2 The level of current unmet demand for accommodation and support, respite services and day programs

2.1 Introduction

In this chapter the level of current unmet demand is estimated in terms of numbers of people:

- with unmet demand for accommodation, accommodation support and respite services;
- with unmet demand for day programs.

The national totals are subdivided into smaller groups, according to the intensity of service the people are estimated to need. This process is designed to enable the costs of meeting unmet demand to be estimated in the following chapter, in particular to avoid the assumption that all people with unmet demand need high levels of service.

Section 2.2 describes the method for estimating the number of people with unmet demand for accommodation, accommodation support and respite services, and presents the estimates. Section 2.3 describes the method for estimating the number of people with unmet demand for day programs, and presents the estimates. The primary data source used in Sections 2.2 and 2.3 is the 1993 ABS Survey of Disability, Ageing and Carers. This survey was the primary source used in the 1995–96 demand study, decided on after a comprehensive review of available sources. Section 2.4 discusses other available data sources. Section 2.5 summarises the results of the chapter.

2.2 Accommodation and support and respite

The 1995 estimates of unmet demand for accommodation, support and respite services were based primarily on data from the 1993 ABS Survey of Disability, Ageing and Carers. The decision to rely on this source was made after an intensive review of other available data sources. These other sources were subsequently used to confirm the order of magnitude and conservatism of the main estimates (Madden et al. 1996). The same broad approach is used in this chapter.

The task in relation to the present study is to update and refine the previous estimates, which related to the year 1993. First, the method for deriving these estimates is outlined.

Estimates from the 1995 demand study

The choice of relevant data items from the ABS survey

The target group for services is defined in the CSDA as:

> persons with disabilities (which) means a person or person with a disability or disabilities that —
>
> (i) are attributable to an intellectual, psychiatric, sensory or a physical impairment or a combination of such impairments;

(ii) are permanent or likely to be permanent; and result in

(a) a substantially reduced capacity … for communication, learning or mobility; and

(b) the need for ongoing support services.

The starting point for the 1995 analysis was a detailed review of all questions in the ABS survey, and their relationship to the target group for CSDA services. The data items from the ABS survey most relevant to the provision of accommodation services to this group of people are as follows.

Severity of 'handicap': Attention is focused in this analysis on people classified by the ABS as having 'severe or profound handicap'. People were not asked in the survey whether they had a disability or handicap. Rather, they were asked a sequence of questions on activity restrictions and limitations which enabled the ABS to group them according to the severity of these limitations. The way in which handicap was determined, and its severity rated, is set out in Box 1.6.

Thus, people aged 5 years and over, with a disability, who reported that they always or sometimes needed help with self-care, mobility or verbal communication, were classified by the ABS as having (respectively) a profound or severe handicap. These people are considered to conform quite well to the definition of the target group of CSDA services (substantially reduced capacity in communication, learning or mobility, and needing ongoing support services); the additional area of self-care included in the ABS severity rating has a clear relationship to daily accommodation support (Table 1.5). Estimates relying on this data item relate to the demand for CSDA services, as illustrated in Figure 1.1; no reliance is placed on inference, as these people are voicing the need for assistance with relevant activities.

The age of the person: While the CSDA does not specifically exclude people above a certain age, many services do so in practice. While people who age 'in the service' can in practice remain, services do not take on new clients who are aged 65 or over. In addition, the overall approach of this study, of seeking to minimise debate about the lower end of the estimated range, weighs against including people who may be eligible for aged care services. The age range considered was therefore 5–64 years. (Severity of handicap is not rated for people under the age of 5.)

Whether the person was living in a household: Only people living in households were included. Questions on unmet needs were not asked of people living in institutions. (People in institutions are further considered in Chapter 4.)

Activities in which help was needed: Questions were asked about the need for help in the activity areas listed in Box 1.6, and in a number of further areas, namely, health care, home help, home maintenance and gardening, meal preparation, personal affairs (financial management and writing letters) and transport.

Whether or not there was a stated unmet need for help: People who needed help were asked the type of assistance they received, whether the source was a formal service or informal assistance, and whether there was an unmet need for help and why.

Because people can report the need for help in more than one area, it was necessary to refine the data analysis, to ensure that each person was counted only once. Because of the decision, outlined above, to focus on people with severe or profound handicap, activities were grouped into a 'hierarchy' of three areas:

- *Area 1:* People's unmet needs were allocated to this area if they reported any unmet need for regular assistance ('severe or profound handicap') in any combination of self-care, mobility and verbal communication (unmet need may also exist in Areas 2 and 3).
- *Area 2:* People's unmet needs were allocated to this area if they had unmet needs for regular assistance in any combination of health care, home help, home maintenance and meal preparation (unmet need may also exist in Area 3) but *none* in Area 1.
- *Area 3:* People's unmet needs were allocated to this area if they had unmet needs for regular assistance in personal affairs or transport, but *none* in Areas 1 or 2.

People reporting unmet needs in Area 1 are the group it was argued are a close fit to the target population for CSDA accommodation services; further, they are reporting unmet need for help in the specific activities in which they need ongoing support.

People reporting unmet needs in Area 2 could also include some people eligible for CSDA services. However, it is not possible to rate the 'severity' of their 'handicap' in relation to these activities, and thus it is not appropriate to assume that the degree to which they need support and have unmet needs in these activities is as great as the support needs of people reporting unmet needs in Area 1. Further, activities in Area 2 relating to meal preparation and home help may be supported by Home and Community Care services as well as by CSDA services. While there is an argument for including a proportion of the unmet needs in Area 2 in the CSDA estimates, the emphasis was (and remains) on deriving a robust lower limit; figures from Area 2 were not included in the estimate.

The reason stated for there being no or not enough formal assistance: The possible categories into which responses were allocated by ABS interviewers were:

- the person did not know of the service;
- the person did not consider their need important enough;
- the person would not ask for the service, for reasons of pride;
- no service was available;
- the person was unable to arrange a service; and
- other.

It was considered that the reasons which most clearly demonstrated unmet demand for CSDA services were that the service was not available or could not be arranged to provide needed formal help with Area 1 activities. Here, there is evidence that the person has identified the relevant service and has expressed a real demand by attempting to access a service, only to find that it was not available at all or access could not be arranged.

