

1 Introduction

The National Disability Administrators (NDA) commissioned the Australian Institute of Health and Welfare (AIHW) to carry out this project, to inform their negotiations about a third Commonwealth/State Disability Agreement (CSDA). The NDA are responsible for the funding and administration of disability support services in all jurisdictions in Australia.

This introductory chapter outlines the objectives of the project and the contents of this report. It also provides some general background to the current Agreement and its operation.

1.1 Project objectives and report outline

The objectives of the project, as specified by the NDA, are to:

- Assess the effectiveness of the unmet need funding in reducing unmet need for disability services by quantifying and describing additional services provided as a result of unmet need funding and, wherever possible, documenting the impact of these services for individuals receiving support. Effectiveness, in this context, refers to the degree to which stated funding objectives have been achieved.
- Identify any remaining unmet need for disability accommodation, in-home support, day programs, respite services, and disability employment services, to obtain an understanding of current shortfalls in services.

The outcomes of this project will inform discussion and negotiations regarding the third CSDA.

Study timeline

The study began on 26 November 2001 with the following key deadlines:

28 February 2002:	Final progress report to the Steering Committee for distribution to all jurisdictions.
8 April 2002: (varied to 15 April by Steering Group)	Draft final report to the Steering Committee for distribution to all jurisdictions.
30 April 2002: (varied to 10 May by Steering Group)	Final report to the Steering Committee for distribution to all jurisdictions.

Report outline

Following this introductory chapter, the second chapter outlines the study method and describes the key concepts used throughout the study. Chapter 3 analyses data provided by jurisdictions on the use of the unmet needs funding, in terms of the services to which various amounts of funding were applied and the clients receiving these services. Chapter 4 then draws together a range of information to consider the first main study question: the effectiveness of the unmet need funding. Chapter 5 outlines information obtained in the course of the study about how the various jurisdictions manage need and demand, and what they know about unmet need. Chapter 6 uses population survey data to construct 'baseline

estimates' of unmet need for the various types of disability support services. Chapter 7 then draws together information from Chapters 5 and 6, as well as other sources, to consider the second main study question: the evidence for remaining unmet need for disability support services. Chapter 8 outlines recommendations for costing remaining unmet need, as required by the study brief.

1.2 The Commonwealth/State Disability Agreement (CSDA)

The second Commonwealth/State Disability Agreement (CSDA) was finalised in May 1998. The Agreement:

- outlines the respective and collective roles and responsibilities of the Commonwealth and the States and Territories in funding, policy setting, planning and management of specialist disability services;
- provides a 'national framework to underpin the provision of specialist disability services across Australia, and a means for measuring and publicising progress of governments towards achieving this national framework'; and
- acknowledges the existence of unmet demand for specialist disability services and agrees to a Ministers' conference on the subject.

The 1998 CSDA sets out the following broad objective for specialist disability services in Australia:

The Commonwealth and the States strive to enhance the quality of life experienced by people with a disability through assisting them to live as valued and participating members of the community. (CSDA 1998 Clause 4(1))

Services provided under the CSDA 1998 are targeted to people who need ongoing support with everyday life activities. The target group is specified as 'people with disabilities':

'people with disabilities' means people with a disability 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 ongoing or episodic support.

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 these responsibilities for all other specialist disability services. Box 1.1 sets out the purposes of these services. Advocacy, print disability and information services (particular types of community support) are considered shared responsibilities under this agreement.

Box 1.1: Service types covered by the CSDA

<i>Accommodation support</i>	<i>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 their existing accommodation.</i>
<i>Community support</i>	<i>Services that 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>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 disabilities, to assist in supporting and maintaining the primary care-giving relationship, while providing a positive experience for the person with a disability.</i>
<i>Employment</i>	<i>Services that either provide employment assistance to people with a disability in obtaining and/or retaining paid employment in another organisation (open employment), and/or that support or employ people with a disability within the same organisation (supported employment).</i>
<i>Other</i>	<i>Other services include service evaluation and training, research and development, and services provided by peak bodies.</i>

Source: AIHW 2001a.

