Box 8.5.

### Box 8.6: Four sets of prevalence estimates of disability groups

*The four approaches used to obtain the estimates in Table 8.1 provide a spectrum of estimates that may suit different purposes. For instance, the first two types may be useful for epidemiological studies and studies on morbidity and disability. The other can be used as broad summary measures in planning generic services or disability-specific support services for people with a disability.*

*All the estimates start with the base 'disability' population defined by the ABS 1998 Survey of Disability, Ageing and Carers. The four types of estimates differ in terms of their use of the survey information about impairment, main disabling condition, all disabling conditions, activity limitations and participation restriction, as well as need for assistance with core activities.*

*Estimates based on reported **main disabling condition** relate to conditions that were identified by the survey respondents as causing the most problems, compared with any other disabling conditions they may also have had. Using this method, the estimates of different disability groups are exhaustive and mutually exclusive. The numbers in each group total the number of people with a disability defined by the 1998 survey.*

*The remaining three sets of estimates are based on **all disabling conditions** and are in diminishing size, corresponding to an increasingly restrictive definition of the group, according to severity, need for assistance or activity limitation.*

*People may experience more than one type of impairment or disabling condition. The prevalence of a particular disability group will be underestimated if only main disabling conditions are considered. The estimates based on all disabling conditions are the most inclusive of the four types of estimation. These estimates include all reported disabling conditions, whether or not these were main disabling conditions. The disability experience of people with multiple disabling conditions may be classified into more than one disability group.*

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

*The approach using data on **all disabling conditions plus a severe or profound restriction** is similar to the previous approach except that a more exclusive 'filter' is used to select only people who reported a severe or profound restriction.*

The AIHW has previously published a series of reports reviewing the existing definitions, data sources and estimates of prevalence relating to three disability groups—intellectual, physical, and acquired brain injury—and provided estimates of the size and profile of these groups based chiefly on the 1993 ABS Survey of Disability, Ageing and Carers (AIHW: Fortune & Wen 1999, Wen & Fortune 1999, Wen 1997). These estimates have now been updated using the 1998 survey data (Table 8.1; see also AIHW 2003f). The ICF and ICD-10 frameworks were used as the main guides for classification of disability groups and disabling conditions.

Prevalence estimates vary with the scope and level of disabilities under consideration. Four sets of estimates are accordingly provided, to support different applications and also to illustrate the variation arising from the different bases of estimation (Box 8.6, Table 8.1).

**Table 8.1: Estimates of main disability groups in Australia, 1998**

| Estimates based on:   | Aged under 65  |                      | Aged 65+       |                      | All ages       |                       |
|---|----------------|----------------------|----------------|----------------------|----------------|-----------------------|
|   | Number ('000)  | % of people aged <65 | Number ('000)  | % of people aged 65+ | Number ('000)  | % of total population |
| <b>All disabling conditions</b>   |                |                      |                |                      |                |                       |
| Intellectual  | 376.9          | 2.3                  | 126.1          | 5.6                  | 503.0          | 2.7                   |
| Psychiatric   | 504.1          | 3.1                  | 264.8          | 11.7                 | 768.9          | 4.1                   |
| Sensory/speech  | 685.7          | 4.2                  | 718.9          | 31.7                 | 1,404.6        | 7.5                   |
| Acquired brain injury   | 159.0          | 1.0                  | 52.0           | 2.3                  | 211.1          | 1.1                   |
| Physical/diverse  | 1,903.9        | 11.6                 | 1,124.6        | 49.6                 | 3,028.5        | 16.2                  |
| <i>All disabling conditions and activity limitations and participation restrictions</i> |                |                      |                |                      |                |                       |
| Intellectual  | 370.4          | 2.3                  | 126.1          | 5.6                  | 496.5          | 2.7                   |
| Psychiatric   | 493.5          | 3.0                  | 263.6          | 11.6                 | 757.1          | 4.1                   |
| Sensory/speech  | 597.9          | 3.6                  | 689.0          | 30.4                 | 1,286.9        | 6.9                   |
| Acquired brain injury   | 150.8          | 0.9                  | 50.8           | 2.2                  | 201.6          | 1.1                   |
| Physical/diverse  | 1,771.2        | 10.8                 | 1,082.2        | 47.7                 | 2,853.4        | 15.3                  |
| <i>All disabling conditions and severe or profound restrictions</i>                     |                |                      |                |                      |                |                       |
| Intellectual  | 184.8          | 1.1                  | 117.1          | 5.2                  | 301.9          | 1.6                   |
| Psychiatric   | 209.9          | 1.3                  | 188.4          | 8.3                  | 398.3          | 2.1                   |
| Sensory/speech  | 218.7          | 1.3                  | 305.5          | 13.5                 | 524.2          | 2.8                   |
| Acquired brain injury   | 75.2           | 0.5                  | 38.2           | 1.7                  | 113.3          | 0.6                   |
| Physical/diverse  | 517.2          | 3.2                  | 458.3          | 20.2                 | 975.4          | 5.2                   |
| <b>Main disabling condition</b>   |                |                      |                |                      |                |                       |
| Intellectual  | 209.0          | 1.3                  | *3.7           | 0.2                  | 212.7          | 1.1                   |
| Psychiatric   | 197.2          | 1.2                  | 87.3           | 3.8                  | 284.5          | 1.5                   |
| Sensory/speech  | 235.8          | 1.4                  | 193.8          | 8.5                  | 429.6          | 2.3                   |
| Acquired brain injury   | 35.7           | 0.2                  | *3.5           | 0.2                  | 39.2           | 0.2                   |
| Physical/diverse  | 1,709.7        | 10.4                 | 934.4          | 41.2                 | 2,644.1        | 14.2                  |
| <b>Total with a disability</b>  | <b>2,387.4</b> | <b>14.5</b>          | <b>1,222.7</b> | <b>53.9</b>          | <b>3,610.1</b> | <b>19.3</b>           |

*Notes*

1. Estimates marked with \* have an associated relative standard error (RSE) of between 25% and 50% and should be interpreted accordingly.
2. Estimates in this table may differ from those in Table A7.4 of the 2001 edition of this report. The previous estimates used ABS definitions that could be compared with earlier editions of this report that used the ABS 1998 and 1993 disability survey data. The ABS definitions have changed since the 1993 survey. The estimates based on all disabling conditions use not only information from responses to the survey screening questions but also the reported disabling conditions coded using the ICD-10 code.

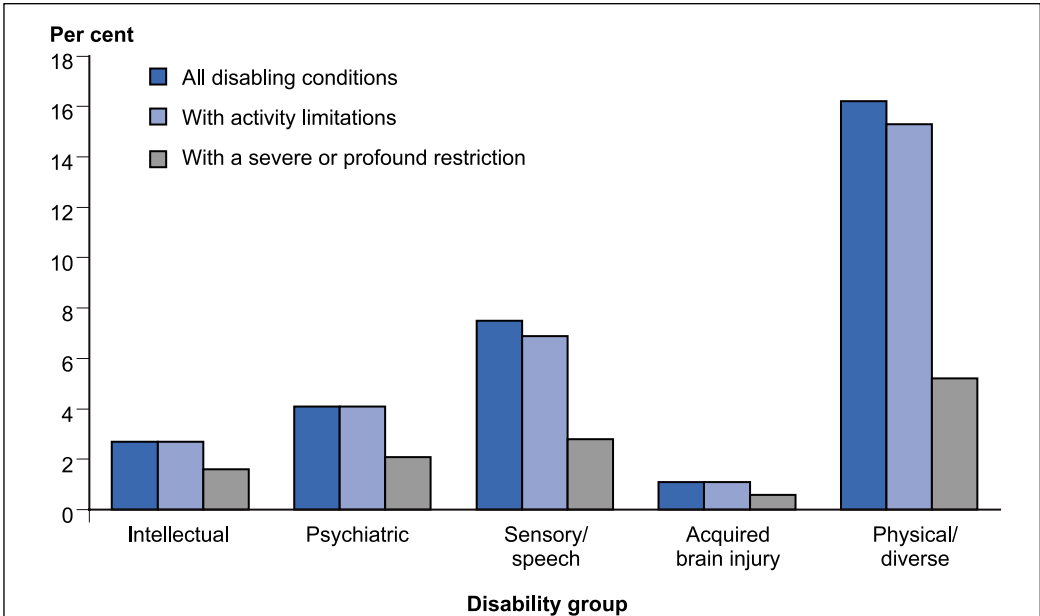
Source: AIHW analysis of ABS 1998 Survey of Disability, Ageing and Carers confidentialised unit record file.

Physical/diverse disabilities were the most prevalent, whichever of the four estimates is considered. Based on consideration of all reported conditions, an estimated 3,028,500 (16.2%) Australians of all ages reported one or more physical/diverse disabilities. Of these, 2,853,400 (15.3% of the total population) also reported one or more activity limitations or participation restrictions and, using the most narrow scope, 975,400 (5.2%) had a severe or profound restriction.

One or more intellectual disabilities were reported by an estimated 503,000 people in 1998, or 2.7% of Australians of all ages, based on consideration of all reported conditions. Of these, 496,500 people (2.7% of the total population) also reported one or more activity limitations or participation restrictions. A more restricted approach includes only people with a severe or profound restriction. In 1998, among Australians with one or more intellectual disabling conditions, 301,900 (1.6% of the total population) had a severe or profound restriction.

Similarly, concentrating on the 'all disabling conditions' estimates, with increasingly narrow focus (Table 8.1, Figure 8.2):

- psychiatric disability was reported for 768,900 people (4.1%), of whom 757,100 (4.1%) had activity limitations or participation restrictions, and 398,300 (2.1%) had a severe or profound restriction;
- sensory/speech disability was reported by 1,404,600 people (7.5%), of whom 1,286,900 (6.9%) had activity limitations or participation restrictions, and 524,200 (2.8%) had a severe or profound restriction



Source: Table 8.1.

**Figure 8.2: Estimates of main disability groups based on all reported disabling conditions, 1998**



- acquired brain injury was reported by 211,100 (1.1%), of whom 201,600 (1.1%) had activity limitations or participation restrictions, and 113,300 (0.6%) had a severe or profound restriction associated with acquired brain injury.

## Trends in population patterns of disability prevalence

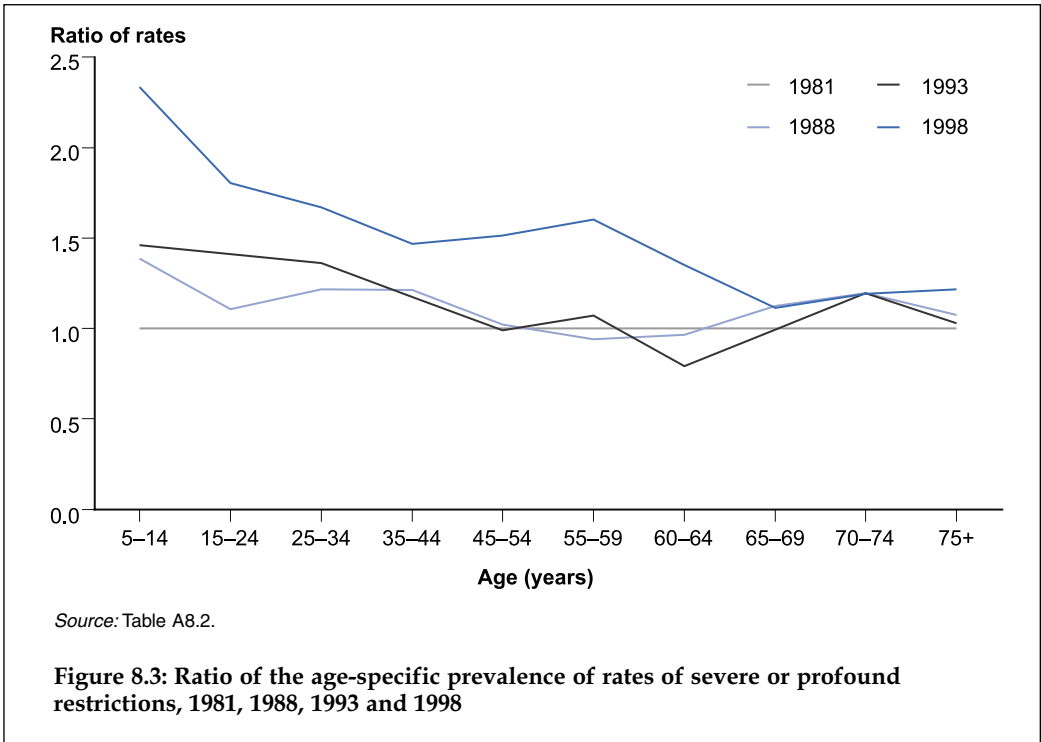
Trends in disability prevalence are of great policy interest in Australia, and it is only by careful consideration of different patterns of change in subgroups of the population, and changes to population survey methods, that these trends can be more completely understood. This section first discusses changes in overall disability prevalence in recent decades – with the main focus on people with severe or profound restrictions – and then describes trends in three broad age groups (under 15 years, 15–64 years and 65+). Each of these age groups has distinct patterns of prevalence and features of policy relevance: the older ages in the 15–64 age group are currently subject to growth largely because of the post-war ‘baby boom’; the 65+ age group is itself ageing for various reasons including enhanced life expectancy; and the youngest age group, also subject to influences from the health system, is the group that informs policy makers of likely longer term needs for services.

Demographic change is affecting reporting disability prevalence, in particular the rapid ageing of the working-age population and the ageing of the older population. Comparative analyses of disability prevalence during 1981–98 suggest that such population ageing has had a strong impact on the prevalence of severe or profound restrictions, particularly in the decade to 1998 (AIHW 2000a).

The age-standardised rates of severe or profound restriction were relatively stable during the 1980s and early 1990s, remaining at around 4% of the Australian population. However, between 1993 and 1998, the rate increased from 4.3% to 5.5% (see Table A8.1). This marked increase was largely the result of changes in survey methods which, in 1998, brought more people with a disability into the scope of the survey (AIHW 2001a:267–9; ABS: Davis et al. 2001).

In order to understand the differences in trends among various age groups, the age-specific prevalence rates of severe or profound restrictions for each of the four ABS disability surveys (1981, 1988, 1993 and 1998) have been compared. The comparison is based on the ratios of the age-specific prevalence rates of severe or profound restrictions for 1988, 1993 and 1998 to those for 1981. Ratio values of 1.0 indicate no change between the rates of the 1981 survey and the rates of the three subsequent surveys; those over 1.0 indicate an increase in rates and those under 1.0 a decrease. These comparisons indicate that the rates for 1998 were higher in most age groups than those for the previous surveys (Figure 8.3). The increases were particularly marked among children aged 5–14 and the working-age population, particularly the older working-age population).

Some light can be shed on changes in reported disability prevalence by looking at the associated changes in reported prevalence and patterns of long-term health conditions. The overall prevalence of most disabling conditions increased over the period 1981–98



(AIHW 2003f:Table 8.3). There were noticeable increases in reported rates of diseases of the ear, respiratory diseases and musculoskeletal conditions, and marked increases in intellectual and psychiatric conditions over the period 1993–98.

### Changes in disability prevalence among children aged under 15 years

There has been a substantial increase in the rates of severe or profound restriction among children, in particular boys. Between 1993 and 1998, the rates for males aged 5–14 increased from 2.7% to 4.9%, more than twice the average increase for males aged 15–64 (Table A8.1).

