

## 6 Population estimates of need

This chapter presents population estimates of unmet need for accommodation, in-home support, respite, day activity and employment services. Estimates based on the 1998 ABS disability survey data are adjusted to 2001.

Section 6.1 provides background information about approach and sources for population data analysis. Sections 6.2 to 6.4 present population estimates of need for disability support services. Section 6.5 provides a range of estimates related to support needs of ageing carers.

### 6.1 Approach and sources for population data analysis

#### Main population data sources

Estimates of unmet demand for accommodation and respite and day activity services in the 1997 demand study were based mainly 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 data sources. These other sources were subsequently used to confirm the magnitude and conservatism of the main estimates (Madden et al. 1996; AIHW 1997a).

Chapter 7 of this report will use population data from this chapter and data on trends in service provisions from Chapter 4 to adjust the unmet need estimates for increase in supply, and to synthesise materials from a range of sources to identify remaining shortfalls. In this chapter two main population data sources are used for baseline estimates and adjusted for population growth of unmet need for disability support services:

- ABS 1998 Survey of Disability, Ageing and Carers, which provides the latest national information on the number of people with a severe or profound core activity restriction and their need and unmet need for formal and informal assistance.
- ABS data on 2001 estimated resident population to take account of changes between 1993 and 2001 in births, deaths and international migration and factor in the effect of population ageing resulting from the interaction of these demographic components.

#### Reported changes in prevalence of disability, 1993 and 1998

The age-standardised prevalence rates of severe or profound core activity restriction were relatively stable during the 1980s and early 1990s, remaining at around 4% of the Australian population (AIHW 1997b; Wen, Madden & Black 1995). However, between 1993 and 1998 the estimated rate of severe or profound core activity restriction, as reported by the ABS, increased from 4.1% (721,000 people) to 6.1% (1,135,900 people), an increase of 2 percentage points or 414,800 people (ABS 1993, 1999a). The increase in the number of people with a severe restriction was particularly significant in 1998 (598,200), which was almost two times the number in 1993 (301,100).

Based on the information and analyses to date, the increase does not reflect a substantial increase in the underlying prevalence of disability. Rather, it is largely due to the changes in design and methods of the 1998 disability survey which 'captured' a larger number of people with a severe or profound restriction than the 1993 survey (AIHW 1999b, 2001b; ABS: Davis et al. 2001).

Two aspects of changes in survey method appear to have impacted significantly on the reported rates of prevalence (AIHW 1999b; Davis et al. 2001). First, modifications in the 1998 ABS survey screening questions (in effect, the criteria for defining disability in the survey) have resulted in an increase in the base disability population who were then asked questions to determine the severity of core activity restrictions. For instance, a new screening question about chronic pain was introduced and changes were made to the wording of other screening questions. People who had been identified by another person as having a long-term health condition but no disability (based on screening questions) were for the first time given an opportunity to answer for themselves whether they were restricted by their condition.

Second, some other developments have resulted in increased capture of severe or profound restrictions. The SF-12 assessment instrument of health status (which included questions on activity) was introduced and placed after the survey screening questions but before questions on core activity restriction. This could have prompted respondents to focus on the day-to-day effect of their condition and thus answer more fully in the subsequent questions on core activity restrictions and need for assistance. Additional information was collected to distinguish severe from moderate restriction in cared accommodation, resulting in an increase in the number of people with a severe restriction in cared accommodation. The introduction of severity assessment of activity restrictions for children under age 5 has identified 28,100 children aged 0–4 with a severe or profound restriction.

Three population groups accounted for about 80% of the reported increase in severe or profound core activity restrictions. People aged 45–64, mostly with musculoskeletal conditions other than arthritis, accounted for almost half of the increase. Children, mainly boys, aged 5–14 with intellectual and behavioural disorders, and older people, especially men, aged 75–79 and 85+, made up a third of the increase together (Davis et al. 2001).

### **Approach to population estimates of unmet need**

To provide baseline population estimates of unmet need for accommodation, in-home support, respite, day activity services and disability employment services, the present study uses an approach generally similar to that used in the AIHW 1997 demand study. A key feature of the 1997 study's approach to estimation was that, although it estimated a spectrum of people's support needs, most effort was directed to making the lower end of the estimated range robust, in order to provide reliable, 'conservative' estimates (AIHW 1997a).

Considering the reported changes in, and subsequent analysis of, prevalence of severe or profound core activity restriction between 1993 and 1998, in particular the large increase in the 'lower end' of the severity spectrum due to the changes in survey methods, it is not appropriate to do a simple update of the 1997 estimates. New data items and information in the 1998 disability survey also open up opportunities for refining the approach to estimation now.

In the 1997 demand study, attention was focused on people classified by the 1993 ABS disability survey as having 'severe or profound handicap' ('severe or profound core activity restriction' in the 1998 survey). In the ABS disability survey definitions, severity of 'handicap' or 'core activity restriction' is measured by the need for, and intensity of, personal assistance in self care, mobility and communication activities, namely whether they 'always' or 'sometimes' needed assistance with these activities. In the 1993 survey, there was no specific question asked about the assistance a person needs within a period or with a particular task. 'Severe or profound handicap' was defined when people with a disability 'sometimes' or 'always' need personal assistance or supervision in the three activities.

One of the new data items in the 1998 disability survey was about how many times per day/week/month on average a person needed personal assistance for a particular activity. Preliminary analyses show that the frequencies of need for assistance with daily activities vary substantially among people with a severe or profound core activity restriction, ranging from less than once per month to 6 or more times a day (Appendix Tables A6.1 and A6.2). This new information allows the present study to define more precisely a spectrum of baseline estimates and grade the range of estimated needs. Detailed operational definitions and methods are presented in each subsequent section on baseline population estimates.

Table 2.1 guides the analysis in this chapter, including the use of these new data items. Jurisdictions were given an opportunity to comment on the table in draft form before the analysis proceeded. One of the results of these comments was the indication of Method 2 in the estimation of need for employment services.

The analysis of population survey data also provides a range of estimates related to support needs of ageing carers. In particular the present study provides estimates mainly relating to the purpose and key principles of the new unmet need funding agreed in the 2000 CSDA Bilateral Agreements. Particular attention will be focused on the group identified as relating to the purpose of Commonwealth funding in these agreements (Box 1.3):

Priority will be given to people with a disability whose carer is aged over 65 (or, in the case of Aboriginal people, aged 45 years or over), including older carers in rural and remote regions. Once these most critical needs are met, attention may then be turned to those families where the carer is approaching this age with an emphasis on those who have been caring for over 30 years.