While, in practice, services are generally directed to people aged under 65 years, the CSDA places no age-based restrictions on access to services.

The first CSDA in 1991 represented an important historical development in the administration of disability services in Australia. Prior to that time, Commonwealth and State responsibilities had not been explicit and both levels of government had been involved, for instance, in accommodation and employment services. During the 1960s and 1970s there had been growth in the provision of such services, especially centre-based accommodation and sheltered employment; non-government service provision was subsidised by governments. State Governments also played a direct role, especially in accommodation service provision. In this era a clear disability philosophy began to emerge, with a human rights focus resulting in new, community-based service models. These new models were reflected in the Commonwealth's *Disability Services Act 1986*, and subsequently in the legislation of other jurisdictions and in the first CSDA (see further detail in AIHW 1993).

This project takes account of this history, and of the current policy and service context. Recent changes include:

- the provision of significant new funding by all jurisdictions and specifically, in the context of this project, the \$210 million nationally in 2000–01;
- innovation in the disability services field, for example:
 - new service types (for instance, individualised funding based on individual needs);
 - new policy directions (for instance, greater efforts to use, dovetail with or encourage transition into generic services such as residential aged care, community care including Home and Community Care (HACC), housing and health);
 - a continuation of trends to smaller community-based accommodation services and in-home support; and
 - wider uptake of apparently successful models pioneered in one jurisdiction, such as the Local Area Coordination model of Western Australia;
- greater recognition of the roles of carers and families, who underpin the success of de-institutionalisation and community care policies;
- continued trends in population growth and ageing, which are expected to impact on the need for disability support services.

1.3 Bilateral Agreements and unmet need funding

The 1998 CSDA allowed for Bilateral Agreements between the Commonwealth and the individual States and Territories.

The purposes of the Bilateral Agreements are to:

- (a) provide for agreement and action between the Commonwealth and individual States on strategic disability issues within the broad national framework;
- (b) provide a continuing procedure for negotiation and agreement between the Commonwealth and individual States 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 to be important to the national framework for disability services, but which are not yet included in the Agreement.

Further Bilateral Agreements were reached in 2000 to deal with 'unmet need'. Key background to these agreements included a paper by Disability Administrators (see Box 1.2). This paper based its main estimates on work previously commissioned by the NDA (AIHW 1997a); an excerpt from the summary of that report is in Appendix 1.

Box 1.2: Supporting Australians with severe or profound disabilities: a service partnership – Excerpt from Administrators’ Report

Since the Commonwealth/State Disability Agreement (CSDA) was first signed in 1991, governments have increased funding to disability services. The impact of this increased funding has been to significantly reform the service system, including changing the types of services provided, and decreasing institutional living options in favour of community based and in-home support options. The impact of additional dollars has primarily been on improving service quality and of benefit to existing service recipients. Consequently, the additional funding provided has not been sufficient to address the unmet demand.

At Clause 8(9)(a) of the new CSDA, signed in May 1998, Ministers agreed the Commonwealth Minister would within 12 months, convene a conference of Ministers to specifically address unmet demand and that Ministers may subsequently agree on the contribution of additional funds for this purpose ...

The Australian Institute of Health and Welfare have estimated the level of unmet demand and the cost of meeting unmet demand as \$293.8m. This paper breaks down the estimates provided by the Institute and proposes a range of options for Ministers to consider as a response to addressing unmet demand.

Three complementary strategies are proposed for Ministers to consider, which include:

- *provision of accommodation support to 750 individuals with profound disabilities who require intensive support with critical out-of-home accommodation needs and for whom family support is not an option (\$37.5m),*
- *addressing the needs of ageing carers through the provision of support delivered in the home or respite services to 8,600 individuals and families, and day programs to 8,160 individuals (\$174.232m),*
- *supporting younger families through the provision of support delivered in the home or respite services to some 4,050 individuals and families, and day programs for a further 3,840 individuals (\$82.057m).*

Officials, in preparing this paper, wish to provide information on which Ministers could make decisions. The paper makes no recommendations and the views expressed within are the consensus view of officials rather than their governments.

