

## 7 Shortfalls—remaining unmet needs

### 7.1 The approach in this chapter

This chapter draws together a range of information from various sources, to address the second main study objective: what are the remaining unmet needs for disability support services funded and provided under the CSDA?

Section 7.2 adjusts the population-based estimates from Chapter 6, to allow for increased supply since 1998. This provides estimates of unmet need for 2001, based on the ABS population survey data. These estimates are then ‘triangulated’ with the data provided by jurisdictions, to arrive at estimates of unmet need for the specified CSDA service types.

Evidence from the peak discussions is summarised in Section 7.3, followed by a summary of some available literature in Section 7.4.

Section 7.5 considers data about the use of other services by people with disabilities: residential aged care, HACC services, services for homeless people, and housing services. Implications of data from income security and insurance systems are briefly considered. Finally, the issue of equipment and environment is discussed.

Section 7.6 uses all this material to reach conclusions about remaining unmet need for specific services:

- accommodation, in-home and respite services;
- community access services; and
- employment services.

### 7.2 Consolidating the estimates of unmet need

The analysis in Chapter 6 resulted in baseline estimates of unmet need for CSDA services for 2001, based on reported unmet needs for formal assistance in relevant activities. This section now adjusts these estimates for increase in supply between 1998 and 2001, and checks the orders of magnitude with the data from the Jurisdiction Survey (Appendix 2) and a further request for data from jurisdictional registers and application processes. The process involved is as follows:

- i. CSDA MDS data and other administrative by-product data are used to estimate increases in service provision between 1998 and 2001.
- ii. The size of these increases is compared with data from the jurisdictions, where available and relevant (from Chapter 3), to check the orders of magnitude of these estimated increases.
- iii. Remaining unmet need is then calculated by simple subtraction (unmet need in 2001, estimated from 1998 population data, minus increase in service supply since 1998).
- iv. The resulting estimates of unmet need are then compared, to check orders of magnitude again, with the information available in some jurisdictions on unmet need as registered in various administrative systems.

This process is carried through for all the main service groups for which unmet need estimates are required, and is explained separately for each services type in the text. The main consolidated estimates are presented in Table 7.1.

### **Accommodation and respite**

The baseline estimate of unmet need for accommodation and respite services in 2001 is 22,200 people (Figure 6.1 and Table 7.1).

The increase in supply of accommodation services is estimated as follows. From Table 4.2 it can be seen that there was an increase between 1998 and 2001 in snapshot day numbers: of 513 in residential services (institutions, large residentials, hostels and group homes) and an increase of 771 for other non-residential services. In order to translate these snapshot numbers to full-year numbers, they can be multiplied by a factor of 1.08 and 2.20 respectively (estimated using Western Australian data – see Table 4.1). This equates to an increase in supply of 2,250 people receiving services. Table 4.2 does not show an increase in respite services between the snapshot days in 1998 and 2001, probably largely illustrating the problematic nature of the snapshot collection for this service type rather than a lack of increase. This means that the snapshot data cannot be used to estimate increases in the supply of respite, and other data must be used alone.

How does this increase in supply of accommodation services compare with data from the jurisdictions presented in Chapter 3? The (incomplete) data in Tables 3.6 and 3.8 show that the unmet needs funding is supporting approximately 900 people in accommodation services and also 800 packages which may or may not include accommodation elements. These figures are not nationally complete and some specifically include people who were previously receiving services. There are, thus, problems in comparison, but the orders of magnitude do not cast great doubt on the ‘new supply’ estimate for accommodation services in Table 7.1.

Respite services are reported to be significantly supported by the unmet need funding – 2,600 people in 2000–01, according to incomplete figures in Tables 3.6 and 3.8, relating to an estimated 35% of total unmet need funding. This could equate to some 7,400 people if information were available for 100% of the funding in that year, and this figure is therefore used for the increase in supply of respite. While respite services may tend to lower the need for or intensity of accommodation support, or act as a useful preventative strategy, rather than supplying all the supports needed, this figure is added to the accommodation services figure to adjust the ‘new supply’ numbers in Table 7.1. This is consistent with the approach in Chapter 2, to treat these services as somewhat substitutable, and on the same spectrum of needs. (While for the purposes of the estimation they can be treated as substitutable they may not be fully so ‘on the ground’, and people needing even small amounts of accommodation support may not have their needs fully met by respite.)

The estimate of unmet need for accommodation support (including in-home support and respite services) is thus 12,500 (by subtraction of the first two columns of Table 7.1).

The final step is to check the estimate of 12,500 against unmet need as indicated by jurisdictional registers and application processes. The figures in the last column indicate that, if numbers for the three States with fairly holistic application processes (holistic in the sense that they avoid double counting of applicants) were used as the basis for national estimates of unmet need, the resulting estimates would be similar to or greater than the figure of 12,500 in the third column of Table 7.1. These processes do not cover all disability

groups in all States and hence may underestimate this category of need; they may also underestimate need to the extent that not all people needing services may apply, but they could also overestimate need, to the extent that not all people applying may be found eligible. Generally, the jurisdictional numbers confirm the order of magnitude of the estimates based on the population survey.

Further confirmation of these numbers comes from the data on the need for respite from Chapter 6. There it was estimated that 5,300 primary carers in the target group of the bilateral agreements had either never received respite and wanted it, or had received it in the previous three months and wanted more. This is in the context of the needs of primary carers overall. In 1998 there were 23,600 primary carers of people with disabilities aged under 65 who reported that they had never received respite but needed it, and a further 17,000 who had received it at some stage but needed more (Chapter 6).

**Table 7.1: Consolidated estimates of unmet need, 2001**

	Baseline unmet need, 2001 (from Figs 6.1, 6.2)	Increase in supply from 1998 to 2001 (see text in 7.2 for explanation)	Unmet need estimate	Cross-check <sup>(a),(b)</sup>
	Column 1	Column 2	Column 3 = column 2 minus column 1	(National equivalent demand estimates, Table 5.4)
<b>Accommodation support &amp; respite</b>	22,200 (accomm./respite)	2,300 (accomm.)  7,400 (respite)	12,500 people	16,000 accomm. (Vic) 11,900 accomm. (Qld) 17,100 accomm. (NT)  16,500 respite (NT)
<b>Community access</b>	10,600 people	2,400 people/places	8,200 places	3,400 (Vic) (day activities only) <sup>(c)</sup> 17,400 (Qld) 16,800 (NT)
<b>Employment<sup>(e)</sup> (Method 1: focus on ADLs)</b>	7,300 people	1,900	5,400 people	3,700 <sup>(d)</sup>
<b>Employment (Method 2: focus on 'guidance')</b>	7,900 people	1,900	6,000 people	3,700 <sup>(d)</sup>

(a) The estimates in the cross-check column have been derived by multiplying the number of people requesting a specific service type (as recorded on the relevant jurisdiction-wide State/Territory 'register' of unmet need) by the inverse of the proportion of the total number of people with a disability aged 0–64 years living in the State/Territory.

(b) It was not possible to develop national equivalent demand estimates from all data presented in Table 5.4. For example, NSW data are not included because the information on supports requested is not recorded on the SAS database. The data presented in Table 5.4 were based on a subset of SAS applicants, i.e. only those with an available eligibility and support plan quality assurance report.

(c) Victoria has invested heavily in community access services, with the highest rates of provision relative to the potential population (SCRSSP 2002: 710).

(d) This figure comprises: for open employment 1,090 not accepted plus 2,249 'outstanding' as at June 2001; for supported employment the figures are 88 not accepted and 312 'outstanding' (see Table 5.2 and footnotes 13 and 14).

(e) 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.

**Community access**

The estimate of unmet need for community access services in 2001 is 10,600 places before adjusting for increased supply (Figure 6.2 and Table 7.1). This figure may underestimate the need for service among 18–20 year-olds, as some jurisdictions assume higher rates of use in these age groups while post-school futures are planned.

The increase in supply between 1998 and 2001 is 2,300 places based on snapshot day data or 2,400 based on ‘typical day’ estimates (Tables 4.1 and 7.2). Table 7.2 indicates that:

- 15,703 consumers used community access services on a snapshot day in 2001;
- 17,446 consumers were estimated to represent a ‘typical day’;
- a total of 88,105 people were estimated to use the services over a full year.

The difference between the first two figures and the last suggests a current high level of low-intensity use of these services (possibly suggesting some differences between historical patterns of service use and provision, and those envisaged by the policy assumptions outlined in Section 6.3).

Because of the policy-related assumption that people who are included in these estimates as eligible for day programs need them five days per week (Section 6.3), it is necessary to use ‘places’<sup>1</sup> estimates to indicate the current supply; the ‘typical day’ figures of 17,466 provide the best available estimate of places. That is, the ‘people estimates’ for unmet need equate to places, and should be discounted by the current level of supply, in terms of places. (If the policy assumption is changed, then the estimation process would have to be changed to consider needs for full-time and part-time places. The number of people would be likely to grow significantly but the number of full-time equivalent places needed might change only slightly.)

The figure of 2,400 is therefore used as representing the increase in supply of community access places between 1998 and 2001.

**Table 7.2: Community access consumers on the 2001 snapshot day and estimates on a typical day and over a full year for 1998 and 2001**

	1998	2001
Services received	13,678	15,974
Consumers on the snapshot day <sup>(a)</sup>	Not available	15,703
Consumers on a typical day <sup>(b)</sup>	15,084	17,466
Consumers over the full year <sup>(b)</sup>	55,486	88,105

(a) ‘Consumers on snapshot day’ are AIHW estimates after use of a statistical linkage key to account for individuals who have received more than one service on the snapshot day.

(b) ‘Consumers on a typical day’ and ‘consumers over the full year’ are estimates provided by CSDA-funded service outlets, provided on their Service Form.

Source: CSDA MDS data, 1998 and 2001.

How does this estimated increase in supply compare with data from the jurisdictions presented in Chapter 3? The (incomplete) data in Tables 3.6 and 3.8 show that the unmet

<sup>1</sup> It is not possible to use the same method of adjusting for supply as was used for accommodation services, as here it is required to translate to full-year places, not people.

needs funding is supporting approximately 1,300 people. Again, these figures may include people who are already receiving community access services, and they relate only to 2000–01. Further, the number of ‘places’ is likely to be considerably lower, based on the ‘intensity’ indications from Table 7.2. There are, thus, problems in comparison, but the orders of magnitude do not suggest that the estimate of 2,400 places for increased supply is an underestimate.

The resulting estimate of unmet need for community access services is thus 8,200 places based on population estimates (by subtraction of the first two columns of Table 7.1).

The final step is to check the estimate of 8,200 places against unmet need as indicated by jurisdictional registers and application processes. The figures in the last column indicate that, if numbers for the three States with fairly holistic application processes were used as the basis for national estimates of unmet need, the resulting estimates would be considerably higher than in the third column of Table 7.1, apart from Victoria where the numbers are incomplete and the rate of supply is recognised to be the highest nationally.

It is therefore concluded that the estimate of unmet need nationally for community access services is 8,200 places. As well as the various steps in this process to ensure that the estimates are conservative, it should be remembered that the survey estimates excluded anyone who reported receiving a ‘day program’ of any kind or level. That is, these estimates included no allowance for ‘under-met’ need.