A number of factors may have contributed to this trend. The high rates for children of school age may partly reflect the impact of the educational system on the identification of disability. ‘Intellectual/learning’ disabling conditions may have a particular impact on school performance. Between 1993 and 1998, the main area of increase in the prevalence of disabling conditions among children of school age was ‘intellectual conditions’ (AIHW 2003f:Table 8.4).

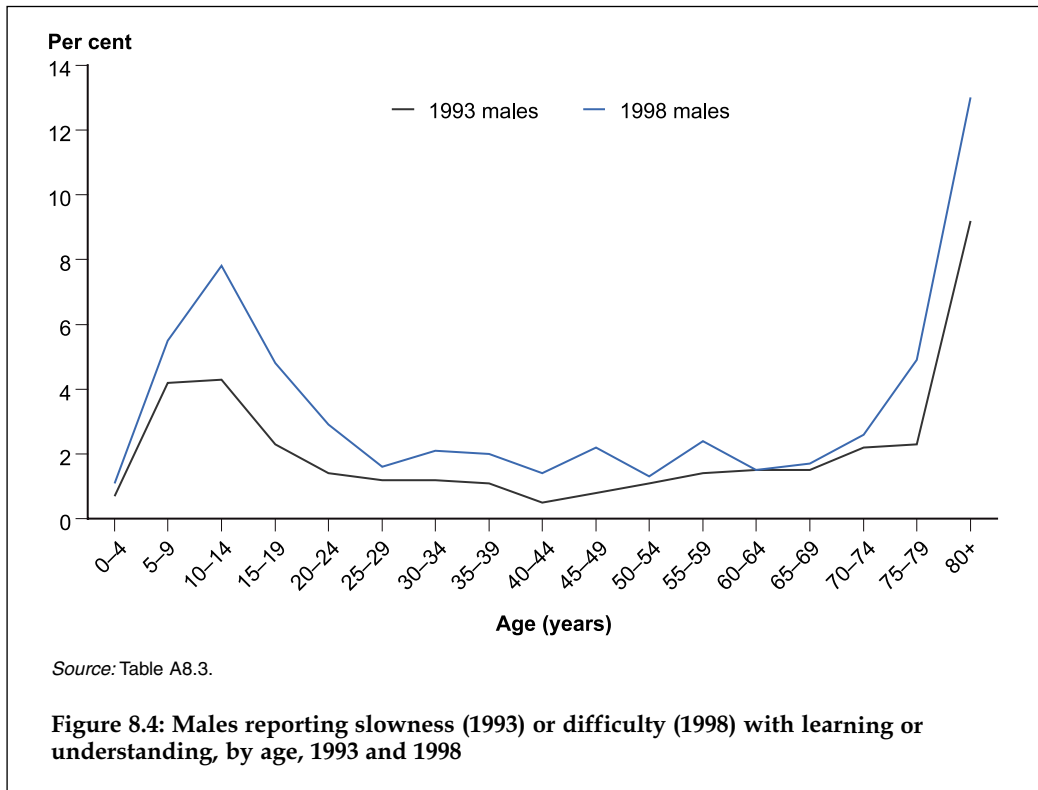
In 1998, about 42,700 children aged 0–14 with a disability reported an Attention Deficit Hyperactivity Disorder (ADHD), either as a main disabling condition or an associated disabling condition. Of these, 38,700 considered ADHD as their main disabling condition, which was about 70% of the total number of intellectual/learning main disabling conditions reported in 1993 by children of that age with a disability. While ADHD was not separately classified in the 1993 survey, it is likely that these figures are

contributing to an increase in reported intellectual disability in these age groups. An increase in prescriptions for the most commonly prescribed drugs to treat ADHD may indicate an increase in the diagnosis of the disorder (ABS: Davis et al. 2001; AIHW 2001a). Both higher levels of diagnosis and heightened awareness among parents, educators and health professionals may have contributed to the increase in reported ADHD.

The change of wording in the screening question, from 'slow at learning or understanding' (1993 survey) to 'difficulty learning or understanding' (1998 survey), may have encouraged reporting of intellectual disability, in particular among males (Figure 8.4). The sharp increase in positive response rates to this screening question was notable in the 5–14 age group, and also among males aged 75 or older (which could be associated with dementia-related conditions).

### Changes in disability prevalence among population of working age (15–64)

Among the working-age population, the age-standardised rate of severe or profound restrictions increased from 2.4% in 1993 to 3.3% in 1998, while the rate had been relatively stable between 1981 and 1993. The increase in 1998 was very evident in the older working-age population, particularly the 55–59 age group (see Table A8.1, Figure 8.3).



Apart from changes in age-specific prevalence rates, population growth also impacts on disability prevalence through changes in population size and age structure. The 'bulge' of the baby-boom generation is currently affecting the age profile of the working-age population, as it moves progressively up the age pyramid. This demographic trend is expected to impact on future disability prevalence, especially in the 55–64 age group in the next 10 years (AIHW 2000a, 2003f).

There is some evidence of a decline in mortality and an increase in life expectancy among some people with an early onset disability (AIHW 2000a:40). These changes may be attributable to a number of factors, such as developments in medical technology, and improvements in health care and social services.

The increase in severe or profound restrictions during 1993–98 may also be influenced by changes in reported prevalence and patterns of long-term health conditions. The age-standardised rate of musculoskeletal conditions for people aged 15–64 with a disability increased from 5.5% in 1993 to 7.5% in 1998 (AIHW 2003f:Table 8.4). The additional screening question about chronic pain could have contributed substantially to the increase in the reporting of these conditions.

### **Changes in disability prevalence among population aged 65+**

The ageing of the aged population has had a strong impact on the prevalence of severe or profound restriction in this age group. Compared with the 1981 survey, the three later surveys reported substantially higher disability prevalence for the older population. The rate of severe or profound restrictions for people aged 65+ rose sharply between 1993 and 1998, from 17.1% to 19.6% (see Table A8.1). The estimated number of people aged 75 or over with such restrictions increased markedly (AIHW 2000a:Table 13.2).

It has been suggested that about half of the increase in the rate of severe or profound restrictions in this age group was due to changes in survey design and the other half to population ageing and probably an actual rise in prevalence among the oldest age groups of the population (ABS: Davis et al. 2001).

Changes in the 1998 survey screening question on learning and understanding things may have increased the number of people reporting conditions associated with dementia (see Figure 8.4). The separate identification of head injury, stroke and other brain damage may have led to greater reporting of these conditions, especially stroke among the older population. Comparative analyses indicated, for the older population, a large rise in the rate of psychiatric disabling conditions during 1993–98, and sharp increases in the rate of circulatory diseases in both the 1993 and 1998 surveys (AIHW 2003f:Table 8.3).

### **Trends in injury and perinatal conditions**

Trends in injury and perinatal conditions can influence disability prevalence. Injury is an important cause of mortality and morbidity in Australia. Over the past two decades, age-standardised rates of death due to injury declined significantly, but less than overall rates of death, due to all causes. During the middle and late 1990s, injury death rates remained static, while all-cause death rates continued to decline (AIHW 2002a).

The Australian Spinal Cord Injury Register data show that 261 new cases occurred during the financial year 1999–2000. About one-third of these were caused by motor vehicle accidents. The age-adjusted incidence rate of spinal cord injury was 1.40 per 100,000 population in that year, a small decrease from 1.45 in 1998–99 (AIHW NISU: O’Connor 2001).

Between 1990 and 1994, the reported overall incidence rate of major congenital malformations declined from 179.8 to 164.4 per 10,000 births. Between 1995 and 1997, the rate remained fairly constant at around 175 per 10,000 births (AIHW: Al-Yaman et al. 2002).

There is a correlation between low birthweight and disability (Bennett 1997). In 1999, there were 17,208 low-birthweight babies (<2,500 g), or 6.7% of all births. Of these, 3,782 were very low-birthweight babies (<1,500 g) and 2,150 were extremely low-birthweight babies (<1,000 g). There was an increase in the proportion of extremely low-birthweight babies between 1991 and 1999 (AIHW NPSU: Nassar & Sullivan 2001).

## 8.4 Services and assistance

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

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

### Income support

#### Commonwealth payments and allowances

The Commonwealth Government is the main source of income support for people with a disability and their carers (Box 8.7).

The Disability Support Pension was the most common payment in 2002 for people with a disability, with close to 659,000 recipients and accounting for over \$6.4 billion expenditure in 2001–02 (Table 8.2). This was followed by the Commonwealth Department of Veterans’ Affairs Disability Pension which was received by over 159,000 veterans at a cost of \$1.2 billion. Combined, the Carer Allowance (Child and Adult) payments accounted for \$645.7 million expenditure and were received by close to 300,000 recipients in June 2002 (115,404 Carer Allowance Child and 153,863 Carer Allowance Adult) (Tables 8.2, 8.3).

As experienced in many countries (see Section 8.2), there has been an upward trend in Disability Support Pension recipient numbers for the last decade (and previously) (Table 8.3). Recent Australian studies have begun to analyse this continuing trend.

## **Box 8.7: Commonwealth disability-related payments and allowances**

**Disability Support Pension (DSP)** is a means-tested income support payment for people aged at least 16 years but under Age Pension age (at date of claim lodgement), who have a physical, intellectual or psychiatric impairment and an overall impairment rating of at least 20 points on the impairment tables. As a result of the impairment, recipients must have an inability to work full-time at full award wages in open employment, and be unable to undertake educational or vocational training which would equip them for work, within the next 2 years of their life. People of the same age who are permanently blind are also eligible for the DSP.

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

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

**Carer Allowance (Child/Adult)** is an income supplement payment available to people caring for a child with a disability or severe medical condition or for an adult with a disability. The person being cared for must require a lot more daily care and attention than a person of the same age who does not have a disability. The Child Disability Assessment Tool and the Adult Disability Assessment Tool are used to assess eligibility for children and adults, respectively. An important eligibility requirement is that the care recipient and carer must live together in the same private residence. Carer Allowance is free of income and assets tests and may be paid on top of Carer Payment or other payments.

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

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

(continued)

## Box 8.7 (continued): Commonwealth disability-related payments and allowances

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

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

*Contenance Aids Assistance Scheme is a program offering assistance to people who have permanent and ongoing incontinence as a result of a neurological condition or severe impairment. The aim of the program is to help eligible clients to meet the costs of continence aids.*

**Table 8.2: Commonwealth disability-related payments and allowances, recipients and expenditure (all ages), 2001–02**

|  | Recipients as at<br>June 2002 | Administered expenses<br>2001–02 (\$m) |
|--|-------------------------------|--|
| Disability Support Pension                   | 658,915                       | 6,404.4                                |
| Mobility Allowance                           | 41,997                        | 67.9                                   |
| Sickness Allowance <sup>(a)</sup>            | 9,522                         | 93.7                                   |
| Carer Allowance (Child/Adult) <sup>(b)</sup> | 269,267                       | <sup>(c)</sup> 645.7                   |
| Carer Payment (DSP/AP/other)                 | 67,260                        | <sup>(d)</sup> 595.8                   |
| Wife Pension (DSP)                           | 44,238                        | 402.0                                  |
| Newstart Allowance (incap.)                  | 76,882                        | <sup>(e)</sup> n.a.                    |
| Youth Allowance (incap.)                     | 5,792                         | <sup>(e)</sup> n.a.                    |
| Contenance Aids Assistance Scheme            | 16,331                        | 9.1                                    |
| Disability Pension (DVA)                     | 159,425                       | 1,200.0                                |

- (a) From July 2002 FaCS introduced a revised method of counting Sickness Allowance, Newstart Allowance, Mature Age Allowance, Partner Allowance, Widow Allowance, Special Benefit, Youth Allowance and Austudy Payment clients, based on eligibility and entitlement.
- (b) Excluded from these counts: 2,216 received both Carer Allowance (Adult) and Carer Allowance (Child) and 11,708 received Carer Allowance (Child) Health Care Card only.
- (c) Administered expenses and recipients for Carer Allowance (Child) and Carer Allowance (Adult) are combined.
- (d) Administered expenses and recipients for Carer Payment (DSP), Carer Payment (AP) and Carer Payment (other) are combined.
- (e) Administrative expenses for Newstart Allowance (incapacitated) and Youth Allowance (incapacitated) are not available as they are included in the larger funding budget for these two programs.

Sources: DVA 2002; FaCS 2002b; FaCS unpublished data.

Cai (2002) found that, while both the increase in inflow rate and the decrease in outflow rate contributed to the growth in recipient numbers, it has been the increase in the inflow rate since the early 1990s which has been the more significant. Other factors, including labour market conditions, policy changes and benefits levels, are also explored in this detailed analysis. In another study, of flows into the Disability Support Pension, it was found that most entrants were aged 50 and over and were likely to enter from outside the income support system and to exit to the Age Pension (Chalmers & Siminski 2003).

**Table 8.3: Recipients of disability-related payments and allowances (all ages), June 1993–June 2002**

|  | 1993    | 1994    | 1995    | 1996    | 1997    | 1998    | 1999    | 2000    | 2001    | 2002    |
|--|---------|---------|---------|---------|---------|---------|---------|---------|---------|---------|
| Disability Support Pension             | 406,572 | 436,234 | 464,430 | 499,235 | 527,514 | 553,336 | 577,682 | 602,280 | 623,926 | 658,915 |
| Mobility Allowance                     | 16,160  | 20,795  | 22,851  | 54,985  | 26,595  | 28,975  | 31,001  | 35,154  | 37,574  | 41,997  |
| Sickness Allowance <sup>(a)</sup>      | 46,579  | 47,132  | 47,311  | 33,215  | 15,759  | 16,285  | 11,181  | 10,733  | 10,942  | 9,522   |
| Carer Allowance (Child) <sup>(b)</sup> | 61,174  | 69,693  | 78,898  | 90,644  | 95,520  | 90,830  | 100,452 | 116,955 | 111,691 | 115,404 |
| Carer Allowance (Adult) <sup>(b)</sup> | 35,025  | 37,169  | 38,408  | 42,047  | 44,103  | 45,675  | 51,857  | 84,104  | 123,350 | 153,863 |
| Carer Payment (DSP)                    | 8,056   | 9,450   | 10,633  | 13,483  | 15,735  | 18,556  | 21,392  | 24,500  | 28,171  | 34,963  |
| Carer Payment (AP)                     | 6,507   | 7,441   | 8,324   | 9,500   | 10,954  | 11,740  | 13,407  | 15,346  | 18,097  | 20,227  |
| Carer Payment (other)                  | 482     | 808     | 1,141   | 2,054   | 2,869   | 3,683   | 5,271   | 7,704   | 10,922  | 12,070  |
| Wife Pension (DSP)                     | 108,327 | 116,036 | 121,839 | 107,803 | 91,307  | 79,892  | 68,523  | 59,934  | 51,225  | 44,238  |
| Wife Pension (AP)                      | 33,520  | 36,539  | 39,611  | 41,125  | 36,577  | 36,233  | 32,196  | 31,362  | 26,476  | 23,730  |
| Newstart Allowance (incap.)            | n.a.    | n.a.    | n.a.    | n.a.    | n.a.    | 48,792  | 59,670  | 68,016  | 76,850  | 76,882  |
| Youth Allowance (incap.)               | n.a.    | n.a.    | n.a.    | n.a.    | n.a.    | n.a.    | 3,929   | 5,883   | 5,959   | 5,792   |
| Disability Pension (DVA)               | 156,923 | 156,286 | 157,298 | 159,079 | 160,145 | 161,829 | 162,810 | 162,730 | 162,505 | 159,425 |

(a) From July 2002 FaCS introduced a revised method of counting Sickness Allowance, Newstart Allowance, Mature Age Allowance, Partner Allowance, Widow Allowance, Special Benefit, Youth Allowance and Austudy Payment clients, based on eligibility and entitlement.