Source: Disability Administrators 1999.

Unmet need funding

Funding allocated under specific Bilateral Agreements between the Commonwealth and State/Territory Governments (‘unmet need funding’) for 2000–01 and 2001–02 is detailed in Table 1.1.

Summary of 2000 bilateral funding objectives

Under Bilateral Agreements with the Commonwealth in 2000, 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’. The purpose and some standard key principles of this funding for all jurisdictions are presented in Box 1.3.

The Bilateral Agreements also noted that the ‘State’s contribution will be used to assist in addressing other priority areas of unmet need’. These ‘other priority areas’ were not specified.

The ‘standard’ principles were included in the Victorian, Queensland, South Australian and Tasmanian Bilateral Agreements with the Commonwealth, and were slightly varied for New South Wales, Western Australia, Australian Capital Territory and Northern Territory, as indicated in Table 1.2.

Table 1.1: Unmet need funding offer: Commonwealth and State contributions

State/Territory	2000–01 \$m			2001–02 \$m		
	Commonwealth offer	State offer	Total	Commonwealth offer ^(a)	State offer	Total
New South Wales	16.84	93.41	110.25	34.45	119.308	153.758
Victoria	12.29	38.4	50.69	25.14	38.4	63.54
Queensland	9.155	9.0	18.155	18.73	18.0	36.73
Western Australia	4.905	9.5	14.405	10.04	15.97	26.01
South Australia	4.045	6.0	10.045	8.28	6.0	14.28
Tasmania	1.315	1.5	2.815	2.69	6.132	8.822
Australian Capital Territory	0.845	1.5	2.345	1.73	1.5	3.23
Northern Territory	0.605	0.652	1.257	1.24	1.23	2.47
Total	50.0	159.962	209.962	102.3	206.54	308.84

(a) The amount tabulated includes indexation of the Commonwealth offer.

Source: Based on Commonwealth Department of Family and Community Services 2001, unpublished data.

Box 1.3: Standard purposes and key principles for all States and Territories, CSDA Bilateral Agreements 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: Commonwealth Department of Family and Community Services & Department of Human Services Victoria 2000.

Table 1.2: Principles of Bilateral Agreements 2000

Vic	Standard (as in Box 1.3)
Qld	Standard (as in Box 1.3)
SA	Standard (as in Box 1.3)
Tas	Standard (as in Box 1.3)
NSW	More detailed principles applied than standard (with four additional principles)
WA	Slightly more detailed requirements in relation to the regional focus (in principle iii, requiring 65% of families to be located in regional WA)
ACT	No statewide or regional service delivery requirement in the ACT
NT	Slightly more detailed requirements in relation to the regional focus (in principle iii, requiring 50% of families to be located in regional areas)

1.4 A statistical picture of the CSDA, its funding and its clients

The principal data sources relating to the CSDA minimum data set (MDS) are:

- the CSDA MDS collections operated by all jurisdictions and the AIHW under the aegis of the National Disability Administrators (for example, AIHW 1999a, 2000a, 2001a); these collections focus on clients and services delivered; and
- the financial data collected annually by all jurisdictions and forwarded to the Productivity Commission for publication under the auspices of the Council of Australian Governments (SCRCSSP 2002).

The Commonwealth/State Disability Agreement Minimum Data Set (CSDA MDS) and its national collections comprise a set of nationally significant data items that are collected in all Australian jurisdictions and an agreed method of collection and transmission. Under the CSDA, the Disability Administrators in all Australian jurisdictions are responsible for 'agreeing on the definitions and overseeing the collection of nationally consistent data' (CSDA Clause 6(5)(f)). The purpose of the CSDA MDS collections is to facilitate the annual collation of nationally comparable data about CSDA-funded services.

Since 1994, the CSDA MDS collections have provided funding bodies, service providers, service users and other stakeholders with information about services delivered under the CSDA and the people receiving those services. The data have been collected about CSDA-funded service providers and people receiving a service from a service provider on a 'snapshot' day, that is, on a single day during each year.

