

# 1 Introduction

## 1.1 Project objectives and report outline

The objective of this study is to investigate the nature of demand, the extent of unmet demand and the projected future demand for key disability support services provided under the Commonwealth State/Territory Disability Agreement (CSTDA).

The Australian Institute of Health and Welfare (AIHW) was commissioned by the Disability Policy and Research Working Group (DPRWG) to undertake this project, which will inform negotiations of a fourth CSTDA. This is the fourth study conducted by the AIHW on the topic of met and unmet demand for disability support services (AIHW: Madden et al. 1996; AIHW 1997, 2002) and is largely an update of analyses conducted in the two most recent studies.

The goal of the Institute in conducting this important work is to provide robust information about the nature of demand for disability support services now and into the future. Key available data sources, namely the Commonwealth State/Territory Disability Agreement National Minimum Data Set (CSTDA NMDS) and data from existing waiting list or registration processes held at the jurisdictional level, do not readily provide this information. This report therefore relies largely on in-depth analysis of population data from the Australian Bureau of Statistics' 2003 Survey of Disability, Ageing and Carers. The underlying assumptions made to generate these derived estimates of demand and unmet demand for disability support services are clearly stated throughout the report.

This report is organised as follows:

- Chapter 1 provides background to the Commonwealth State/Territory Disability Agreement and a statistical picture of the services it delivers.
- Chapter 2 outlines the framework and method for the study.
- Chapter 3 presents a profile of met demand in 2004–05, using data from the Commonwealth State/Territory Disability Agreement National Minimum Data Set (CSTDA NMDS).
- Chapter 4 presents available information from jurisdictions that administer the CSTDA about their methods of managing demand, and their data on unmet demand.
- Chapter 5 presents population estimates of demand and unmet demand for the key service types (accommodation and respite, community access and disability employment services).
- Chapter 6 provides projections of future demand for disability support services, largely focusing on future growth in the numbers of people with severe or profound core activity limitation.
- Chapter 7 presents information on service interfaces and other issues that have the potential to influence demand for CSTDA disability services, to provide a broader context within which the data presented in earlier chapters, including estimates of unmet demand, can be interpreted.
- Chapter 8 presents the key conclusions from this study.

## 1.2 The Commonwealth State/Territory Disability Agreement

The Commonwealth State/Territory Disability Agreement specifies the responsibilities of Australian governments in providing disability support services. Under the third Agreement of 2002–07, the Australian Government is responsible for the planning, policy setting and management of disability employment services, and the states and territories are responsible for all other disability support services, including accommodation support, community access, community support and respite services. Governments share responsibility for advocacy, information and print disability services. Box 1.1 describes the service types covered by the CSTDA.

The CSTDA states that the following objective underpins the national framework for services for people with disabilities:

The Commonwealth and States/Territories strive to enhance the quality of life experienced by people with disabilities through assisting them to live as valued and participating members of the community (CSTDA 2003).

In recognition of the 'heightened vulnerability' of people with disabilities and the complementary nature of specialist and generic services for people with disabilities, the 2002–07 CSTDA also includes the following five policy priority areas in working towards the objectives of the CSTDA:

- strengthen access to generic services for people with disabilities
- strengthen across government linkages
- strengthen individuals, families and carers
- improve long-term strategies to respond to and manage demand for specialist disability services
- improve accountability, performance reporting and quality (CSTDA 2003).

Under the CSTDA it is agreed that specialist disability services are provided only to benefit people with disabilities, where:

'people with disabilities' means people with disabilities attributable to an intellectual, psychiatric, sensory, physical or neurological impairment or acquired brain injury (or some combination of these) which is likely to be permanent and results in substantially reduced capacity in at least one of the following:

- self care/management
- mobility
- communication

requiring significant ongoing and/or long-term episodic support and which manifests itself before the age of 65 (CSTDA 2003).

While these high level statements of the objective and target group of the Agreement guide practice on the ground across Australia, there are no nationally comparable eligibility requirements, assessment methods or waiting list systems.

Negotiations for a fourth CSTDA commenced in 2006.