## **Employment services**

There were two baseline estimates derived for employment support services in Chapter 6, based on two alternative approaches to estimation – in turn based on different assumptions about the program. The first approach ties itself to the CSDA target group definition, focusing on the need for assistance with self care, mobility and communication; in line with the approach to accommodation services, some evidence of relatively high support needs is used to include people in the estimates: people are included in the estimates only if they needed at least daily assistance with at least one of these activities (see Table 2.2). This approach resulted in an estimate of unmet need for employment services in 2001 of 7,300 people (Figure 6.2 Method 1, and Table 7.1).

The alternative approach focuses more on the need for ‘guidance’ than on the need for assistance with the ADLs (self care, mobility and communication). This approach results in an estimate of unmet need for employment services in 2001 of 7,900 people (Figure 6.2 Method 2, and Table 7.1).

Both sets of estimates include ‘discouraged workers’, that is, people who are not in the labour force but who consider themselves able to work with special assistance or arrangements. This is an accepted approach to ‘mainstream’ labour market analysis, and is in line with current welfare reforms that seek to assist people to participate in the workforce, where possible, or in other community activities (Newman 1999; see also Chapter 6).

The increase in supply of services since 1998 is complex to estimate, as is now discussed. (Steps ii and iv – see Section 7.2 – are not carried out as the Commonwealth did not have unmet need funding and hence its questionnaire provided no information on increase in supply.)

## Commonwealth data and definitions

Clients are referred from Centrelink to specialist employment services and/or to Commonwealth Rehabilitation Services. Table 5.2 and associated footnotes shows that, in 2000–01, there were:

- 16,413 referrals to open employment services, of which 13,074 were accepted, 1,090 were not accepted, and 2,249 were still 'outstanding' at the end of the year. In 396 cases where the referral was 'not accepted' it was recorded that 'no vacancy' was available; and
- 2,206 referrals to supported employment services, of which 1,806 were accepted, 88 were not accepted, and 312 were still 'outstanding' at the end of the year. In 28 cases it was recorded that 'no vacancy' was available.

The various counts in Commonwealth CSDA employment service collections are described in Box 7.1, tabulated in Table 7.3 and discussed in the following text, so as to work towards estimating the increase in supply between 1998 and 2001.

### **Box 7.1: Selected consumer 'count' definitions for Commonwealth employment support services 1998–2001**

#### **Commonwealth census definitions of 'on the books', 1998–2001**

##### **Data Guide 1998, 1999**

*'Number of consumers "on the books" on snapshot day is the number of consumers listed with your service on 21 October 1998 (26 May 1999), for whom you normally provide support (i.e. include consumers actually supported on the day as well as those who generally receive support from the service but didn't on 21 October 1998 (26 May 1999)).'*

##### **Data Guide 2000, 2001**

*From 2000, the number of consumers "on the books" was asked as a separate question, rather than included in a section asking for various consumer count figures. The definition was slightly clarified to exclude inactive consumers.*

*'Number of consumers "on the books" on snapshot day is the number of consumers listed with your service on 30 June 2000 (30 June 2001) excluding consumers who are inactive (e.g. on long-term leave or have exited your service) on 30 June 2000 (30 June 2001).'*

*The 2000 and 2001 Data Guides also provided additional supporting text to define the types of consumers who should be included in the count of consumers 'on the books'. Thus, consumers 'on the books' means the number of consumers listed with your service on 30 June 2000 (30 June 2001) excluding consumers who are inactive (e.g. on long-term leave or have exited your service on 30 June 2000 (30 June 2001)), that is the sum total of Eligible Job Seekers, workers meeting Worker Target, workers not meeting Worker Target and Independent workers'.*

#### **Commonwealth census definitions of consumers receiving active support in the financial year, 2000–01**

##### **Data Guide 2000, 2001**

*From 2000, an additional consumer count was introduced to the census collection.*

*'The number of consumers receiving active employment assistance program support during 1999–00 (2000–01), is the number of consumers who received active support between 1 July 1999 (2000) up to and including 30 June 2000 (2001) (i.e. this includes those consumers who received support during the financial year but did not on 30 June 2000 (2001) as well as those consumers who were inactive, exited or on long-term leave and independent workers who did not receive support during 1999–00 (2000–01) but whose last episode of support was within the last 24 months).'*

*Source: FaCS 1998 and 1999 Census publications (FaCS 1999, 2000a), FaCS 2000 and 2001 Census Data Guides (FaCS 2000b, 2001a).*

**Table 7.3: Employment services: various counts**

<b>All specialist disability employment services</b>	<b>1997</b>	<b>1998</b>	<b>1999</b>	<b>2000</b>	<b>2001<sup>(a)</sup></b>
Snapshot day (MDS)	17,840	18,137	17,858	17,475	17,855
Snapshot day (Commonwealth)	17,840	18,604	18,402	17,615	
Typical day	19,739	20,176	20,037	20,242	
Census week		27,634	27,657	28,880	
'On the books'	35,054	39,684	40,832	45,950	
<b>Total assisted in the year</b>				<b>53,427</b>	
Employed consumers	24,996	27,671	28,670	31,396	
<b>Open employment services</b>	<b>1996–97</b>	<b>1997–98</b>	<b>1998–99</b>		
NIMS estimated clients (received support over the year including applicant support) <sup>(b)</sup>	26,062	31,158	35,151		
Mean support hours per client	55.0	50.0	47.0		

(a) FaCS census data for 2001 are not yet available.

(b) NIMS refers to the National Information Management System for open employment services for people with disabilities.

Sources: AIHW 1999a, 2000a, 2001a, 2002; Anderson & Golley 1998, 1999; Anderson, Psychogios & Golley 2000; Black & Maples 1998; FaCS 1999, 2000a, 2001b.

Using the CSDA MDS data, there is no increase apparent in snapshot day (or typical day) figures from 1998 to 2001 (Table 7.3). This implies that either (a) there has been no increase in clients over the period, or (b) the ratio between clients on the snapshot day and clients over the year has decreased. There has been some increase in the number of consumers during the census week which lends some support to (b).

There are no complementary data on the number of clients seen in a year (as there was for Western Australia, see Table 4.1) to compare with the snapshot day figures. The Commonwealth census of employment support services, however, does record the number of consumers 'on the books' and there has been a large increase in this number from 1998 to 2000.

The number of consumers on the books is not equivalent to the number of clients who received a service in the last year. On the census form this item has a broad definition (see Box 7.1) that would seem to allow a service provider to include any client on the client list regardless of when the last service was received (those who 'generally receive support'). The glossary definition similarly includes anyone who has 'registered or commenced a support program' regardless of when this occurred and further defines a consumer to include independent workers who last received support in the last two years (FaCS 2000b, 2001a).

The importance of carefully defining an annual figure is shown by the difference between the number on the books (45,950) and the 'total assisted in the year' (53,427) for 2000. The latter figure has a wider definition again and explicitly includes inactive clients (Box 7.1).

The increase in the number of consumers on the books is therefore difficult to interpret, but lends itself to three possible explanations: (a) an increase in clients actively receiving services, (b) an accumulation of people with some connection to the service but not being very actively serviced, and/or (c) larger numbers of people receiving services of declining intensity. The definition of the 'on the books' figure would appear to allow for some accumulation of clients from previous years but who are no longer receiving a service, and

this may support explanation (b). Another possibility is that the amount of hours per client is decreasing while the number of clients is increasing (that is, explanation (c)). This would lead to a change in the ratio between the consumers on the snapshot day and consumers over a longer period, and there could be a trend in one and not in the other. There is support for explanation (c) in historical evidence for the years 1996–97 to 1998–99, for open employment services, of a decline in the number of hours of support per client (Anderson & Golley 1998, 1999; Anderson, Psychogios & Golley 2000). The available data make it difficult to say which of the three explanations is the most likely.

‘Employed consumers’ is a subset of ‘consumers on the books’ and so has similar problems to those outlined above.

### **Estimating increase in supply of employment services, and remaining unmet need**

The above discussion illustrates the complexity of estimating the increase in supply of employment services.

The AIHW does not consider that the ‘on the books’ numbers are statistically useful for this purpose. The definition relates to people to whom services ‘normally provide support’. The new definition in 2000, of ‘total assisted in the year’, specifically includes people who are ‘inactive’.

On the other hand, it is not satisfactory to use snapshot day numbers, showing no increase in supply. It is considered that there is solid evidence of increase in supply, although possibly at decreasing levels of intensity.

It is therefore considered that the most satisfactory indicator of increased supply may be the trends in census week consumers (Table 7.3), as best illustrating trends in active service provision.

The increase from 1998 to 2000 was 1,246. Pro-rating this forward to the year 2001 (the census week numbers for which are not yet available) provides an estimate of 1,900 (approximately).

Resulting estimates of unmet need are then (by subtraction of Column 1 from 2 in Table 7.1):

- 5,400 if emphasis is placed on high support needs with ADLs (Method 1 – see Chapter 6);
- 6,000 if emphasis is placed on the need for guidance and, while assistance with ADLs is needed, the assistance is not at such a high level as for Method 1.

The final step is to check these estimates against available data from the Commonwealth (the administering jurisdiction). Centrelink streams their ‘customers’ towards specialist employment support services or other services (see Table 5.2). As at June 2001 there were 3,700 people who were either ‘outstanding’ (waiting to be placed) or ‘not accepted’ for various reasons. Are these figures adequate indicators of unmet need for these services? On the one hand these people have been considered eligible for these services by Centrelink, that is, there is little overestimation of need from this cause. On the other hand, the figures may screen out some forms of expression of need for these services and may not adequately include numbers of people not in the labour force (but perhaps on the Disability Support Pension) who could benefit from assistance to help them back to work.

It is therefore concluded that the lower of the population estimates should be used – that is, that 5,300 is the appropriate estimate of unmet need for employment support services, being closer to the administrative numbers.

### **7.3 Unmet needs: views from peak discussions**

The study team obtained valuable information during three discussions with peak organisations, held in Canberra, Brisbane and Melbourne (see Section 2.3 for description of the process, and Appendix 3 for the agenda and a list of participants). Those attending represented many years of experience in the field, a range of perspectives, and brought valuable expertise and knowledge to the discussions.

This section summarises the key issues raised and discussed in relation to 'unmet need'. Material from these discussions relating to 'effectiveness' is contained in Chapter 4.

It is always challenging to attempt to summarise the richness and feeling of the material covered in three days of discussion. The study team has concentrated on highlighting issues that were:

- a view shared by several people or heard in several of the discussions;
- particularly relevant to the investigation of 'unmet need';
- of national significance; and/or
- of a serious, even if possibly exceptional, nature.

'Case stories' are a feature of this section and have been chosen to illustrate more general issues. It was not possible to include all case stories heard and emphasis was placed on 'typical' stories that could explain or illustrate a more general point. In a project such as this it is not possible to test all details of the stories heard. Further, the discussions were not held in every jurisdiction and, in any case, such groups cannot necessarily be considered as representative of all views in the jurisdiction.

Nevertheless, there were at least three members of the study team present throughout each discussion, and the team has made a judgment that the nature of the material included in this section is of relevance and value to the consideration of unmet need. The material included has been documented in a way that seeks to make the point generally, without identifying individuals, or highlighting particular programs or jurisdictions.

#### **Unmet needs of existing clients: 'under-met need'**

All groups wanted the study team to note that there are unmet needs among existing CSDA clients. Typical examples include:

- An individual with a spinal cord injury applied for and received assistance, to help him within his home, but not for assistance within the community. For this individual 'getting out of bed, does not mean getting into the community'.
- A young woman with high support needs does not receive enough support for her father to return to the labour force.
- Inadequate in-home support for a person in a wheelchair has meant that she sleeps in her wheelchair with her head against a table, as she can not get herself in or out of bed.