(b) Excluded from these counts in 2002: 2,216 received both Carer Allowance (Adult) and Carer Allowance (Child) and 11,708 received Carer Allowance (Child) Health Care Card only.

Sources: AIHW 2001a; DVA 2002; FaCS 2002b; FaCS unpublished data.

The study also highlighted the importance of initiatives to assist young people, particularly males, to make a successful transition from school to the labour market. High rates of disability among female sole-parent recipients were also found.

Several other payments and allowances experienced upward trends in recipient numbers between 1993 and 2002 (Table 8.3). The number of people receiving the Carer Allowance (Adult) almost doubled between 2000 and 2002 (from 84,104 to 153,863). Similarly, there was a noticeable increase in the number of people receiving the various Carer Payments, which rose overall by close to 20,000 recipients over the same period.

Several reasons have been suggested to explain the increase for these payment types, including: demographic changes (e.g. ageing population and an associated rise in the number of people with a disability); greater awareness of these payments; reduction in



access to other forms of income support (e.g., widow and wife pensions); and the increase in number of people with disabilities and medical conditions being cared for at home (FaCS 2002b). The Wife Pension (DSP/AP) has continued its downward trend in response to the payment being closed to new applicants since 1995.

## Concession cards

The Commonwealth Government provides a range of concession cards for eligible people with a disability and their carers (Box 8.8). These cards entitle the holder to various concessions on specific Commonwealth, state and territory, and local government services, as well as some private sector concessions. Eligibility for some concession cards is dependent upon receipt of a disability-related or income support payment or pension. The concession areas vary across the country, and concessions are granted at the states' and territories' discretion. Such coverage may include ambulance travel for isolated patients, glasses, dental care, taxi subsidies, and so on. The core areas agreed by state and territory governments are energy consumption, water and sewerage, municipal rates and transport (including public transport, motor vehicle registration and licence fees).

### Box 8.8: Commonwealth concession cards (all ages)

*A Pensioner Concession Card is automatically issued to people receiving a number of income support payments, including Disability Support Pension and Carer Payment recipients, as well as people aged over 60 years who have been continuously receiving one of the following payments for more than 9 months: Newstart Allowance, Sickness Allowance, Widow Allowance, Partner Allowance, Parenting Payment or Special Benefit. The card entitles the holder to Commonwealth health concessions, such as low-cost medicines under the Pharmaceutical Benefits Scheme, as well as additional health, household, educational and recreational concessions from state and local government authorities. In June 2002, close to 3.1 million people were covered by a Pensioner Concession Card.*

*A Health Care Card is automatically issued to people receiving most types of income support payments from Centrelink, including: Newstart Allowance, Sickness Allowance, Mobility Allowance (if not getting DSP) and Carer Allowance (Child) (for the direct use of the child only). The card entitles the holder to Commonwealth health concessions, such as low-cost medicines under the Pharmaceutical Benefits Scheme, as well as a more limited range (than the Pensioner Concession Card) of state and local government concessions. Holders of the Health Care Card receiving Sickness Allowance may also be entitled to free hearing services and redirection of their postal articles (for a maximum of 6 months) free of charge. In June 2002, over 1.7 million people were covered by the Health Care Card.*

*The Gold Repatriation Health Card entitles some veterans, including disabled veterans and their dependants, to free treatment for all health conditions. The White Repatriation Health Card provides access to health services for veterans with specified conditions/disabilities. As at June 2002, there were 281,448 Gold Card holders and 59,268 White Card holders.*

*Sources: DVA 2002; FaCS unpublished data.*

**Table 8.4: Worker's compensation claims with non-fatal outcomes resulting in work absences of 60 days or more, 1999-2000**

| Nature of injury or disease                           | Age group (years) |              |              |              |              |              | Total         |
|---|-------------------|--------------|--------------|--------------|--------------|--------------|---------------|
|   | <20               | 20-29        | 30-39        | 40-49        | 50-54        | 55+          |               |
| Injury/poisoning                                      |                   |              |              |              |              |              |               |
| Fractures   | 144               | 744          | 910          | 896          | 470          | 528          | 3,692         |
| Sprains/strains of joints and adjacent muscles        | 433               | 3,562        | 5,222        | 5,788        | 2,458        | 2,222        | 19,690        |
| Contusions with intact skin surface & crush injury    | 74                | 342          | 429          | 430          | 218          | 210          | 1,703         |
| Open wound  | 130               | 459          | 346          | 292          | 133          | 126          | 1,486         |
| Other injury poisoning                                | 109               | 461          | 521          | 455          | 198          | 193          | 1,933         |
| <i>Total injury/poisoning</i>                         | <i>890</i>        | <i>5,568</i> | <i>7,428</i> | <i>7,861</i> | <i>3,477</i> | <i>3,279</i> | <i>28,504</i> |
| Nervous system and sense organs                       | 4                 | 71           | 124          | 158          | 86           | 83           | 526           |
| Musculoskeletal system and connective tissue diseases | 27                | 263          | 512          | 561          | 250          | 208          | 1,821         |
| Mental disorders                                      | 26                | 261          | 478          | 737          | 351          | 184          | 2,037         |
| Other diseases/not stated/not available               | 22                | 136          | 207          | 227          | 122          | 168          | 888           |
| <b>Total</b>  | <b>969</b>        | <b>6,299</b> | <b>8,749</b> | <b>9,544</b> | <b>4,286</b> | <b>3,922</b> | <b>33,776</b> |

*Notes*

1. Some figures include minor random adjustments in order to account for small cell values, for confidentiality reasons.
2. Of the 33,776 claims, male claimants accounted for 22,182 claims.
3. Totals include not stated.

Source: National Workers Compensation Statistics database, viewed 23 April 2003, <[www.nohsc.gov.au/OHSInformation/NOSI/](http://www.nohsc.gov.au/OHSInformation/NOSI/)>.

## Personal injury compensation schemes

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

The National Workers Compensation Statistics database includes claims for workers compensation, made under the Commonwealth, state and territory legislation as a result of a fatality, or temporary or permanent disability requiring an absence from work of 1 week (5 working days) or more.

During 1999-2000, 33,776 claims were made for workers compensation involving events with non-fatal outcomes in the most serious category recorded, that is resulting in 60 days or more absence from work (Table 8.4). Of these, 84% involved injury or poisoning, followed by mental disorders (6%), then diseases of the musculoskeletal system and connective tissue. The most common claims recorded under the injury or poisoning category included 'sprains and strains of joints and adjacent muscles', accounting for 69% of all injuries and poisoning, followed by 'fractures' (13%) and 'contusions with intact skin surface and crush injury' (6%). Two-thirds (66%) of all claimants for these events were male.

## Disability support services

### CSDA-funded disability support services

Services provided under the Commonwealth/State Disability Agreement (CSDA) are designed for people who need ongoing support with everyday life activities. Under the second CSDA (1998), it was agreed that the Commonwealth has responsibility for the planning, policy setting and management of employment services, while the states and territories have responsibility for all other specialist services, including accommodation support, community support and respite.<sup>6</sup> Advocacy, print disability, alternative formats of communication, and information services are considered shared responsibilities under this agreement.

While, in practice, services are generally directed to people aged under 65 years, the CSDA places no age-based restrictions on access to them. The new CSTDA specifies that the disability should be manifest before the age of 65 years (for further details on the new agreement, see Section 8.2).

Information on disability support services provided or funded under the CSDA is collected in the framework of the CSDA Minimum Data Set (MDS), developed in 1993 and jointly maintained by the AIHW and the Commonwealth, states and territories, under the auspices of the National Disability Administrators (comprising the heads of government disability services throughout Australia).

Consumers and service providers supply data on a 'snapshot' day to funding departments in each jurisdiction, and the Institute collates these data nationally. Since 1999 a statistical linkage key has been collected; this enables the number of consumers to be estimated from data on services received without any consumers being personally identified (see AIHW 2003a for further information). The use of a snapshot day permits the number of consumers to be estimated at a point in time and can also be regarded as a sample of the people who use CSDA-funded services. The number of consumers in this snapshot sample, as a proportion of consumers over the year, will differ by service type. In particular, it will be greater for accommodation and most community access services, which in general are used on a more frequent basis than employment, community support and respite services. The collection has been redeveloped and, from 2002–03, will cover consumers for the full financial year (see Box 8.4).

### CSDA service types and funding

The total government expenditure on disability support services by Australian governments under the CSDA in 2001–02 was \$2.75 billion, an increase of 7.9% in real terms from the level in 2000–01. Accommodation support services accounted for over half of this expenditure (\$1,412 million) (Table 8.5). Around one-tenth of funding was spent on each of the following: community access services (\$304 million), community support services (\$299 million), and employment services (\$261 million). Total expenditure on respite services accounted for 6% of funds (\$156 million), and a further \$221 million was spent on administration.

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<sup>6</sup> See AIHW 2003a for a complete list of services and their definitions.

**Table 8.5: CSDA funding of services by Australian governments, by service group, 2001–02 (\$'000)**

| <b>Service group</b>                | <b>NSW</b>     | <b>Vic<sup>(a)</sup></b> | <b>Qld<sup>(b)</sup></b> | <b>WA<sup>(c)</sup></b> | <b>SA<sup>(d)</sup></b> | <b>Tas</b>    | <b>ACT<sup>(e)</sup></b> | <b>NT<sup>(f)</sup></b> | <b>C'wth<sup>(g)</sup></b> | <b>Australia</b> | <b>Per cent</b> |
|-------------------------------------|----------------|--------------------------|--------------------------|-------------------------|-------------------------|---------------|--------------------------|-------------------------|----------------------------|------------------|-----------------|
| Accommodation support               | 529,683        | 416,581                  | 160,580                  | 126,361                 | 108,534                 | 43,517        | 20,020                   | 6,756                   | —                          | 1,412,032        | 51.4            |
| Community support                   | 74,657         | 92,766                   | 34,114                   | 50,089                  | 26,614                  | 6,311         | 6,021                    | 8,517                   | —                          | 299,088          | 10.9            |
| Community access                    | 86,975         | 129,426                  | 40,563                   | 15,450                  | 12,302                  | 10,674        | 2,325                    | 1,354                   | 4,606                      | 303,675          | 11.1            |
| Respite                             | 57,798         | 36,633                   | 26,562                   | 13,689                  | 7,397                   | 6,190         | 2,490                    | 770                     | 4,525                      | 156,052          | 5.7             |
| Employment                          | —              | —                        | —                        | —                       | —                       | —             | —                        | —                       | 261,247                    | 261,247          | 9.5             |
| Other support                       | 7,321          | 30,275                   | 4,205                    | 8,802                   | 5,891                   | 1,284         | 200                      | 232                     | 6,006                      | 64,214           | 2.3             |
| Advocacy, info and print disability | 832            | 6,005                    | 3,653                    | 1,307                   | 1,870                   | 1,562         | 873                      | 66                      | 12,694                     | 28,862           | 1.1             |
| <i>Subtotal</i>                     | <i>757,267</i> | <i>711,685</i>           | <i>269,676</i>           | <i>215,698</i>          | <i>162,607</i>          | <i>69,538</i> | <i>31,928</i>            | <i>17,695</i>           | <i>289,077</i>             | <i>2,525,171</i> | <i>92.0</i>     |
| Administration                      | 77,364         | 62,746                   | 24,706                   | 9,981                   | 12,232                  | 3,580         | 4,142                    | 1,899                   | 24,066                     | 220,716          | 8.0             |
| <b>Total</b>                        | <b>834,631</b> | <b>774,431</b>           | <b>294,382</b>           | <b>225,679</b>          | <b>174,839</b>          | <b>73,118</b> | <b>36,069</b>            | <b>19,594</b>           | <b>313,143</b>             | <b>2,745,886</b> | <b>100.0</b>    |

(a) Service reclassifications were made in Vic in 2000, 2001 and 2002. See SCRCSSP 2003: Table 13A.21 for more information.

(b) Method of apportioning government administration expenditure in Qld changed in 1999–2000 and again in 2000–01 as a result of improved financial reporting systems and with the establishment of Disability Services Queensland.

(c) WA's 2000–01 expenditure for accommodation support, community support, community access and respite reflects increased state business plan funding, including Commonwealth unmet need funding. An improved cost allocation and payments database has been used for WA data in 2001–02.

(d) Expenditure for SA decreased from 2000–01 to 2001–02 because some funding was transferred out of disability services (from accommodation support) and reporting changed (in community support, advocacy, information and print disability and other support) to be consistent with the CSTDA Schedule A State Funding. Administration and total expenditure excludes some government agencies receiving funding from Department of Human Services.

(e) In the ACT, only services under the Disability Services funding program are counted. Excludes services funded through the HACC program.

(f) Expenditure variations in 2001–02 for the disability service types reflect changes in service provision under an individual funding model.

(g) Commonwealth administrative expenditure is an estimate only and is based on average staffing levels.

Source: SCRCSSP 2003: Table 13A.21.

The Commonwealth Government's direct funding (\$289 million) to disability support services under the CSDA was mostly for employment services. The Commonwealth also provided some of the funds expended by state and territory governments (\$501 million). Its overall contribution to total CSDA funding was 30% (SCRCSSP 2003).

The CSDA MDS collection reported on 8,142 service outlets in 2002 (AIHW 2003a). The majority of service outlets (74%) were provided by the non-government sector. Accommodation support services accounted for the largest proportion of service outlets (3,478 or 43%), followed by community access services (18%) and community support services (15%).

## Consumers of CSDA services

The number of consumers receiving CSDA-funded services on a snapshot day in 2002 was 65,809, in comparison with 62,752 in 1999 (Tables 8.6, 8.7). Similar to previous years, close to three-fifths of consumers (37,677) were male (AIHW 2003a). In 2002, accommodation support services were accessed by over 22,000 consumers, followed by community access (18,866) and employment services (18,242). Just over one-third of all consumers were in Victoria. New South Wales had the next highest proportion (26%), followed by Queensland (14%). Western Australia and South Australia each contributed around 10% of all consumers.

Recent years have seen a steady rise in the numbers of consumers accessing CSDA-funded services on the snapshot day. These increases are occurring within the context of population growth and ageing, and increased funding and service provision in recognition of the growth in demand from these demographic changes, and the existing unmet need for these services (see Section 8.5). Between 1999 and 2002, the proportion of consumers accessing accommodation support services remained constant, at around 34%, as with employment services (28%) and respite (5%) (Table 8.7). A shift can be seen in the number of consumers accessing community support and community access services between 2001 and 2002 (27% to 20% for community support, and 25% to 29% for community access). This change may be attributed to the reclassification of some service types as a result of the redevelopment of the CSDA MDS (AIHW 2003a).