Views were put to the 1995 study team that there are very good reasons for including some people from other categories. In the income security field, for instance, lack of knowledge of a service is seen to be a failing of the service rather than a lack of demand for it. Similarly, people may not consider their need important enough only because they have low expectations that they will be eligible for the sorts of services that are available. The relatively large number of cases where people's reasons have been grouped as 'other' could sometimes be dealt with statistically by distributing

them on a pro rata basis to the other more explicit categories. Any of these considerations could lead to an increase in the estimates.

The 1995 study team, however, maintained its focus on the two groups where there could be little argument that unmet demand was demonstrated; the data on the other reasons for unmet need were referred to, in order to indicate possible higher points on a range of estimates.

Principal findings of the 1995 demand study

Table 2.1 shows that in 1993 an estimated 13,500 people (total of the two numbers shaded, rounded) with profound or severe handicap, aged 5–64 years, and living in households, reported unmet needs for formal help with self-care, mobility or verbal communication, and could not obtain this help because the service was not available or could not be arranged. These people could also have unmet needs in Areas 2 and 3.

As outlined above, in the discussion of the data items involved in the analysis, this figure of 13,500 was considered to represent a lower limit for the figure referred to in the terms of reference of the 1995–96 study—the 'number of people who would significantly benefit from accommodation support, respite' services under the CSDA—because of the activity areas of unmet need and the high level of this need.

A further 4,500 people, with similar unmet needs and in similar circumstances, 'did not know of a service'. As outlined above, there are good reasons for considering some of these people in the estimates of unmet demand, especially as they may live in generally under-resourced areas, for instance in rural or remote Australia (although the survey does not support reliable regional estimates).

Table 2.1: People aged 5–64 years and over with a profound or severe handicap in households—reasons for no formal or not enough formal help, by area of unmet need,[(a)] Australia, 1993[(b)]

Reasons for none or not enough help received[(c)]	Area 1	Area 2	Area 3
Did not know of a service	4,600	9,300	2,000
Need not important enough	20,000	10,900	4,200
Would not ask/pride	14,900	10,600	500
No service available	8,000	4,900	1,600
Unable to arrange service	5,400	2,000	1,200
Other	17,100	8,000	2,000
Total	**70,000**	**45,800**	**11,400**

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

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

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

Source: Madden et al. 1996:Table 5.3.

Conservative nature of the estimates

This estimate of unmet demand for accommodation and respite services was considered to be conservative. Its order of magnitude and its conservative nature were confirmed at the time by:

- the finding that, among people with 'severe or profound handicap' and the need for ongoing support, there were 7,700 whose principal carer was a parent aged 65 years or more, suggesting that service enhancements were needed in the very near future;
- the projected 19% growth in the number of people with 'severe or profound handicap' aged 45–64 years, between 1995 and the year 2001;
- estimates from State waiting list data and a non-government study of accommodation support needs of people with an intellectual disability;
- the lack of knowledge of respite care—approximately 59,000 principal carers of people with severe disabilities did not know or did not know enough about respite care and provided this as the main reason for not having used it;
- the estimate that there were, in 1993, approximately 7,000 carers of people with severe disabilities for whom there was no respite care service available.

To allow for standard errors in the survey data, the estimate of 13,500 should be represented as a range of 11,000–16,000.[3]

A key feature of the 1995 study's approach to estimation was that most effort was directed to making the lower end of the estimated range robust, that is, to provide reliable, 'conservative' estimates.

[3] The accuracy of the estimates from the ABS survey should be taken into account. As a general guide, estimates of less than 8,000 have a relative standard error of greater than 25% and estimates of less than 1,900 have a relative standard error of greater than 50%. Therefore, the standard error of the estimate of 13,500 is about 2,500; that is, with 67% confidence it would be predicted that the 'true' estimate of the number of people in the category was between 11,000 and 16,000.

A key feature of the process was the step-by-step exclusion of any group where there was doubt about the existence of unmet demand (Figure 2.1).