By spreading resources more widely, it was suggested, unmet need may become more invisible. It was stated that some clients receiving accommodation support are having the response to their needs limited because of under-funding to the agencies concerned.

## **Fees and contributions**

Client fees and contributions were raised as a matter of concern for a number of reasons. They are seen to contribute to 'under-met need' (see examples following) but they may also impact on eligibility for related services (see later discussion of HACC). The study team was told:

- Client contributions are increasing. Often fees exceed the available income of the person with a disability, meaning that the family must meet the shortfall or their family member risks exclusion from services. For instance, where clients live in residential accommodation and fees exceed income, who pays for pharmacy, etc.?
- Although people access day programs, the cost of these services often does not leave much money for the individuals to live off. For example, one individual receiving the Disability Support Pension pays 15% of his pension per day to access this service.
- Continence aids are a large expense and assistance schemes do not usually cover the additional family bills ('\$450 per annum for nappies is not enough').
- The high cost of respite services is a major issue for many families. Participants reported that often the cost of attending a respite service is met by using emergency respite money, which eventually runs out leaving people with nowhere to turn. One mother caring for her 12-year-old daughter with Down Syndrome and autism had 6 weeks of continually interrupted sleep over the Christmas break, with her daughter engaging in constant outbursts of obsessive eating and faeces smearing when not watched. The carer called, exhausted, saying that they needed a break and were not sure if they could continue in the caring role because of the amount of stress placed on the family. In this instance, the only respite available to the family was a private house – the cost of which was \$246 per day during the week and \$310 per day on the weekend – too high for the family to meet the cost.

## **Needs of people who are receiving nothing**

All discussions reflected the view that there is considerable unmet need remaining. Some participants specifically stated that the total unmet need funding of \$510 million was not enough to make a major impact on unmet needs. Others noted that the extra funding had done some good but more was needed. One participant noted that the people on the Victorian Service Needs Register for accommodation support can expect to wait 810 days on average for this support to be provided: 'At that rate it will take 12 years for everyone on the register now to get a service.'

There was a general perception among participants that only 'urgent' needs were being met by the new funding rounds. It was suggested by some that these urgent and serious needs often related to health issues, rehabilitation, psychiatric, drug and alcohol issues. That is, the interface with other systems, perhaps particularly the health system, was considered not to be working well.

Further, it was argued that some unmet need is invisible to funding departments, as the low 'success rates' of applications (estimated by participants in one jurisdiction as being about 1 in 10) are discouraging people from applying. Statistics quoted by participants illustrated their point: In October 2001, 485 individual new applications for funding were received from one Queensland region. Of these, only 59 received funding (and not all priority 1 applications received funding). In another region, it was reported, there were 268 applications for packages of family support, only 5 of which were successful.

## **Groups missing out**

A number of groups in the population require more attention and consideration in the overall CSDA program, according to the peak discussions. Their unmet needs arise because of:

- service borders, particularly affecting people with psychiatric disabilities, acquired brain injury, and people with high and complex needs more generally; however people with physical disabilities may also miss out, perhaps because their needs are not seen as so urgent or central for the CSDA program; and
- Australia's history and geography, particularly affecting people of Indigenous origin and people of culturally and linguistically diverse backgrounds.

## **Psychiatric disability**

- Service users with mental health issues and psychiatric disabilities 'tend to get disregarded' for day services and respite. This is a case where the disability does not fit in with the service type structure.
- Some carers were said to feel discriminated against if their children have a psychiatric disability.
- Several participants considered that the health and disability systems are often 'unresponsive to the same real needs', often in relation to psychiatric disability.
- In many cases Individual Lifestyle Packages 'are not well suited to people with psychiatric disabilities' because of their fluctuating level and type of support needs. A number of participants believed that, because of this, people with psychiatric disability tend to be allotted low priority by assessment panels and therefore are under-represented in the award of packages.

## **Acquired brain injury (ABI)**

The following stories and issues were raised with the study team:

- A funded agency took over the management of two group homes each with four places. Before the agency had an opportunity to advertise the two vacant places, they had 38 applications, the majority from young people with acquired brain injuries.
- One participant noted that the proportion of people with ABI in the population is similar to that of people with intellectual disabilities, yet the presence of ABI clients in CSDA services is significantly lower. A high proportion of people with ABI do not have ageing carers and were therefore 'locked out' of the Commonwealth funding.
- Behavioural difficulties of people with ABI often 'shut them out' from receiving service, because service providers 'are not experienced enough to deal with their behaviours'. Often these service users need to obtain a blend of money across a range of departments (including health, justice administrations) to have enough money pooled together to afford service provision from appropriate service providers.
- The local area coordination model seems to be effective for a range of disability groups, but does not work well for people with acquired brain injury; they do not seem to be 'within the service network'.
- Advocates for ABI believe that if CSDA services continue to be funded according to service type, it will not benefit people with ABI, who will continue to have their needs not met. A highly regarded service model that addressed the needs of people with high

or complex needs was the Commonwealth's More Intensive Flexible Services program, which has ceased operation.

### **Physical disabilities**

- An individual with a physical disability, who is not eligible to receive assistance, has trained his dog to help him put on and take off his trousers.
- Parents with a physical disability sometimes rely on their children (sometimes as young as 10 years of age) to be their primary carer, as they are not eligible for support. As the child's role has become that of a primary carer, they often do not attend school.

### **High support needs and 'high risk' clients**

There was a view expressed that 'the needs of people with severe and challenging behaviours are now on the map and, for those who are accessing something, they are being quite well resourced'. In fact, when CSDA funding is crisis-driven, it may be directed to people with very serious needs in areas such as health, rehabilitation, psychiatric or drug and alcohol issues. It was said that, in one region, 4 of 30 applicants ranked as urgent in one round were people with intellectual disability. This example was considered to illustrate the need for cooperation across the service sector and concern that CSDA dollars are being spread over a wider population than in the past: 'We're not saying that these people should miss out, but the disability bucket can't pick it all up.'

Nevertheless, it was considered that the disability/medical interface is an area where families and individuals have complex needs or dual diagnosis, where staff lack knowledge and skills and 'cracks in the service system appear'. Further, when applying or registering for a service or funding, the person with the disability has to identify which other services they receive. If service providers become aware of the multiple funding they may cease support.

A range of stories was told, illustrating the point that people with complex needs or multiple disabilities often have difficulty finding appropriate care or support:

- A man is caring for his wife with schizophrenia and multiple sclerosis. She did not qualify for an Aged Care Assessment, and residential respite was not the preference of the carer. A facility was located which was able to support the physical needs of the care recipient, but workers were not appropriately trained to meet her mental health needs. And while there is a facility on the other side of the city that offers respite to those with a mental illness, they are not able to meet high physical support needs. There is no appropriate facility identified for this care recipient.

One participant spoke of four deaths of clients in the last 12 months. This participant's view was: 'This "system", this terrible mess we have, kills people':

- Only one of these was a so-called 'good death'. The client had a terminal illness and was taken home to die (her wish). Because of the complicated interface between disability and health services, it was hard to achieve the person's wish to die at home with her family.
- One person is believed to have committed suicide although the outcome of the coroner's report is not yet known. He was found drowned in a creek, only hours after he was released from a hospital's psychiatric services (perhaps partly because his speech was hard to understand). Over the years he had been sexually abused and physically

assaulted in his own home, which he needed to share with people to meet his financial obligations.

- One person died in hospital following surgery. He had elected to have a colostomy, despite the relatively high risks in his state of health, because he could not bear the indignity of regularly waiting for an hour or more before being cleaned.

People with high support needs are often classified as 'high risk' people. Service providers, it was said, can be reluctant to provide service to these people because of insurance problems; they are at risk of being sued if any mishaps occur.

### **People of Indigenous origin**

The study team had some difficulty ensuring that it made contact with people able to discuss these issues authoritatively, but did hear these stories in the course of the peak discussions.

- The application process can be difficult for people of Indigenous origin, especially in remote areas. Written applications may tend to exclude people from services. The role of local area coordinators in these areas may be crucial for successful allocation of assistance to people needing it (see also Section 4.4).
- An agency in a remote area received a sum of unmet need funding in March 2001. This service has had difficulty spending this money due to the cultural nature of service provision within their community. Within Indigenous communities, cultural laws may prohibit certain kinship links to care for each other. Therefore, informal carers may not be available and service provision needs to come from outside the community.

The establishment of a new National Indigenous Disability Network should ensure that the needs of Indigenous people with disabilities are more clearly and authoritatively described.

### **People from culturally and linguistically diverse backgrounds**

A range of concerns were raised about people of cultural and linguistic diversity:

- There is not enough information about the services available for people with disabilities, that people from non-English-speaking backgrounds could understand.
- People may not be aware that assistance is available, for example, funding packages, equipment and services, or understand what the services provide (for example, respite, continence aids). That is, there may be 'latent demand' in these groups.
- Service providers may not be sympathetic or understanding of the traditional ways of caring for families.

It was thought that this population group may feel that the only time they should apply for support is 'when they hit crisis'. Ageing carers within this population group have further cultural barriers and, when they become too old to provide the caring role, they turn their kin over to mainstream services.

### **Rural and remote areas**

Each peak discussion provided examples of difficulties for people in rural or remote regions of Australia. Examples included:

- Often people with disabilities in remote areas are required to travel far distances in order to receive any type of service. The availability of services is often inadequate. Individuals

who engage in petrol sniffing or self-inflicted injuries are often sent straight to jail and receive no services at all.

- Some shires in rural areas have no respite services available.
- ‘Outreach towns’ in rural and remote areas are those towns that have no community services and rely solely on outreach support from other places. The outreach support is often unreliable. ‘There is a great need for lateral thinking in providing services to outreach towns’ according to some participants. An example was given of innovation from the field to make support services more accessible to people living in ‘outreach towns’. Often the only avenue for support for people in regional locations was telephone support, often accessed only for crisis situations. One association now offers support to rural families affected by mental illness via carer training and support, for example, suicide prevention and coping skills. It is in the process of seeking funds to set up a ‘virtual support service’, including chat groups, web-based information services and video links.

### **Border issues—other service areas**

The ‘border issues’ between the health and disability service areas have been mentioned in the previous discussion of problems for people with psychiatric disabilities and acquired brain injuries. The study team heard about border issues with other systems as well: aged care, transport, education and systems (such as health) responsible for equipment provision and housing. As well, of course, there are geographic border issues when people cannot obtain services from the closest provider because it is ‘over the border’.

### **Nursing homes**

Younger people in nursing homes were viewed as generally inappropriately serviced. Participants stated that if these population groups are not included within the study, then they would not be counted and little would be done to address the issue.

Young people living in rural areas are being placed in nursing homes, as an alternative to having to travel to respite centres only available in metropolitan regions. This was not always viewed with disfavour. Although it is not the most ideal accommodation or service setting, it may be the most appropriate service option for them. For example, they are still within their rural community where family and friends are able to visit.