**Table 8.6: Consumers of CSDA-funded services on a snapshot day, by service type and state and territory, 2002**

| Service group          | NSW           | Vic           | Qld          | WA           | SA           | Tas          | ACT        | NT         | Australia     | Per cent     |
|------------------------|---------------|---------------|--------------|--------------|--------------|--------------|------------|------------|---------------|--------------|
| Accommodation support  | 6,069         | 7,412         | 3,314        | 1,987        | 2,373        | 798          | 297        | 124        | 22,373        | 34.0         |
| Community support      | 3,105         | 4,724         | 1,409        | 2,344        | 1,189        | 149          | 213        | 80         | 13,211        | 20.1         |
| Community access       | 3,960         | 8,938         | 2,253        | 1,093        | 1,692        | 654          | 220        | 57         | 18,866        | 28.7         |
| Respite                | 612           | 1,151         | 515          | 459          | 339          | 46           | 56         | 36         | 3,214         | 4.9          |
| Employment             | 5,924         | 4,485         | 2,616        | 2,245        | 2,032        | 521          | 288        | 134        | 18,242        | 27.7         |
| <b>Total consumers</b> | <b>17,343</b> | <b>23,096</b> | <b>9,065</b> | <b>6,676</b> | <b>6,655</b> | <b>1,829</b> | <b>797</b> | <b>389</b> | <b>65,809</b> | <b>100.0</b> |

### Notes

1. Consumer data are estimates after use of a statistical linkage key to account for individuals who received more than one service on the snapshot day. Totals may not be the sum of the components since individuals may access more than one service type on the snapshot day. There were 41 consumers who accessed services in more than one state or territory, mainly in 'border' areas.
2. Data for consumers of the following CSDA-funded service types are not collected: advocacy, information/referral, combined information/advocacy, mutual support/self-help groups, print disability/alt. formats of communication, research & evaluation, training & development, peak bodies, and other support services.

Source: AIHW 2003a.

**Table 8.7: Consumers of CSDA-funded services on a snapshot day, by service group, 1999–2002**

| Service group         | 1999          |          | 2000          |          | 2001          |          | 2002 <sup>(a)</sup> |          |
|-----------------------|---------------|----------|---------------|----------|---------------|----------|---------------------|----------|
|                       | No.           | %        | No.           | %        | No.           | %        | No.                 | %        |
| Accommodation support | 20,916        | 33.3     | 21,335        | 34.2     | 21,775        | 34.1     | 22,373              | 34.0     |
| Community support     | 15,720        | 25.1     | 17,159        | 27.5     | 17,011        | 26.7     | 13,211              | 20.1     |
| Community access      | 14,901        | 23.7     | 14,895        | 23.9     | 15,703        | 24.6     | 18,866              | 28.7     |
| Respite               | 3,010         | 4.8      | 2,598         | 4.2      | 2,702         | 4.2      | 3,214               | 4.9      |
| Employment            | 17,734        | 28.3     | 17,373        | 27.9     | 17,730        | 27.8     | 18,242              | 27.7     |
| <b>Total</b>          | <b>62,752</b> | <b>—</b> | <b>62,341</b> | <b>—</b> | <b>63,830</b> | <b>—</b> | <b>65,809</b>       | <b>—</b> |

(a) Due to the re-categorisation of the service type 'recreation/holiday programs' in 2002, the service groups 'community support' and 'community access' should be considered together in 2002 when comparing with previous years data.

#### Notes

1. Consumer data are estimates after use of a statistical linkage key to account for individuals who received more than one service on the snapshot day.
2. Data for consumers of the following CSDA-funded service types were not collected: advocacy, information/referral, combined information/advocacy, mutual support/self-help groups, print disability/alt. formats of communication, research & evaluation, training & development, peak bodies, and other support services.
3. Data provided by the Commonwealth are preliminary and cover 99% of Commonwealth-funded services.

Sources: AIHW 2000c, 2001b, 2002c, 2003a, 2003c.

**Table 8.8: Consumers of CSDA-funded accommodation services on a snapshot day, 2002**

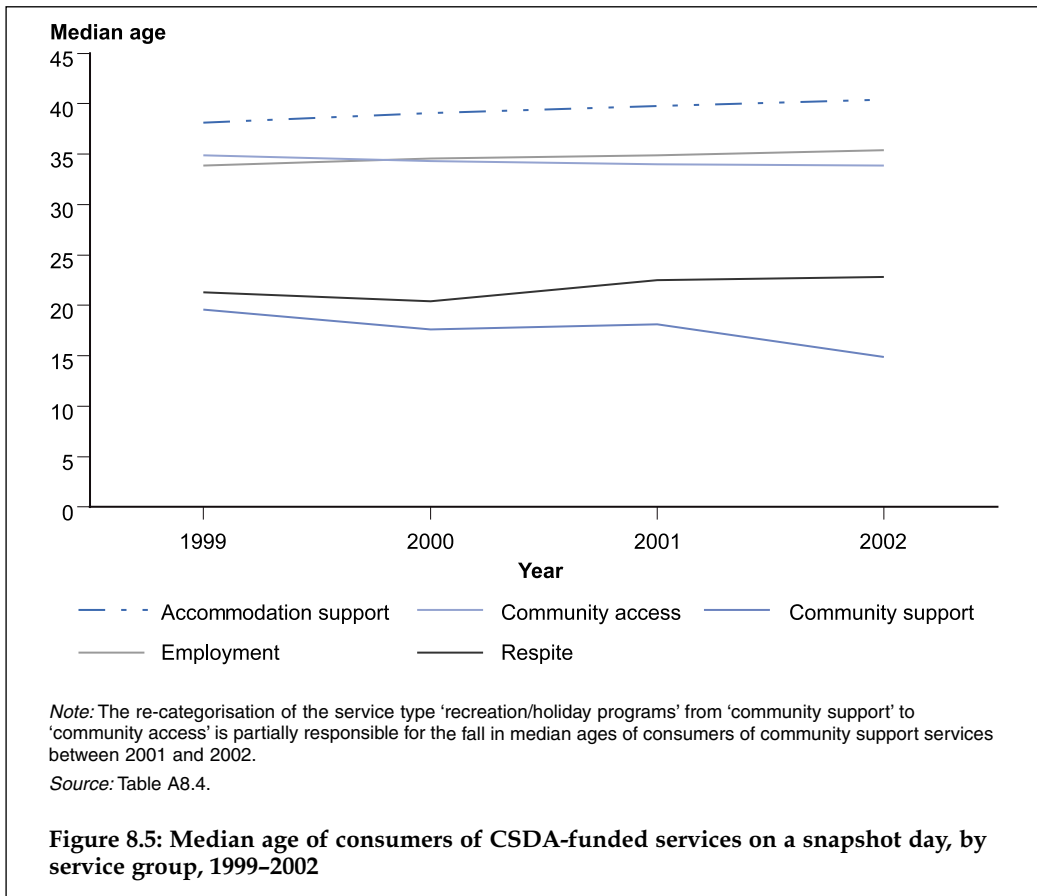
| Service type                  | Age group (years) |            |              |               |              |              | Not stated | Total         |
|-------------------------------|-------------------|------------|--------------|---------------|--------------|--------------|------------|---------------|
|                               | 0–4               | 5–14       | 15–24        | 25–44         | 45–64        | 65+          |            |               |
| Large residential/institution | 0                 | 20         | 176          | 2,069         | 1,727        | 377          | 11         | 4,380         |
| Small residential/institution | 0                 | 1          | 57           | 362           | 204          | 24           | 1          | 649           |
| Hostels                       | 0                 | 27         | 29           | 266           | 242          | 62           | 16         | 642           |
| Group homes                   | 2                 | 97         | 1,009        | 5,114         | 2,835        | 369          | 102        | 9,528         |
| Attendant care/personal care  | 0                 | 6          | 87           | 453           | 491          | 67           | 39         | 1,143         |
| In-home accommodation support | 7                 | 105        | 614          | 2,700         | 1,565        | 282          | 140        | 5,413         |
| Alternative family placement  | 3                 | 108        | 98           | 20            | 7            | 0            | 15         | 251           |
| Other accommodation support   | 1                 | 15         | 162          | 206           | 94           | 5            | 48         | 531           |
| <b>Total</b>                  | <b>13</b>         | <b>376</b> | <b>2,211</b> | <b>11,111</b> | <b>7,110</b> | <b>1,180</b> | <b>372</b> | <b>22,373</b> |

Note: Consumer data are estimates after use of a statistical linkage key to account for individuals who have received more than one service on the snapshot day.

Source: AIHW analysis of the 2002 CSDA MDS data.

Usage of specific accommodation support services on the 2002 snapshot day varied across age groups (Table 8.8). Group homes were the most utilised accommodation service type overall (used by 9,528 of 22,373 consumers, or 43%). However, for those aged 5–14 years, both alternative family placement and in-home accommodation support were the most common. For those aged 65 years or over, 377 of 1,180 people (32%) were living in large residentials/institutions, a much higher rate than for those in this accommodation type overall (4,380 of 22,373, or 20%).

The median age of consumers of CSDA-funded services gradually rose over the years 1999–2002: from 33.1 to 34.0 (see Table A8.4). Median ages for those using accommodation support, employment services and respite increased between 1999 and 2002, despite a small decline between 1999 and 2000 for respite services (Figure 8.5).



In contrast, the median age for consumers of community access and community support services fell. The most obvious decline was for community support services between 2001 and 2002. This appears to be at least partially due to the re-categorisation of service types (see AIHW 2003a). In particular, the reclassification of recreation services from community support to community access would have contributed to this decline.

Close to 40,000 people receiving CSDA-funded services in 2002 reported an intellectual disability as their primary disability (Table 8.9). The next most frequently reported were physical disability (8,002) and psychiatric disability (4,896). Consumer trends for 1999-2002 reveal that the proportions of consumers in most primary disability groups remained steady over this 3-year period. However, there was considerable variation in the patterns of service use among different primary disability groups (AIHW 2003a:Figure 3.4).

Of all reported disability groups (that is, primary disability and all other significant disability groups), intellectual and physical disabilities remain the two most commonly reported disabilities. Just over two-thirds (69%) of consumers reported intellectual as one of their disabilities, while 29% reported physical. Despite being reported as a primary disability by less than 1% of consumers, speech disabilities are the third most common overall, reported by 22% of consumers as one of their primary disability groups.

**Table 8.9: Disability group(s) of consumers of CSDA-funded services on a snapshot day, 1999–2002**

|                                      | Primary disability group |               |               |               | All reported disability groups, including primary |        |        |        |
|--------------------------------------|--------------------------|---------------|---------------|---------------|---|--------|--------|--------|
|                                      | 1999                     | 2000          | 2001          | 2002          | 1999  | 2000   | 2001   | 2002   |
|                                      | (Number)                 |               |               |               | (Number)  |        |        |        |
| Intellectual                         | 38,225                   | 37,479        | 37,575        | 39,909        | 42,744  | 42,446 | 42,752 | 45,398 |
| Specific learning/ADD <sup>(a)</sup> | 729                      | 923           | 942           | 911           | 2,002   | 2,062  | 2,213  | 4,351  |
| Autism                               | 1,937                    | 2,133         | 2,299         | 2,500         | 3,666   | 4,064  | 4,267  | 4,956  |
| Physical                             | 7,904                    | 7,673         | 7,911         | 8,002         | 17,718  | 17,826 | 18,123 | 19,354 |
| Acquired brain injury                | 2,143                    | 2,290         | 2,761         | 2,427         | 2,911   | 3,122  | 3,613  | 3,371  |
| Neurological                         | 1,759                    | 1,738         | 1,916         | 2,266         | 8,792   | 9,002  | 9,636  | 10,689 |
| Deafblind                            | 213                      | 168           | 179           | 170           | 516   | 518    | 528    | 558    |
| Vision                               | 1,606                    | 1,359         | 1,553         | 1,716         | 6,117   | 5,930  | 6,102  | 7,047  |
| Hearing                              | 837                      | 847           | 885           | 854           | 3,856   | 3,736  | 3,744  | 3,944  |
| Speech                               | 333                      | 335           | 334           | 405           | 11,855  | 12,450 | 12,146 | 14,463 |
| Psychiatric <sup>(b)</sup>           | 5,149                    | 5,381         | 5,419         | 4,896         | 8,995   | 9,323  | 9,735  | 9,767  |
| Developmental delay                  | 1,411                    | 1,576         | 1,439         | 1,106         | 1,908   | 2,200  | 2,015  | 1,880  |
| Not stated                           | 506                      | 439           | 617           | 647           | n.a.  | n.a.   | n.a.   | n.a.   |
| <b>Total</b>                         | <b>62,752</b>            | <b>62,341</b> | <b>65,831</b> | <b>65,809</b> | —   | —      | —      | —      |

- (a) The increase in the number of consumers reporting this disability type as another significant disability is partly due to the improved collection procedures in one jurisdiction.
- (b) Although psychiatric disability proportions fell between 2001 and 2002, these figures are not directly comparable due to policy changes in SA. The decrease is not completely accounted for by the drop in numbers within this jurisdiction (see AIHW 2003a).

*Notes*

1. Consumer data are estimated after use of a statistical linkage key to account for individuals who received more than one service on the snapshot day.
2. Data for consumers of the following CSDA-funded service types were not collected: advocacy, information/referral, combined information/advocacy, mutual support/self-help groups, print disability/alt. formats of communication, research & evaluation, training & development, peak bodies, and other support services.
3. The total for 'all reported disability groups' adds to more than the total number of consumers, since consumers may be counted in more than one disability group.
4. Data provided by the Commonwealth for the years 1999–2002 are preliminary and therefore do not cover 100% of Commonwealth-funded services.

Sources: AIHW 2000c, 2001b, 2002c, 2003a, 2003c.

## Indigenous Australians accessing CSDA-funded services

On the 2002 snapshot day, 1,670 or 2.5% of CSDA consumers (or 2.7%, excluding the 5% of consumers for whom Indigenous status was not known) were identified as being of Aboriginal or Torres Strait Islander origin, or both (Table 8.10). This was very similar to the proportion (2.6%) of Indigenous Australians in the general population aged under 65 in 2002 (AIHW 2003a:Table 3.11). However, it is likely that this amounts to under-representation in or poor access to these services, as the limited evidence available points to higher rates of disability among Aboriginal and Torres Strait Islander peoples (AIHW 1997a:304).



**Table 8.10: Consumers of CSDA-funded services on a snapshot day, by support needed and Indigenous status, 2002**

| Frequency of support needed in activities of daily living | Indigenous   |              | Non-Indigenous |              | Total         |              |
|---|--------------|--------------|----------------|--------------|---------------|--------------|
|   | Number       | Per cent     | Number         | Per cent     | Number        | Per cent     |
| Always or unable to do                                    | 772          | 46.2         | 25,650         | 42.3         | 27,364        | 41.6         |
| Sometimes   | 642          | 38.4         | 22,854         | 37.7         | 24,359        | 37.0         |
| None but uses aids  | 51           | 3.1          | 2,098          | 3.5          | 2,241         | 3.4          |
| None  | 194          | 11.6         | 9,372          | 15.4         | 9,976         | 15.2         |
| Not known   | 11           | 0.7          | 714            | 1.2          | 1,869         | 2.8          |
| <b>Total</b>  | <b>1,670</b> | <b>100.0</b> | <b>60,688</b>  | <b>100.0</b> | <b>65,809</b> | <b>100.0</b> |

*Notes*

1. Consumer data are estimates after use of a statistical linkage key to account for individuals who have received more than one service on the snapshot day.
2. Data for consumers of the following CSDA-funded service types were not collected: advocacy, information/referral, combined information/advocacy, mutual support/self-help groups, print disability/alt. formats of communication, research & evaluation, training & development, peak bodies, and other support services.
3. Totals include 3,451 consumers whose Indigenous status was not stated.
4. Data provided by the Commonwealth are preliminary and cover 99% of Commonwealth-funded services.