All jurisdictions are now moving away from the 'snapshot' collection toward a full-year data collection strategy that will provide data about all clients receiving services during the year (the redeveloped CSDA MDS). Western Australia and the Commonwealth already collect full-year data and will implement the new collection in July 2002.

Expenditure

The total government expenditure on disability support services by Australian governments under the CSDA in 2000-01 was \$2.5 billion, an increase of 5.3% in real terms from the level in 1999-00 (SCRCSSP 2002). Accommodation support services account for over half this expenditure, with about one-tenth of funding each for community support, community access and employment support services (Table 1.4). The rising trends in costs and expenditure can be seen in Tables 1.3 and 1.4, and in Figure 1.1; they will be further discussed in Chapters 3 and 4.

Table 1.3: Current government expenditure and real government expenditure (in 2000–01 prices) per place on CSDA accommodation support services, Australia (dollars) ^{(a), (b), (c)}

	1998–99	1999–2000	2000–01
Government expenditure per government provided institutional/large residential place			
Current government expenditure	67,574	72,778	79,725
Real government expenditure (2000–01)	72,154	76,234	79,725
Government expenditure per government provided community accommodation and care place			
Current government expenditure	66,955	74,771	73,324
Real government expenditure (2000–01)	71,493	78,322	73,324
Government funding per non-government provided institutional/large residential place			
Current government expenditure	27,672	29,973	30,701
Real government expenditure (2000–01)	29,547	31,396	30,701
Government funding per non-government provided community accommodation and care place			
Current government expenditure	36,756	39,683	46,208
Real government expenditure (2000–01)	39,247	41,567	46,208

(a) Based on total expenditure divided by the number of places on a snapshot day (rather than average number of places during the year).

(b) Change from 1998–99 reflects the refinement of the process, based on accrual accounting, used to allocate expenditure between institutions and community accommodation.

(c) Data for non-government provided places reflect government expenditure and not full cost of providing accommodation places. Government makes a contribution towards non-government provided places.

Source: SCRSSP 2002, tables 13A.18 and 13A.19.

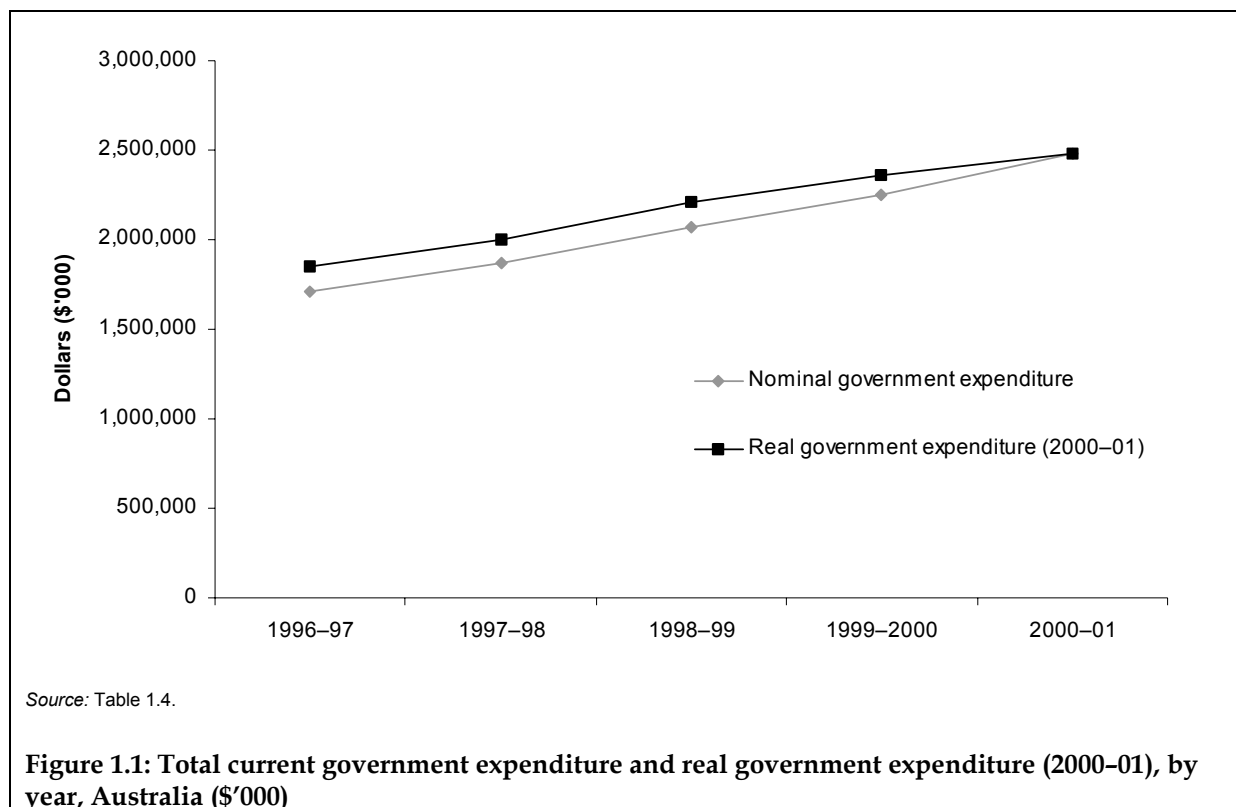
Table 1.4: Current government expenditure and real government expenditure (in 2000–01 prices), by service type, by year, Australia (\$'000)