## **Methods of updating population growth from 1998 to 2001**

This chapter makes adjustments in baseline estimates of unmet need for services from 1998 to 2001 in line with population growth. Chapter 7 further adjusts these baseline estimates of unmet need for increase in service supply.

The process for adjusting or updating the baseline estimates of unmet need from 1998 to 2001 relies on an underlying assumption in relation to the prevalence of severe and profound core activity restrictions – the age- and sex-specific prevalence rates of severe or profound core activity restriction remain constant between 1998 and 2001.

As mentioned previously in this section, the increase in reported prevalence in 1998 is considered not to reflect a substantial increase in the underlying age- and sex-specific prevalence rates but an increased ‘capture’ in the survey estimates. Hence, the present study uses the 1998 disability survey data to construct baseline population estimates and then update the estimates to 2001 by projecting them forward using overall population growth, appropriately adjusted for age and sex.

Detailed steps for adjustments were as follows:

- Step 1: Calculate the age- and sex-specific rates of severe and profound core activity restriction in 1998, using the estimated numbers of people with a severe or profound core activity restriction living in households in each age and sex category, divided by the number of people in that age and sex category in the overall 1998 populations (AIHW analysis of ABS 1998 Survey of Disability, Ageing and Carers confidentialised unit record file).
- Step 2: Calculate estimates of the numbers of people with severe or profound restriction living in households in 2001, using the rates calculated for 1998 in Step 1, and applying them to the 2001 population (Table A6.3).

- Step 3: Calculate the 2001 estimate for age group 0–64 years (subtotal from Step 2).
- Step 4: Calculate unmet need proportions for each category of baseline estimates in 1998, as a proportion of the total number in age group 0–64 years (1998).
- Step 5: Using these proportions derive equivalent baseline estimates for 2001 by applying the proportions from Step 4 to the 2001 total from Step 3.

### **Main relevant data items from the 1998 ABS survey**

This section outlines main relevant data items used for baseline estimates of unmet need. More specific data items relating to particular service types are presented in the subsequent relevant sections.

The data items from the 1998 ABS survey most relevant to the provision of CSDA services are as follows.

#### **Activity restrictions and their severity**

In the 1998 disability survey a person is considered to have a disability if he/she has a 'limitation, restriction or impairment', which has lasted, or is likely to last, for at least six months and restricts everyday activities (ABS 1999a:67). A 'specific restriction' is defined as a restriction in core activities (self care, mobility and communication), schooling or employment (Box 6.1).

In the 1998 survey four levels of core activity restriction are determined, based on whether a person needs help with, has difficulty with, or uses aids or equipment for any of the core activities. A person's overall level of core activity restriction is determined by the highest level of restriction the person experienced in any of the core activity areas. Profound core activity restriction refers to a person who is unable to do, or always needs help with, a core activity. Severe core activity restriction refers to a person who sometimes needs help with a core activity, or has difficulty understanding or being understood by family or friends, or, who can communicate more easily using sign language or other non-spoken forms of communication.

People with a severe or profound core activity restriction conform quite well to the definition of the target group of CSDA services (substantially reduced capacity in communication, learning or mobility, and needing ongoing or episodic support services). The group is accepted as comprising the 'potential population' for CSDA services, within which more specific targets can be identified (AIHW 1997b, 1997c).

### **Box 6.1: ABS 1998 Survey of Disability, Ageing and Carers: restrictions and their severity**

*Specific restrictions are:*

- *core activity restrictions; and/or*
- *schooling or employment restrictions.*

*Core activities are:*

- *self care – bathing or showering, dressing, eating, using the toilet, and managing incontinence;*
- *mobility – moving around at home and away from home, getting into or out of a bed or chair, and using public transport; and*
- *communication – understanding and being understood by others: strangers, family and friends.*

*A core activity restriction may be:*

- *profound – unable to perform a core activity or always needing assistance;*
- *severe – sometimes needing assistance to perform a core activity;*
- *moderate – not needing assistance, but having difficulty performing a core activity; or*
- *mild – having no difficulty performing a core activity but using aids or equipment because of disability.*

*Source: ABS 1999a.*

### **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 generally take on new clients who are aged 65 or more. 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 0–64 years.

### **Whether the person is living in a household**

Only people living in households were included. In the survey, questions on unmet needs were not asked of people living in institutions.

### **Activities in which help was needed**

People who were 'captured' into the survey by the screening questions, and all people aged 60 years or over, were asked about their need for assistance with various daily activities. In addition to three 'core activities' (self care, mobility and communication), questions were asked about other activities: health care, housework, property maintenance, paper work, meal preparation, transport and guidance.

Survey respondents could report the need for assistance with more than one activity. Need for assistance is defined as needing help or supervision with daily activities due to disability or old age. Where a person cannot cook meals or drive, for example, because the person has never learned these skills or has not been accustomed to performing these activities, the person is not considered as having a relevant need for assistance (ABS 1999a:70).

The questions on need for 'guidance' were added in the 1998 disability survey. Need for guidance refers to need for assistance with 'making and maintaining relationships, coping with emotions, and making decisions or thinking through problems' (ABS 1999b).

### **Frequency of need for assistance because of disability**

In the 1998 survey additional questions were asked about how often does a person need assistance with a particular activity. The categories of the frequency in the confidentialised unit record file of the survey data include: does not need, <1/month, 1-3/month, 1/week, 2-6/week, 1/day, 2/day, 3-5/day and 6+/day.

### **Whether or not there was a stated unmet need for help**

People who needed help were asked about the type of assistance they received and whether the source was a formal service or informal assistance, and whether there was an unmet need for help and why.

### **The reason stated for there being no or not enough formal assistance**

The possible categories into which responses were allocated by the 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;
- the person was unable to arrange a service;
- no service was available;
- not eligible for service (additional category in the 1998 survey);
- service costs too much (additional category in the 1998 survey);
- service does not provide sufficient hours (additional category in the 1998 survey); and
- other.

It was considered in both the 1995 and 1997 AIHW demand studies that the reasons that most clearly demonstrated unmet demand for CSDA services were that the service was not available, or could not be arranged. Here, this is evidence that the person has identified the relevant service and has expressed a real need by attempting to access a service, only to find that it was not available at all or access could not be arranged (AIHW 1997a). This study will maintain the focus on the same two groups. In addition, and for the same reasons, the new 1998 categories of 'service costs too much' and 'service does not provide sufficient hours' are also considered to provide evidence that need was translated into some kind of action, and these categories are also included in the analysis.