Source: AIHW 2003a.

Overall, two-fifths (42%) of all CSDA consumers reported needing continual support in ‘activities of daily living’ (self-care, mobility and/or communication). A slightly higher proportion of Indigenous consumers reported this need (46%), compared with other consumers reporting (42%). Approximately 15% of Indigenous consumers reported needing no support with activities of daily living (including those who needed only aids), compared with 19% of non-Indigenous consumers.

### Life areas and frequency of support for CSDA-funded consumers

Data on the support needs of consumers in nine main life areas are collected through the CSDA MDS. The data item provides a framework consistent with international classification standards and Australian population data and into which the common assessment tools used in the disability services field can be mapped (see AIHW 2003b: ch. 8).

For simplicity of analysis, data on the overall support needs are grouped into three main life areas:

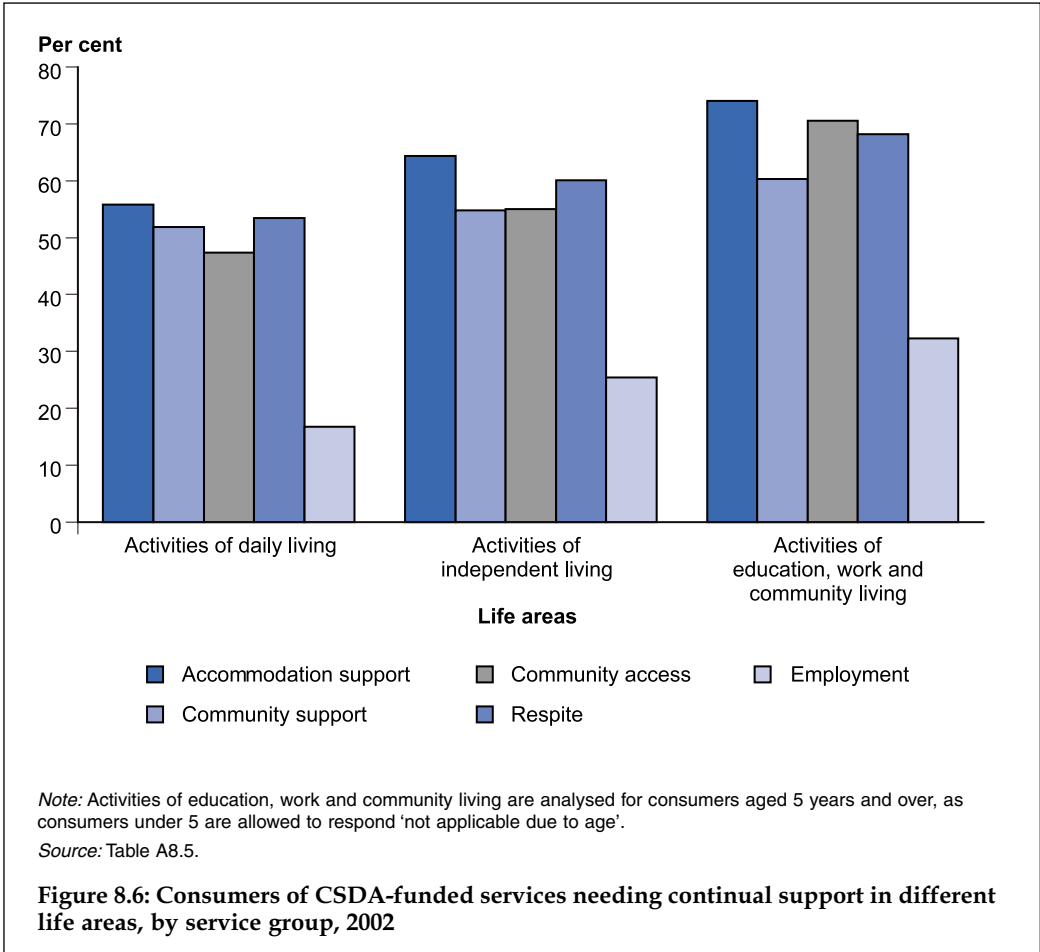
- Activities of daily living (ADLs) – self-care; mobility; and communication.
- Activities of independent living (AILs) – interpersonal interactions and relationships; learning, applying knowledge, and general tasks and demands; and domestic life.
- Activities of work, education and community living (AWECs) – education; community (civic) and economic life; and working.

Consumers of accommodation support services have the highest need for continual support in the three main life areas (ADL 56%, AIL 64% and AWEC 74%) (Figure 8.6). CSDA consumers receiving employment support services constitute the lowest proportion requiring continual support (ADL 17%, AIL 25% and AWEC 32%).

Of the three life areas, the 'activities of work, education and community living' group is found to have the largest proportion of consumers always needing support (58%). This proportion varies between service groups, from just under one-third (32%) of employment consumers, to almost three-quarters (74%) of accommodation support consumers. The 'activities of independent living' group has the next largest proportion always needing support, with 48% of consumers. Also for this category, employment services has the smallest proportion (25%) and accommodation support the largest (64%). Finally, just over two-fifths (42%) of consumers reported that they always needed support with 'activities of daily living', ranging from 17% for employment services to 56% for accommodation support.

**Consumer location**

The 2002 CSDA MDS snapshot collection was the first time that consumer postcode has been available for all states and territories. It was also the first time that these data have been analysed using the Remoteness Areas of the Australian Standard Geographical Classification, replacing the former national standard classification of metropolitan urban, rural, remote and other areas (see AIHW 2003a for further information).



**Table 8.11: Location of consumers of CSDA-funded services on a snapshot day, 2002**

|                                       | NSW       | Vic       | Qld       | WA        | SA        | Tas     | ACT              | NT      | Australia  |
|---------------------------------------|-----------|-----------|-----------|-----------|-----------|---------|------------------|---------|------------|
| <b>People aged under 65 years</b>     |           |           |           |           |           |         |                  |         |            |
| All                                   |           |           |           |           |           |         |                  |         |            |
| Australians                           | 5,747,855 | 4,196,712 | 3,212,033 | 1,696,456 | 1,294,388 | 408,032 | 294,203          | 192,464 | 17,044,642 |
| Major cities                          |           |           |           |           |           |         |                  |         |            |
|                                       | 4,142,136 | 3,102,506 | 1,686,038 | 1,193,174 | 926,970   | 0       | 293,559          | 0       | 11,344,383 |
| Inner regional                        |           |           |           |           |           |         |                  |         |            |
|                                       | 1,154,404 | 877,670   | 810,116   | 204,474   | 161,639   | 258,428 | 644              | 0       | 3,467,903  |
| Outer regional                        |           |           |           |           |           |         |                  |         |            |
|                                       | 409,199   | 211,578   | 578,966   | 165,881   | 152,648   | 139,795 | 0                | 103,702 | 1,761,768  |
| Remote                                |           |           |           |           |           |         |                  |         |            |
|                                       | 34,678    | 4,959     | 86,457    | 84,204    | 39,504    | 7,548   | 0                | 40,660  | 298,010    |
| Very remote                           |           |           |           |           |           |         |                  |         |            |
|                                       | 7,438     | 0         | 50,456    | 48,724    | 13,627    | 2,260   | 0                | 48,102  | 172,579    |
| <b>Consumers</b>                      |           |           |           |           |           |         |                  |         |            |
| All                                   |           |           |           |           |           |         |                  |         |            |
| consumers                             | 17,194    | 22,278    | 9,065     | 6,594     | 6,591     | 1,823   | 792              | 389     | 64,685     |
| Major cities                          |           |           |           |           |           |         |                  |         |            |
|                                       | 11,779    | 14,668    | 4,940     | 5,100     | 5,262     | 0       | 781              | 0       | 42,515     |
| Inner regional                        |           |           |           |           |           |         |                  |         |            |
|                                       | 4,131     | 6,278     | 2,431     | 728       | 639       | 1,360   | 8                | 0       | 15,552     |
| Outer regional                        |           |           |           |           |           |         |                  |         |            |
|                                       | 1,201     | 1,319     | 1,535     | 533       | 595       | 454     | <sup>(a)</sup> 2 | 199     | 5,836      |
| Remote                                |           |           |           |           |           |         |                  |         |            |
|                                       | 68        | 13        | 115       | 166       | 82        | 9       | <sup>(a)</sup> 1 | 125     | 578        |
| Very remote                           |           |           |           |           |           |         |                  |         |            |
|                                       | 15        | —         | 44        | 67        | 13        | 0       | —                | 65      | 204        |
| <b>Consumers per 1,000 population</b> |           |           |           |           |           |         |                  |         |            |
| All                                   |           |           |           |           |           |         |                  |         |            |
| consumers                             | 3         | 5.3       | 2.8       | 3.9       | 5.1       | 4.5     | 2.7              | 2       | 3.8        |
| Major cities                          |           |           |           |           |           |         |                  |         |            |
|                                       | 2.8       | 4.7       | 2.9       | 4.3       | 5.7       | —       | 2.7              | —       | 3.7        |
| Inner regional                        |           |           |           |           |           |         |                  |         |            |
|                                       | 3.6       | 7.2       | 3         | 3.6       | 4         | 5.3     | 12.4             | —       | 4.5        |
| Outer regional                        |           |           |           |           |           |         |                  |         |            |
|                                       | 2.9       | 6.2       | 2.7       | 3.2       | 3.9       | 3.2     | —                | 1.9     | 3.3        |
| Remote                                |           |           |           |           |           |         |                  |         |            |
|                                       | 2         | 2.6       | 1.3       | 2         | 2.1       | 1.2     | —                | 3.1     | 1.9        |
| Very remote                           |           |           |           |           |           |         |                  |         |            |
|                                       | 2         | —         | 0.9       | 1.4       | 1         | 0       | —                | 1.4     | 1.2        |

(a) These consumers resided in outer regional and remote areas outside of the ACT but accessed services within the ACT.

*Notes*

1. The number of consumers in each Remoteness Area (RA) was estimated based on consumers' residential postcodes. Some postcode areas were split between two or more RAs. Where this was the case the data were weighted according to the proportion of the population of the postcode area in each RA.
2. Consumer data are estimates after use of a statistical linkage key to account for individuals who received more than one service on the snapshot day. Totals for Australia may not be the sum of the components since individuals may have accessed services in more than one state or territory on the snapshot day.
3. Data for all consumers exclude 1,124 consumers whose location was not known. Location was classified as 'not known' only if all the postcodes provided by all services attended by the consumer were not stated.
4. Data for consumers of the following CSDA-funded service types were not collected: advocacy, information/referral, combined information/advocacy, mutual support/self-help groups, print disability/alt. formats of communication, research & evaluation, training & development, peak bodies, and other support services.
5. Data provided by the Commonwealth are preliminary and cover 99% of Commonwealth-funded services.

Source: AIHW 2003a.

Table 8.11 reveals that, based on the population of Australians under 65 years of age, it was inner regional areas that had the highest rates of consumers (4.5 per 1,000 population). This was followed by major cities (3.7), outer regional areas (3.3), remote (1.9) and finally very remote areas (1.2).

Victoria and South Australia had the highest rates overall (5.3 and 5.1, respectively). For major cities, South Australia had the highest rate (5.7 per 1,000), while for inner regional areas Victoria had the highest rate (7.2). Victoria also had the highest rate in outer regional areas (6.2), and the Northern Territory in remote areas (3.1). It is possible that the locations of consumers may be influenced by the availability of and access to disability services, and people with disabilities may move to be closer to these services.

The proportion of Indigenous consumers using services on the 2002 snapshot day increased with the remoteness of their geographical location (Table 8.12). Indigenous consumers represented 2.5% of consumers overall, but they comprised a smaller proportion in capital cities (1.4%). Much larger proportions were found in outer regional (7.4%), remote (24.1%) and very remote (50.0%) areas.

**Table 8.12: Location of consumers of CSDA-funded services on a snapshot day, by Indigenous status, 2002**

|                 | Major cities  | Inner regional | Outer regional | Remote       | Very remote  | Not known    | Total         |
|-----------------|---------------|----------------|----------------|--------------|--------------|--------------|---------------|
| <b>Number</b>   |               |                |                |              |              |              |               |
| Indigenous      | 616           | 373            | 431            | 139          | 102          | 9            | 1,670         |
| Non-Indigenous  | 40,178        | 14,325         | 5,177          | 426          | 98           | 484          | 60,688        |
| Not stated      | 1,727         | 854            | 228            | 13           | 5            | 625          | 3,451         |
| <b>Total</b>    | <b>42,520</b> | <b>15,552</b>  | <b>5,836</b>   | <b>578</b>   | <b>204</b>   | <b>1,118</b> | <b>65,809</b> |
| <b>Per cent</b> |               |                |                |              |              |              |               |
| Indigenous      | 1.4           | 2.4            | 7.4            | 24.1         | 50.0         | 0.8          | 2.5           |
| Non-Indigenous  | 94.5          | 92.1           | 88.7           | 73.7         | 47.8         | 43.3         | 92.2          |
| Not stated      | 4.1           | 5.5            | 3.9            | 2.2          | 2.2          | 55.9         | 5.2           |
| <b>Total</b>    | <b>100.0</b>  | <b>100.0</b>   | <b>100.0</b>   | <b>100.0</b> | <b>100.0</b> | <b>100.0</b> | <b>100.0</b>  |

*Notes*

1. Consumer data are estimates after use of a statistical linkage key to account for individuals who received more than one service on the snapshot day.
2. The number of consumers in each Remoteness Area (RA) was estimated based on consumers' residential postcodes. Some postcode areas were split between two or more RAs. Where this was the case the data were weighted according to the proportion of the postcode area in each RA.
3. Data for consumers of the following CSDA-funded service types were not collected: advocacy, information/referral, combined information/advocacy, mutual support/self-help groups, print disability/alt. formats of communication, research & evaluation, training & development, peak bodies, and other support services.
4. Data provided by the Commonwealth are preliminary and cover 99% of Commonwealth-funded services.

Source: AIHW analysis of 2002 CSDA MDS data.

**Table 8.13: People aged 10–64 years in aged care homes by age, sex and state/territory, 30 June 2002**

| Age (years)                                | NSW          | Vic          | Qld          | WA         | SA         | Tas        | ACT       | NT        | Australia    |
|--|--------------|--------------|--------------|------------|------------|------------|-----------|-----------|--------------|
| 10–29                                      | 28           | 12           | 24           | 2          | 4          | 2          | 0         | 1         | 73           |
| 30–49                                      | 391          | 216          | 217          | 88         | 54         | 22         | 4         | 12        | 1,004        |
| 50–64                                      | 1,794        | 1,202        | 1,023        | 377        | 293        | 124        | 38        | 56        | 4,907        |
| <b>Total 10–64</b>                         | <b>2,213</b> | <b>1,430</b> | <b>1,264</b> | <b>467</b> | <b>351</b> | <b>148</b> | <b>42</b> | <b>69</b> | <b>5,984</b> |
| Total 10–64 (% of all permanent residents) | 4.6          | 4.3          | 5.1          | 4.1        | 2.7        | 4.0        | 3.0       | 20.5      | 4.4          |

*Note:* There were also 132 respite residents aged between 10 and 64 at 30 June 2002.