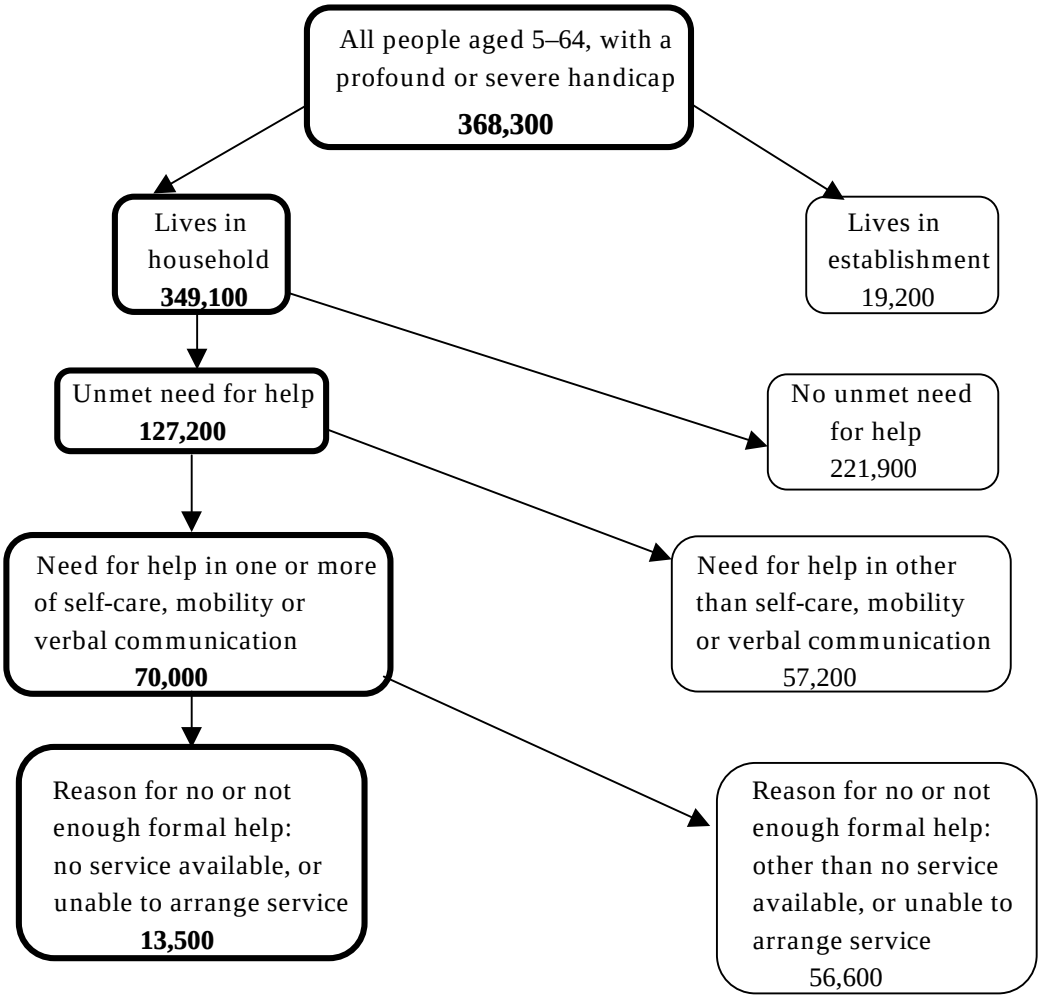

Figure 2.1: Step-by-step exclusion process to estimate unmet demand for accommodation and support and respite

In 1993 there was a total of 368,200 people with severe or profound handicap aged under 5–64 years. Of these, a total of 19,200 were living in 'health establishments'. These people were not asked to report on unmet need for assistance, and for this very practical reason were excluded from further consideration. The implicit assumption that these people have no unmet needs for formal services is conservative, in a period when:

- there is evidence of people remaining in hospitals and nursing homes, particularly following traumatic injury, because of the absence of suitable long-term accommodation support (see Section 2.4); and
- there is considerable effort either to enhance the quality of institutions or to place people living in institutions into community-based accommodation.

In terms of Figure 1.1, some of these people may be considered to have a 'potential need' for community-based services. There is some further discussion of this issue in Chapter 4.

People could report unmet needs for formal assistance in a range of areas, and 127,200 did so. Only the 70,000 reporting unmet ongoing needs for formal assistance with self-care, mobility or verbal communication were included in the estimates of unmet demand. Those with unmet needs for formal assistance in activities such as meal preparation, home help, personal affairs, transport, or health care were excluded.

Finally, only those 13,500 who were considered to have translated their need into a demand, by establishing that the service was unavailable or could not be arranged, were finally included in the estimate, omitting those who gave other reasons for their unmet need for formal assistance not being met.

This overall process illustrates the extent to which 'need' may exceed 'demand', as illustrated in Figure 1.1.

Adjusting for increases in demand and supply since 1993

Both demand and supply were likely to have grown between 1993 and 1996, and it was necessary to consider how to allow for any changes. Several methods were used and compared.

Updating estimates of unmet demand

Projections were carried out on the figure of 13,500 for unmet demand for accommodation places in 1993, as follows.

The process for updating the national estimates of unmet demand for accommodation, support and respite (13,500 in 1993) to 1996 relies on a key finding in relation to the prevalence of severe and profound handicap. The age- and sex-standardised rates of severe and profound handicap have been found to be relatively stable over the three ABS disability surveys, at just over 4% of the total population, and 2.5% of the population aged 15–64 (Wen at al. 1995). This finding is consistent with the possibility that:

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

The 1993 unmet demand estimates, which were based on a subset of people with severe or profound handicap, can therefore be updated essentially by projecting them forward using overall population growth, appropriately adjusted for age and sex. (This process assumes that supply will have kept pace with population growth, that is, that met demand will not have dropped as a proportion of overall demand.)

In detail, the steps used were as follows:

> Step 1: Calculate the age- and sex-specific rates of severe and profound handicap in 1993, using the estimated numbers of people living in households in each age and sex category, divided by the number of people in that age and sex category in the overall 1993 populations (AIHW analysis of ABS 1993 Survey of Disability, Ageing and Carers data).
>
> Step 2: Calculate estimates of the numbers of people with severe or profound handicap living in households in 1996, using the rates calculated for 1993 in Step 1, and applying them to the 1996 population. (This step is justified by the

key finding outlined above, that age- and sex-standardised rates of severe and profound handicap appear stable.)

Step 3: Calculate 1996 estimate for age group 5–64 years (subtotal from Step 2).

Step 4: Calculate proportions for each cell of Table 2.1, as a proportion of the total number in age group 5–64 years (1993).

Step 5: Using these proportions, derive an equivalent of Table 2.1 for 1996 by applying the proportions from Step 4 to the 1996 total from Step 3.

The results of these calculations are presented in Table 2.2. Based on 1993 survey results, and allowing *only* for population growth since then, an estimated 14,000 people in 1996 would have unmet demand for accommodation, support and respite services provided under the CSDA (an increase of some 3.7%).

Table 2.2: People aged 5–64 years and over with a profound or severe handicap in households, reasons for no formal or not enough formal help, by area of unmet need,[(a)] Australia, 1996[(b)]—projection allowing for population growth *only*

Reasons for none or not enough help received	Area 1	Area 2	Area 3
Did not know of a service	4,800	9,800	2,100
Need not important enough	21,000	11,500	4,400
Would not ask/pride	15,700	11,200	500
No service available	8,400	5,200	1,700
Unable to arrange service	5,600	2,100	1,200
Other	18,000	8,400	2,100
Total	**73,500**	**48,100**	**12,000**

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

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

Source: AIHW analysis of ABS 1993 Survey of Disability, Ageing and Carers data; ABS 1997.

Increase in total demand

Since 1993 the target population for CSDA support services (people with 'severe or profound handicap' in ABS terms) has grown from 368,300 to 386,500 in 1996, an increase of some 5%. This is slightly higher than the percentage growth in estimated unmet demand based on population change alone.

The estimated supply of accommodation services in 1994 was approximately 21,200 (Madden et al. 1996:55). Thus the total demand in 1993 would have been of the order of 34,700 (supply plus unmet demand, in terms of Figure 1.1). It could therefore be anticipated that, to keep pace with population growth alone, total supply should have increased by almost 5% or some 1,735 places.