Views were put to the study team that there are very good reasons for including some people from other categories. In the income security field, for example, 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. Any of these considerations could lead to an increase in the estimates of unmet need (Madden et al. 1996; AIHW 1997a).

### **CSDA MDS and ABS data—and Table 2.1**

Table 2.1 outlined how some of the ABS disability survey questions are to be related to the study questions about need for the various kinds of disability services provided under the CSDA. The table was 'tested' with National Disability Administrators in the progress report, to confirm that the level of support needed was similar to their general expectations of the target group and the program. It was further tested by comparing related data from the two

relevant sources – the ABS population survey and the CSDA MDS collections. Questions relating to need for assistance in the CSDA MDS are designed to be similar to the ABS disability survey questions to allow comparison between the two data sources. Comparisons of frequency of need for assistance between people aged under 65 with a severe or profound core activity restriction living in households and consumers of CSDA-funded services are illustrated in Table 6.1.

The comparisons include need profiles of both CSDA consumers as a whole and consumers of CSDA employment services. In addition to basic daily activities, the frequencies of need for assistance with education, work and leisure activities for the CSDA consumers are also included in the comparisons, since employment services focuses more on the need for assistance with these activities. No questions in the population survey asked about frequency of need for help with education, work and leisure activities. Hence, frequency of need for help with ‘guidance’ is included for people with a severe or profound core activity restriction, as it is considered to be associated with education and work participation.

The CSDA consumers overall have a much smaller proportion of people with ‘no’ support needs in ‘self care’ and ‘communication’, compared to people in the population (in households) with severe or profound core activity restriction. That is, there is some justification for placing some additional ‘severity’ criteria on the survey data before including people into the estimates for unmet need for CSDA services. This equates to screening out the ‘lower end’ of support needs of the 1998 survey (which the previous discussion suggests is, in a sense, ‘inflated’ compared to the 1993 survey).

For self care the difference in frequencies of need for help indicate:

- higher proportions among the CSDA consumers with ‘occasional’ need for support (25%) compared to the population needing assistance ‘1/week or less’ (22%); and
- higher proportions of the CSDA consumers needing ‘frequent or continual’ support (45%) compared to the population needing assistance ‘2–6/week or more’ (35%).

For communication activity the CSDA consumers overall are much less likely not to need support (27% versus 78%) and much more likely to need ‘frequent’ or ‘continual’ support (43%) than people in the population for ‘2–6/week or more’ (16%). This highlights the ‘high support’ profile generally of the CSDA consumers.

For mobility there is a larger proportion of the CSDA consumers needing ‘no support’ (41%) than of people with severe or profound restrictions in the population (29%). This is probably related to the predominance of intellectual disability among the CSDA consumers, compared to physical in the population, and to the fact that CSDA services do not include transport services while need for assistance with transport is included in the ABS mobility questions.

The consumers of CSDA employment services are much more likely to need support with their education, work and leisure activities than their activities of basic daily living (Table 6.1; see also Table A4.1). This supports the idea that the population baseline estimates of need for disability employment service be based on other needs than the activities of basic daily living. The population survey questions on need for help with ‘guidance’ provide an opportunity for looking at these other needs. The data indicate a relatively high proportion of ‘no’ support need for help with guidance among people with a severe or profound core activity restriction, compared to a very low ‘no’ need for help with education, work and leisure in the consumers of CSDA service. This may be partly because the population data include people living in households only, and partly because of the predominance of intellectual disability in the CSDA consumers, compared to physical in the population.

Some data limitations related to the comparison should be noted:

- while the CSDA MDS questions are designed to be the same as the ABS questions to allow comparison with the survey, the alignment of 'occasional' to 1/week or less, and frequent to 2-6 times per week, is inferred and cannot really be justified;
- if there is unmet need the current CSDA clients may not adequately reflect all those in the population with unmet need; and
- people in institutions are not included in the ABS population disability survey.

Despite these caveats, overall, the comparison of the two data sources supports the criteria for inclusion in the population baseline estimates, that is, the decision not to include all people with severe or profound restriction in the 1998 survey, but to exclude some of the 'lower end' of support needs in the 1998 survey. Equally, the study team could not ignore the new survey questions and the potentially increased analytical power of the 1998 survey. As will be seen, these different ways of adapting to the new survey counterbalance each other in the estimation process to some extent.

**Table 6.1: Comparison of people aged under 65 with a severe or profound core activity restriction living in households (1998) and consumers of CSDA-funded services (2001) by frequency of need for assistance**

Severe or profound		Consumers of CSDA services		Consumers of CSDA employment services	
	% of total		% of total		% of total
<b>Self care</b>					
No need	43.2	No need	30.6	No need	50.4
1/week or less	21.8	Occasional	24.9	Occasional	32.6
2–6/week	7.5	Frequent	18.5	Frequent	11.8
At least 1/day	27.5	Continual	26.0	Continual	5.2
<b>Total</b>	<b>100.0</b>	<b>Total</b>	<b>100.0</b>	<b>Total</b>	<b>100.0</b>
		<b>Total number <sup>(a)</sup></b>	<b>60,007</b>	<b>Total number <sup>(a)</sup></b>	<b>16,657</b>
<b>Mobility</b>					
No need	29.1	No need	41.1	No need	59.5
1/week or less	34.5	Occasional	24.1	Occasional	26.1
2–6/week	12.9	Frequent	15.9	Frequent	9.1
At least 1/day	23.5	Continual	18.9	Continual	5.3
<b>Total</b>	<b>100.0</b>	<b>Total</b>	<b>100.0</b>	<b>Total</b>	<b>100.0</b>
		<b>Total number <sup>(a)</sup></b>	<b>60,977</b>	<b>Total number <sup>(a)</sup></b>	<b>17,287</b>
<b>Communication</b>					
No need	78.2	No need	26.8	No need	33.9
1/week or less	6.1	Occasional	29.9	Occasional	38.7
2–6/week	4.5	Frequent	19.6	Frequent	18.6
At least 1/day	11.2	Continual	23.6	Continual	8.8
<b>Total</b>	<b>100.0</b>	<b>Total</b>	<b>100.0</b>	<b>Total</b>	<b>100.0</b>
		<b>Total number <sup>(a)</sup></b>	<b>61,059</b>	<b>Total number <sup>(a)</sup></b>	<b>17,358</b>
<b>Guidance</b>		<b>Education, work and leisure</b>		<b>Education, work and leisure</b>	
No need	52.7	No need	3.3	No need	3.0
1/week or less	20.4	Occasional	19.4	Occasional	36.0
2–6/week	7.4	Frequent	26.6	Frequent	36.5
At least 1/day	19.4	Continual	50.7	Continual	24.5
<b>Total</b>	<b>100.0</b>	<b>Total</b>	<b>100.0</b>	<b>Total</b>	<b>100.0</b>
<b>Total number</b>	<b>636,000</b>	<b>Total number <sup>(a)</sup></b>	<b>59,282</b>	<b>Total number <sup>(a)</sup></b>	<b>17,368</b>

(a) Excluded 'Not applicable' and 'Do not know'.