	1996–97	1997–98	1998–99 ^(b)	1999–2000	2000–01
Accommodation					
Current government expenditure	901,754	971,746	1,062,827	1,157,066	1,291,549
Real government expenditure (2000–01)	978,321	1,040,784	1,134,856	1,212,013	1,291,549
Community support					
Current government expenditure	167,826	183,574	201,949	250,211	274,574
Real government expenditure (2000–01)	182,075	196,616	215,635	262,093	274,574
Community access					
Current government expenditure	147,621	180,035	209,412	221,700	245,760
Real government expenditure (2000–01)	160,155	192,826	223,604	232,228	245,760
Respite					
Current government expenditure	73,817	87,105	101,660	114,709	147,422
Real government expenditure (2000–01)	80,084	118,686	108,550	124,394	147,422
Other services					
Current government expenditure	76,470	86,295	75,507	73,982	1 85,959
Real government expenditure (2000–01)	82,963	92,426	80,625	77,495	85,959
Subtotal					
Current government expenditure	1,513,802	1,665,874	1,835,953	2,021,373	2,240,354
Real government expenditure (2000–01)	1,642,335	1,809,619	1,960,377	2,121,601	2,240,354
Employment					
Current government expenditure	191 063	201 767	223 495	220 989	241 126
Real government expenditure (2000–01)	207 286	216 101	238 642	231 484	241 126
Administration expenditure					
Current government expenditure	146 314	157 119	184 598	203 705	195 091
Real government expenditure (2000–01)	158 737	168 281	197 108	213 378	195 091
Total					
Current government expenditure	1 707 911	1 869 682	2 066 914	2 250 310	2 481 480
Real government expenditure (2000–01) ^(a)	1 852 927	2 002 514	2 206 990	2 357 173	2 481 480

(a) The 1997–98 real funding amount was calculated by adding the State/Territory real funding amounts because of anomalies in the published data.

(b) Change from 1998–99 to 1999–00 reflects the refinement of the process, based on accrual accounting, used to allocate expenditure between institutions and community accommodation.

Source: SCRCSSP 2002, tables 13A.7 and 13A.8.



Consumers

State distribution

Over one-third of the total 63,830 consumers on the 2001 snapshot day were in Victoria (21,868 or 35%). New South Wales had the next highest number (16,877), followed by Queensland (8,546) and Western Australia (7,513).