### **Box 1.1: Definitions of service groups covered by the Commonwealth State/Territory Disability Agreement**

<i>Accommodation support</i>	<i>These are services that provide accommodation to people with a disability and services that provide the support needed to enable a person with a disability to remain in his or her existing accommodation or move to a more suitable or appropriate accommodation.</i>
<i>Community support</i>	<i>These services provide the support needed for a person with a disability to live in a non-institutional setting (not including support with the basic needs of living such as meal preparation and dressing included under accommodation support).</i>
<i>Community access</i>	<i>These are services designed to provide opportunities for people with a disability to gain and use their abilities to enjoy their full potential for social independence. People who do not attend school or who are not employed full time mainly use these services.</i>
<i>Respite</i>	<i>Respite services provide a short-term and time-limited break for families and other voluntary caregivers of people with a disability, to assist in supporting and maintaining the primary caregiving relationship, while providing a positive experience for the person with a disability. Although there are therefore two 'clients' – the carer and the person with a disability – in the CSTDA NMDS collection, the person with a disability is regarded as the client. Statistical tables in this report reflect this perspective.</i>
<i>Employment</i>	<i>There are two types of employment services that provide employment assistance to people with a disability. The first type, open employment, provides assistance in obtaining and/or retaining paid employment in the open labour market. The second type, supported employment, provides employment opportunities and assistance to people with disabilities to work in specialised and supported work environments. Before 1 December 2004, there was also a third employment service type, dual open/supported services, which provided a combination of both open and supported employment services.</i>
<i>Advocacy, information and print disability</i>	<i>Advocacy services are designed to enable people with a disability to increase the control they have over their lives through the representation of their interests and views in the community. Information services provide accessible information to people with disabilities, their carers, families and related professionals. This service group also includes mutual support/self-help groups – special interest groups that promote self-advocacy – and print disability, which includes alternative formats of communication for people who by reason of their disabilities are unable to access information provided in a print medium.</i>
<i>Other</i>	<i>Includes research and evaluation, training and development, peak bodies, and any other support services completely outside any of the defined service types above.</i>

Source: AIHW 2006b.

## 1.3 Bilateral agreements

Bilateral agreements between states/territories and the Australian Government, relating to CSTDA services, have been a widely used adjunct to the CSTDA since they were first introduced in the 1998 Commonwealth/State Disability Agreement.

The purposes of the bilateral agreements are to:

- (a) provide for agreement and action between the Commonwealth and individual States/Territories on strategic disability issues within the broad national framework
- (b) provide a continuing procedure for negotiation and agreement between the Commonwealth and individual States/Territories on transfer of responsibility for particular services from one level of government to another and
- (c) bring into the scope of the Agreement those specialist disability services which are mutually agreed between the Commonwealth and individual States/Territories to be important to the national framework for disability services, but which are not yet included in the Agreement (CSDA 1998).

Bilateral agreements were reached in 2000 to address 'unmet need'. Under these agreements with the Commonwealth, all jurisdictions were funded to 'help address unmet needs by providing additional services which enable people with disabilities who have ageing carers to remain supported within their families in their local communities' (for example, FACS & DADHC 2000). Details of these bilateral agreements are provided in the 2002 AIHW demand study. The 2002 study was designed to assess the effectiveness of the 'unmet needs' funding in reducing unmet need for disability services and identify any remaining unmet need for disability accommodation, in-home support, day programs, respite services and disability employment services (AIHW 2002).

The purpose and some standard key principles of this funding for all jurisdictions are presented in Box 1.2.

The 'unmet need' funding was subsequently continued under the 2002-07 CSTDA. Further bilateral agreements negotiated during the current CSTDA have also focused on the needs of ageing carers of people with disabilities.

This study is largely an update of the previous unmet demand study conducted by the AIHW in 2002 and does not include new terms of reference to explore, for example, the impact of bilateral agreements made after the 2000 'unmet need' agreements. However, given the ongoing focus on the needs of ageing carers in subsequent bilateral agreements and the overall CSTDA, data on the support needs of ageing carers are again presented as part of this study (Chapter 7).