### **HACC**

Many examples of HACC – CSDA interface concerns were raised, illustrating a range of issues relating to unmet need, the role of local government, client fees and varying impacts on eligibility:

- Unmet need: In one area it was said that HACC and other services are covering areas traditionally serviced by ‘disability’ funding. One participant claimed that referrals from young people with a disability to HACC Option services have risen from 20% to 40%.
- Participants speculated how much HACC service people aged 0–64 years would still receive if the fee for service were removed.
- If CSDA funding were given to an individual to complement their HACC or other funding, it is likely that the HACC or other funding would cease, and the individual would be left with a shortfall of funds to cover the required level of support. An example was given of HACC funding being withdrawn when CSDA supplementary funding

started. It was stated that the same happened with education therapy and health services.

## **Transport**

Transport is raised as an issue 'at every single forum' these participants attend. It is thought that governments are placing the issue in the 'too hard basket'.

Transport is essential in being able to access employment and day activities, yet transport support appears to be shrinking. Examples given included:

- A few years ago a system existed where service providers picked up service users from their house and drove them to the service agency. However, due to costs and no funding for transport from the department, service users have to fend for themselves and make individual arrangements for transport.
- Criteria for entry to employment services often include 'the ability to travel independently'. Therefore if an individual can not catch, for example, a taxi on their own then they are usually excluded from employment services. Those individuals who can catch a taxi independently are often faced with a cost issue; if a taxi fare costs, say, \$45 and they get paid \$50, they are left with little income.
- The move from in-centre training to community access has also increased transport (and other) costs. This generally means the costs are shifted to the family.
- Alternatively, day programs 'often now charge for transport to their service'. This results in cost shifts across programs (for example, to the Multi-Purpose Taxi Scheme) and to clients and their families.
- 'The council bus service lost its funding' (in a large regional centre). The participant's daughter is unable to use a taxi due to tracheostomy (needs a carer with her at all times). 'So I do a lot of driving.' The school her daughter attends is across town. The money given to reimburse petrol to get to special pre-school is 'not enough'.
- One transport assistance scheme is considered effective but people are only eligible if they need to travel 100 km or more to see a medical doctor or dentist (that is, 50 km to see an occupational therapist for a wheelchair fitting would not qualify).

Transport is an essential that has to be paid for somehow. Flexible respite is often called on to pay for transport assistance, according to case stories provided by Carers Victoria in follow-up to the Melbourne discussion. For instance, one young man living with his parents was assisted to attend a day centre with the transport paid for by the flexible respite program. This then enabled the parents to share activities with their daughter who also has disabilities.

It was said that 'the Commonwealth is delaying the adoption of uniform transport standards' under the Disability Discrimination Act. This makes the vision of accessible public transport a more distant possibility.

## **Equipment**

Equipment also 'is raised at most forums'. Stories told at peak discussions illustrated a range of unmet needs and program gaps:

- The frequency of people with physical disabilities acquiring equipment and provisions from hospitals has increased (such as tracheostomy bags). In response to this, hospitals 'are no longer providing equipment'.
- Throughout remote areas of Australia, the cost and availability of equipment often puts the products out of people's reach, for example, 'computers that can speak, bush wheelchairs, mattresses, etc.' Accessing medication in remote areas is costly, and often involves travelling long distances to a pharmacy.
- For people with disabilities to access one medical subsidy scheme that includes the provision of equipment, they must acquire a referral from an occupational therapist. With a shortage of therapists in rural and remote regions it becomes impossible for people to obtain a referral and in turn acquire equipment.
- Within another jurisdiction it was reported there is a limited range of equipment available, for example, wheelchairs and shower chairs can be obtained but not a hoist or bed. Often service users rely on discretionary funding from other organisations or departments to obtain equipment such as communication aids, oxygen and continence aids. Recently, brokerage services have received an increased number of requests to provide white goods – the Salvation Army and other organisations no longer provide electrical products, for fear of being sued.
- There has been a reduction of services to Independent Living Centres in some areas, resulting in shortage of equipment for people in rural and remote regions. The lack of funding and reduction of service have meant that the people outside the metropolitan area must either travel to receive services or use telephone support.
- 'Access to equipment is particularly problematic for services provided in the home.'

### **Education**

It was reported that there are gaps in Commonwealth-State funding arrangements relating to kindergarten aides. The upshot is that children with disabilities are not able to attend for the same hours that other children attend kindergarten. Also, children appear to be eligible for an aide only if they are assessed as being a danger to themselves or others. 'This is not about inclusion', according to one participant.

### **Disability, ageing and service borders**

The study team heard about two main concerns, illustrating different aspects of the apparent grey areas between disability services and aged care services:

- The debate about cost shifting leaving people in a 'service hole': For instance in one jurisdiction there are a number of people with a disability who have been working for a business service and are ageing (physical deterioration), who should be planning for their future. These people, however, have found it difficult to plan to move, say, from employment to day activities or post-employment services. 'Retirement' as a normal life transition is seen as a case of 'cost shifting' from the Commonwealth to State/Territory governments.
- Access to generic services including aged care services: Ageing people with disabilities have difficulties accessing appropriate lifestyle services, as well as generic services. People with an intellectual disability or acquired brain injury are 'often turned away

from generic senior citizen clubs and activities, because the support services these people require are not available’.

## **The interface between employment services and other CSDA-funded services**

In response to the Jurisdiction Survey, most States and Territories noted their concern regarding current Commonwealth policies in relation to specialist disability employment services, particularly the reform of the business service or supported employment sector. State and Territory funding bodies appear to share a common belief that, due to changing policy, certain clients (for example, those with high support needs, older clients or people with lower levels of productivity), who once would have been supported in Commonwealth-funded employment programs, are no longer eligible for employment services. It is believed that these policies are contributing to increased demands on State-funded services such as day activities and residential support (for example, the need to staff group homes during the day).

A contrasting view, put forward at some peak discussions, is that Commonwealth-funded employment services sometimes experience difficulty in seeking to transfer older workers, say, 50–60 years of age, from employment services to more appropriate day activities. This issue relates to the planned transition from work to retirement and early onset ageing of some people with disabilities.

Some of these issues may be clarified and quantified in the NDA-commissioned report ‘Disability Service Provision for People with High Support Needs: Improving Access to Employment Assistance and the Interface between Commonwealth and State/Territory Funded Programs for People with High Support Needs’. This report is not yet publicly available.

## **Service types**

While much was said in the peak discussions about unmet need for disability support and related services generally, there was considerable attention focused on two service types: respite and employment.

### **Respite, including centre-based respite**

It was considered by many participants, in more than one jurisdiction, that the apparent government focus on in-home support ignores ‘the fact that people still need residential accommodation options’, including centre-based respite.

One statement wove this theme in with other themes concerning service quality and the need for choices equivalent to those for older people (see also Section 4.3):

The government currently pays \$250 per day for respite for a worker to come into the family home (under the National Respite for Carers Initiative). This daily rate translates to a cost of \$91,000 per annum (to government). Some clients and carers would prefer this level of funds to be spent on a community facility respite option. It is seen as discriminatory that aged people can access a wide variety of services (including centre-based respite) but not people under 65. A facility-based respite option would mean that service providers would be more likely to attract qualified, skilled staff who would stay in the job over time and experience job satisfaction. That is, this option would lead to a higher quality service.

Participants commented that in-home respite has the following consequences: the support worker comes into the home, is fed, uses the utilities, bed etc. which is all paid for by the carer or the family; the carer then has to leave the house in order to capitalise on the respite – they cannot just enjoy a break at home.

Another advocate reported that the State's own consultation processes identified respite as an area of critical need. The key issues raised were insufficient respite support – inadequate respite services, particularly those that are age-appropriate and/or culturally sensitive – and the need for a range of respite care options for people with a disability, and their parents or carer, both within their own homes and outside them. This participant considered that the resulting State plan did not adequately reflect these needs.

An advocacy organisation in another jurisdiction has noticed a large unmet need for respite including residential respite:

- For example, a carer with no ongoing supports is caring for her 24-year-old daughter with an intellectual disability, 24 hours a day, 7 days a week. She receives no support from other family members who are unable to cope with the daughter's challenging behaviours, nor does she receive weekend respite. As her daughter is not involved in any work programs, the carer is constantly trying to find activities for her daughter to do during the day. In order to get a break the carer has been paying for her own respite.

The principal of a special school, it was reported, asked parents what was the biggest challenge or concern they have for their children. The majority of parents indicated that their biggest concern was obtaining out-of-home respite for their child, so that the parents could take a break and 'recharge their batteries' and spend some quality time with the rest of their family.

### *Siblings*

Respite is vital to ease pressure on families and make 'space' for siblings:

- A mother and father, close to retirement age, have been caring for their profoundly intellectually disabled daughter for her entire life. Their other daughter has very little contact with her family, having found the family situation difficult. The couple also had a son with psychiatric disabilities who committed suicide. 'This should never happen.'

### *Quality respite*

- 'A real need exists for flexible respite options for young people with a disability where both the carer and the care recipient enjoy the break from one another. Presently, this is not occurring, and although the carer does receive a break from the care recipient, carers often feel guilty and cannot relax as they feel they are leaving their children in inappropriate accommodation. There needs to be age-appropriate, fun respite options available for recipients, so they will enjoy respite and look forward to going.'
- One respite program was described as 'Claytons respite – the respite you have when you're not having respite'. The key reason is that the service does not focus on when the carer may need a break.
- People with disabilities are being hospitalised as an alternative to respite care. Families are subjected to feelings of abandoning their child and are often asked to sign a form, agreeing to pick their family member up from hospital within a certain time period.

### *Inadequate early intervention services for children*

In some cases, the study team was told, respite services are substituting for early intervention services. Parents are very anxious to access adequate early intervention services for their children but the experience is that there are not enough services or hours available, particularly in some local areas.

### **Employment**

The study team was told: 'Demand exceeds supply for open and supported employment services.' Further, there were examples given of resources being inadequate for worthwhile needs:

- People with high support needs 'are in danger of being locked out of business services' as the agencies now require an EBA (formal award structure) to access case-based funding dollars and many services are not able to achieve this with such clients.
- There are positive gains for those who access employment services but dollars for support are insufficient.
- Employment services are seeing an increase in people with psychiatric disability, who often have more challenging needs. Services are also seeing an increase in clients with work-related injuries (for example, from the declining manufacturing sector), and it is hard to find these people new jobs.
- The new system of case-based funding makes the system more client-focused and more accountable, which is good. But the job subsidies of \$1,400 do not compare with the Job Network subsidies of \$8,000. Many business services are also blocked from participating in case-based funding because they do not have EBAs.
- Case-based funding streams people into 1 of 5 levels of support. Based on those levels, employment agencies can decide not to assist a person if their funding does not meet a person's level of needs.
- 'Case-based funding is an outcome-based program whereby an individual outcome is required within 18 months of the person with the disability accessing the service. Of the 18 months, 6 months needs to be in the workforce for it to be an outcome, leaving 12 months to prepare an individual for the labour force. This outcome may be hard to achieve for people with psychiatric disabilities, as they have high and intermittent levels of need. With case-based funding, individuals only have two attempts at achieving an outcome; they fail, they are ineligible for future service.'
- 'There is a general belief that when an individual completes school their next goal is to obtain paid employment.' People with disabilities who apply for one post-school options program and who indicate 'paid employment' as one of their goals, then become ineligible, as employment is the person's primary objective and this is a Commonwealth-funded program. 'This can in turn become a major gap for the individuals affected as they may not be able to receive employment services.'

### *Attendant care in the workforce*

People would like to see this program re-opened to new clients as demand is significant. Lack of attendant care creates barriers to the Job Network and employment generally.

## Carers and ageing

One of the main messages about carers and ageing, heard by the study team in the discussions, was the concern that there is 'no retirement' from the full-time carer role. 'Carers have a right to retire, like everyone else in the community.'