Source: AIHW analysis of ABS 1998 Survey of Disability, Ageing and Carers confidentialised unit record file; AIHW analysis of CSDA MDS 2001 national data set.

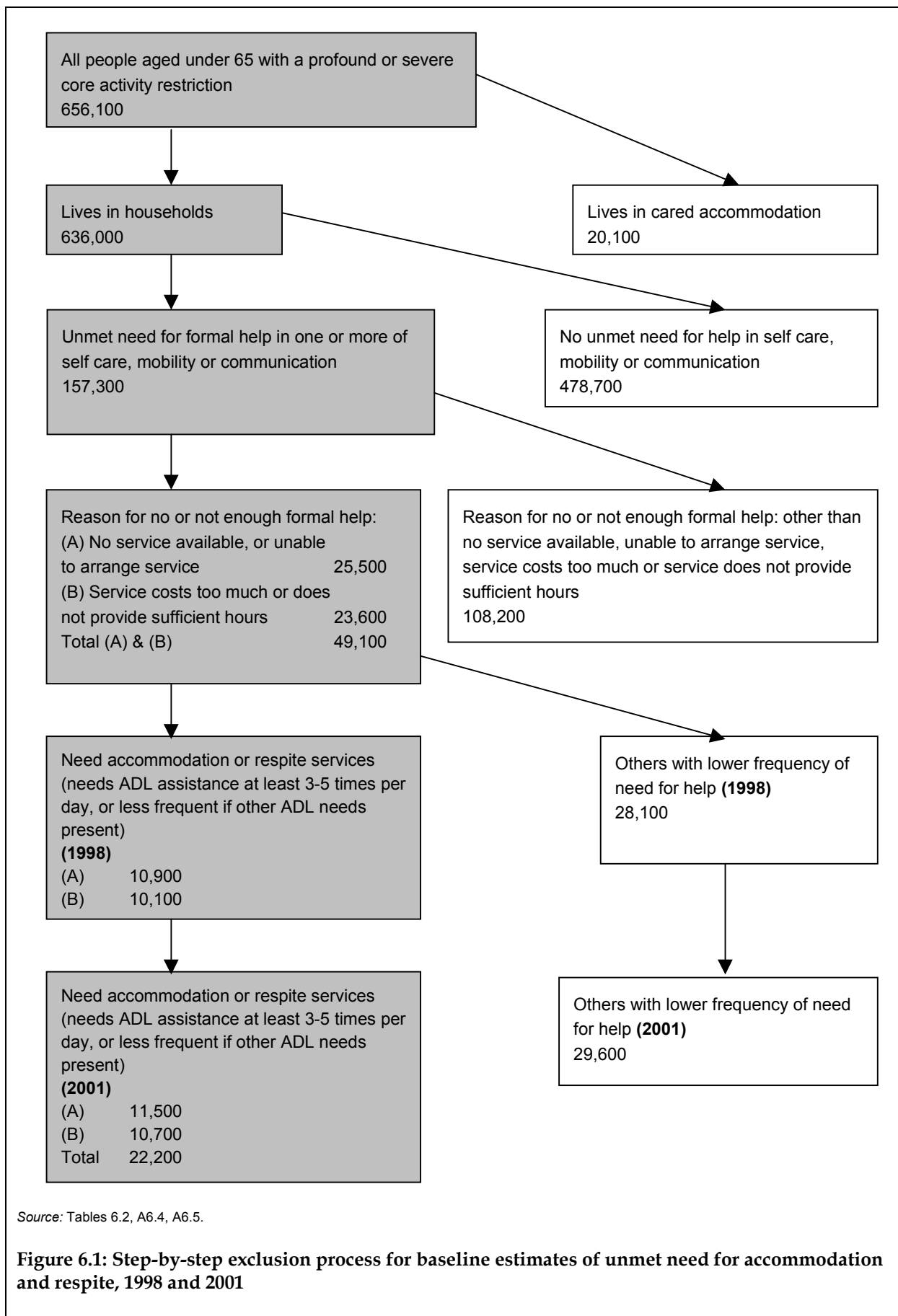
## **6.2 Accommodation and respite services: estimates of unmet need**

The 1997 AIHW demand study estimated that there were 13,400 people aged 5–64 years with ongoing support needs, living in households, reporting unmet needs for formal help with self care, mobility or verbal communication (and possibly other activities as well), who could not obtain this help because a service was not available or could not be arranged. These people comprised the estimate for unmet demand for accommodation and respite services in 1996 (AIHW 1997a).

Taking an approach similar to that used in the 1997 study and using additional data categories from the 1998 survey, the current baseline estimates start by focusing on people aged under 65 with a severe or profound core activity restriction living in households who:

- reported at least one reason for receiving no help or not enough help from formal services in any combination of self care, mobility and communication activities (unmet need may also exist in other activities); and
- gave as the main reason for no or not enough formal assistance that no service was available or that they were unable to arrange service or that service costs too much or that service does not provide sufficient hours.

A step-by-step exclusion process to estimate unmet need for accommodation and respite services is presented in Figure 6.1. This process was designed to exclude any group where there was doubt about the existence of unmet need.



Source: Tables 6.2, A6.4, A6.5.

**Figure 6.1: Step-by-step exclusion process for baseline estimates of unmet need for accommodation and respite, 1998 and 2001**

In 1998 there were 656,100 people with a severe or profound core activity restriction aged less than 65 years. Of these, a total of 20,100 were living in cared accommodation. These people were not asked in the survey to report on unmet need for assistance, and for this very practical reason were excluded from further consideration. This left 636,000 people who were living in households.