### **Box 1.2: Standard purposes and key principles for all states and territories, CSDA bilateral agreements in 2000**

#### *FUNDS TO ASSIST THE IN-HOME SUPPORT AND RESPITE CARE NEEDS OF PEOPLE WITH DISABILITIES WITH AGEING CARERS*

(a) *Purpose:*

*To help address unmet needs by providing additional services which enable people with disabilities who have ageing carers to remain supported within their families in their local communities.*

*The State's new contribution will be used to assist in addressing other priority areas of unmet need.*

(b) *Key Principles:*

- (i) *Priority will be given to people with a disability whose carer is aged over 65 (or, in the case of Aboriginal people, aged 45 years or over), including older carers in rural and remote regions. Once these most critical needs are met, attention may then be turned to those families where the carer is approaching this age with an emphasis on those who have been caring for over 30 years.*
- (ii) *In supporting families, the new services will focus on a range of supports which respond most appropriately to individual circumstances and provide respite to the carer so as to enable the person with a disability to continue living at home.*
- (iii) *Funding will be allocated Statewide, with a focus on support provided to families located in regional areas.*
- (iv) *A focus will be on building and strengthening the capacity of communities.*
- (v) *The new services will not result in cost shifting across jurisdictions or programs.*
- (vi) *Where appropriate, the new services will be integrated with, and supplementary to (and not replace), existing disability and aged care funding, including Carer Respite Centres.*
- (vii) *The Commonwealth funding component of the new services must be publicly acknowledged by the State.*
- (viii) *Wherever possible, existing reporting mechanisms will be utilised.*

Source: FACS & DHS 2000.

## **1.4 A statistical picture of the CSTDA in practice**

The CSTDA includes a requirement that all participating governments provide information according to the Commonwealth State/Territory Disability Agreement National Minimum Data Set (CSTDA NMDS). This section provides some background to the CSTDA NMDS and then uses data from the CSTDA NMDS collections to provide a brief statistical picture of the CSTDA on the ground. A brief overview of CSTDA-related government expenditure is also provided, based on financial data collected annually by jurisdictions and forwarded to the Productivity Commission for publication under the auspices of the Council of Australian Governments (SCRGSP 2006).

## The CSTDA NMDS

The CSTDA NMDS and its associated collections comprise a set of nationally significant data items that are collected in all Australian jurisdictions (state, territory and Australian governments) and an agreed method of collection and transmission.

The purpose of the CSTDA NMDS collections is to facilitate the annual collation of nationally comparable data about CSTDA-funded services and obtain reliable, consistent data with minimal burden on disability service providers. The CSTDA NMDS generates comprehensive information about the five broad CSTDA service groups (accommodation support, community support, community access, respite and employment) and the clients using these service types (see Box 1.1).

Between 1994 and 2002, this information was collected on one snapshot day in the year. In recognition of the changing information needs in the disability services field, the AIHW and the National Disability Administrators (now the Disability Policy and Research Working Group) redeveloped the collection. The most significant change resulting from this redevelopment was that data are now collected on a full-year, ongoing basis. There are also additional data items about, for example, informal carers, individual funding status and (for selected service types) service quantity. Full-year data have been collected since 2003–04.

## Expenditure

The total government expenditure on disability support services by Australian governments under the CSTDA in 2004–05 was \$3.6 billion. Accommodation support services accounted for half this expenditure (50%), with around one-tenth of funding to each of community access (12%), community support (11%) and employment services (9%) (Table 1.1).

**Table 1.1: Expenditure on disability support services by Australian, state and territory governments, by service group and administration expenditure, 2004–05**