Table 1.5: Consumers of CSDA-funded services on a snapshot day, service type by State and Territory, Commonwealth, States and Territories, 2001

Service type	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Total	%
Accommodation support	6,111	7,068	3,361	2,101	2,020	719	281	116	21,775	34.1
Community support	3,383	5,525	1,506	3,764	2,316	174	216	129	17,011	26.7
Community access	3,663	7,979	2,180	705	489	504	145	39	15,703	24.6
Respite	553	998	438	386	165	78	47	37	2,702	4.2
Employment	6,019	3,929	2,652	2,099	2,101	513	279	139	17,730	27.8
Total consumers	16,877	21,868	8,546	7,513	6,218	1,604	825	422	63,830	100.0

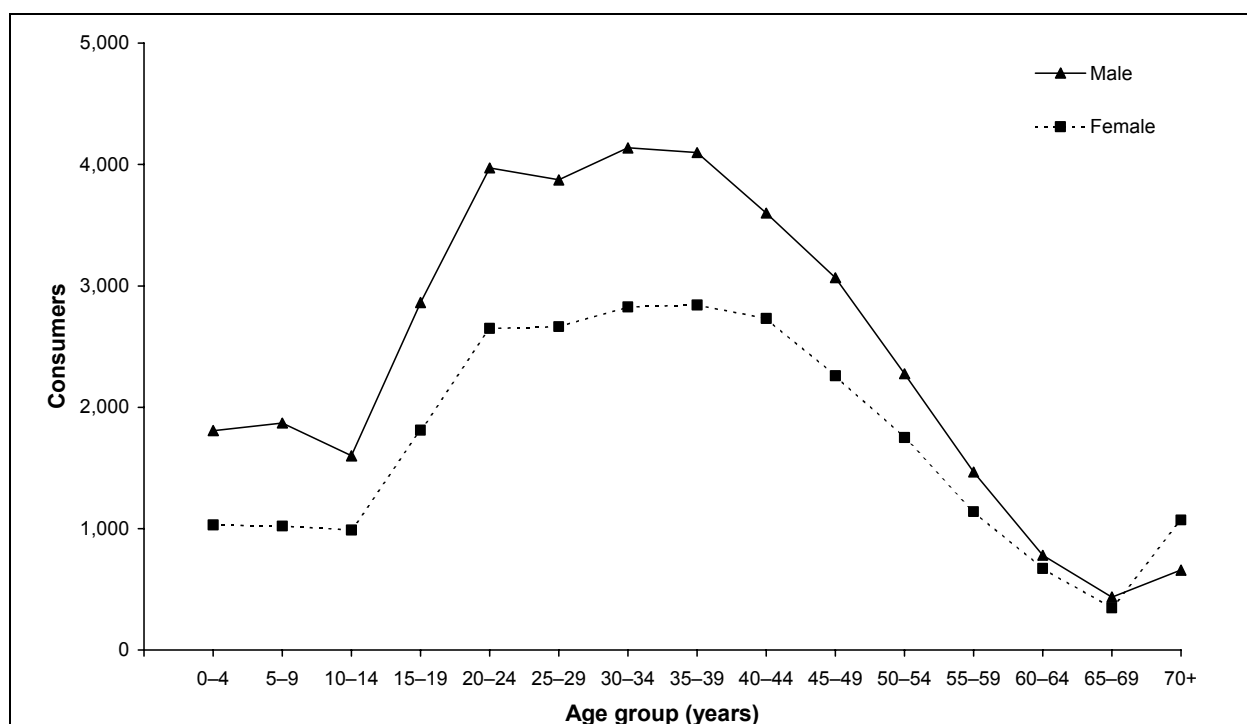
Notes

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. Totals may not be the sum of the components since individuals may access more than one service type on the snapshot day. There were 43 consumers who accessed services in more than one State or Territory, mainly in 'border' areas.
2. Data for consumers of CSDA-funded services with service types Advocacy, Information/referral, Combined advocacy/information, Print disability/alt. formats of communication, Service evaluation/training, Peak bodies, Research/development and Other were not collected.
3. Data provided by the Commonwealth are preliminary and cover 99% of Commonwealth-funded services.