*Source:* AIHW analysis of data supplied by DoHA from the ACCMIS Warehouse.

## Other disability support services

### Residential aged care and HACC

People who have a disability and are aged less than 65 years may receive accommodation and other support services within the aged care sector. Nationally, there were 5,984 people aged 10–64 years living permanently in aged care homes on 30 June 2002, accounting for 4.4% of permanent residents of all ages (Table 8.13); in addition, there were 132 respite residents aged under 65. As in previous years, residents aged 50–64 accounted for over 80% (4,907) of people under 65 in residential aged care. However, there were 73 permanent residents aged 10–29 in these services. Permanent residents aged under 65 as a percentage of all permanent residents varied considerably among the states and territories, ranging from 2.7% in South Australia to 20.5% in the Northern Territory. The higher rate in the Northern Territory could be related to its higher proportion of Aboriginal and Torres Strait Islander people, who have patterns of earlier admission to residential aged care than the rest of the population (AIHW 2002d:50). The issue of ‘younger people in nursing homes’ has become of such concern that a coalition of peak disability organisations has formed, to advocate moving these people out of aged care facilities and into community based placements with appropriate support (Young People in Nursing Homes Consortium 2003).

During the 12 months to 30 June 2002, an estimated 583,156 clients received services from the Home and Community Care (HACC) program (see Table A7.10). Of these, at least 133,469 clients (or 23% of all HACC clients) over this period were aged under 65 years (see Box 7.4 for further details about this program).

### Rehabilitation and hearing services

CRS Australia is funded by the Commonwealth Government to provide vocational rehabilitation services to people with disabilities with the aim of assisting them to gain or retain employment. A total of 17,091 new clients received a program of assistance in the financial year 2001–02, along with 13,114 existing clients. Of the 10,790 new clients who completed a rehabilitation program, 6,103 achieved an employment outcome of 13 weeks or more (FaCS 2002b).

Over half (57.3%) of new CRS Australia clients had a physical disability, followed by 26% with a psychiatric disability and 5.3% with acquired brain injury. People with a sensory disability accounted for 4.4% of new clients, while 3.3% had an intellectual or learning disability.

The Office of Hearing Services purchases hearing services from a national network of private sector service providers and Australian Hearing, which is the sole government-funded provider of hearing services. Australian Hearing specifically delivers services to children and young adults up to the age of 21 and age pensioners. Hearing services were provided to 167,107 clients in the period 2000–02. Of these clients, 123,366 were pensioners and veterans, 35,236 were children, and 8,505 were ‘Other’, such as COMCARE and CRS clients or defence personnel (Australian Hearing 2002).

### Equipment and related services

A range of government and non-government equipment services is available to people with disabilities (AIHW: Bricknell 2003). These services target specific disability or population groups (e.g. people with hearing impairments, war veterans) or are more generic in provision, supplying an array of aids and equipment specifically to assist people with self-care, mobility, communication and other needs.

In 1998, 48% of people with a disability used some form of aid. Of this group, 40% were under the age of 65 years. The use of aids and equipment was more likely in older age groups and for those with more severe core activity restrictions (AIHW: Bricknell 2003).

Medical aids were the most used of the six aid and equipment categories listed in Table 8.14. At least 40% of all aids used by people with disabilities in each age group were medical aids. Mobility aids were the second most used aid for people aged 15–29, 30–44 and 45–64, accounting for 17–18% of all aids used. Self-care or communication aids were the third most commonly used aid.

**Table 8.14: People aged 0–64 years with a disability, by use of aids and equipment and age group, 1998**

| Type of aid            | 0–14 yrs     |              | 15–29 yrs    |              | 30–44 yrs    |              | 45–64 yrs    |              |
|------------------------|--------------|--------------|--------------|--------------|--------------|--------------|--------------|--------------|
|                        | No. ('000)   | Per cent     | No. ('000)   | Per cent     | No. ('000)   | Per cent     | No. ('000)   | Per cent     |
| Self-care              | 28.4         | 15.9         | 24.3         | 12.3         | 47.2         | 13.2         | 117.9        | 15.1         |
| Mobility               | 21.2         | 11.8         | 33           | 17.1         | 60.1         | 16.8         | 137.8        | 17.7         |
| Communication          | 28.5         | 15.9         | 24           | 12.1         | 58.5         | 16.4         | 119.1        | 15.3         |
| Hearing                | 10.1         | 5.6          | 10.2         | 5.1          | 19           | 5.3          | 73.3         | 9.4          |
| Meal preparation       | *3.0         | 1.7          | *4.3         | 2.2          | 13.2         | 3.7          | 20.9         | 2.7          |
| Medical                | 88.1         | 49.1         | 101          | 51.2         | 159.7        | 44.6         | 309.5        | 39.8         |
| <b>Total aids used</b> | <b>179.3</b> | <b>100.0</b> | <b>197.4</b> | <b>100.0</b> | <b>357.7</b> | <b>100.0</b> | <b>778.5</b> | <b>100.0</b> |
| Number of users        | 118.2        |              | 134.8        |              | 222.4        |              | 483          |              |
| Average no. of aids    | 1.5          |              | 1.5          |              | 1.6          |              | 1.6          |              |

#### Notes

1. Estimates marked \* have an associated relative sampling error of between 25% and 50%. These estimates should be interpreted accordingly.
2. Self-care aids include eating, showering, toileting, incontinence and dressing aids. Mobility aids include electric wheelchair/scooters, manual wheelchairs, canes, crutches, walking sticks, walking frames, seating/bedding aids, car aids and other mobility aids. Communication aids include low- and high-tech reading and writing aids, low- and high-tech speech aids, mobile/cordless phones and fax machines. Hearing aids include hearing aids proper and cochlear implants.

Source: AIHW: Bricknell 2003.

For children under 15 years, self-care and communication aids each accounted for 16% of all aids. Aids for mobility made up 12%. Around 5–6% of all aids used by people under 45 years were hearing aids or cochlear implants. For people aged 45–64 years, this proportion rose to 9%.

Little difference existed between age groups in the average number of aids used. People aged under 30 years used on average 1.5 aids each, compared with an average of 1.6 aids used by people aged between 30 and 64 years.

## Relevant generic services

### Health services

People with disabilities, like the rest of the population, need to access health services as a result of illness, and there is growing interest in the question of how effective this access is.

Durvasula and Beange (2001) reviewed emerging evidence that people with intellectual disabilities have poorer health outcomes, in terms of lower life expectancy and more prevalent health problems, and that they do not access health services, in particular preventive health care, to the same extent as the rest of the population. The same authors have found higher mortality rates among people with intellectual disability in a Sydney area (Durvasula et al. 2002). It has been suggested that people with intellectual disabilities are more likely to develop other physical and mental health problems than the general population (Lennox & Beange 2000). Despite this, it appeared that people with intellectual disabilities were less likely to undergo health screening and were less exposed to health promotion than other patients attending general health services. Possible barriers in providing general health care for people with developmental disabilities include a lack of comprehensive medical histories and insufficient physical access to community facilities (Burbidge 2003; Parmenter et al 1999). Health professionals treating people with various disabilities have on occasion not had sufficient knowledge of a specific condition, preventing the provision of effective health care (Buzio 2001; Parmenter et al. 1999). Specific health targets have been suggested for this population group in order to counter these risks, for instance standards about the frequency of checking dental health, hearing and vision (Beange et al. 1999).

The need for health service improvements within the disability services sector has again been highlighted by the NSW Community Services Commission (Mullane 2002). In 1999–2000, ‘a total of 69 deaths of people with disabilities were notified to the Disability Death Review Team. Of these 51 deaths were reported to be linked to underweight (17 people), swallowing difficulties (23 people) and/or tube feeding (11 people).’

Gaps in health service delivery to people with high/complex needs were identified. Improvements needed included the reduction of risk factors such as dysphagia, respiratory infection and underweight, and improved processes in the area of palliative care and end-of-life decision making. ‘Less than optimal procedures and practices around infection control’ were observed.

The Centre for Developmental Disability Studies in Sydney has been involved in programs funded by the NSW Health Department to sensitise hospital staff to the needs

of people with disabilities, and is developing a training package for doctors relating to cervical screening for women with disabilities (Parmenter 2003).

### **Education and training**

Students with disabilities may attend either 'special' schools, or mainstream schools that offer 'special' or 'support' education services or classes that address their specific educational needs. Enrolment in special education services or programs, in both mainstream and special schools, is conditional on satisfying specified criteria, which are determined by the government of the state or territory in which the student resides. Services provided and criteria used to assess the severity of disability and subsequent eligibility for education support programs vary between jurisdictions. For example, criteria relating to social or emotional impairment exist in some jurisdictions, such as New South Wales, but not in others, for example the Australian Capital Territory (SCRCSSP 2003).

In 2002, there were 101,930 students with disabilities: 80,689 in government schools, of whom 81% attended mainstream schools, and 21,241 in non-government schools, of whom 91% attended mainstream schools (Table 8.15). The proportion of students with disabilities attending mainstream schools in the government sector varied between jurisdictions, from 66% in Victoria to 95% in Tasmania and the Northern Territory. Similarly, in the non-government sector, the proportion attending mainstream schools varied from 88% in New South Wales to 100% in the Northern Territory. This may reflect jurisdictional variation in the availability of special schools and in enrolment integration policies.

Students with a disability as a proportion of all students attending government and non-government schools ranged from 2% in Queensland to 10% in the Northern Territory. In all jurisdictions, the proportion was greater in government schools than in non-government schools.

Post-school education data are available for Vocational Education and Training students. In 2001, 4% of such students identified themselves as having a 'permanent or significant disability'. The percentage was highest in Tasmania (6%) and lowest in Western Australia (3%) (SCRCSSP 2003).

A senate inquiry into the education of students with disabilities reported on 'whether current policies and programs for students with disabilities are adequate to meet their education needs', making 19 recommendations covering teacher training, the development of schooling options and funding models, and related services (Commonwealth of Australia 2002:v). The report recommended the development of national definitions of disabilities; the AIHW submission to the inquiry recommended use of existing international and national standards as a basis for improving consistency.



**Table 8.15: Students with disabilities attending government and non-government schools, 2002<sup>(a)</sup>**

|  | NSW             | Vic             | Qld             | WA <sup>(b)</sup> | SA              | Tas            | ACT            | NT             | Total            |
|--|-----------------|-----------------|-----------------|-------------------|-----------------|----------------|----------------|----------------|------------------|
| <b>Government schools</b>                        |                 |                 |                 |                   |                 |                |                |                |                  |
| Mainstream                                       | 16,755          | 12,211.0        | 10,121.9        | 7,930             | 10,924          | 2,805.5        | 1,160          | 3,695          | 65,595.9         |
| Special  | 3,915           | 6,170.5         | 2,534.5         | 883               | 939             | 148.1          | 299            | 193            | 15,093.0         |
| <i>Total</i>                                     | <i>20,670</i>   | <i>18,381.5</i> | <i>12,656.4</i> | <i>8,813</i>      | <i>11,863</i>   | <i>2,953.6</i> | <i>1,459</i>   | <i>3,888</i>   | <i>80,688.9</i>  |
| Percentage attending mainstream schools          | 81.1            | 66.4            | 80              | 90                | 92.1            | 95             | 79.5           | 95             | 81.3             |
| Percentage of all government school students     | 2.8             | 3.4             | 2.9             | 3.5               | 6.8             | 4.7            | 3.9            | 11.9           | 3.5              |
| <b>Non-government schools<sup>(c)</sup></b>      |                 |                 |                 |                   |                 |                |                |                |                  |
| Mainstream                                       | 7,954.9         | 4,718.8         | 2,296.3         | 1,282.6           | 2,360.6         | 295.4          | 259.7          | 193.6          | 19,361.9         |
| Special  | 1,105.0         | 491.1           | 91.6            | 28.8              | 148.0           | 13.2           | 1.2            | 0              | 1,878.9          |
| <i>Total</i>                                     | <i>9,059.9</i>  | <i>5,209.9</i>  | <i>2,387.9</i>  | <i>1,311.4</i>    | <i>2,508.6</i>  | <i>308.6</i>   | <i>260.9</i>   | <i>193.6</i>   | <i>21,240.8</i>  |
| Percentage attending mainstream schools          | 87.8            | 90.6            | 96.2            | 97.8              | 94.1            | 95.7           | 99.5           | 100            | 91.2             |
| Percentage of all non-government school students | 2.6             | 1.9             | 1.3             | 1.3               | 3.2             | 1.5            | 1.2            | 2.3            | 2                |
| <b>Total students with disabilities</b>          | <b>29,729.9</b> | <b>23,591.4</b> | <b>15,044.3</b> | <b>10,124.4</b>   | <b>14,371.6</b> | <b>3,262.2</b> | <b>1,719.9</b> | <b>4,081.6</b> | <b>101,929.7</b> |
| Total all students ('000)                        | 1,099.8         | 817.9           | 629.4           | 355.5             | 252.4           | 83.9           | 60.7           | 41.2           | 3,340.9          |
| Percentage of all school students                | 2.7             | 2.9             | 2.4             | 2.9               | 5.7             | 3.9            | 2.9            | 9.9            | 4.9              |

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

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

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

Source: DETYA 2002 Non-government Schools Census, unpublished data; and data provided to AIHW by state and territory education authorities.

## Employment assistance

Job seekers with a disability can access employment assistance via the disability employment assistance 'gateway', which is an assessment and referral service provided by Centrelink. Via the gateway, job seekers can be helped to access any of three options: disability employment assistance or vocational rehabilitation services funded by the Commonwealth Department of Family and Community Services (FaCS), or the Job Network services funded by the Commonwealth Department of Employment and Workplace Relations (DEWR). Job seekers who wish to access FaCS-funded services may do so either by approaching Centrelink or by going directly to a service provider.

All job seekers accessing Job Network services undergo a Job Seeker Classification Instrument assessment to identify the relative difficulty applicants have in gaining employment and to determine the level of assistance they should receive within the Job Network. Job seekers accessing disability employment assistance funded by FaCS are also required to undergo this assessment if they are assisted under case-based funding.

Previously, the streaming of job seekers with a disability to one of the three disability employment service options was based on an assessment of their employment needs as determined by Work Ability Tables. After a review carried out by DEWR and FaCS (FaCS 2002c), the Work Ability Tables were found not to provide a profile of the job seeker’s specific needs for ongoing employment support services or rehabilitation and were replaced by the Disability Employment Indicators on 31 March 2003 after a 4-month trial. These indicators take a more functional approach, seen to be applicable across a range of disability types without making any assumptions about a person’s ongoing support needs according to their disability type. This assessment may be triggered as a result of the Job Seeker Classification Instrument, or used as a stand-alone assessment.

During the period March 2002 to February 2003 inclusive, there were 53,079 referrals for 49,269 people to disability employment assistance and vocational rehabilitation. Of these, 33,433 referrals (63%) came through Centrelink and 19,646 (37%) had gone initially to service providers (FaCS unpublished data).