Increase in supply

States and Territories were asked to provide an estimate of increases in supply since 1993. Information received was patchy, and gave what are regarded as incomplete estimates of increased supply—1,100 additional places in accommodation and support, and respite services.

Financial data

In this context it is worth noting that State and Territory expenditure on 'aged and disabled' welfare services, net of Commonwealth transfers, has fallen, in real terms, over the period 1992–93 to 1995–96, from $1,204 million to $1,148 million (1989–90 constant prices) (AIHW 1997a:Table A2.1). Commonwealth transfer payments have risen in real terms over the same period, from $346 million to $621 million (1989–90 constant prices). The combined payments have risen by some 14% in real terms, thereby increasing faster than population growth over the same period. There has been strong growth over this period of Commonwealth funding of Home and Community Care services, and it is not possible to split the overall growth between aged care and disability services.

Resulting adjustments

Taken together, the above data do not provide conclusive evidence that the increase in supply of accommodation and related places has grown faster than the overall increase in demand; that is, it has not made inroads on unmet demand. Further tabulations and estimates of unmet demand for accommodation services for 1996–97 will therefore be presented on the basis of the 1993 data, without further adjustment.

Differentiating intensity of service needed

From the analysis so far, we know that the people with unmet demand for accommodation, support or respite always or sometimes need assistance with self-care, mobility or verbal communication (Table 2.1, Box 1.6). Some of these people may need full-scale accommodation services, requiring quite intense levels of assistance. Some may, however, need quite low levels of service, for instance a few hours of personal assistance or respite care per week.[4] Some may also be receiving some formal service, even though not enough.

In order to proceed, in the following chapter, to estimate the costs of meeting the needs of these people for formal services, it is necessary to refine the estimated number of people by attempting to group them according to the intensity of the service they are likely to need. This subdivision allows lower costs to be applied to the 'lower end' of the spectrum of needs, and higher costs to the higher levels of need. After considering the data available in each jurisdiction, it was again decided that the best way of subdividing the national estimates was to carry out further analysis using the ABS survey.

Before proceeding, it was decided to amend the previous rounding of the figure in Table 2.1 (13,500) to 13,400, so as to simplify the further subdivision of the figures.

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[4] Some of these people could also have some of their needs met by the provision of suitable equipment. It has been suggested that the provision of equipment within services can reduce the need for personal care provided by service staff or informal carers and can enable people to use lower levels of formal services, and retain higher levels of independence (Ernst and Young 1996), although quantification of these effects was not estimated. So it is simply assumed here that there is a further range of other, substitutable services to which CSDA funding, estimated in Chapter 3, could be directed to achieve the same purpose as low levels of accommodation support services.

The most obvious split of the 13,400 people was first to separate those with severe handicap (who *sometimes* need assistance with self-care, mobility or verbal communication) from those with profound handicap (who *always* need assistance).

A second subdivision of the group looks at the *number* of these activities with which people needed assistance (one, two or three of self-care, mobility or verbal communication).

Table 2.3 presents this subdivision for those with unmet demand for formal services (i.e. the 13,400 estimate being used for 1993 and 1996).

Table 2.3: People aged 5–64 years with a profound or severe handicap in households[(a)] who reported unmet needs for formal help[(b)] and could not obtain this help because the service was not available or could not be arranged, by number of activities needing assistance,[(c)] Australia, 1993 and 1996

	Number of activities needing help			
	1	2	3	Total
Profound handicap	3,000	2,400	1,500	6,800
	22.2%	17.8%	11.1%	51.1%
Severe handicap	4,600	1,900	—	6,600
	34.6%	14.3%	—	48.9%
Total	7,600	4,300	1,500	13,400

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

(b) Unmet need was defined as having reported at least one reason for receiving no help or not enough help from formal assistance in self care, mobility or verbal communication.

(c) Activities include self-care, mobility and verbal communication.

Source: AIHW analysis of ABS 1993 Survey of Disability, Ageing and Carers data.

A similar table for *all* people with severe or profound handicap aged 5–64 years is presented (Table 2.4) to enable some comparison with Table 2.3, where some of the estimates are relatively small numbers.

It can be seen that those with reported unmet demand tend to have higher levels of need for assistance: 28.9% of the total are in Group (P 2,3) in Table 2.3, compared to 20.1% (11.43% + 8.78%) in that Group in Table 2.4. (Table A2.1 at the end of the paper gives the same information, by disability group.)

Table 2.4: People aged 5–64 years with a severe or profound handicap in households, by whether there were reported unmet needs for formal help,[a] by number of activities needing assistance,[b] Australia, 1993[c]

	Profound handicap				Severe handicap			
	Number of activities needing help				Number of activities needing help			
	1	2	3	Total	1	2	3	Total
People with reported unmet needs for formal help								
%	13.63	13.84	6.09		45	20.3	1.15	100.00
Total	17,300	17,600	7,700	42,700	57,200	25,800	1,500	84,500
People with no reported unmet needs for formal help								
%	22.64	10.06	10.32		40.68	15.48	0.84	100.00
Total	50,200	22,300	22,900	95,500	90,300	34,300	1,900	126,500
Total people with a profound or severe handicap in households								
%	19.35	11.43	8.78		42.25	17.23	0.95	100.00
Total	**67,600**	**39,900**	**30,600**	**138,100**	**147,500**	**60,200**	**3,300**	**211,000**

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

(b) Activities include self-care, mobility and verbal communication.

(c) Because this table refers to people in households, the total is different from that in Table 1.3 which includes all people including those living in 'health establishments'.

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

Source: AIHW analysis of ABS 1993 Survey of Disability, Ageing and Carers data.

The numbers in Table 2.3 are now subdivided a third and final time, according to whether people are already receiving some formal service. This final split is presented in Table 2.5.