Age and sex

Just over 58% (37,136) of consumers were male. Males represented the majority of consumers in all 5-year age groups except for the 70+ group. The age groups containing the most consumers were the 30–34 year group (6,967) and the 35–39 year age group (6,949).

While the shape of the age distribution has been fairly constant over the years, there are some trends emerging. The median age of people using CSDA accommodation, respite and employment services has risen between 1999 and 2001 (from 38.1 years to 39.8 years for accommodation, 21.3 years to 22.5 years for respite and from 33.9 years to 34.9 years for employment (AIHW 2002)), whilst the median age of people using community access or community support has fallen slightly over the same period (from 34.9 years to 34.0 years for community access and 19.6 years to 18.1 years for community support).



Source: AIHW 2002.

Figure 1.2: Consumers of CSDA-funded services on a snapshot day, age group by sex, Commonwealth, States and Territories, 2001

Disability group

Among consumers of CSDA-funded services, the most reported primary disability group was intellectual disability, with 37,575 consumers. The second most reported primary disability group was physical disability, with 7,911 consumers, followed by psychiatric disability with 5,419 consumers (Table 1.6).

Table 1.6: Consumers of CSDA-funded services on a snapshot day, primary disability group by age group, Commonwealth, States and Territories, 2001

Primary disability group	Age group (years)						Not stated	Total	
	0–4	5–14	15–24	25–44	45–59	60+		No.	%
Developmental delay	1,266	173	0	0	0	0	0	1,439	2.3
Intellectual	240	2,340	7,474	18,338	7,256	1,575	352	37,575	58.9
Specific learning/ADD	29	235	503	135	25	4	11	942	1.5
Autism	331	710	623	531	66	4	34	2,299	3.6
Physical	466	1,333	1,250	2,612	1,476	643	131	7,911	12.4
Acquired brain injury	25	91	300	1,214	827	255	49	2,761	4.3
Deafblind	10	11	17	72	21	33	15	179	0.3
Vision	45	83	130	285	213	766	31	1,553	2.4
Hearing	95	103	142	240	128	156	21	885	1.4
Speech	178	67	27	26	19	6	11	334	0.5
Psychiatric	9	26	586	2,672	1,377	329	420	5,419	8.5
Neurological	127	186	213	605	534	198	53	1,916	3.0
Not stated	19	141	37	57	25	16	322	617	1.0
Total consumers	2,840	5,499	11,302	26,787	11,967	3,985	1,450	63,830	100.0

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 CSDA-funded services with service types Advocacy, Information/referral, Combined advocacy/information, Print disability/alternative formats of communication, Service evaluation/training, Peak bodies, Research/development and Other were not collected.
3. Data provided by the Commonwealth are preliminary and cover 99% of Commonwealth-funded services.

All other significant disability groups are also recorded for each CSDA consumer (see Figure 1.3). For example, while 334 consumers (0.5% of CSDA consumers) reported a speech disability as their primary disability group, 12,146 consumers (19% of CSDA consumers) reported that speech disability was present (that is, either a primary or other significant disability group).

Service outlets

There were 7,712 service outlets funded to provide services in 2001 (Table 1.7). Of these a total of:

- 3,405 (44%) provided accommodation support services;
- 1,785 (23%) provided community support services;
- 1,098 (14%) provided community access services;
- 813 (11%) provided employment services; and
- 519 (7%) provided respite services.