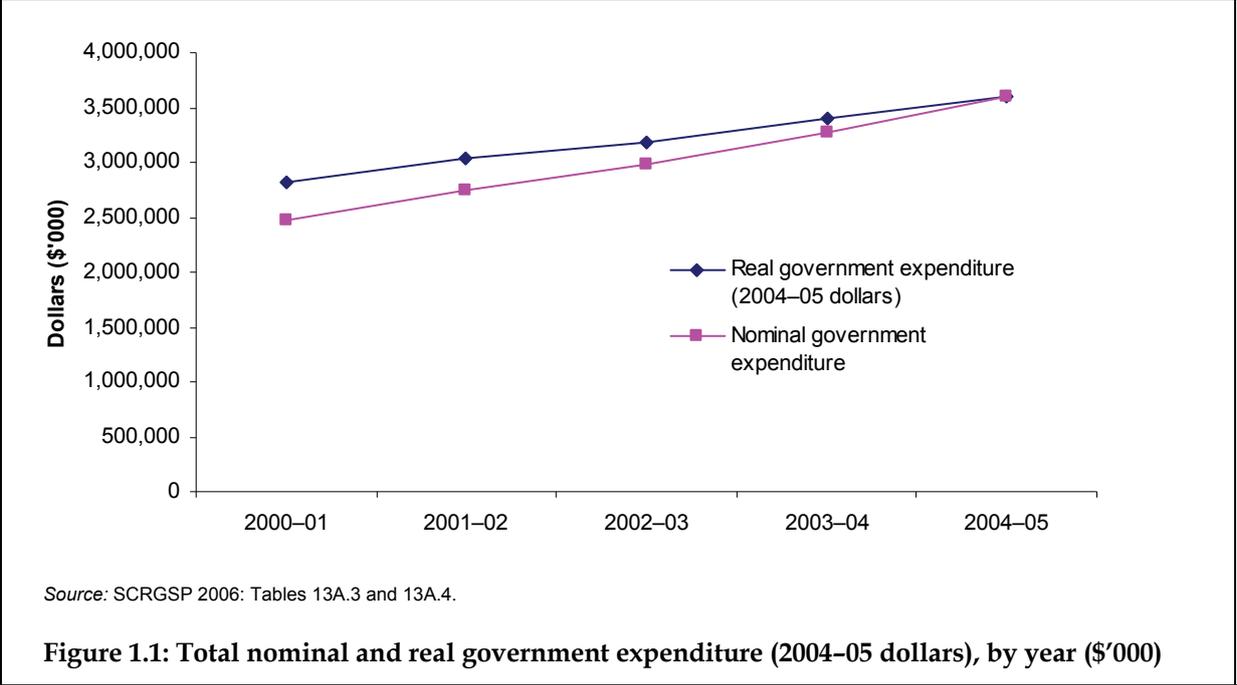
Service group	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Aust Govt	Australia
\$ million										
Accommodation support	652.8	515.5	233.3	158.3	142.7	54.9	27.5	13.8	—	1,798.8
Community support	85.6	146.1	53.7	49.9	33.9	9.1	11.0	9.9	—	399.2
Community access	125.8	165.9	61.3	22.5	16.4	13.2	3.6	2.1	7.7 <sup>(a)</sup>	418.6
Respite	65.6	46.5	40.3	19.6	8.9	5.9	4.0	1.5	4.5 <sup>(a)</sup>	196.7
Employment	—	—	—	—	—	—	—	—	324.5	324.5
Advocacy, information and print disability	8.0	7.2	6.6	2.2	4.0	2.0	0.9	0.1	14.1	45.1
Other support	2.1	41.5	3.9	14.3	13.6	1.0	1.7	0.1	58.9	137.0
<i>Subtotal</i>	<i>940.0</i>	<i>922.7</i>	<i>399.1</i>	<i>266.6</i>	<i>219.4</i>	<i>86.1</i>	<i>48.7</i>	<i>27.5</i>	<i>409.7</i>	<i>3,319.9</i>
Administration	112.0	81.7	38.2	14.7	5.2	5.4	8.5	1.2	32.6	299.5
<b>Total</b>	<b>1,052.0</b>	<b>1,004.5</b>	<b>437.3</b>	<b>281.3</b>	<b>224.6</b>	<b>91.4</b>	<b>57.2</b>	<b>28.8</b>	<b>442.3</b>	<b>3,619.4</b>

(a) Australian government funded community access and respite services are funded under the CSTDA from the Employment Assistance and Other Services appropriation fund.

Note: Figures may vary from those published in the *Report on government services 2006* (SCRGSP 2006) owing to the use of different counting rules in particular jurisdictions (e.g. some jurisdictions may include funding for psychiatric-specific services in Table 1.1 but not in SCRGSP 2006).

Sources: SCRGSP 2006; and unpublished data provided to AIHW from each jurisdiction.

Total government expenditure has increased in real terms from \$2.8 billion in 2000–01 to \$3.6 billion in 2004–05 (Figure 1.1).