Inferences are also made, and presented in Table 2.5, about the level of service it is reasonable to assume these people might receive in order to meet their need for formal services (and in order to proceed in the next chapter to translate the people estimates into cost estimates). These inferences draw on information received by the study team from the various Australian jurisdictions, about the current and immediately anticipated service provision practices in operation. These practices include, chiefly:

- new clients are generally not being assigned to large institutions;
- people with high-level support needs are being supported in group homes or in their own homes; and
- in-home respite is generally preferred to residential respite, where possible, although flexibility and choice of respite option are considered desirable.

These practices reflect the emphasis in the field on community-based services, and the support of existing networks and carers. While on the one hand this leads to assumptions that less intensive service *types* are being provided, it also indicates the need for perhaps higher *levels of support* within these service types. For instance, group homes and in-home support are being used by people with high levels of support need.

Table 2.5: People with unmet demand for accommodation and support and respite: level of assistance needed and inferred service needs

Level of assistance needed	No. of people	%	Service needs inferred
People needing assistance in 2 or 3 activities, and *always* needing assistance in at least 1 (Groups (P2), (P3)):	**3,900**	**29.1**	
• No formal assistance now	1,500	11.2	Group homes or high level of in-home support (say 30 hours per week)
• Some formal assistance now	2,400	17.9	Additional assistance equivalent to medium level of in-home support (say 15 hours per week)
People always needing assistance in 1 activity only (Group (P1)):	**3,000**	**22.4**	
• No formal assistance now	2,300	17.2	Medium level of in-home support (say 10 hours in-home support, respite)
• Some formal assistance now	700	5.2	Occasional service — say 5 hours per week
People needing assistance in 2 activities — sometimes (Group (S2))	**1,900**	**14.2**	**Occasional service — say 5 hours per week**
People sometimes needing assistance in 1 area only (Group (S1))	**4,600**	**34.3**	**Occasional service — say 3 hours per week**
Total	**13,400**	**100.0**	

Notes

1. Activities include self-care, mobility and verbal communication.

2. Estimates of 1,900 or less have a relative standard error (RSE) of 50% or more. Estimates of 8,000 or less have an RSE of 25% or more. These estimates should be interpreted accordingly. In this table, estimates are rounded to the nearest 100.

Source: AIHW analysis of ABS 1993 Survey of Disability, Ageing and Carers data.

The groups of people with unmet demand for accommodation and support and respite are as follows. (Further discussion of inferences about levels of service appears in Chapter 3 on costs.)

There are an estimated 1,500 people who need assistance with two or three activities (self-care, mobility or verbal communication) and who *always* need assistance with at least one, and who want formal assistance but are currently receiving *none*. These could be people who need assistance every time they bathe, dress or go to the toilet, or move outside the house. The group could include people with cerebral palsy, paraplegia, quadriplegia, or people with profound intellectual disability who need considerable assistance with self-care and communication activities. It is assumed that these people need high levels of support, either in group homes or as in-home support.

There are approximately 2,400 people with similar needs for constant assistance, but who are receiving some level of formal support already. It is not possible, based on the ABS survey, to quantify what services the people are receiving. It will therefore be assumed that they need services at about half the level of the first group (some may need more, some less), that is, approximately an additional 15 hours of in-home support per week. (In the next chapter the consequences of making different assumptions about the number of hours received by this group are explored.)

There are approximately 2,300 people who *always* need assistance in just one of self-care, mobility or verbal communication areas, but who are receiving *none* of the formal assistance they desire. Because these are very basic and constant needs the need for support is still quite high, and it is assumed that they would need approximately 10

hours of in-home support or respite per week. This level of support could mean, for instance, formal assistance with lifting and bathing someone is provided to a carer, or that the carer is able to have two shopping expeditions or other activity without having to worry about their son or daughter with intellectual disability, who needs assistance with communication.

There are a further 700 people approximately who have similar levels of need for assistance, but who are receiving some formal service now. It will be assumed that their unmet demand for services could be met by the provision of, say, an additional five hours per week of respite or accommodation support.

The remaining two groups have 'severe' handicap, that is, they sometimes need assistance with one or more of the three activities (self-care, mobility or verbal communication). Approximately 1,900 people sometimes need assistance with two of these activities and will be assumed to require approximately five hours per week to meet their unmet demand for formal service. Those who need assistance in only one area (some 4,600) will be assumed to need only minimal levels of assistance, that is, three hours per week of in-home support.

2.3 Day programs

Day programs are generally services designed to provide opportunities for people with a disability to gain and use their abilities to enjoy their full potential for social independence. These services are mainly used by people who do not attend school, or who are not employed full-time.

The services:

- range from educational to leisure and recreational pursuits;
- range from facility to home-based activities;
- include supervision and physical care, and models which link people into activities which are offered to the total community; and
- range from long-term day support to highly specific, time-limited and goal-oriented education that maximises personal independent functioning and may complement other community options services.

These services, for the purposes of this study, are taken to be CSDA MDS service types 3.00 to 3.03 inclusive, as listed in Box 1.2 of the report.

Policy assumptions underlying estimation

In preparing the estimates for unmet demand for day programs, the following assumptions are made about their nature and purpose.

Day programs are designed for people with a disability, with high levels of support needs and:

- who are not in, and not likely to be in, the labour force (including supported employment);
- who are not studying or likely to study.

The purpose of day programs is to provide meaningful activity for people, so that they continue to develop, receive stimulation and experience social interaction and community participation (see Table 1.5).

Day programs should be provided at such a level that family carers are not obliged to provide 24-hour care for people with high support needs on a lifelong basis. That is, from the time people with high-level support needs are 18 years old and have left school, they may still be receiving accommodation support from their families, but should not be reliant on them for the equivalent of 'day programs'.

The approach to estimation, then, is to:

- use a parsimonious approach to including people in the estimates for demand for these programs (in particular to exclude people who are eligible for employment support); but to
- assume that most people requiring these programs require them five days per week.

Estimates of unmet demand for 1993

In 1993 there were an estimated 50,500 people with severe or profound handicap aged 18–64 years, living in households, not in the labour force or studying, reported to be permanently unable to work, and who did not go out as often as they would have liked **because of their own illness or condition** (Table 2.6). The restriction of 'wanting to go out more' is imposed on Table 2.6 simply to ensure that demand is not being inferred among people who do *not* wish to go out more—that is, wanting to go out more is, for this group, a necessary but not sufficient condition to establish unmet demand for day programs.