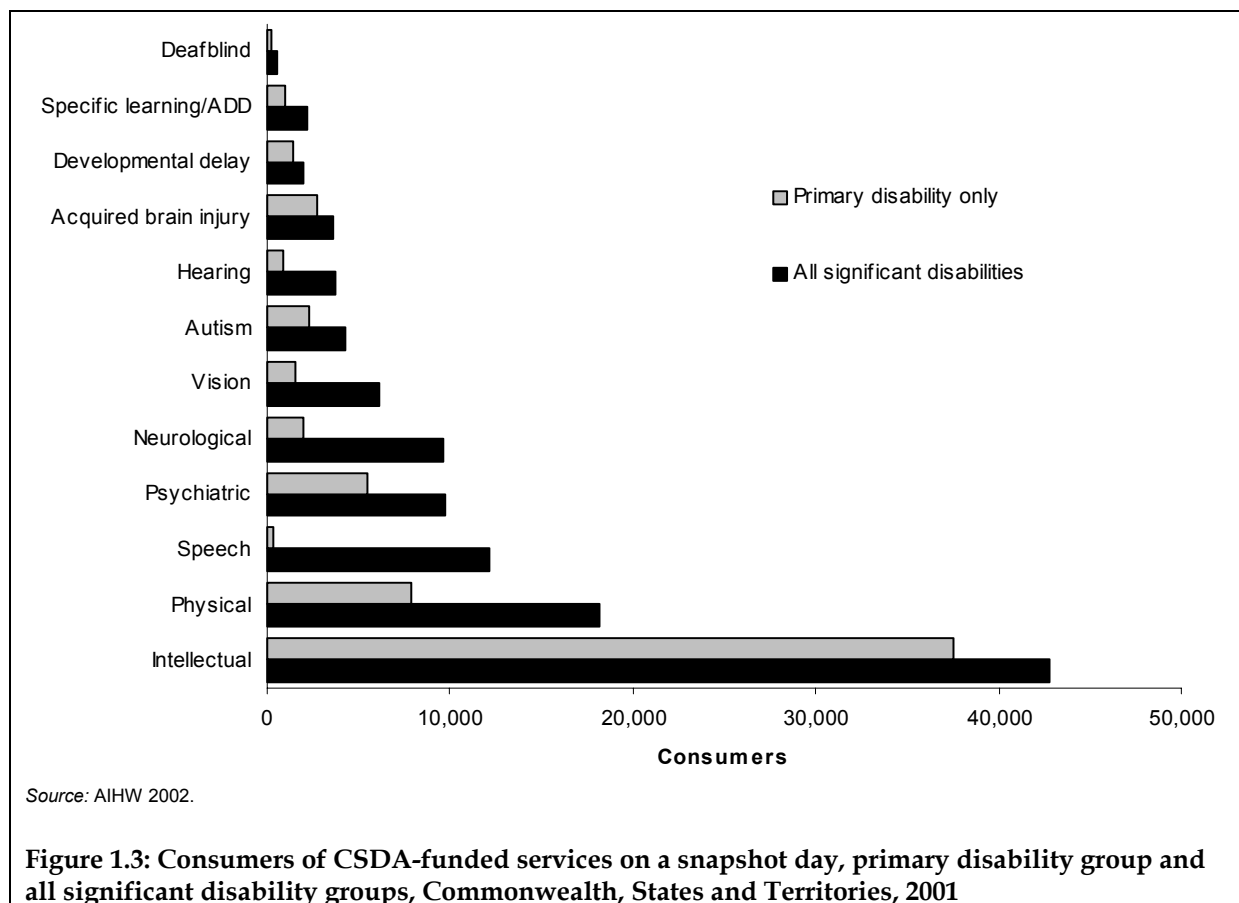


Table 1.7: Outlets of CSDA-funded services on a snapshot day, service type by State and Territory, Commonwealth, States and Territories, 2001

Service type	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Total	%
Accommodation support	961	1,063	445	360	462	86	14	14	3,405	44.2
Community support	343	699	236	198	184	50	46	29	1,785	23.1
Community access	303	494	180	37	30	40	7	7	1,098	14.2
Respite	135	172	117	38	31	10	7	9	519	6.7
Employment	309	186	127	59	75	33	12	12	813	10.5
Other	7	18	41	–	18	3	3	2	92	1.2
Total outlets	2,058	2,632	1,146	692	800	222	89	73	7,712	100.0

Notes

1. A service outlet may be a single outlet, or an aggregation of two or more outlets of the same service type, for a service provider.
2. Data provided by the Commonwealth are preliminary and cover 99% of Commonwealth-funded services.