‘Positive outcomes’ were achieved by 60% of the 14,368 people with disabilities who received job matching assistance from the Job Network, 39% of those who received job search training assistance and 41% of those who received intensive assistance (Table 8.16).

Intensive assistance is one of three main programs available to job seekers through the Job Network. It provides individually tailored assistance in preparing for and obtaining suitable employment, and is the service used most by job seekers with a disability (Table 8.16). In 2001–02, job seekers with a disability accounted for 41,783 intensive assistance exits (or 16% of all such exits). Of these, 41% achieved a positive outcome of either being employed or in training or education, 3 months after completion of the program. This compares with 50% of all job seekers achieving a positive outcome.

**Table 8.16: Number of job seekers accessing the Job Network and positive outcomes as at 30 June 2002**

|                              | Job seekers with a disability |                   | All job seekers |                   |
|------------------------------|-------------------------------|-------------------|-----------------|-------------------|
|                              | Number                        | Positive outcomes | Number          | Positive outcomes |
| Job matching (placements)    | 14,368                        | 59.9%             | 239,031         | 70.4%             |
| Job search training (exits)  | 4,033                         | 39.1%             | 80,854          | 47.6%             |
| Intensive assistance (exits) | 41,783                        | 41.2%             | 270,093         | 50.1%             |

Source: DEWR 2003.

## Housing and accommodation assistance

In 2001–02, about 6,310 new public housing allocations were made to households with special needs due to disability, accounting for 41% of all special needs allocations (see Table 5.27). Also in 2001–02, there were 172 community housing providers that targeted people with a disability, and these providers assisted 4,318 households with a disability (AIHW 2003h).

In 2002, of all income units receiving FaCS Commonwealth Rent Assistance (CRA), 294,275 (32%) were ones in which the principal client had a disability. Nationally, average weekly rents for CRA recipients were slightly lower for income units in which the principal client had a disability (\$118.4), compared with all income units (\$130.8) (AIHW 2003g).

**Table 8.17: SAAP support periods: Main source of income prior to seeking assistance, by reasons for seeking assistance, 2001–02 (per cent)**

| Reason for seeking assistance                   | Disability Support Pension | DVA Disability Pension | Total receiving a disability pension | All SAAP clients |
|---|----------------------------|------------------------|--------------------------------------|------------------|
| Usual accommodation unavailable                 | 23.1                       | 24.7                   | 23.2                                 | 21.8             |
| Time out from family/other situation            | 14.8                       | 16.9                   | 14.9                                 | 18.4             |
| Relationship/family breakdown                   | 19.5                       | 22.6                   | 19.7                                 | 30.3             |
| Interpersonal conflicts                         | 15.4                       | 16.3                   | 15.5                                 | 18.1             |
| Physical/emotional abuse                        | 13.2                       | 23.5                   | 13.7                                 | 21.2             |
| Domestic violence                               | 14.1                       | 30.4                   | 14.7                                 | 27.0             |
| Sexual abuse                                    | 3.0                        | 4.7                    | 3.1                                  | 3.1              |
| Financial difficulty                            | 40.4                       | 27.1                   | 39.8                                 | 32.6             |
| Eviction/previous accommodation ended           | 18.9                       | 16.0                   | 18.7                                 | 20.1             |
| Drug/alcohol/substance abuse                    | 23.0                       | 16.6                   | 22.7                                 | 15.4             |
| Emergency accommodation ended                   | 4.4                        | 4.5                    | 4.4                                  | 4.1              |
| Recently left institution                       | 5.0                        | 3.4                    | 5.0                                  | 3.0              |
| Psychiatric illness                             | 17.6                       | 8.0                    | 17.2                                 | 5.0              |
| Recent arrival to area with no means of support | 16.5                       | 13.7                   | 16.4                                 | 10.7             |
| Itinerant                                       | 12.3                       | 5.1                    | 12.0                                 | 7.0              |
| Other   | 9.3                        | 7.6                    | 9.2                                  | 9.2              |
| Gambling  | 2.6                        | 1.6                    | 2.6                                  | 1.4              |
| <b>Total number of support periods</b>          | <b>18,100</b>              | <b>800</b>             | <b>18,900</b>                        | <b>133,800</b>   |

### Notes

1. A small number of records are excluded from this table due to missing information.
2. This table does not include support periods at high-volume SAAP agencies as the question on reason for seeking assistance was not included on the client form for high-volume agencies.
3. Clients may give multiple reasons for seeking assistance, so percentages do not sum to 100.
4. Figures have been weighted to adjust for agency non-participation and client non-consent.

Source: SAAP Client Collection.

The prevalence of homelessness among people with a disability appears to be significant, although available data are limited. In 2001–02, 14% of support periods provided under the Supported Accommodation Assistance Program (SAAP) were for clients who reported the Disability Support Pension or DVA Disability Pension as their main source of income. This figure may be an underestimate, as information on source of income is not collected for SAAP high-volume agencies, whose clients are predominantly men, and a higher percentage of male than female SAAP clients report a disability pension as their main source of income.

Compared with all SAAP clients, a greater proportion of clients receiving a disability pension reported financial difficulty as a reason for seeking assistance (40%, compared with 33% for all clients) (Table 8.17). They were also more likely to report drug, alcohol or substance abuse (23%, compared with 15%) and psychiatric illness (17%, compared with 5%), and less likely to report relationship breakdown (20%, compared with 30%) and domestic violence (15%, compared with 27%) as reasons for seeking assistance.

**Unpaid care**

For those people aged under 65 years with a disability, who need help with self-care, mobility or communication, most assistance is provided by family and friends. For all activities surveyed in 1998, informal co-resident carers supplied the vast majority of assistance (Table 8.18). Formal services provided about the same level of help as carers who did not reside with the person who needed the help. Many people did not receive the assistance required, including some 27,000 who needed help with self-care and 31,000 who needed help with mobility.

In recognition of the importance of unpaid care and its relationship to the support provided by formal services, Chapter 3 in this edition is devoted to the topic.

**Table 8.18: People aged under 65 years with a severe or profound core activity restriction living in households: main source of assistance, activity in which help needed, 1998 ('000)**

| Activity with which help needed | Type of provider |                      |                          | Total |
|---------------------------------|------------------|----------------------|--------------------------|-------|
|                                 | No provider      | Informal co-resident | Informal non-co-resident |       |
| <b>Under 65 years</b>           |                  |                      |                          |       |
| Self-care                       | 26.7             | 305.5                | 14.5                     | 361.2 |
| Mobility                        | 30.6             | 343.9                | 47.9                     | 451.0 |
| Communication                   | *6.0             | 113.6                | **0.8                    | 138.3 |
| Health care                     | 16.6             | 240.9                | 14.6                     | 321.9 |
| Housework                       | *8.6             | 207.5                | 17.9                     | 252.6 |
| Property maintenance            | 21.0             | 209.7                | 39.1                     | 309.9 |
| Paperwork                       | *8.7             | 98.0                 | 14.2                     | 129.9 |
| Meal preparation                | *6.0             | 104.8                | *4.8                     | 121.6 |
| Transport                       | *8.8             | 224.3                | 41.5                     | 293.6 |

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

*Source:* AIHW 2000a:Table A15.3.

## 8.5 Outcomes

This section provides a brief overview of outcomes for people with a disability in the community, particularly those with communication restrictions. This is followed by recent national data on service-related outcomes; the focus is on a major recent study of unmet need for disability support services and the section does not attempt to provide a complete review of the research that has occurred in the last 2 years on evaluating or improving specific services.

The outcomes of disability services may be considered in three broad categories: consumer outcomes, community outcomes, and service-related outcomes. Consumer outcomes are defined here in terms of broad participation in the community, and the ICF domains for activities and participation provide a useful, standard framework for their measurement. Community outcomes reflect an aggregation of individual consumer outcomes, and also factors that can only be measured at community level, such as community attitudes to disability and equity of access to services. Service-related outcomes may relate to how well a service is achieving specified outcomes for clients or how well it is conducting its business, for instance in terms of efficiency or service quality (AIHW 2000b, 2001a:302-7).

### People-related outcomes

Outcomes for people with a disability have been reported in previous editions, using the ICF framework to shape an examination of the extent of their participation in a broad range of life areas (AIHW 1999b:255-65; AIHW 2001a:308-13). These outcomes are reported relative to others in the community, in line with the United Nations Standards (UN 1994). Similar broad indicators of participation are now being included in the annual report on government services (see, for instance, SCRCSSP 2002:697-705).

People with disabilities in 1998 were participating in many areas of Australian life, although often not to the same extent as the overall population. They tended to report lower levels of health, and were less likely to have finished school or be active in the paid workforce. They tended to have lower incomes than the rest of the population, although the receipt of government payments diminished these differences. The main focus of their social activities was family and friends, who were also the main providers of assistance to them.

These analyses in previous editions of this report have revealed some positive trends in recent years. People with disability were more likely in 1998 to be living in the community than in previous years. There appeared to be increasing rates of school attendance, especially in 'ordinary' school classes. While people with a disability, especially those with severe or profound restrictions, had poorer labour market outcomes (both participation and employment rates) than did others, improvements in the general labour market did flow through to them.

The influence of the environment on disability outcomes, including via the provision of aids and equipment, is an area where better information is required. Available data have been sought and summarised in a recent report (AIHW: Bricknell 2003). Aids and equipment are clearly of great importance to people with a disability, with almost 50% of them using some form of equipment in 1998. The number of aids used rose with the

severity of restriction, people with a profound core activity restriction using 3.5 aids on average, and people with primary carers more likely to be using aids (see also Section 8.4).

## Communication restrictions

Communication is a basic human activity and need, and a key element in social participation. Communication is one of the three 'core activities' in the ABS Survey of Disability Ageing and Carers, and the need for assistance with any one of these defines the ABS notion of 'severe or profound core activity restriction'. However, data on people with such restrictions are predominantly data about people with mobility or self-care needs; in 1998 there were 516,400 people in households needing assistance with self-care, 724,600 with mobility and 166,900 with communication (AIHW 2000a:107). It is therefore of interest to describe more fully the outcomes for this smaller but important group, especially in view of the finding that, among people receiving disability support services, effective spoken communication has been found to be closely related to the need for other supports, for instance self-care (AIHW 1999a).

This section explores the relationship between communication restrictions and other outcomes for people with a disability. It is useful to keep in mind the definitions and methods of the ABS survey when considering data from it (Box 8.9).

### Box 8.9: 'Communication' in the ABS population survey

*Communication activities in the ABS survey included understanding or being understood by family and friends and/or strangers.*

*Communication restrictions were rated as:*

- *profound, when the person was unable to communicate or always needed help with the activity;*
- *severe, if the person sometimes needed help, had difficulty understanding or being understood by family and friends, or could communicate more easily using sign language or other non-spoken forms of communication;*
- *moderate, if the person needed no help but had difficulty communicating;*
- *mild, if the person needed no help, had no difficulty, but used 'aids and equipment'.*

*Survey results were based on personal interviews where possible. Proxy interviews were conducted for people aged under 15 years and for those aged 15–17 years whose parents did not permit them to be personally interviewed.*

*Questions about assistance with communication were asked only in respect of people aged 18 years or more with a disability where the interview was by proxy, and persons aged 5–17 years with a disability and interviewed by proxy, where the person was reported as being slow at learning/understanding, having a mental illness, or a hearing loss, or loss of speech, or a nervous/emotional condition, or head injury, or brain damage.*

*Source: ABS 1999.*

**Table 8.19: Level of communication restriction among people with a disability living in households, 1998**

| Level of communication restriction   | Core activity restriction <sup>(a)</sup> |              |                        |              | Total with a disability |              |
|--------------------------------------|--|--------------|------------------------|--------------|-------------------------|--------------|
|                                      | Severe or profound                       |              | Not severe or profound |              | No. ('000)              | Per cent     |
|                                      | No. ('000)                               | Per cent     | No. ('000)             | Per cent     |                         |              |
| Profound                             | 58.3                                     | 6.1          | 0.0                    | 0.0          | 58.3                    | 1.7          |
| Severe                               | 118.6                                    | 12.3         | 0.0                    | 0.0          | 118.6                   | 3.5          |
| Moderate                             | 28.9                                     | 3.0          | 55.2                   | 2.2          | 84.1                    | 2.5          |
| Mild                                 | 83.6                                     | 8.7          | 266.0                  | 10.8         | 349.5                   | 10.2         |
| Total with communication restriction | 289.4                                    | 30.1         | 321.2                  | 13.0         | 610.6                   | 17.8         |
| No restriction                       | 672.2                                    | 69.9         | 2,143.2                | 87.0         | 2,815.4                 | 82.2         |
| <b>Total</b>                         | <b>961.6</b>                             | <b>100.0</b> | <b>2,464.4</b>         | <b>100.0</b> | <b>3,426.0</b>          | <b>100.0</b> |

(a) Refers to a person's overall severity level of core activity restriction, which is determined by their highest level of restriction in self-care, mobility and communication activities.

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

In 1998, of the 3,426,000 people with a disability living in households, 961,600 or 28.0% had a severe or profound restriction (Table 8.19). Of these, 18.4% had a severe or profound communication restriction, 11.7% had a mild or moderate restriction, and almost 70% had no communication restriction. This table and the following analysis focus on people with severe or profound core activity restrictions, and explore the differences within this group, between those with communication restrictions of any severity and others.

### Communication and schooling

Of people aged 5–20 with severe or profound restrictions and living in households, most had a communication restriction—93,700 or 62% (Table 8.20). Those with such restrictions were much more likely than the others to be attending a special school (19.7%, compared with 5.6%) and much less likely to be attending school in an ordinary class (42.8%, compared with 58.7%).

**Table 8.20: People aged 5–20 with a severe or profound restriction living in households, by school attended and communication restriction, 1998**

|                                 | Communication restriction |              | No communication restriction |              |
|---------------------------------|---------------------------|--------------|------------------------------|--------------|
|                                 | No. ('000)                | Per cent     | No. ('000)                   | Per cent     |
| Ordinary school class           | 40.1                      | 42.8         | 33.6                         | 58.7         |
| Ordinary school (special class) | 25.3                      | 27.0         | 6.8*                         | 11.9         |
| Special school                  | 18.5                      | 19.7         | 3.2*                         | 5.6          |
| Not applicable                  | 9.8                       | 10.5         | 13.6                         | 23.8         |
| <b>Total</b>                    | <b>93.7</b>               | <b>100.0</b> | <b>57.2</b>                  | <b>100.0</b> |

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

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

**Table 8.21: People aged 15–64 years with a severe or profound restriction living in households: labour force status and employment restrictions, by communication restriction, 1998 (per cent)**

|   | <b>Communication<br/>restriction</b> | <b>No<br/>communication<br/>restriction</b> |
|---|--------------------------------------|---|
| <b>Labour force status</b>  |                                      |   |
| Employed  | 20.8                                 | 32.8  |
| Unemployed  | *3.7                                 | *3.8  |
| Total in the labour force   | 24.5                                 | 36.6  |
| Not in the labour force   | 75.5                                 | 63.4  |
| <b>Employment restrictions</b>  |                                      |   |
| Restricted in type of job   | 44.0                                 | 42.3  |
| Restricted in number of hours   | 13.0                                 | 29.2  |
| Difficulty in changing job or getting a better job                        | 37.4                                 | 34.5  |
| Need for time off work  | *7.3                                 | 15.2  |
| Need for employer provided equipment and/or special arrangements          | 20.4                                 | 12.8  |
| Need for ongoing supervision or assistance                                | 20.6                                 | *7.7  |
| Need for support person   | 53.4                                 | 46.8  |
| <b>Other employer arrangements</b>  |                                      |   |
| A disability support person or someone at work to assist/train on the job | 14.5                                 | *3.3  |
| Special equipment   | 9.7                                  | *4.6  |
| Training or retraining  | *7.5                                 | **1.0                                       |
| Different duties  | *4.8                                 | *4.6  |
| <b>Severity of employment restriction</b>                                 |                                      |   |
| Profound  | 51.4                                 | 43.8  |
| Severe  | 22.5                                 | 10.8  |
| Moderate  | 23.4                                 | 36.8  |
| Mild to no employment restriction   | **2.6                                | *8.6  |
| <b>Total number ('000)</b>  | <b>79.2</b>                          | <b>413.1</b>                                |

*Notes*

1. Estimates marked with \* have an associated relative standard error (RSE) of between 25% and 50%. Estimates marked with \*\* have an associated RSE of 50% or more. These estimates should be interpreted accordingly.
2. Total may not equal the sum of the components as the questions on employment restriction were asked separately in the survey.