As one participant put it:

- 'In-home support should not be a life sentence to the family carer. For 38 years I haven't had a chance to be myself'.

In the meantime:

- 'All people, including full-time carers, are entitled to a proper break every year – at least two weeks.'

The study team also heard that carers wanted choice. Some parents do wish to continue to live with and support their offspring with disabilities, and they want the support to do so.

On carer support generally: 'A question I have put to many MPs and bureaucrats since 30 September 2000 relates to the Federal government's buzzword, "mutual obligation". The question is: why is it that it is fair and just that private schools are funded up to \$5,721 per student per year – because private schools saved the Australian taxpayers \$2.2 billion per annum. Carers, usually family members, have taken on the task of looking after those in need – their unpaid services were worth \$27.2 billion in 1999–2000. Thus, if we take the private school equation, that is, \$2.2 billion = \$5,721, this means carers should get \$27.2 billion = \$77,805! I feel sure that carers would be happy with half that amount.'

On carer outcomes:

- One carer spoke of losing seven friends in the last year. All were full-time carers of people with severe–profound disabilities and most died at less than 60 years of age. This was considered an indication of the immense stress on carers following deinstitutionalisation. Often the only next step for the people cared for is homelessness or a nursing home for the aged because 'mum dropped dead'.
- One carer who has cared for almost 40 years but is not yet an 'ageing carer' advised a younger mother to keep trying to get adequate support 'otherwise you'll end up like me!' (meaning experiencing long-term dissatisfaction with the level of support she and her family have received from the service system).

### How much did 'ageing carers' benefit from unmet needs funding?

- It was unclear to participants how much of the unmet needs funding has gone to people with ageing carers. Participants were interested in why these people were not found and who has benefited instead.
- In the case of one program, funds only went to people judged as 'urgent' on the register. It was believed by some participants (but not others) that ageing carers might be less likely to have said they need help immediately and therefore be ranked as only 'high' need (on the assumption that ageing carers 'will hang on'). Again, it was stated that the reluctance of some governments to provide long-term residential accommodation meant that ageing carers could not always get the service they really needed.
- Another view was that ageing carers *do* want services. It was said that some are wary of accepting small offers of support, such as, 1 hour per week of support, because they believe they will then be removed from waiting lists completely. 'They also have a history of a system where their Five-Yearly General Services Plan is reviewed at the end

of each five-year period, they re-state what services they need and are advised again that those services are not available.'

The AIHW received correspondence from a range of people about this study. One letter vividly illustrated both the benefits of growth funding and the remaining needs for some older carers. This carer, of an adult daughter with severe brain injury following a car accident, wrote as follows:

For 12 years I hardly had a day off and I don't know how I survived. Four years ago I received a MIRACLE ... a 'package'. I now get 40 hours help a week. Not all problems however were solved by the package. Life is, nevertheless, now 'life' again ... no longer does day follow relentless day in pain, weariness and desperation as before. My thoughts are always with those who have no help of any kind. I still nurse 128-hour weeks though. Try that when you are seventy! ...

Policy and legislation for the disabled is being funded by forcing old people like us to live in poverty and slavery ...

The thought I want to leave you with as I conclude is:

We are old. We are poor. We are tired. We are ignored. We are used. We are fearful of the future. We need help!

## **Funding, infrastructure and planning life transitions**

In addition to the specific issues documented above, the peak discussions frequently raised more general issues relating to service infrastructure and funding generally.

On the size of the Commonwealth's contribution: This looks larger than it really is, because of the Commonwealth's 'tax clawback' capacity, if its funding is used to employ people (for example, in service provision).

On volunteers: Funded organisations are finding it increasingly difficult to replace ageing committee members and supporters. As a result some committees are seeking larger agencies to take them over, although others are trying to remain independent. What they are finding is that the families who 'got things started' are not being replaced.

On aged care funding disparity: One participant noted the disparity between funding and support for the aged (those over 65 years) and younger people with disabilities, arguing as follows. Aged care services (targeting 33% of the population with disability) are better funded than services targeting the 67% of people with disability aged between 0–64 years. 'There is a perception that if the person is less than 65 years the family has to do the job and only once they are older than 65 and their support becomes a Commonwealth responsibility, will the government step in.'

On planning transitions and escaping from crisis management: 'Unmet need will not be met until we have planned transitions at each stage of the life cycle.'

## **Flexibility is the key—'one size does not fit all'**

There was a consistent theme across discussions that truly person-centred solutions can best meet the needs of each individual. Attempting to fit individuals into pre-defined program options does not always lead to satisfactory outcomes. For instance, some participants felt that government decisions on the types of services that will be funded (for example, in-home

support) are based predominantly on 'ideology' and consultation with service providers. These decisions limit the choices of clients and their families.

Another participant put it this way: 'The issues and views of the disability sector are not homogeneous and reflect the wide diversity and impact of disability on individuals' and families' lives. Thus it is valid that some views contradict. What this means is that the comfort of a "one size fits all" approach by government is not an option.'

## 7.4 Unmet needs: literature and other sources

The study team searched for recent and reliable accounts of the existence and experience of any unmet need such as articles, peak body newsletters, government and peak body reports on consumer consultations. The key points raised in the literature are detailed below.

### Accounts of remaining unmet needs

Recent Australian reports and papers were sought, for evidence about unmet need in the years of relevance to the study, particularly 2000–01. These needs may relate directly to services funded under the CSDA, or may relate to more indirect effects on CSDA services. The issue of equipment is a good example, where the study team heard much at the peak discussions; most assistance is provided under other programs, but the effects of inadequate supply feed into additional needs for CSDA assistance.

### Equipment and therapy

Nita Curtis spoke at the ACROD 2001 convention, on the effect of the CSDA and what it meant to her as a parent (and foster parent) and carer (Nita Curtis, personal communication). After suggesting that the CSDA had made little difference to her life, she continued:

If I am going to highlight something that has had the most impact on myself and my young people it would have to be the issues of aids and appliances and therapy... These three items alone have the means of making or breaking the caring role, both within the family home ... and also for staff caring for people in many different accommodation facilities.

She went on to speak about the importance of lifting equipment, wheelchairs that prevent pressure sores and other health problems, communication devices 'that help people with disabilities to tell us what is wrong so that immediate action can be taken before things go too far'. Without them: 'Frustration, illness, pain and discomfort set in. People with disabilities suffer. Parents give up. Carers get ill and tired and wear out.'

For adults especially:

... it is a frightening state of affairs. There are long waiting lists for therapy. Even longer waiting lists for equipment. One of the major providers of adult therapy and equipment has 92 clients who will be on the waiting list for at least 24 months ... And that means no assessments, no maintenance and very fragmented service and access to a therapist ...

I have been told the story of a young woman in an Aboriginal community in the cross border region who is currently being transported by her carers in a wheelbarrow, because her equipment is broken and waiting times for a new or repaired one are long. There is also the story of two young Aboriginal men who, because of lack of equipment and services, are forced to live in an institution almost 2,000 km from their families. Can you imagine their lives?...

If I wish to continue to care for my children, then having the right equipment and services will allow me to do this much longer.

The Physical Disability Council of New South Wales has called for substantial increases in the funds available for the New South Wales equipment scheme Program of Appliances for Disabled People (PADP), stating that: 'such is the scale of unmet need that we believe the PADP budget should be increased from \$13 million to \$26 million per annum' (PDCN 2001).

### **Attendant care**

In 2001, the Physical Disability Council of New South Wales recommended that 'the government should accelerate its timetable and introduce new funds now to meet the total estimate of 250 people whose need for support from the Attendant Care Program is currently unmet' in New South Wales (PDCN 2001). This followed an earlier discussion paper which claimed that funding for the Attendant Care Program has decreased by 20% since the program was transferred from the Commonwealth to the States in 1993 and that waiting lists have increased (PDCN 2002).

### **Appropriate residential accommodation support and respite**

Unmet needs for out-of-home accommodation support and respite were reported at all peak discussions. The following case study was included in a recent bulletin of the National Council on Intellectual Disability:

Mrs X went into hospital leaving her daughter, for whom she has provided care for the past 47 years, at home by herself. Mrs X, well into her 80s, placed her daughter on the accommodation waiting list over five years ago. After her hospital admission, her daughter was placed into emergency respite care and has remained there even though her mother has had to go to a nursing home. The future for her daughter is unknown and it is expected she will remain in 'respite' for a considerable time (NCID 2001).

A New South Wales parliamentary report found, in December 2000, that: 'Permanent supported accommodation stands out as the area of greatest need for disability services in NSW. Other areas of need cannot be effectively addressed unless demand for accommodation services is substantially reduced ... The disability services system is focused largely on crisis management as a result of this relentless pressure for accommodation' (NSW Legislative Council 2000).

The placement of young people in nursing homes is widely considered inappropriate. A recent article noted that such placements are particularly inappropriate where: an individual is placed in a nursing home because there is nowhere else to place them; their support needs are greater than can be managed in existing accommodation; or their parents have been placed in a nursing home and they are expected to follow (NCID 2001). Another article discussed the issue of young people (usually with acquired brain injury and neurological conditions) in nursing homes, outlining the problems encountered. These include staff not being trained to meet the residents' needs; little peer support; few opportunities to participate in community life; and little or no access to required therapy services (Multiple Sclerosis Society of Australia 2002).

The following case study concerns a man who is at risk of being placed in a nursing home as he is receiving no care hours:

Mr X has spinal cord injury and is dependent for most tasks including personal care, domestic, community activities and feeding. He is currently still in hospital, where professionals have

stated he will require approximately 34 hours per week attendant care (minimum 23 hours per week) to return to the community. He lives with his wife and children but the care team is concerned that the lifting tasks will not be possible for his wife. He has been referred to all possible care options, with no success. In one case he has been advised he will be considered a priority which means he will move from a list of 60 applicants to a group of 20. He has been advised that the waiting time is approximately 8 months.

In the context of the third CSDA negotiation, ACROD has highlighted its concern that Commonwealth funding should not be restricted to the supply of in-home support for ageing carers when community accommodation is often a higher priority for people with disabilities and their families (ACROD 2001).

Carers Australia have identified particular problems with residential respite care (Carers Australia 2001a). They note that there are long waiting lists generally and that residential respite care is 'usually unavailable in rural areas where respite beds are often used as rehabilitation beds and acute beds are often used for respite beds'. They also note the inflexibility of services and the lack of appropriate centre-based day activity programs.

A mother and father caring for their 30-year-old son with severe disabilities provided the following case story:

Our son still lives at home. He has little fine motor control, is non-verbal, has no literacy, cannot feed, dress or toilet himself but has good social interaction skills. We are allocated one day per month for respite. This is in-home respite. We desperately need this respite. We do not access centre-based respite. I know of no other job that insists you be at work for 30 days out of every month. Instead of less assistance we need more. My husband and I believe we deserve a real break ... As a family we have had no real holidays. Yet still we are required to give the rest of our lives to this one person to save this country money so it can be better spent on others.

### **Day activities**

Carers Victoria issued a paper in 2000 on the carer perspective of the Victorian Day Activities Consultation. The paper highlighted similar issues to those raised at the three peak discussions. Some of these follow (Carers Victoria 2000).

Carers of people with acquired brain injury and challenging behaviours find it more difficult to find suitable day activities. The father of an adult son with ABI noted:

Social activities for young people with disabilities are scarce. There is only one group in the area ... They can take 22 [people] for 1 day per week, there are another 22 on the waiting list. They can't find enough assistants to run the group.