People living in households could report unmet needs for formal services in a range of activities. The 157,300 people who reported unmet needs for formal services with self care, mobility or communication were included in the estimates of unmet needs. Those with unmet needs for formal assistance only in activities such as health care, guidance, housework, meal preparation, paperwork, property maintenance and transport were excluded.

Only those 49,100 people who were considered to have clearly demonstrated their unmet need by establishing that the service was unavailable or could not be arranged (25,500) or that service cost too much or service did not provide sufficient hours (23,600) were included as a basis for final estimates. Those who gave other reasons for their unmet need for formal assistance not being met were excluded.

Finally, according to the reported frequency of need for assistance in daily activities, only 21,000 (10,900 plus 10,100) out of the 49,100 people were included in the baseline estimates of unmet needs (Tables 6.1, A6.4 and A6.5) (see also Table 2.1 and earlier discussion in this chapter).

The resulting estimate is that, in 1998, there were 21,000 people needing accommodation and/or respite services because of their areas of unmet need and their higher frequency of need for assistance. This group consists of people who:

- needed assistance with one core activity and needed help at least 3 to 5 times a day;
- needed assistance with two core activities and needed help at least twice daily or more for one activity; and
- needed assistance with three core activities and needed help at least once daily or more for one activity.

The remaining 28,100 people who required lower frequencies of assistance were not included in the baseline estimates of unmet needs.

Table 6.2 also presents adjustments for increase in baseline estimates of unmet needs between 1998 and 2001. The number of people aged under 65 with unmet need for accommodation and respite services is projected to have increased from 21,000 to 22,200<sup>1</sup>.

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<sup>1</sup> Like any population sampling survey data, the ABS 1998 disability survey data are subject to sampling error. As a general guide, estimates of less than 2,600 have an associated relative standard error (RSE) of 50% or more and estimates of less than 9,000 have an associated RSE between 25% and 50%. The RSE of the estimate of 22,200 is about 3,300. Therefore, there are about two chances in three that the actual number of people in this category was within the range 18,900 to 25,400 and about 19 chances in 20 that it was within the range 15,800 to 28,600.

**Table 6.2: People aged under 65 with a severe or profound core activity restriction living in households, who reported as having an unmet need for formal services with core activities, by unmet need for accommodation and respite services, 1998 and 2001 ('000)<sup>(a)</sup>**

	Age groups		
	0–4	5–64	0–64
<b>1998 survey estimates</b>			
Unmet need for formal help in one or more core activity	9.8	147.5	157.3
Reason for no or not enough formal help:			
(A) No service available, or unable to arrange a service	**2.4	23.1	25.5
(B) Service costs too much or does not provide sufficient hours	*3.1	20.5	23.6
<i>Total (A) &amp; (B)</i>	*5.5	43.6	49.1
Unmet need for accommodation & respite services			
(A) No service available, or unable to arrange a service	**2.1	9.2	10.9
(B) Service costs too much or does not provide sufficient hours	*2.7	*8.2	10.1
<i>Total (A) &amp; (B)</i>	*4.8	17.4	21.0
Others with lower frequency of need for help	**0.8	26.2	28.1
<b>Total severe or profound living in household</b>	<b>27.5</b>	<b>608.5</b>	<b>636.0</b>
<b>2001 update (for population growth)</b>			
Unmet need for formal help in one or more core activity	9.7	156.0	165.9
Reason for no or not enough formal help:			
(A) No service available, or unable to arrange a service	**2.4	24.5	26.9
(B) Service costs too much or does not provide sufficient hours	*3.1	21.7	24.9
<i>Total (A) &amp; (B)</i>	*5.4	46.1	51.8
Unmet need for accommodation & respite services			
(A) No service available, or unable to arrange a service	**2.1	9.8	11.5
(B) Service costs too much or does not provide sufficient hours	*2.6	*8.7	10.7
<i>Total (A) &amp; (B)</i>	*4.7	18.4	22.2
Others with lower frequency of need for help	**0.7	27.7	29.6
<b>Total severe or profound living in household</b>	<b>27.0</b>	<b>643.6</b>	<b>670.7</b>

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

Source: AIHW analysis of ABS 1998 Survey of Disability, Ageing and Carers confidentialised unit record file and unpublished data table; ABS 2001.

### 6.3 Community access services: estimates of unmet need

Community access services (predominantly day activity) 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 (see Box 1.1). These services are mainly used by people who do not attend school, and who are not employed full-time. The purpose of the services is to provide meaningful activity for people with a disability, so that they continue to develop, receive stimulation and experience social interaction and community participation.

The policy assumptions underlying the 1997 estimation are that day programs were designed for people with a disability, with high-level support needs and:

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

It was stated then that: '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"' (AIHW 1997a). The study team in 2001 continues this assumption. It should be noted, however, that the assumption (not critical to these particular estimates) that family carers might continue care for the children all their lives is questionable (see description of the 1997 estimates in Appendix 1).

While taking a similar approach to the 1997 study, the present study refined the 1997 estimates in the following aspects. The estimates:

- use more information, other than support need with basic daily activities, to tie the estimates more closely to the policy assumptions outlined;
- take account of the possible interface between disability employment services and community access services, that is, to consider the unmet need of people who are not in the labour force (not looking for job) but were reported as 'could work with special arrangements, equipment, training or assistance' (these are considered potentially eligible for employment services); and
- use the new ABS survey data item on frequency of need for help with core activities to refine the lower end of the estimated range.

Figure 6.2 illustrates the process to estimate unmet need for community access services and Tables 6.3 and 6.4 contain further explanatory data.

In 1998, there were an estimated 492,300 people with a severe or profound core activity restriction aged 15–64 years, living in households. Of these, 321,700 people were not in the labour force (not looking for work); see Table 6.4.

There are three sub-groups of those who were not in the labour force. First, 13,400 people were reported as 'could work with special arrangements, equipment or assistance'. This group will be considered in Section 6.4 in preparing baseline estimates of unmet need for disability employment services. Second, 222,300 people stated that they 'could not work at all' for various reasons (Table 6.4); of these, 19,100 people were attending supervised day programs for disability (Table A6.6). The third group consists of 85,900 people who did not state whether they could work or not but were not in the labour force for different reasons. Of these, 9,600 people were attending day programs.