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

## Communication and employment

In 1998, there were 79,200—or 16% of the 492,300 people aged 15–64 years with severe or profound restrictions, living in households—who had a communication restriction (Table 8.21). As for education, the presence of communication restrictions correlated with poorer employment outcomes and more employment restrictions, compared with outcomes for others with severe or profound restrictions not including communication. Those people with communication restrictions were:

- more likely to be not in the labour force—75.5% were not, compared with 63.4% of those without a communication restriction;
- less likely to be employed—20.8%, compared with 32.8%;
- more likely to need equipment or special arrangements (20.4%), supervision or assistance (20.6%) or a support person (53.4%); these figures compare with 12.8%,



7.7% and 46.8% respectively, for people with severe or profound restrictions but no communication restriction;

- more likely to have severe or profound employment restrictions—73.9% (compared with 54.6% of people without a communication restriction).

### **Communication restrictions, age, sex and assistance**

There were some marked differences between males and females with communication restrictions (AIHW 2003i). Of people aged under 65 years with a severe or profound restriction, 69% of those with communication restrictions were male. Communication restrictions also correlated with a particular pattern of care, in that people with such restrictions were much more likely to be receiving a combination of both informal and formal assistance—65% (compared with 32.9% of those with other severe or profound restrictions).

An interesting feature of communication restrictions emerges when Tables 8.20 and 8.21 are compared. There were more people with severe or profound core activity restrictions and communication restrictions in the relatively narrow age range 5–20 years (93,700) than there were among those aged 15–64 years (79,200). This appears to reflect a compounding of two effects: that relatively more people in younger age groups in 1998, particularly males, reported severe or profound restrictions (Figure 8.3), and that it was more likely that people in these age groups reported communication restrictions—62% (93,700 of 150,900, Table 8.20), compared with 16% (79,200 of 492,300, Table 8.21). There is a range of possible factors here, the most obvious being that, in the earlier years of life, schools and parents are aware of learning and communication difficulties and may be actively addressing them. In older years these problems may ameliorate because of earlier interventions, or people may find activities and environments where these restrictions have less effect on their lives and are hence less likely to be reported in the survey. This statistical pattern aligns with the finding that relatively more young males were recorded as having difficulty with ‘learning and understanding things’ (see Figure 8.4), and with the peaking in intellectual disability estimates in these age ranges (AIHW: Wen 1997).

## **Service-related outcomes**

Service planning and budgeting rely on four separate but interrelated components: dealing with unmet need or demand; planning for growth in the target population; ensuring viability in the face of wages, insurance and other cost growth; and taking the initiative on ‘creative service strategies’ in the light of these realities as well as developments in service philosophy, evaluation research and stated consumer priorities (Shean 2003). The National Disability Administrators recently commissioned two related studies to inform them on the first three topics (AIHW 2002b; SPRC 2002).<sup>7</sup> The SPRC study suggested that growth of 2.3% nationally would be needed to deal with population increase and some anticipated cohort effects of service use patterns; further, it was suggested that indexation for wages growth would best address the need to adjust for cost increases.

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<sup>7</sup> The first two topics had been the subject of a previous study commissioned by the Administrators (AIHW 1997b).

The AIHW study was to:

- assess the effectiveness of unmet need funding in reducing unmet need for disability services; Australian governments had made available additional funding for these services, totalling \$519 million over the 2 years 2000–01 and 2001–02; and
- identify any remaining unmet need for disability accommodation, in-home support, day programs, respite services and disability employment services, in order to obtain an understanding of current shortfalls in services.

The outcomes of the project were to inform discussion and negotiations regarding the third Commonwealth/State Disability Agreement (CSDA).

### **Effectiveness of unmet need funding**

The unmet need funding was found to have been effective in putting additional services on the ground. Estimates of the size of these effects varied considerably according to the data used. Using CSDA MDS data as a basis, the numbers of new accommodation places and new community access places were estimated as 920 and 1,315 respectively (AIHW 2002b:xviii).

These additional services were recognised and appreciated in the field, according to discussions with peak disability groups held in the course of the study. The views of the field were perhaps best summed up by one participant in these discussions who commented: ‘I now feel more confident that there is a chance of some assistance in areas where there was virtually none’.

Further, the nature of some of the additional services—particularly the focus on flexibility, the use of individual packages and local area coordination mechanisms—was positively viewed. Where there was flexibility and responsiveness, there were stories of consumers, carers and service providers working together to achieve good outcomes, and often cost-effective ones. The effectiveness of these newer services had been verified by literature drawn on by jurisdictions in developing new approaches.

Nevertheless, these peak discussions also raised issues about the effectiveness of CSDA services and the program overall (AIHW 2002b:111–13). One participant pointed out that effectiveness was, ultimately about ‘doing human things well’—how services are delivered may matter as much as what is delivered. Other themes included: choice regarding the nature and timing of services; consumer autonomy including, for instance, involvement in planning; mutual respect; and stability and quality of staffing. Issues relating to program management were also raised: the need for balance, in terms of promoting flexibility and innovation while still maintaining a significant body of stable, cost-effective services and infrastructure.

Despite the new resources provided, there was still a view that greater focus was needed on proactive planning and case management, so as to move from only offering assistance to people when they reach crisis, to planning transitions with people ahead of time.

### **Ageing carers**

A number of jurisdictions specifically addressed the issue of ageing carers by providing individualised packages or programs using the Commonwealth unmet needs funds; these numbers totalled nearly 3,000 people across six jurisdictions (AIHW 2002b).

The main messages from the consultations with peak organisations regarding ageing carers were:

- Respite is useful and appreciated.
- Centre-based respite is needed as well as in-home respite.
- What is often on ageing carers' minds is 'handing over' or retiring. Packages and residential arrangements are greatly valued when they allow the carer to begin withdrawing from the primary role.

As one carer put it: 'In-home support should not be a life sentence ... for 38 years I haven't had a chance to be myself'. For these people, the need is to plan and be assured of future care and accommodation arrangements, often for a son or daughter they have cared for over many years. This assurance is critical to their physical and mental health as they themselves age.

### **Remaining unmet need for specific services**

A number of data sources were used to develop and refine the estimates of remaining unmet need. Population survey data were useful as they relate to all people across the community who report specific needs for assistance. As well, data from those jurisdictions that maintain registers of service needs or have holistic application processes (holistic in the sense that they avoid double-counting of applicants) were extrapolated to provide national indications of urgent unmet needs for service. Orders of magnitude of estimates based on these different approaches were compared, and estimates refined in a process of triangulation. The AIHW made the estimates on a conservative basis, with the aim of providing reliable 'lower bound' estimates.

The resulting estimates of remaining unmet need in 2001 (Table 8.22) were:

- 12,500 people needing accommodation and respite services;
- 8,200 places for community access services (which could in practice be accessed by more than one person); and
- 5,400 people needing employment support.

There was further evidence that the service system for people with disabilities was under pressure:

- Jurisdictions reported that they were providing most new services to people with very urgent needs. There appeared to be between 6 and 24 times more people seeking services and on jurisdiction registration or waiting lists in 2000–01 than were removed from these lists (usually because they were offered a service). Waiting times reported were long (AIHW 2002b:114–36).
- Pressures at the service boundaries were evident: aged care services, housing, transport, health and equipment services were examples of related service areas where the study team heard evidence of pressure or scarcity (AIHW 2002b:196–204).
- Qualitative evidence came from the peak discussions about the nature and effects of unmet need (AIHW 2002b:179–92).

**Table 8.22: Estimates of unmet need for specific services, 2001**

|   | <b>Estimate of unmet need</b> | <b>Description of group</b>   |
|---|-------------------------------|---|
| <b>Accommodation and respite</b>          | 12,500 people                 | People needing assistance at least 3–5 times per day with ADL <sup>(a)</sup> or less frequent assistance with multiple ADLs, who need assistance from a formal service but cannot get it because no service is available, it costs too much, they are otherwise unable to arrange a service, or it does not provide sufficient hours.<br><i>Confirmed by:</i> Numbers of people on state registers in three jurisdictions                 |
| <b>Community access<sup>(b)</sup></b>     | 8,200 places                  | Places for people not in the labour force, aged 18–64 years, who need at least daily assistance with two or more ADLs; they are not studying; the main reason they are not currently looking for a job is their own disability or illness; they wish to go out more often but are not doing so because of their disability or illness.<br><i>Confirmed by:</i> Numbers of people on state registers in three jurisdictions                |
| <b>Employment support<sup>(b,c)</sup></b> | 5,400 people                  | Unemployed people who <i>either</i> need at least daily assistance with any ADL <i>or</i> need at least weekly assistance with guidance, PLUS People not in the labour force who could work with special assistance; the main reason they are not currently looking for a job is their own disability or illness; they <i>either</i> need at least daily assistance with any ADL <i>or</i> need at least weekly assistance with guidance. |

(a) Activities of daily living (ADLs) are self-care, mobility and communication.

(b) Community access and employment estimates exclude people who are currently attending any day program.

(c) Employment estimates were prepared before the 2002–03 Commonwealth budget announcements. These estimates may need to be revised if there is change in assumptions about the expected labour force participation of people currently receiving the Disability Support Pension, or in policy on eligibility for services.

*Source:* AIHW 2002b.

## 8.6 Conclusion

Disability is something that affects most people in the population, to varying degrees and at different life stages. For those most profoundly affected, disability can be a dominant feature of their lives, requiring great amounts of time, effort and, frequently, passionate advocacy.

Disability is a multidimensional concept that can be measured in various ways, depending on the scope and definition used.

In 1998, 3,610,300 people of all ages (19.3% of the population) reported ‘disability’ in the sense that they had one or more of 17 impairments, limitations or restrictions which had lasted or were likely to last for at least 6 months and which restricted everyday activities in some way. Of these, 2,385,100 people were aged under 65 (14.6% of the population in that age group), of whom 655,000 (4% of the population aged under 65) had a severe or profound core activity restriction, meaning that they sometimes or always needed assistance or supervision with self-care, mobility or communication.

The major disability groups in 1998 similarly ranged in size depending on the definition of disability used. Prevalence estimates were as follows:

- According to the broadest approach, 16.2% of Australians of all ages (11.6% of those aged under 65) reported physical/diverse disability; 2.7% (2.3% of people aged under 65), intellectual disability; 7.5% (4.2% of those aged under 65), sensory/speech disability; 4.1% (3.1% of under-65s), psychiatric disability; and 1.1% (1% of under-65s), disability related to acquired brain injury.
- A more restricted approach includes only those people with a severe or profound restriction. Among these people 5.2% of the total population (3.2% of people aged under 65) had 'physical/diverse' disability; 1.6% (1.1% of those aged under 65), intellectual disability; 2.1% (1.3% of under-65s), psychiatric disability; 2.8% (1.3% of under-65s), sensory/speech disability; and 0.6% (0.5% of under-65s), acquired brain injury .

Trends in disability prevalence are being affected by a complex range of factors. Particularly important are the effects of population ageing, and the ageing of the baby-boom generation in particular, as well as the emerging new features of disability in younger age groups. Services, then, are being provided and managed in a context of growth in the target population.

A number of major programs of national significance provide services and support to people with disabilities.

The largest income support programs are:

- the Disability Support Pension, with almost 660,000 recipients in June 2002 and expenses of \$6.4 billion in 2001–02;
- the Disability Pension (DVA), with almost 160,000 recipients in June 2002 and \$1.2 billion expenses; and
- the Carer Allowance (Child), with 115,404 recipients, and the Carer Allowance (Adult), with 153,863 recipients; together these allowances had combined expenses of \$645.7 million in 2001–02.

Disability support services under the CSDA were provided to 65,809 people on a snapshot day in 2002. National expenditure on this program totalled \$2.75 billion in 2001–02, of which 51.4% went to accommodation support services—services whose clients have the highest support needs.

A range of other services are accessed by people with disabilities, including home and community care (HACC) services; rehabilitation, hearing and equipment services; education, employment and housing. While almost 6,000 people aged under 65 were permanent residents of aged care homes on 30 June 2002, this 'access' is widely considered to reflect unmet need for more suitable services, particularly for those people—more than 1,000—aged under 50 years. Generic health services are also the subject of increasing attention from the disability sector, in terms of their adequacy and responsiveness to the special needs of people with disabilities.

Service outcomes, then, are mixed. Significant resources and intense efforts are expended on the provision of services to people with disabilities. All Australian governments are involved in initiatives to increase funding and enhance the quality of services. However, as well as the question marks over generic services such as aged care and health, there are recognised shortfalls in the provision of disability support

services: 12,500 people needing accommodation or respite services in 2001; 5,400 needing employment support; and a shortfall of 8,200 places for community access programs.

Family and friends provide most of the assistance to people with disabilities. Older carers are increasingly expressing their need to plan and be assured of their son's or daughter's future care and accommodation arrangements, and their concerns about the shortfalls in support services.

People with disability are participating in a wide range of areas of Australian life, although generally not to the same extent as the overall population. A picture of this participation has been built up in successive editions of these biennial reports and is summarised in Section 8.5. This 2003 edition focuses on the interesting area of 'communication'. Communication restrictions were found to correlate with poorer education and employment outcomes. Communication restrictions, like intellectual disability, appear to be more likely to be reported for people, particularly males, in younger age ranges.

Disability data and their infrastructure have improved over the 10 years since these biennial reports began but, as with services, further improvements beckon. There is now an agreed international classification (the ICF) on which data concepts and collections can be built, and the Australian ICF User Guide has been developed to promote its sensible use in Australia and these concepts are now reflected in national data dictionaries. There are also key national data collections that use these concepts and standards, including the main population survey and the national collection on disability support services. The national data collection for disability support services under the CSTDA has been redeveloped and will enable a much more complete picture of these services and their users. Efforts are again being made to develop a suitable question on disability for the population census. All this represents significant progress towards enhanced and more consistent disability data.

These achievements provide a foundation for further improvements in national disability data, perhaps in the area of income support, as well as for a wide range of health and other generic services. The challenge will be to implement cost effective data enhancements so that better and 'joined up' information is available, useful to people working in the various fields dealing with human functioning and disability, and meaningful to and desired by the people with disabilities.

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