There is a serious lack of day programs for the post-school age group. One mother of a 20-year-old daughter with cerebral palsy wrote:

We had our daughter at home for 3 years after she left school. I had to get funding for her from 3 different agencies. The waiting lists were horrific. Then I only got two days per week ... To get funding I was desperate, crying, could hardly speak. Meanwhile my daughter was getting worse.

### **Transport**

One parent described how their family had 'fallen through the gaps' of the service system. The parent noted that children are assessed for services according to their disability not their needs. In doing this they often miss out on or are ineligible for certain service responses:

... we applied for a subsidy under a disabled transport scheme with full reports from his practitioners and other services we accessed, only to be told that our son was not severe enough to meet the criteria and to re-apply again if his condition worsened – he had died before we received the letter – I don't think you can get much worse than that. (Christine: CONNECTIONS Info Exchange 2001)

The Physical Disability Council of New South Wales has called for \$10 million to be added to the recurrent spending budget of the Taxi Transport Subsidy Scheme to increase the subsidy limit from 50% of the metered fare to 75% (PDCN 2001).

### **Interface issues and planning for life transitions**

The interface between Commonwealth and State/Territory funded services appears to be a concern for people with disabilities, service providers and governments. ACROD recently called for greater efforts to 'remove the barriers and blockages that prevent people with disability from moving between State/Commonwealth administered services and vice versa, as they enter new life stages and their needs and aspirations change' (ACROD 2001).

One particular area of concern is the interface between services for the aged and services for younger people with disabilities. For example, Carers Australia has called for a substantive national approach to assist carers, including transport allowances, flexible and innovative respite care services, counselling support and Community Aged Care Packages for ageing carers of people with disabilities (Carers Australia 2001b). Such efforts require smooth pathways between programs administered by various State/Territory and Commonwealth funding areas.

### **Costs of disability**

Fees and contributions required for disability services, raised as issues in the peak discussions, are a serious matter for people with disabilities. Their incomes are lower on average than the rest of the population, and they are more likely to be reliant on government pensions. Some 70% of those with profound core activity restrictions (always needing assistance with ADLs) and 56% of those with severe restrictions (sometimes needing assistance) had incomes in the lowest two quintiles, compared to 31% of people with no disabilities (AIHW 1999b:262). Their expenses in some areas are higher, for instance for medical care and health expenses, and possibly also for transport and personal care goods (Thomas 1997, cited in AIHW 1997b:338).

### **The mutual support of the formal and informal care systems**

Australia's service system has been successful in providing services to complement informal care, to sustain the efforts and choices of carers. Families and carers, in turn, are a critical part of the support system for people with disabilities, and have been a key factor in the successful de-institutionalisation (or non-institutionalisation) of large numbers of people (see Chapter 4).

Thus the formal system could be conceptualised as complementing the informal system where it needs help rather than taking over after the informal system has 'crashed'. People without family carers certainly need assistance. But the costs of not providing assistance to people caring for family members with 'severe disability' are potentially very large.

## 7.5 Evidence from analysis of 'other services' data

### Disability and ageing

The number of people in the CSDA 'potential population' group (those with ongoing needs for assistance in self care, mobility or communication) is growing and ageing. Between 2000 and 2006, it has been estimated that those aged under 65 years will grow by 9%, those aged 15–64 years by 12%, and the group aged 45–64 years will grow by 19.3% or 59,500 people (AIHW 2000c). Survival to older ages is now a reality for some people with an early onset disability. Of people with these ongoing needs for assistance, 11% of those aged 45–64 years reported an early onset disability (that is, acquired before age 18).

Trends in income support payments paint a similar picture of growth and ageing. There were in June 2000 some 602,000 recipients of the Disability Support Pension, almost double the number in 1989, and in June 2001 there were 623,926 (AIHW 2001b; FaCS 2001c). Growth rates have slowed in recent years, including for men aged 50+ years, but for women aged 50+ rates per population have continued to increase throughout this period.

Thus it is likely that the users of disability services will age in profile, and this is borne out by analyses of the CSDA MDS service data (AIHW 2002). The service borders between disability and aged care, already on the policy agenda and of some concern during the peak discussions, are likely only to become more important.

Age as a single factor cannot predict the need for services, nor effectively define service borders. In the AIHW study of disability and ageing it was found, after a range of analyses that:

... it does not seem from the foregoing analysis that any of these factors (e.g. age, age at onset, disabling condition) could reliably be used as proxy indicators of need. None could provide a suitable single basis for devising policies and services for particular groups of people. Put another way, the best indicator of need is need – defined and assessed by methods agreed among potential service providers and funders. Factors such as age, age at onset and disabling condition could inform individual needs assessments, but should not be seen as primary determinants of need. (AIHW 2000c: 203)

Some differences between people aged under 65 years and those aged over 65, in terms of their needs for assistance, are summarised in Table 7.4.

**Table 7.4: People with a severe or profound core activity restriction living in households: differences in need for assistance and sources of assistance between people aged under 65 and those aged 65 or over, Australia, 1998**

	Under 65 years		65 years or over	
	Number ('000)	%	Number ('000)	%
<b>Need for assistance</b>				
One of 10 daily activities <sup>(a)</sup>	633.4	99.6	324.6	99.6
More than one core activity	264.3	41.5	122.4	37.6
All three core activities	56.0	8.8	17.0	5.2
<i>Total severe or profound</i>	636.0		325.6	
<b>Main source of assistance is a formal service provider assistance<sup>(b)</sup></b>				
Self care	14.5	4.0	17.8	11.5
Mobility	28.6	6.3	22.2	8.1
Communication	18.0	13.0	—	—
Health care	49.8	15.5	95.4	44.1
Housework	18.6	7.4	60.0	26.5
Property maintenance	40.0	12.9	74.9	30.0
Paperwork	*9.0	7.0	*5.1	*4.6
Meal preparation	*6.0	*4.9	23.7	19.7
Transport	18.9	6.4	22.8	9.8
<b>Main source of assistance is a co-resident carer<sup>(b)</sup></b>				
Self care	305.5	84.6	113.4	73.1
Mobility	343.9	76.2	148.1	54.1
Communication	113.6	82.1	25.3	88.5
Health care	240.9	74.8	92.8	42.9
Housework	207.5	82.2	129.5	57.3
Property maintenance	209.7	67.7	112.9	45.3
Paperwork	98.0	75.4	70.0	63.4
Meal preparation	104.8	86.2	86.3	71.8
Transport	224.3	76.4	108.5	46.7

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

(b) As a percentage of people of that age group who need assistance with that particular activity.

— Nil or rounded to zero.

Source: AIHW 2000c, Table 19.2.

## Use of residential aged care by people under 65—their profile

There were almost 6,000 people aged under 65 living in aged care homes on 30 June 2001, 1,014 being aged under 50 years (Table 7.5a). There is a widespread view that many of these people are inappropriately accommodated (see, for example, Sections 7.3 and 7.4). A further 146 residents aged 15–64 years were receiving respite in aged care homes; some views were expressed in the peak discussions that, especially in rural areas, this can be preferable to forcing the client to move long distances to receive respite.

There were 681 residents of Indigenous origin aged under 65 (Table 7.5b). This represents 28% of all Indigenous residents, a much higher proportion than for non-Indigenous clients

(4.1%). (People of Indigenous origin are eligible for aged care services at earlier ages in recognition of their poorer health experience and early ageing.)

It would be a useful data development, producing more comparable data, if the residential aged care collections included the key CSDA MDS items of 'disability group' and 'support needs', or something comparable.

Trends in de-institutionalisation were presented in Chapter 4. It could perhaps be argued that the history of de-institutionalisation of joint psychiatric/intellectual disability establishments, begun in the 1980s, has left gaps. Is evidence of such perceived gaps found in the reports of unmet needs of people with psychiatric disability and ABI, and the concerns about younger people in nursing homes?

### **Use of HACC services**

Table 7.6 shows the age of and service type received by HACC clients for 1 July to 30 September 2001. Around 19% of all HACC clients over this period were aged under 65 years. Of all service types, respite services had the highest percentage of clients aged under 65 years (32%), including 11% of clients who were under 40 years. For the other service types, the proportion of clients aged under 65 years ranged from 11% (for home meals) to 29% (counselling and social support). Note that the agency response rate for this collection during this time period was less than 80%, so results should be interpreted with caution.

**Table 7.5a: People living in aged care homes, by age and sex, by State/Territory, 30 June 2001**

Age	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Australia
<b>Female</b>									
15–29	19	4	12	3	4	0	0	1	43
30–49	200	88	111	46	27	16	5	1	494
50–64	859	549	458	214	150	58	11	26	2,325
<i>Total 15–64</i>	<i>1,078</i>	<i>641</i>	<i>581</i>	<i>263</i>	<i>181</i>	<i>74</i>	<i>16</i>	<i>28</i>	<i>2,862</i>
65+	33,066	23,010	16,908	8,038	9,413	2,649	1,019	149	94,252
<b>All ages</b>	<b>34,144</b>	<b>23,651</b>	<b>17,489</b>	<b>8,301</b>	<b>9,594</b>	<b>2,723</b>	<b>1,035</b>	<b>177</b>	<b>97,114</b>
<i>Total 15–64</i>									
<i>% of all ages</i>	<i>3.2</i>	<i>2.7</i>	<i>3.3</i>	<i>3.2</i>	<i>1.9</i>	<i>2.7</i>	<i>1.5</i>	<i>15.8</i>	<i>2.9</i>
<b>Male</b>									
15–29	14	10	9	0	2	2	0	1	38
30–49	215	104	125	37	22	7	1	9	520
50–64	973	625	508	185	138	52	24	23	2,528
<i>Total 15–64</i>	<i>1,202</i>	<i>739</i>	<i>642</i>	<i>222</i>	<i>162</i>	<i>61</i>	<i>25</i>	<i>33</i>	<i>3,086</i>
65+	11,951	8,108	6,481	2,743	3,173	891	341	116	33,804
<b>All ages</b>	<b>13,153</b>	<b>8,847</b>	<b>7,123</b>	<b>2,965</b>	<b>3,335</b>	<b>952</b>	<b>366</b>	<b>149</b>	<b>36,890</b>
<i>Total 15–64</i>									
<i>% of all ages</i>	<i>9.1</i>	<i>8.4</i>	<i>9.0</i>	<i>7.5</i>	<i>4.9</i>	<i>6.4</i>	<i>6.8</i>	<i>22.1</i>	<i>8.4</i>
<b>Persons</b>									
15–29	33	14	21	3	6	2	0	2	81
30–49	415	192	236	83	49	23	6	10	1,014
50–64	1,832	1,174	966	399	288	110	35	49	4,853
<i>Total 15–64</i>	<i>2,280</i>	<i>1,380</i>	<i>1,223</i>	<i>485</i>	<i>343</i>	<i>135</i>	<i>41</i>	<i>61</i>	<i>5,948</i>
65+	45,017	31,118	23,389	10,781	12,586	3,540	1,360	265	128,056
<b>All ages</b>	<b>47,297</b>	<b>32,498</b>	<b>24,612</b>	<b>11,266</b>	<b>12,929</b>	<b>3,675</b>	<b>1,401</b>	<b>326</b>	<b>134,004</b>
<i>Total 15–64</i>									
<i>% of all ages</i>	<i>4.8</i>	<i>4.2</i>	<i>5.0</i>	<i>4.3</i>	<i>2.7</i>	<i>3.7</i>	<i>2.9</i>	<i>18.7</i>	<i>4.4</i>

Note: 146 residents aged 15–64 years receiving respite care are excluded.