## The CSTDA on the ground

### Service users and service groups

During 2004–05, there were 200,493 users of CSTDA-funded services (Table 1.2). Victoria recorded the highest percentage of service users (38%), followed by New South Wales (23%) and Queensland (14%).

Of the five broad service groups, the most commonly accessed was community support (used by 46% of all service users), followed by employment services (32%), community access services (22%), accommodation support services (17%) and respite services (12%) (Table 1.2). Patterns of service usage varied across jurisdictions. Further details about the specific service types offered within these broad service groups are provided in Chapter 3. It should be noted that, following the introduction of a redeveloped CSTDA NMDS in 2002, recreation and holiday programs were reclassified from the community support to the community access service group. This reclassification is accounted for in the analysis presented in Chapters 3 and 5.

**Table 1.2: Users of CSTDA-funded services, service group by state/territory, 2004–05**

Service group	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Total	%
Accommodation support	5,980	13,199	5,034	3,371	4,550	1,128	338	190	33,787	16.9
Community support	19,082	33,521	8,497	16,511	9,832	1,943	2,508	910	92,610	46.2
Community access	6,761	19,540	6,392	4,431	4,863	1,513	374	305	44,166	22.0
Respite	4,129	11,150	3,761	2,744	1,470	265	287	182	23,951	11.9
<i>Total state/territory services</i>	<i>28,521</i>	<i>60,069</i>	<i>16,432</i>	<i>19,499</i>	<i>15,447</i>	<i>3,658</i>	<i>3,087</i>	<i>1,350</i>	<i>147,748</i>	
Employment	19,037	18,567	12,340	6,151	5,919	1,768	793	395	64,835	32.3
<b>Total service users</b>	<b>45,148</b>	<b>75,110</b>	<b>27,229</b>	<b>23,346</b>	<b>19,612</b>	<b>5,154</b>	<b>3,753</b>	<b>1,655</b>	<b>200,493</b>	
<b>Total per cent</b>	<b>22.5</b>	<b>37.5</b>	<b>13.6</b>	<b>11.6</b>	<b>9.8</b>	<b>2.6</b>	<b>1.9</b>	<b>0.8</b>		

*Notes*

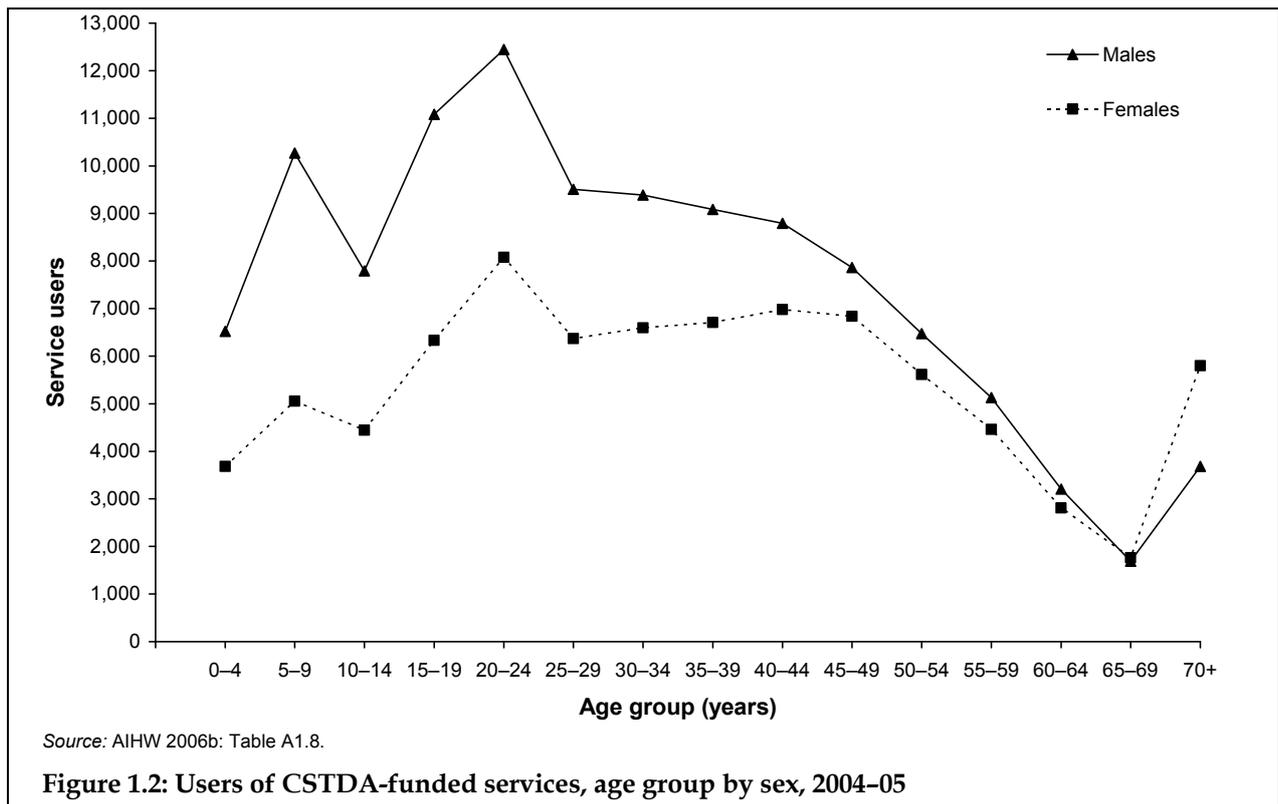
1. Service user data are estimates after use of a statistical linkage key to account for individuals who received services from more than one service type outlet during the 12-month period from 1 July 2004 to 30 June 2005. Totals for each state/territory may not be the sum of components since individuals may have accessed services in more than one service group during the 12-month period. Totals for Australia may not be the sum of the components since individuals may have accessed services in more than one state or territory during the 12-month period.
2. Service user data were not collected for all CSTDA service types.
3. Employment totals do not include the 804 people categorised as 'independent workers' during 2004–05.