The focus then shifted to those who did not attend day programs in the second and third groups, 203,200 and 76,300 respectively. Further restrictions were imposed to select about 63,000 people who were aged 18–64, not studying, who were not looking for a job mainly because of their own illness or disability, and who did not go out as often as they would have liked because of their own illness or condition. The restriction of 'wanting to go out more' is imposed simply to ensure that unmet need 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 need for community access services.

In 1998 there were, thus, 9,900 people aged 18–64 years with a severe or profound core activity restriction living in households who (Table 6.3):

- (a) were not in the labour force (were not looking for a job) and were reported as ‘could not work at all’;
- (b) the main reason for not looking for a job is their own illness or disability;
- (c) were not currently studying;
- (d) would have liked to go out more but were prevented from doing so by their illness or condition (that is, they expressed some need for more activity);
- (e) were not currently attending supervised activity programs for disability; and
- (f) needed at least daily assistance in two or three of the self care, mobility or communication activities.

These numbers provide the baseline estimates of unmet need for community access services in 1998 (in line with Table 2.1).

Between 1998 and 2001, the baseline estimate of need for community access (day activity) services is projected to have increased from 9,900 people to 10,600 people.

Sensitivity analyses indicate that if some of the ‘lower end’ of support needs are included in the estimates, the results will be higher than the above baseline estimates. For instance, if we expanded the scope to people who needed at least twice-daily assistance with one or more (not two or more) core activities, the estimates of unmet needs for community access services would be 18,100 people in 1998 and 19,400 in 2001.

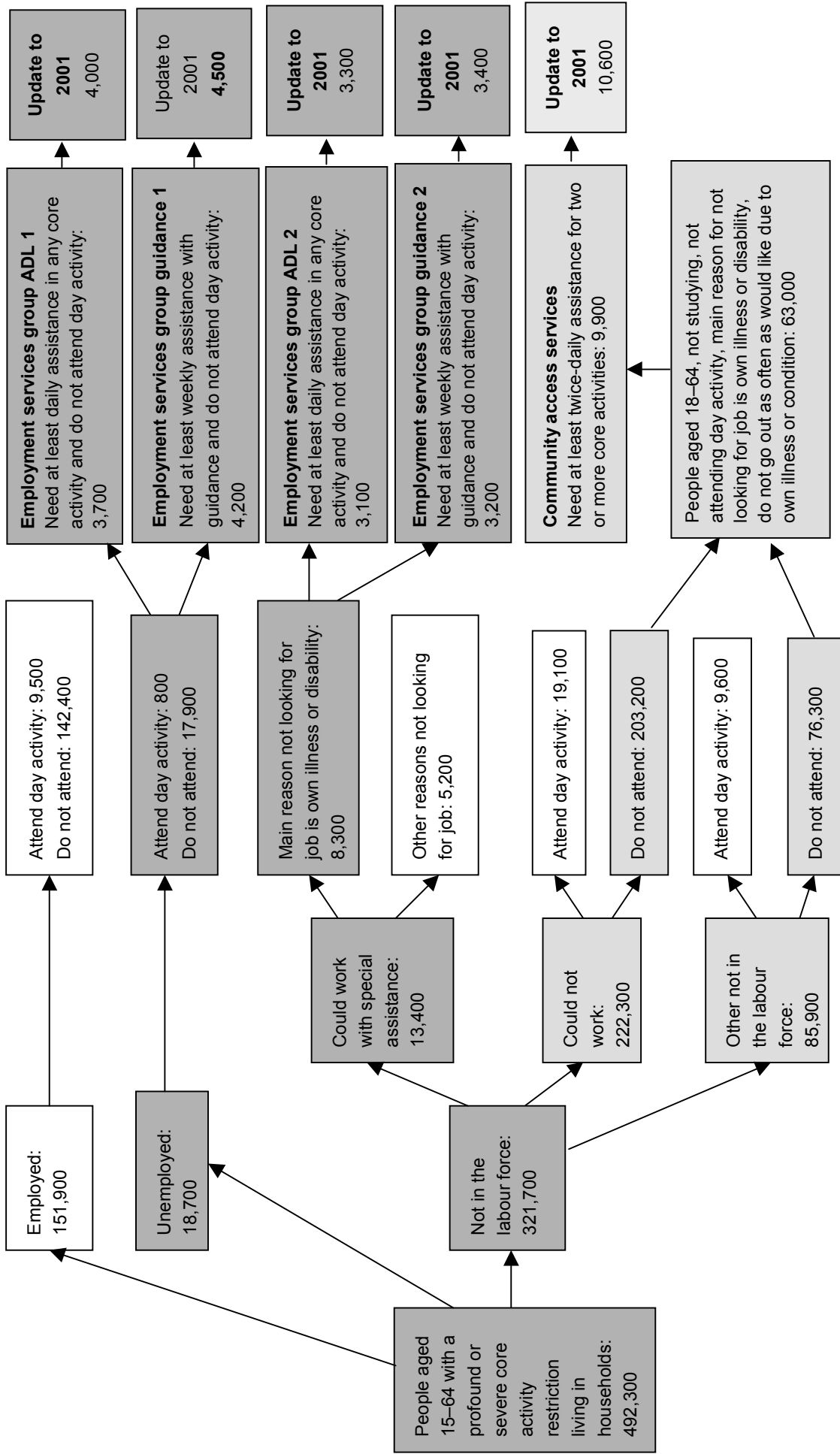
It should be noted that the estimates make no specific allowance for possibly higher rates of use of post-school options services by people aged 18–20 years whereas some jurisdictions do attempt to provide post-school options services to a wider group of 18–20 year-olds.

**Table 6.3: People aged 18–64 with a severe or profound core activity restriction, in households, cannot work and not studying, not looking for job due to their own illness or disability, not going out as often as they would like because of their own illness or condition, not attending supervised activity program for disability or older, by number of activities in which help needed, by frequency of need for help, 1998 and 2001 (‘000)<sup>(a)</sup>**

Frequency of need for help	Number of core activities			Does not need help with core activities	Total	Total needing help with core activities
	One	Two	Three			
<b>1998 survey estimates</b>						
At least 1/day for two or more ADLs	0.0	*8.7	**1.2	0.0	9.9	9.9
Other lower frequencies	31.9	20.4	**0.7	**1.2	54.2	53.0
<b>Total</b>	<b>31.9</b>	<b>29.1</b>	<b>**2.0</b>	<b>**1.2</b>	<b>64.1</b>	<b>63.0</b>
<b>2001 update (for population growth)</b>						
At least 1/day for two or more ADLs	0.0	9.3	**1.3	0.0	10.6	10.6
Other lower frequencies	34.1	21.8	**0.8	**1.3	58.0	56.7
<b>Total</b>	<b>34.1</b>	<b>31.2</b>	<b>2.1</b>	<b>**1.3</b>	<b>68.6</b>	<b>67.3</b>

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

Source: AIHW analysis of ABS 1998 Survey of Disability, Ageing and Carers confidentialised unit record file; ABS 2001.