The table further divides the group in a way similar to Table 2.3, according to the number of activities (ADLs) with which people need assistance, and the frequency of assistance needed. The group ranges from those who need assistance with all three activities and *always* need assistance in at least one (6.7%) to those who *sometimes* need assistance in only one area (28.9%).

Table 2.6: People aged 18–64 years with a severe or profound handicap, in households, permanently unable to work and not studying, who do not go out as often as they would like because of their own illness or condition, by number of activities with which they need assistance

Level of assistance needed	No.	%
People needing assistance in all 3 activities, and *always* needing assistance in at least 1 (Group (P3))	3,400	6.7
People needing assistance in 2 activities, and *always* needing assistance in at least 1 (Group (P2))	8,400	16.6
People always needing assistance in 1 activity (Group (P1))	13,200	26.1
People needing assistance in 2 activities—sometimes (Group (S2))	10,900	21.6
People sometimes needing assistance in 1 activity (Group (S1))	14,600	28.9
Total	**50,500**	**100.0**

Note: Estimates of 1,900 or less have a relative standard error (RSE) of 50% or more. Estimates of 8,000 or less have an RSE of 25% or more. These estimates should be interpreted accordingly. In this table, estimates are rounded to the nearest 100.

Source: AIHW analysis of ABS 1993 Survey of Disability, Ageing and Carers data.

These figures are *not* considered to provide an estimate for unmet demand for day programs. The figure will be further adjusted in two ways, so as to tie the estimation approach more closely to the policy assumptions outlined previously.

First, those who require only occasional assistance (severe handicap) will be excluded. This amounts to assuming that these people are the responsibility of employment programs, and retains a conservative approach to including people in the numbers, reducing the possible total by some 25,500, to 25,000 (approximately).[5]

Second, the figure will be adjusted for current supply in order to estimate *unmet* demand. The figure is not yet adjusted for current supply, because the ABS survey does not ask an explicit set of questions about unmet needs for formal assistance (and people's attempts to obtain such services) in areas related to day programs. The analysis cannot therefore proceed as it did for accommodation, support and respite; the estimates must make some other allowance for current provision of day programs. The most conservative possible adjustment will be made for current supply, essentially treating the 25,000 estimate as an estimate of total demand for places, rather than unmet demand, even though the filtering has introduced an element of 'unmet demand' because of the requirement that people must state that they wish to go out more.

Table 1.2 indicates that:

- 11,455 people used day (community access) programs on a snapshot day in 1996;
- 12,788 clients using services were estimated to represent service use on a typical day;
- a total of 64,994 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 previous policy assumptions reflecting current targeting strategies).

Because of the policy assumption that people who are actually eligible for day programs need them five days per week, it is necessary to use 'places' estimates to indicate the current supply; the 'typical day' figures of 12,788 provide the best available estimate of places. That is, the 'people estimates' of unmet demand represent demand for 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 but the number of full-time equivalent places might change only slightly.)

This further reduces the number of people with unmet demand for day programs by some 13,000 to 12,000. Splitting the remaining 12,000 into the three groups being retained from Table 2.6, and in the same ratio, gives Table 2.7 following.

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[5] The study team also considered discounting some of the people in Group (P1). However it was considered that this group, not in the labour force, not studying, permanently unable to work, and always needing help with an ADL would otherwise represent a day-long and life-long responsibility to families and carers. Their exclusion from unmet demand estimates would violate the principles suggested in section 1.3 on carers, and the policy assumptions outlined earlier in this section concerning society's expectations of carers of adult people with profound handicap.

Adjusting for changes since 1993

Because a figure for 'current supply' has been used, it is necessary only to have a figure for 'current demand' for 1996 from which to subtract supply.[6] In the above process, it is the 1993 figure for demand which has been used, a figure which could be expected to have grown by 1996, possibly by 5% if in line with population growth. Its use therefore contributes to conservatism in unmet demand estimation. No adjustment is needed if this conservative approach is taken, and the results in Table 2.7 apply also to 1996.

Table 2.7: Unmet demand for day programs among people with profound handicap[(a)] aged 18–64 years, 1993 and 1996

Level of assistance needed	No.	%	Service needs inferred
People needing assistance in all 3 activities, and *always* needing assistance in at least one (Group (P3))	1,600	13.8	5 days per week, intensive support
People needing assistance in 2 activities, and *always* needing assistance in at least one (Group (P2))	4,050	33.3	5 days per week, moderate support
People always needing assistance in 1 activity (Group (P1))	6,350	52.9	5 days per week, low support
Total	**12,000**	**100.0**	

(a) These are people in households not in the labour force, not studying, considered permanently unable to work, and wanting to go out more but unable to do so because of their own illness or condition.

(b) Estimates of 1,900 or less have a relative standard error (RSE) of 50% or more. Estimates of 8,000 or less have an RSE of 25% or more. These estimates should be interpreted accordingly. In this table, estimates are rounded to the nearest 100.

Source: Table 2.6; AIHW analysis of ABS 1993 Survey of Disability, Ageing and Carers data.

The figure of 12,000 can be considered conservative because:

- people with 'severe handicap' have been excluded, as the responsibility of employment programs;
- it excludes people who are employed even part-time, thereby excluding people who are able to attend supported employment programs two days per week but may require a day program for the other days;
- it offers no additional service to current users of the programs; and
- by subtracting *all* current places from the figure of 50,500, we are in effect assuming that 50,500 is an estimate of total demand; but if some current services

[6] States and Territories were asked to provide an estimate of increases in supply since 1993. Information received was patchy, and gave what are regarded as incomplete estimates of increased supply, namely that there was an increase of some 3,000 places in day programs. If the CSDA MDS data are used, with attempts to estimate the effects of missing or double counted data, it is possible that supply, in terms of 'typical day' figures, has increased from around 9,000 in 1994 to 13,000 approximately in 1996. This confirms the information from the States, and is considerably in excess of a 5% increase expected on the basis of population increase. However, since a 'total supply' figure was available for use in the estimation process, these data were not central to the argument.