Source: AIHW 2006b.

## Age and sex

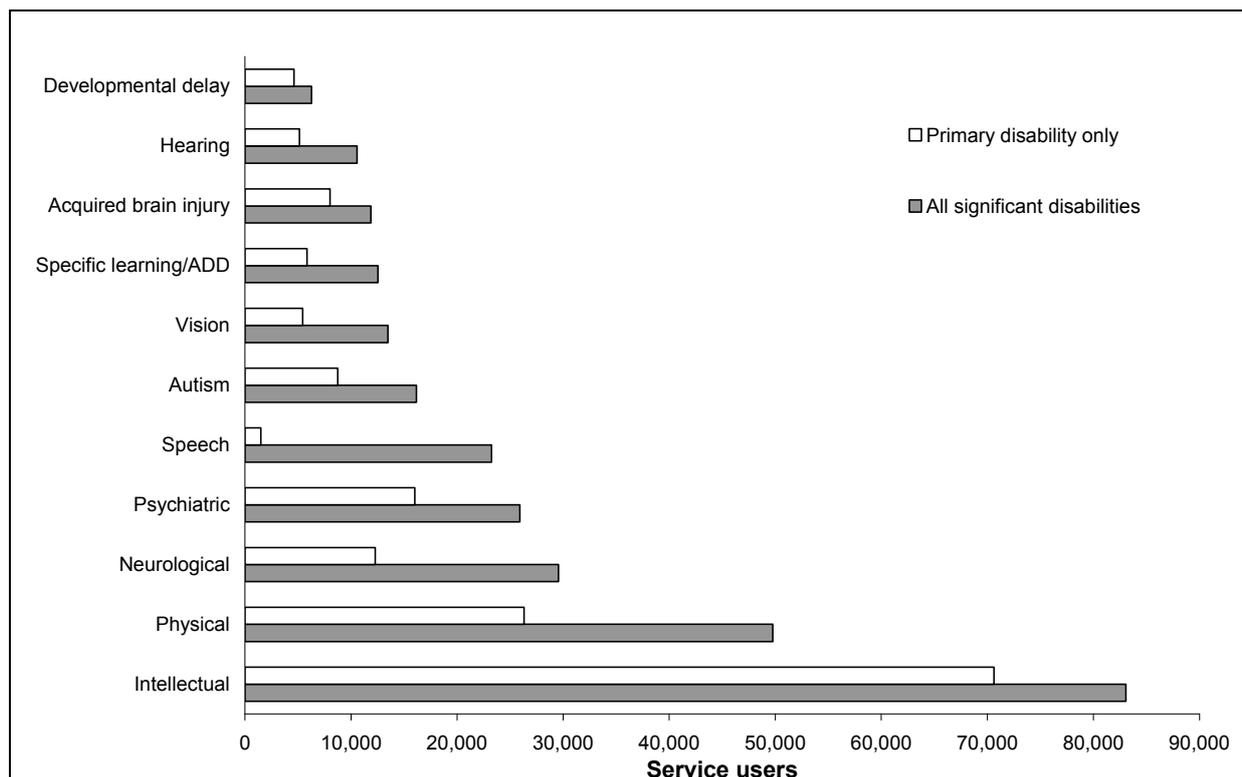
Around 56% (113,066) of service users were male, with more males than females in all 5-year age groups, except those aged 70 years and over (Figure 1.2). The largest number of service users was in the 20–24 year age bracket, for both males and females.