Sources: Tables 6.3, 6.4, 6.5, 6.6, 6.7, 6.8, 6.9 and A6.6.

Figure 6.2: Process for estimates of unmet need for community access and employment services, 1998 and 2001

**Table 6.4: People aged 15–64 with a severe or profound core activity restriction living in households, who were not in the labour force and who were reported as ‘could not work at all’ by main reason for not looking for work, 1998<sup>(a)</sup>**

Main reason for not looking for work	No. ('000)	%	Total not in the labour force ('000)
Not applicable	34.4	76.5	44.9
Retired	15.2	61.7	24.6
Own ill health/disability	154.9	78.1	198.4
Pregnancy	0.0	0.0	**1.5
Study/returning to study	0.0	0.0	12.3
Does not need/want to work	*2.9	47.2	*6.1
Pension/welfare payment might be affected	**1.2	64.1	**1.9
Childcare reasons	**2.3	34.5	*6.8
Ill health/disability other than self	*5.0	50.5	10.0
Other family considerations	**1.9	57.2	*3.2
Too old	*3.1	72.6	*4.3
Lacks schooling, training or experience	0.0	0.0	**0.7
Other reason/Don't know why not looking for work	**1.4	20.3	*7.0
<b>Total</b>	<b>222.3</b>	<b>69.1</b>	<b>321.7</b>

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

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

## 6.4 Disability employment services: baseline estimates of unmet need

Employment services provide assistance to people with a disability in obtaining and/or retaining paid employment (see Box 1.1)

### Employment restrictions and need for assistance

The overall picture of labour force status indicated that among people aged 15–64 with a severe or profound core activity restriction living in households, 321,700 people were not in the labour force and 18,700 were unemployed, while 151,900 people were employed. Among those who were not in the labour force 54% were females, while males had a higher proportion of unemployment (57%) than females (Table 6.5).

There appears to be a strong correlation between being not in the labour force or unemployed and severity of restriction and level of needs for assistance. Over 80% of people who were not in the labour force had a severe or profound employment restriction (Table 6.5). The proportion of severe employment restriction was higher for unemployed people than employed people while no one in the labour force reported a profound employment restriction.

An employment restriction is determined, in the ABS disability survey, for a person aged 15–64 with a disability if, because of their disability, they:

- are permanently unable to work;

- are restricted in the type of work they can/could do;
- need/would need at least one day a week off work on average;
- are restricted in the number of hours they can/could work;
- require/would require an employer to provide special equipment, modify the work environment or make special arrangements;
- need/would need to be given ongoing assistance or supervision; and
- would find it difficult to change job or get a better job (ABS 1999b:67).

About 73% of people who were not in the labour force said that they would need a support person if they were employed (Table 6.5). This illustrates that, as for the overall labour force, it is important to give attention to the 'discouraged worker' who may have given up seeking work but still wants to and could work. For people in the labour force, a substantially higher proportion of unemployed people than employed people reported various employment restrictions, such as need for time off work and need for employer to provide equipment or special arrangements.

The profile of support needs for non-core activities indicates additional support needs among people who, by definition, need assistance for self care, mobility or communication. People who were not in the labour force reported higher proportions of support needs for all the non-core activities than those of employed people. People who were unemployed or were not in the labour force reported higher proportions of needing guidance and help with transport which were closely related to work participation.

**Table 6.5: People aged 15–64 with a severe or profound core activity restriction living in households: labour force status, by employment restrictions, severity of employment restriction, requirements to enable workforce participation, 1998 ('000)<sup>(a)</sup>**

	Employed		Unemployed		Not in the labour force	
	No. ('000)	%	No. ('000)	%	No. ('000)	%
<b>Age</b>						
15–19	*7.0	4.6	**2.0	10.6	21.7	6.7
20–64	144.9	95.4	16.7	89.4	300.0	93.3
<b>Sex</b>						
Males	77.2	50.8	10.7	57.1	147.5	45.8
Females	74.8	49.2	*8.0	42.9	174.2	54.2
<b>Employment restrictions<sup>(b)</sup></b>						
Restricted in type of job	125.2	82.4	16.5	88.1	68.0	21.1
Restricted in number of hours	83.9	55.2	11.3	60.5	35.7	11.1
Difficulty in changing job or getting a better job	104.3	68.6	14.9	79.6	52.9	16.4
Need for time off work	28.6	18.8	*8.5	45.3	31.6	9.8
Need for employer-provided equipment and/or						
Special arrangements	26.4	17.4	*8.9	47.8	33.6	10.4
Need for ongoing supervision or assistance	19.5	12.8	*3.4	18.3	25.3	7.9
Need for support person	0.0	0.0	0.0	0.0	235.8	73.3
<b>Other employer arrangements<sup>(b)</sup></b>						
A disability support person or someone						
at work to assist/train on the job	14.4	9.5	**0.8	4.3	10.0	3.1
Special equipment	10.2	6.7	*4.8	25.8	11.6	3.6
Training or retraining	**2.5	1.6	0.0	0.0	*7.7	2.4
Different duties	*8.9	5.9	**1.1	5.7	12.6	3.9
<b>Severity of employment restriction</b>						
Profound	0.0	0.0	0.0	0.0	221.6	68.9
Severe	19.5	12.8	*3.7	20.0	39.4	12.3
Moderate	112.7	74.1	14.3	76.4	43.5	13.5
Mild to no employment restriction	19.8	13.0	**0.7	3.5	17.1	5.3
<b>Need for assistance with none-core activities<sup>(c)</sup></b>						
Guidance	44.3	29.2	*8.9	47.8	144.6	45.0
Health care	70.4	46.3	*7.7	41.4	171.1	53.2
Housework	64.4	42.4	*7.6	40.4	180.7	56.2
Property maintenance	84.3	55.5	12.5	66.6	213.8	66.5
Paperwork	26.6	17.5	**2.4	12.7	100.9	31.4
Meal preparation	28.9	19.0	*2.8	15.1	89.9	27.9
Transport	65.0	42.8	9.3	49.8	186.8	58.1