The study team also considered the possibility of subtracting from demand the 'supply' to various support needs groups using the data in Table 2.8. However, because of the very large number of people with relatively low support needs ('severe' rather than 'profound') in Table 2.8, the result would have been very high cost estimates. Table 2.8 raises a query about the comparability of support needs as reported by service providers and individual people; these people are receiving services at a time of excess demand and must be assumed to have commensurately high support needs.

users did not wish to go out more, they would not have been included in the original 50,500 figure, and if we knew their number we could allow for it, with the result that the unmet demand estimates would be correspondingly higher.

The process of estimation is illustrated in Figure 2.2, showing the step-by-step process of estimating unmet demand by a fairly conservative process of exclusion.

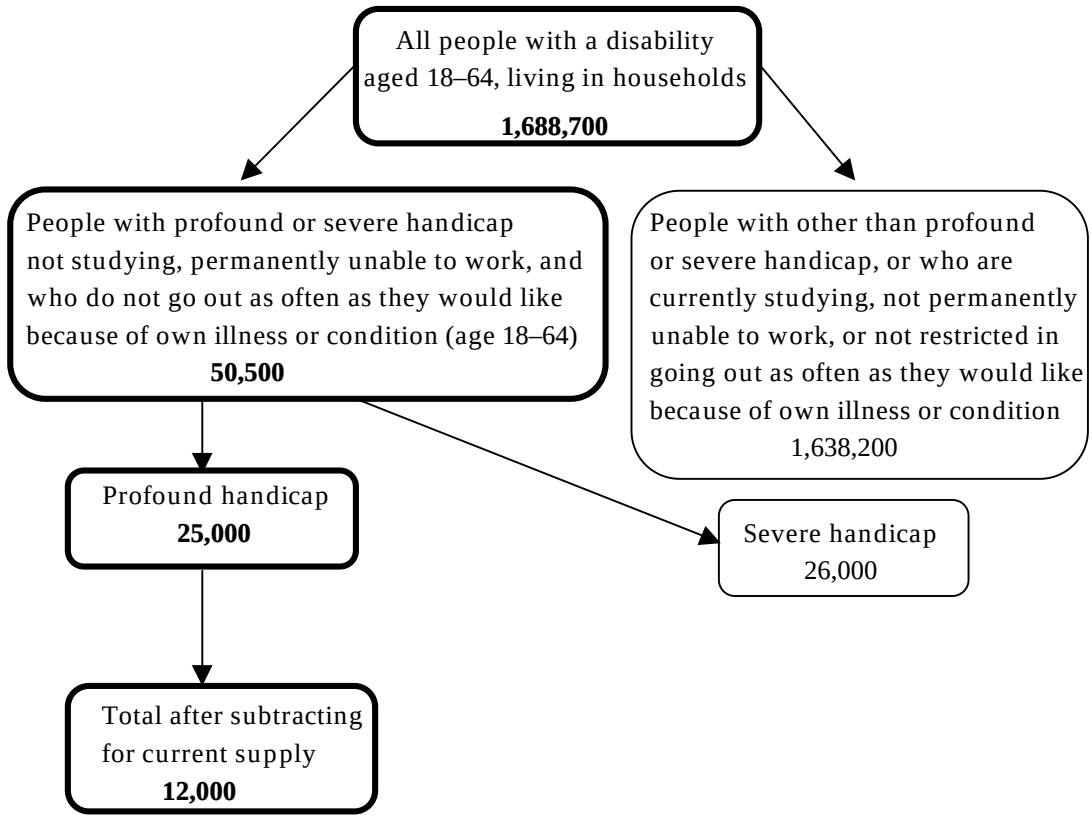

Figure 2.2: Process to estimate unmet demand for day programs

There are some further features of these estimates worth recording.

First, a sizeable proportion of these people may be aged 60–64 years and may be considered in transition from day programs or supported employment programs to retirement-style day activities.

Second, consideration was given to the extent of overlap which might exist with the previous estimate of unmet demand for accommodation services. It is estimated that approximately 1,500 people included in the estimates for unmet demand for day programs also had unmet demand for accommodation support services (AIHW analysis of ABS Survey of Disability, Ageing and Carers Survey). It is not considered that either unmet demand estimate should be discounted. The reasons are:

- The services are considered to meet different needs and to occur at generally different times of the day.
- The estimation methods did not duplicate each other, that is, the unmet needs allocated to one service were different from those considered for the other service. This means that neither estimate was inflated by double counting unmet needs.

- A reverse argument was, on the contrary, put forward by some jurisdictions, namely that an unmet need for day programs was quite likely to put intolerable, long-term pressure on families and carers, and to pose a higher risk of potential need for accommodation support services, if the overall living arrangements broke down.

2.4 Other data sources

The 1995 demand study included a review of the available literature to identify other data sources to support, or contrast with, the conclusions derived from the methods used in the study. Data examined covered areas such as current supply data, waiting list data, data on younger people with a disability in nursing homes, a survey conducted by a national peak consumer organisation, data on homelessness, and State and Territory funding round information.

This section builds on the work done previously, by examining supply data in more detail, updating State and Territory waiting list data where available, and examining recent data on people with an intellectual disability in the criminal justice system.

The main findings of this section are:

- The CSDA client profile suggests that the inferences in Tables 2.5 and 2.7 about the support needs profile of people with unmet demand is indeed conservative.
- For respite and accommodation services, available waiting list data confirm the order of magnitude of the estimates of unmet demand and also the assumption used that any increase in supply since 1993 has not diminished unmet demand since 1993.
- The over-representation of people with intellectual disability in the criminal justice system confirms a general picture of 'service overflow' and unmet need among this group (see also Madden et al. 1996:42–47).

Data on CSDA clients

Tables 2.5 and 2.7 provide data from the ABS Disability, Ageing and Carers survey on severity of handicap, and the number of activity areas of need for help, of a subset of the general population. A similar break-down of CSDA service recipients is provided in Table 2.8, to enable a comparison to be drawn. Over 90% of service recipients in all broad service types were in the severe or profound handicap categories (ABS defined). Community access services had the highest level (9.8%) of service recipients with neither severe nor profound handicap recorded.