Females had a higher median age than males – 35.1 years for females and 29.4 years for males – and this difference was observed across all five broad service groups (AIHW 2006b:Appendix Table A1.9 and Figure 3.2). The overall median age of CSTDA service users increased by 0.5 years between 2003–04 and 2004–05 – from 30.4 years to 30.9 years (AIHW 2006b:Figure 3.3).



### Disability groups

Among CSTDA service users in 2004-05, intellectual disability was the most commonly reported disability group, both in terms of the reported primary disability (35%) and overall (when considering reporting of both primary and 'other significant' disabilities) (41%) (Figure 1.3). Physical disability was the next most frequently reported group (13% as a primary disability and 25% overall). Psychiatric disability was the third most commonly reported primary disability group (8%), and neurological the third overall (15%).



Source: AIHW 2006b:Table 3.7.

**Figure 1.3: Users of CSTDA-funded services, primary disability group and all significant disability groups, 2004-05**

### Service type outlets

Under the CSTDA NMDS, a service type outlet is the unit of a funded agency that delivers a particular CSTDA service type at or from a discrete location. If a funded agency provides, for example, both accommodation support and respite services or group homes and attendant care, it is counted as two service type outlets.

There were 8,448 service type outlets funded to provide services in 2004-05, of which:

- 3,637 (43%) provided accommodation support
- 1,551 (18%) provided community access services
- 1,301 (15%) provided community support
- 709 (8%) provided respite services
- 711 (8%) provided employment services (Table 1.3).

**Table 1.3: CSTDA service type outlets funded by Australian, state and territory governments, service type by state/territory, 2004–05**

<b>Service type</b>	<b>NSW</b>	<b>Vic</b>	<b>Qld</b>	<b>WA</b>	<b>SA</b>	<b>Tas</b>	<b>ACT</b>	<b>NT</b>	<b>Total</b>	<b>%</b>
Accommodation support	858	1,186	662	410	309	90	72	50	3,637	43.1
Community support	254	389	277	202	124	12	20	23	1,301	15.4
Community access	342	590	319	128	98	55	11	8	1,551	18.4
Respite	143	213	159	92	70	12	10	10	709	8.4
Other support	2	52	42	16	26	8	5	3	154	1.8
Employment support	241	162	118	56	79	35	10	10	711	8.4
Advocacy, information and print disability	24	165	63	28	43	36	22	4	385	4.6
<b>Total service type outlets</b>	<b>1,864</b>	<b>2,757</b>	<b>1,640</b>	<b>932</b>	<b>749</b>	<b>248</b>	<b>150</b>	<b>108</b>	<b>8,448</b>	<b>100.0</b>

*Notes*

1. A service type outlet may, in some cases, represent two or more locations that provide the same service type. (See AIHW 2006b:Section 2.4 for discussion of the definition of 'service type outlet'.)
2. Advocacy, information and print disability includes 86 Australian government funded and 299 state/territory government funded outlets.
3. All employment service type outlets are Australian government funded.

Source: AIHW 2006b.