Source: AIHW analysis of data supplied by the Department of Health and Ageing from the Aged and Community Care Management Information (ACCMIS) Warehouse.

**Table 7.5b: People living in aged care homes, Indigenous status by age and State/Territory, 30 June 2001**

Age	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Australia
<b>Indigenous</b>									
15–29	1	0	4	1	1	0	0	1	8
30–49	5	0	11	10	0	0	0	4	30
50–64	20	2	49	45	1	0	0	36	153
<i>Total 15–64</i>	<i>26</i>	<i>2</i>	<i>64</i>	<i>56</i>	<i>2</i>	<i>0</i>	<i>0</i>	<i>41</i>	<i>191</i>
65+	109	23	143	114	20	7	3	71	490
<b>All ages</b>	<b>135</b>	<b>25</b>	<b>207</b>	<b>170</b>	<b>22</b>	<b>7</b>	<b>3</b>	<b>112</b>	<b>681</b>
<i>Total 15–64</i>									
<i>% of all ages</i>	<i>19.3</i>	<i>8.0</i>	<i>30.9</i>	<i>32.9</i>	<i>9.1</i>	<i>0.0</i>	<i>0.0</i>	<i>36.6</i>	<i>28.0</i>
<b>Not Indigenous</b>									
15–29	26	12	16	1	5	2	0	0	62
30–49	313	164	201	68	43	22	6	5	822
50–64	1,516	1,052	832	309	250	104	33	11	4,107
<i>Total 15–64</i>	<i>1,855</i>	<i>1,228</i>	<i>1,049</i>	<i>378</i>	<i>298</i>	<i>128</i>	<i>39</i>	<i>16</i>	<i>4,991</i>
65+	39,729	28,784	21,902	9,811	10,987	3,435	1,327	159	116,134
<b>All ages</b>	<b>41,584</b>	<b>30,012</b>	<b>22,951</b>	<b>10,189</b>	<b>11,285</b>	<b>3,563</b>	<b>1,366</b>	<b>175</b>	<b>121,125</b>
<i>Total 15–64</i>									
<i>% of all ages</i>	<i>4.5</i>	<i>4.1</i>	<i>4.6</i>	<i>3.7</i>	<i>2.6</i>	<i>3.6</i>	<i>2.9</i>	<i>9.1</i>	<i>4.1</i>
<b>Unknown</b>									
15–29	6	2	1	1	0	0	0	1	11
30–49	97	28	24	5	6	1	0	1	162
50–64	296	120	85	45	37	6	2	2	593
<i>Total 15–64</i>	<i>399</i>	<i>150</i>	<i>110</i>	<i>51</i>	<i>43</i>	<i>7</i>	<i>2</i>	<i>4</i>	<i>766</i>
65+	5,179	2,311	1,344	856	1,579	98	30	35	11,432
<b>All ages</b>	<b>5,578</b>	<b>2,461</b>	<b>1,454</b>	<b>907</b>	<b>1,622</b>	<b>105</b>	<b>32</b>	<b>39</b>	<b>12,198</b>
<i>Total 15–64</i>									
<i>% of all ages</i>	<i>7.2</i>	<i>6.1</i>	<i>7.6</i>	<i>5.6</i>	<i>2.7</i>	<i>6.7</i>	<i>6.3</i>	<i>10.3</i>	<i>6.3</i>
<b>Total</b>									
15–29	33	14	21	3	6	2	0	2	81
30–49	415	192	236	83	49	23	6	10	1,014
50–64	1,832	1,174	966	399	288	110	35	49	4,853
<i>Total 15–64</i>	<i>2,280</i>	<i>1,380</i>	<i>1,223</i>	<i>485</i>	<i>343</i>	<i>135</i>	<i>41</i>	<i>61</i>	<i>5,948</i>
65+	45,017	31,118	23,389	10,781	12,586	3,540	1,360	265	128,056
<b>All ages</b>	<b>47,297</b>	<b>32,498</b>	<b>24,612</b>	<b>11,266</b>	<b>12,929</b>	<b>3,675</b>	<b>1,401</b>	<b>326</b>	<b>134,004</b>
<i>Total 15–64</i>									
<i>% of all ages</i>	<i>4.8</i>	<i>4.2</i>	<i>5.0</i>	<i>4.3</i>	<i>2.7</i>	<i>3.7</i>	<i>2.9</i>	<i>18.7</i>	<i>4.4</i>

Note: 146 residents aged 15–64 years receiving respite care are excluded.

Source: AIHW analysis of data supplied by the Department of Health and Ageing from the Aged and Community Care Management Information (ACCMIS) Warehouse.

**Table 7.6: HACC clients by service type and age, July–September 2001**

Age group (years)	0–39	40–49	50–54	55–59	60–64	Under 65 subtotal	65+	Total
<b>Number</b>								
Home help	2,574	2,223	1,591	1,937	2,833	11,158	63,896	75,055
Personal care	1,043	569	366	468	667	3,113	14,044	17,160
Nursing	2,172	1,258	935	1,173	1,620	7,158	26,632	33,793
Allied health care	821	547	439	556	864	3,227	13,047	16,275
Respite	20	14	7	8	7	56	121	177
Centre-based day care	2,314	918	635	788	1,288	5,943	19,223	25,166
Home meals	512	588	479	605	972	3,156	24,840	27,998
Centre meals	765	403	327	399	650	2,544	11,609	14,153
Home maintenance	457	492	432	528	865	2,774	17,516	20,290
Transport	2,178	1,146	836	1,045	1,537	6,742	29,986	36,728
Assessment/case management/case planning	3,436	1,627	1,208	1,492	2,199	9,962	39,978	49,946
Counselling and social support	3,254	1,157	726	898	1,117	7,152	17,530	24,682
Other	149	114	54	77	77	471	1,169	1,641
<b>Total</b>	<b>13,259</b>	<b>6,936</b>	<b>4,874</b>	<b>6,089</b>	<b>9,072</b>	<b>40,230</b>	<b>171,041</b>	<b>211,287</b>
<b>Percentage</b>								
Home help	3.4	3.0	2.1	2.6	3.8	14.9	85.1	100.0
Personal care	6.1	3.3	2.1	2.7	3.9	18.1	81.8	100.0
Nursing	6.4	3.7	2.8	3.5	4.8	21.2	78.8	100.0
Allied health care	5.0	3.4	2.7	3.4	5.3	19.8	80.2	100.0
Respite	11.3	7.9	4.0	4.5	4.0	31.6	68.4	100.0
Centre-based day care	9.2	3.6	2.5	3.1	5.1	23.6	76.4	100.0
Home meals	1.8	2.1	1.7	2.2	3.5	11.3	88.7	100.0
Centre meals	5.4	2.8	2.3	2.8	4.6	18.0	82.0	100.0
Home maintenance	2.3	2.4	2.1	2.6	4.3	13.7	86.3	100.0
Transport	5.9	3.1	2.3	2.8	4.2	18.4	81.6	100.0
Assessment/case management/case planning	6.9	3.3	2.4	3.0	4.4	19.9	80.0	100.0
Counselling and social support	13.2	4.7	2.9	3.6	4.5	29.0	71.0	100.0
Other	9.1	6.9	3.3	4.7	4.7	28.7	71.2	100.0
<b>Total</b>	<b>6.3</b>	<b>3.3</b>	<b>2.3</b>	<b>2.9</b>	<b>4.3</b>	<b>19.0</b>	<b>81.0</b>	<b>100.0</b>

*Notes*

1. Figures are based on the people receiving HACC services (care recipients), and do *not* include data on their carers. Hence respite numbers relate to HACC care recipients, not their carers.
2. Totals for all service types are not the sum of individual service types since a client may access more than one service during the quarter.
3. Totals for all ages include 16 clients whose age was missing.
4. 'Other' service types include linen services and other food services.
5. The service type 'nursing' includes both home-based and centre-based nursing services.
6. Data should be interpreted with caution given that less than 80% of HACC-funded agencies submitted data.

Source: AIHW analysis of HACC MDS third quarter collection 2001, linked data.

## **Use of SAAP services by people with disabilities**

Disability-related pension recipients accounted for 17% of all SAAP (Supported Accommodation Assistance Program) clients in 1999-00 (AIHW 2001b). In the same period, a total of 17,300 and 11,300 support periods were received by this group from general and high volume SAAP agencies, representing 14% and 34% of all support periods delivered (AIHW forthcoming a).

Repeat use of SAAP services was highest for disability-related pension recipients, with requests for accommodation support (76%) and 'other' support (82%) being the primary reasons for seeking assistance (AIHW 2001b). This group also tended to stay in living situations, such as living in parks, squats or on the street, twice as often as other groups (6% compared to the national average of 3%).

These numbers suggest that there are significant numbers of people with a disability living in the community who are not living in stable housing or receiving essential support services.

It appears probable that many SAAP services and hence SAAP users are not included in population surveys. While 'homelike' facilities could be included, larger or more secure facilities may not be. Thus these people are likely to be a group under-represented by the disability population survey estimates, that is, they are not represented (not included) in the estimates of unmet need.

## **Housing**

Access to affordable and appropriate housing for people with disabilities has the capacity to reduce demands on the specialist disability services sector. A report prepared in 2001 on behalf of the Disability Support and Housing Alliance highlights the significant disadvantage that people with disabilities face in their search for appropriate housing, particularly for people with high support needs (McNamara 2001). The report makes a series of recommendations, including a number of recommendations in relation to improving the level of accessible, affordable housing. The report also highlights the range of relevant issues in relation to accessible and affordable housing (such as ensuring access to a range of housing types; access to modifications where necessary; housing locations that fit with the person's aspirations, lifestyle, access requirements and support needs; choice of living companions).

### **Impact of boarding house closures**

Private boarding houses operate on a for-profit basis in most States and Territories, with the regulatory regime covering their operation varying by jurisdiction. These unfunded facilities have tended to offer accommodation and limited support (such as meals and some supervision) to people with intellectual and/or psychiatric disabilities, most commonly in larger urban centres. Various government inquiries have expressed concern for some years about the accommodation and support offered in these houses, in relation to quality of accommodation and food provided, the poverty of residents and insecurity of tenure (Commission of Inquiry into Poverty 1975; South Australian Health Commission 1988; Human Rights and Equal Opportunity Commission 1993).

A combination of factors has led to a decline in the number of beds offered, including:

- changed regulations in some jurisdictions, or uncertainty about future regulatory regimes;

- 'gentrification' of inner city areas where many of these facilities operated, leading to an increase in property values providing alternative investment opportunities with higher returns;
- ageing building stock requiring significant capital investment to meet building and fire regulations, leading to closures;
- retirement of operators with limited new operators entering the industry;
- fewer closures of institutions; and
- possibly, a change in the expectations and lifestyles of people who may formerly have sought boarding house accommodation.

Residents who previously lived in boarding houses would not have been included in the population of people living in 'households' counted by the Australian Bureau of Statistics. Thus a new population of people seeking disability funded accommodation may have resulted from the decline in boarding home beds and/or from government actions designed to rehouse residents seen to be inappropriately housed.