Current service recipients were most likely to have a reported need for help in two or three of the activity areas of personal care, mobility or verbal communication, with people with a recorded profound level of handicap in ABS terms much more likely to require help in all three areas, when compared with those with severe handicap.

Accommodation service recipients had the highest reported levels of both profound handicap (58.2%) and need for help with all three activities (62.5%).

Table 2.8: Recipients of CSDA-funded services, broad service type by ABS category of severity of handicap and number of activities needing assistance, States and Territories, CSDA MDS, 1996

	ABS severity of handicap										
	Profound			Severe			All severity				
Service type	1	2	3	1	2	3	1	2	3	None	Total
	Number										
Accommodation	157	1,608	6,665	1,065	1,886	2,400	1,222	3,494	9,065	712	14,493
In-home support	56	483	927	743	735	754	799	1,218	1,681	461	4,159
Community support	378	1,489	4,228	1,760	2,346	1,729	2,138	3,835	5,957	1,070	13,000
Community access	176	839	4,091	1,396	1,548	2,075	1,572	2,387	6,166	1,099	11,224
Respite	36	345	1,063	248	502	301	284	847	1,364	112	2,607
	Percentage										
Accommodation	*1.1*	*11.1*	*46.0*	*7.3*	*13.0*	*16.6*	*8.4*	*24.1*	*62.5*	*4.9*	*100.0*
In-home support	*1.3*	*11.6*	*22.3*	*17.9*	*17.7*	*18.1*	*19.2*	*29.3*	*40.4*	*11.1*	*100.0*
Community support	*2.9*	*11.5*	*32.5*	*13.5*	*18.0*	*13.3*	*16.4*	*29.5*	*45.8*	*8.2*	*100.0*
Community access	*1.6*	*7.5*	*36.4*	*12.4*	*13.8*	*18.5*	*14.0*	*21.3*	*54.9*	*9.8*	*100.0*
Respite	*1.4*	*13.2*	*40.8*	*9.5*	*19.3*	*11.5*	*10.9*	*32.5*	*52.3*	*4.3*	*100.0*

Notes

1. Excludes missing and not known responses.
2. Data for recipients of CSDA services funded by the Australian Capital Territory are not available for 1996.

Source: Unpublished data from the 1996 CSDA MDS collection.

Waiting lists

Table 2.9 provides an update of available State and Territory waiting list and funding round data, relating mainly to people with an intellectual disability.

The numbers identified under the accommodation support area, although incomplete, are broadly similar to that identified in the 1996 demand study. This confirms both the conclusion in the previous study that State waiting list data are commensurate with the estimates of unmet demand in this report (see Madden et al. 1996:27, 53–54), and the conclusion in the previous section of this report that increase in supply since 1993 has not made inroads on unmet demand.

Table 2.9: Available State and Territory waiting list data, primarily for people with an intellectual disability

	Accommodation support			Respite			Day programs			
State	Crisis	Other	Total	Crisis	Other	Total	Crisis	Other	Total	Source and comments
NSW	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	
Vic.	297	843	1,140	n.a.	n.a.	n.a.	1,162	1,062	2,224	Dept of Human Services Service Needs Register (SNR)
Qld	111	130	241	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	Dept of Families, Youth and Community Care: Intellectual disability, direct services only
WA	n.a.	n.a.	256	n.a.	n.a.	705	n.a.	n.a.	758	Disability Services Commission
SA	n.a.	n.a.	168	n.a.	n.a.	n.a.	n.a.	n.a.	86	Intellectual disability only, from Intellectual Disability Services Council (IDSC)
Tas.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	
ACT	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	
NT	n.a.	n.a.	53	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	

Source: Data supplied by individual jurisdictions.

Service 'overflow'

A recent study (New South Wales Law Reform Commission 1996) has reported on the issue of people with an intellectual disability in the criminal justice system in New South Wales, and describes the most recent New South Wales prison study as showing that people with an intellectual disability comprise at least 12–13% of the prison population (based on the results of both intelligence tests and social adaptive skills). It was also suggested that people with an intellectual disability were over-represented in other parts of the criminal justice system.

Anecdotal evidence was provided by all States and Territories during the 1995 study, and confirmed in more recent discussion, indicating that inappropriate use of services does exist. Examples given were:

- people using respite beds as permanent accommodation;
- people with Acquired Brain Injury being placed in group homes for people with intellectual disability where this may be inappropriate;
- people using aged care nursing homes or hospitals as long-term accommodation; and
- people in accommodation services due to the lack of suitable day activity options and support.

Home and Community Care (HACC) services

Home and Community Care (HACC) services provide a range of services, primarily as aged care, but also to people aged under 65 years with a disability. A number of HACC and CSDA service types can be seen as potentially overlapping, for instance personal care, home-based respite and centre-based respite services.

In 1993–94 (the last year for which data were available), about 17.9% of the total number of HACC clients at the time were aged under 65 years (Table 2.10)

Table 2.10: HACC clients aged under 65 years, by type of service and by State and Territory, 1993–94 (%)

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

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

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

Source: AIHW 1997a:326.

Nationally, home help was the most used service among HACC clients aged under 65, but there was considerable variation among the States and Territories, with high levels of home nursing use in Queensland, Western Australia and Tasmania. Home respite and centre day care services were also frequently used, as were home paramedical, home maintenance and transport. There was considerable variation in the use of transport services: 46.9% of clients in New South Wales compared with a national average of 24.2% and the lowest rate, 7.4%, in Western Australia.

Potentially, then, any CSDA 'overflow' could be directed to HACC services and to some extent vice versa. Anecdotal evidence suggests that HACC services are more likely to pick up younger clients with physical disability only. The large proportion of CSDA clients with intellectual disability is consistent with this suggestion. There are no HACC data on disability groups enabling further analysis along these lines.

2.5 Estimates of unmet demand

In summary, there are estimated to be, in 1996:

- 13,400 people with unmet demand for accommodation, support and respite services, with a spectrum of service needs estimated in Table 2.5;
- 12,000 people (or equivalent full-time places) with unmet demand for day programs, with a spectrum of service needs estimated in Table 2.7.

These estimates are considered to be conservative for reasons detailed in the chapter, and summarised in the report's Summary.