## Health

While people with a disability have frequently wished to distance themselves from a 'medical model' of disability, it is nevertheless recognised that, when they are sick, they need access to appropriate health services (see, for example, Parmenter 2000). This need occurs whether people are in residential care or in the community.

A recent review of the 211 deaths of people with disabilities who died in care in New South Wales between 1991 and 1998 pointed to a range of improvements needed to avoid premature death: the need for health screening and reviews by health professionals, for better training of other staff and for adequate monitoring systems, for example, in the handling of epilepsy (New South Wales Community Services Commission 2001).

As systems promote de-institutionalisation, it becomes crucial to ensure that the health needs of vulnerable people in the community can be ascertained and met. The health status of people with intellectual disability in a Sydney area has been suggested to be considerably worse than the rest of the population in Australia (Beange, McElduff & Baker 1995) and there have been more recent, similar findings in the United States of America (Horwitz et al. 2000).

Literature on the health care needs of people with disabilities is not reviewed here. However, one specific example is provided to illustrate one of many complex interfaces between the primary health sector and the disability services sector. A recent study into the experience of adults with cerebral palsy who are hospitalised found that many hospital staff had little knowledge of cerebral palsy and the needs of people with cerebral palsy (Buzio 2001). As a result of the lack of knowledge, over 60% of respondents chose to rely on the assistance of either family and friends, paid support workers, or both, to provide basic care during their hospital stay. This has clear implications for specialist disability support services.

People with mental illness often have associated disabilities. Almost one in five adult Australians were found to have had a 'mental disorder' at some time during the 12 months prior to an ABS survey in 1997 (ABS 1998). Of these, 44% had 'mild, moderate or severe disability', as measured by the Brief Disability Questionnaire. Only a small proportion of people with mental disorders now spend extended periods in psychiatric hospitals or

residential facilities; most are cared for in the community. There were 1,301 available beds in public community residential mental health care services that were staffed for 24 hours a day (AIHW 2001c).

A recent community consultation with carers in Victoria noted that 'when faced with the complexity of health, disability and community carer service systems, carers reported great confusion and difficulty in finding out what was available and what they and their relative were entitled to' (Nankervis & Rebeiro 2000:28). Carers had a range of concerns and made the following statement:

Given the life long nature of disability support needs and care requirements, carers requested that:

- better information be given within the medical/health sector at the outset, and that
- linking occur to a specific case worker with the capacity for ongoing outreach, current information provision, regular review of care needs and service advocacy (Nankervis & Rebeiro 2000:29).

There is generally no systematic information on the experience of people with disability in the health service system.

## **Insurance**

Insurance has a triple possible impact on the CSDA program. People excluded from benefits (because of the fault aspects of insurance) create pressures for government schemes (the Disability Support Pension as well as the CSDA). Insurance costs are said to be impacting on the financial viability of NGOs and the resources available for support services. And insurers can be reluctant to insure some high support needs and 'dangerous' clients.

## **Equipment and environmental modifications**

The environment of a person with a disability, including the equipment available to them, is recognised as a key factor in the creation of disability (ICF, Chapter 2). The provision of equipment has significant potential to increase autonomy for people with disability and, in the context of the CSDA, significantly reduce reliance on personal assistance. Further, there is evidence that equipment, for some people and some types of disability, is preferred to the provision of personal assistance (Verbrugge, Rennert & Madans 1997). The principles of 'universal design' of physical spaces suitable to all align with the idea of 'resilient communities' and the promotion of autonomy rather than being 'serviced'.

All governments and a range of non-government organisations undertake funding and operation of equipment schemes in Australia. In many cases these schemes provide cost-free, essential aids and equipment for people with disabilities based on eligibility criteria. Eligibility criteria may be based on: veteran status, specific impairment (for example, hearing)—such criteria are common for Commonwealth schemes as well as a range of criteria including demonstration of financial hardship and lack of assistance from other sources.

In 1996, as part of the evaluation of the first CSDA, an equipment study was commissioned and recommended that a more consistent national approach to eligibility and assessment for equipment would be useful. Some State schemes have since undergone review, resulting in a widening of the range of items available and the eligibility criteria (see AIHW: Bricknell et al forthcoming b).

Other studies have suggested significant unmet need for equipment (for example, ACROD 2002; Carers Australia 2001c; Ernst & Young 1996; PDCN 2000, 2001).

Equipment schemes are a key aspect of the CSDA service 'environment' and, like the environment for people with disabilities, are key factors in the efficacy of CSDA services and the needs they are required to meet.

## **7.6 Conclusions on remaining unmet need for specific services**

The estimation of unmet need for disability support services is a complex task. The AIHW has used a number of sources, both quantitative and qualitative, to develop and refine the estimates. Population survey data have been used because they focus on 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) have been extrapolated to provide national indications of unmet needs for services. Orders of magnitude have been compared and estimates refined in a process of triangulation.

The resulting estimates of remaining unmet need in 2001 are:

- 12,500 people needing accommodation and respite services;
- 8,200 places for community access services; and
- 5,400 people needing employment support.

### **Conservative basis of estimates**

The AIHW has made these estimates on a conservative basis, with the aim of providing reliable 'lower bound' estimates. This is considered more useful than making higher estimates which, while perhaps more in the mid-range, may be subject to more debate.

Need for CSDA accommodation support services was not inferred on the basis of population estimates of need for assistance alone. Further filters were placed on the analysis, insisting that there was expressed unmet need for formal assistance and some evidence of having tried to obtain it. Reasons for not obtaining formal assistance were examined and some excluded from the estimates, including people who 'did not know the service existed'; many would argue that this significant group of people should be included.

The estimates exclude people in 'health establishments' including hospitals and nursing homes.

The estimates of unmet need for community access services make no specific allowance for possibly higher rates of use of post-school options services by 18-20-year-olds.

While the accommodation and respite unmet needs estimates may include some people who are receiving some services<sup>2</sup> the community access and employment services estimates do not. That is, for the latter service types there is no inclusion of people with possibly 'under met' need.

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<sup>2</sup> The estimation of cost would require being able to estimate what proportion of the accommodation and respite clients may already receive some services (see Chapter 8). This figure cannot reliably be estimated from the 1998 ABS confidentialised unit record file but should be able to be estimated from the full file.

It should also be remembered that these estimates do not represent the sum total of unmet need for CSDA services, as community support services are not included in the estimates (not being in the project brief).

### **Other evidence on the need for respite**

These estimates should, further, be seen in the context of other information about the unmet needs of carers. In 1998 there were 23,600 primary carers of people with disabilities aged under 65 who reported that they had never received respite but needed it, and a further 17,000 who had received it at some stage but needed more. In relation to the older carers, it was estimated that 5,300 primary carers in the target group of the bilateral agreements had either never received respite and wanted it, or had received it in the previous three months and wanted more. Further, it is estimated that in 2001:

- there were 32,700 primary carers in the target groups of the bilateral agreements: 16,500 in Group A and 16,200 in Group B;
- a total of 5,300 primary carers had either never received respite and wanted it, or received it at some stage but needed more;
- some 10,200 care recipients in the two groups could not manage at home alone for a few hours, and 6,700 recipients could not manage at home alone even for less than one hour;
- about 14,500 primary carers of the two groups had been in a caring role for 30 years or more; and
- a total of 15,900 primary carers spent, on average, 40 hours or more per week providing care.

### **Further evidence: urgency of criteria and under-reporting in registers**

There are other information and data that provide evidence of needs beyond those estimated:

- Evidence from jurisdictions that they are providing most new services to people with very urgent needs. There appear to be between 6 and 24 times more people seeking services than are actually receiving them. Waiting times reported are long. The data in Chapter 5 paint a rather grim picture of the extent of unmet need in the sector.
- The peak discussions confirmed this and suggested, anecdotally, that community knowledge of this was possibly dampening the numbers of applications.

### **Pressures at the program boundaries**

There are, in addition, a range of issues raised by other sources of data and by the peak discussions that suggest the overall service system for people with disabilities is under pressure.

- People in the CSDA broad target group (those with ongoing needs for assistance in self care, mobility or communication) are growing in number and **ageing**. Between 2000 and 2006, it has been estimated that those aged under 65 years will increase by 9%, those aged 15–64 years by 12%, and the group aged 45–64 years will increase in number by 19.3% or 59,500 people.
- There were almost 6,000 people aged under 65 living in **aged care homes** on 30 June 2001, 1,014 being aged under 50 years. None of the needs of these people are considered in the estimates in Table 7.1.

- There are high numbers of people with disabilities using **services for the homeless**, and their need for support services is recorded by these service providers. Disability-related pension recipients accounted for 17% of all SAAP clients in 1999–2000. Repeat use of SAAP services was highest for disability-related pension recipients, with requests for accommodation support (76%) and ‘other’ support (82%) being the primary reasons for seeking assistance.
- The **health system** is another vital interface with the disability services system. The health care of people in residential establishments has been highlighted as a concern during reviews of deaths in residential establishments. But equally there is evidence that the health needs of people with a disability in the community could be improved. The more de-institutionalisation is achieved, the quality of care, including health care, in the community has to remain visible. There may be groups who are particularly vulnerable, such as people with psychiatric disabilities, acquired brain injury and complex needs.
- **Insurance** has a triple possible impact on the CSDA program. People excluded from benefits (because of the fault aspects of the legal and insurance systems) create pressures for government schemes (the Disability Support Pension as well as the CSDA). Insurance costs are said to be impacting on the financial viability of NGOs and the resources available for support services. And insurers can be reluctant to insure some high support needs and ‘dangerous’ clients.
- **Transport** is a need reported at the peak discussions and elsewhere. It is described as a basic need which, if not met, can preclude participation in the workforce, day programs or community activities generally.
- **Equipment and environmental modifications** were frequent topics at the peak discussions as well as in the peak and consumer literature. These are potentially important for promoting autonomy, as a source of carer assistance and for ‘prevention’ of high needs for personal assistance. For instance, lifting equipment can sustain a carer’s health and ability (and willingness) to provide assistance to a person with significant physical disabilities for many years. National systems for their provision appear to be fragmented.

### Qualitative evidence of unmet needs

Peak discussions gave a qualitative picture of the nature and effects of unmet needs. It is almost impossible to summarise succinctly the discussions and case stories heard in the course of three days in February and March, and outlined in Section 7.3. A small selection follows:

- An individual with a spinal cord injury receives assistance to help him within his home, but not for assistance within the community. For this individual ‘getting out of bed, does not mean getting into the community’.
- A young woman with high support needs does not receive enough support for her father to return to the labour force.
- Inadequate in-home support for a person in a wheelchair has meant that she sleeps in her wheelchair with her head against a table, as she can not get herself in or out of bed.
- A mother caring for a 12-year-old child with Down syndrome and autism had continually broken sleep for 6 weeks, and was dealing with a range of very difficult behaviours during the day. The only respite available to her would have cost \$246 per day during the week and \$310 per day on the weekend. As a result she had no respite.

- A funded agency took over the management of two group homes each with four places. Before the agency had an opportunity to advertise the two vacant places, it had 38 applications, the majority from young people with acquired brain injuries.
- A person died in hospital following surgery. He had elected to have a colostomy, despite the relatively high risks in his state of health, because he could not bear the indignity of regularly waiting an hour or more before being cleaned.
- A man is caring for his wife with schizophrenia and multiple sclerosis, and the couple is looking for a respite service. One service can support the woman's physical needs and another, on the other side of town, can offer respite for people with mental illness but cannot support her physical needs. There is no appropriate respite for them.