(continued)

**Table 6.5 (continued): People aged 15–64 with a severe or profound core activity restriction living in households: labour force status, by employment restrictions, severity of employment restriction, requirements to enable workforce participation, 1998 ('000)<sup>(a)</sup>**

	Employed		Unemployed		Not in the labour force	
	No. ('000)	%	No. ('000)	%	No. ('000)	%
<b>How often attended supervised activity program for disability</b>						
Not applicable	**1.4	0.9	0.0	0.0	**1.8	0.6
Does not attend	141.0	92.8	17.9	95.6	290.6	90.3
3–5 days/week	**1.6	1.1	0.0	0.0	*6.6	2.0
1–2 days/week	*2.8	1.9	**0.6	3.4	12.7	4.0
1/fortnight or occasionally	*5.1	3.3	**0.2	1.0	10.0	3.1
<i>Total attended</i>	9.5	6.3	**0.8	4.4	29.3	9.1
<b>Total</b>	<b>151.9</b>	<b>100.0</b>	<b>18.7</b>	<b>100.0</b>	<b>321.7</b>	<b>100.0</b>

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

(b) Total may be not equal to the sum of the components as the questions on employment restrictions, arrangements and requirements were asked separately in the survey.

(c) Total may be less than sum of the number of people needing assistance with each activity type, as people may need help with more than one activity.

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

### Unmet needs for disability employment services

Two alternative approaches are used in estimating unmet needs for CSDA employment services. 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 screen people into the estimates: people are included in the estimates only if they need at least daily assistance with at least one of these core activities (see Table 2.1).

The alternative approach focuses more on the need for 'guidance' than on the need for assistance with the ADLs (self care, mobility and communication). These methods are described in turn below, and summarised in Figure 6.2.

#### *Method 1 Activities of daily living (ADL)*

The baseline estimates of unmet needs for employment services focus on two groups of people aged 15–64 years with a severe or profound core activity restriction living in households. Group ADL1 consists of people who:

- (a) were unemployed (that is, looking for either full-time or part-time work);
- (b) were not currently attending supervised activity programs for disability; and
- (c) needed at least daily support in any of the self care, mobility or communication activities.

Group ADL2 consists of people who:

- (a) were not in the labour force but were reported as 'could work with special arrangements, equipment, training or assistance';
- (b) their main reason for not looking for a job is their own illness or disability;
- (c) were not currently attending supervised activity programs for disability; and
- (d) needed at least daily support in any of the self care, mobility or communication activities.

Figure 6.2 illustrates the process to estimate unmet need for employment services.

In 1998, of the total 492,300 people aged 15–64 with a severe or profound core activity restriction living in households, 151,900 people were employed. Of these employed people, 9,500 (6.3%) were also attending day programs. Some of these could have been receiving employment services. More than 80% of employed people were restricted in type of job and over 55% were restricted in number of working hours (Table 6.5). Some needed their employers to provide equipment and/or make special arrangements (17.4%), and/or to provide ongoing supervision or assistance (12.8%) (Table 6.5). Some of these people could need other employment assistance, but are not included in the baseline estimates of unmet need.

The baseline estimates of unmet need for employment service focus on people who are unemployed or who were not in the labour force but could work with special assistance. There were 18,700 people who were unemployed, that is, actively looking for work. Of these, 3,700 needed at least daily assistance in any of self care, mobility and communication activities and did not attend day programs. These 3,700 people comprise the first group of *Method 1 (ADL)* in the baseline estimates of unmet needs for employment services.

It is also important to consider a proportion of people not in the labour force. 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 (see, for example, Newman 1999). It is especially important for people with disabilities, whose labour market experience is not as good as that of the overall community (see, for example, AIHW 1999b & 2001b).

Of those who were not in the labour force, 13,400 stated that they could work with special support, such as special arrangements, equipment, training or other assistance. However, people in this group stated different reasons for not looking for work. A majority – 8,300 people – reported the main reason as their own illness or disability while 5,200 people reported various other reasons for not looking for work (Table 6.6). The focus then is on the 8,300 people who clearly state that they could work with special assistance and their main reason for not looking for a job is their own illness or disability. Within this group, there were 3,100 people who needed at least daily assistance in any of the self care, mobility and communication activities, and did not attend day programs. These 3,100 people comprised the second group of *Method 1 (ADL)* in the baseline estimates of unmet needs for employment services.

These two groups totalled 6,800 people in 1998. The baseline estimates of unmet need for employment services are projected to have increased between 1998 and 2001 from 3,700 to 4,000 for Group One, and from 3,100 to 3,300 for Group Two. These two groups totalled 7,300 people in 2001 (Tables 6.7 and 6.8) – Method 1.

**Table 6.6: People aged 15–64 with a severe or profound core activity restriction living in households: who were not in the labour force but could work with special arrangements, equipment, training or assistance, by main reason for not looking for work, 1998<sup>(a)</sup>**

<b>Main reason for not looking for work</b>	<b>No. ('000)</b>	<b>%</b>	<b>Total not in the labour force ('000)</b>
Not applicable	**1.2	2.7	44.9
Retired	**2.0	8.3	24.6
Own ill health/disability	*8.3	4.2	198.4
Pregnancy	0.0	0.0	**1.5
Study/returning to study	**0.4	3.2	12.3
Does not need/want to work	**0.7	11.3	*6.1
Pension/welfare payment might be affected	0.0	0.0	**1.9
Childcare reasons	0.0	0.0	*6.8
Ill health/disability other than self	0.0	0.0	10.0
Other family considerations	0.0	0.0	*3.2
Too old	**0.2	4.9	*4.3
Lacks schooling, training or experience	0.0	0.0	**0.7
Other reason/Don't know why not looking for work	**0.6	8.9	*7.0
<b>Total</b>	<b>13.4</b>	<b>4.2</b>	<b>321.7</b>

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

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

**Table 6.7: People aged 15–64 with a severe or profound core activity restriction living in households: who were unemployed, by number of core activities needing assistance, by frequency of need for assistance, by attendance of supervised activity program for disability, 1998 and 2001 ('000)<sup>(a)</sup>**

Number of activity and frequency of need for help	Attendance of supervised day activity		
	Yes	No	Total
<b>1998 survey estimates</b>			
(A) One ADL at least 1/day	0.0	**0.8	**0.8
(B) Two ADLs at least 1/day	0.0	*2.7	*2.7
(C) Three ADLs at least 1/day	0.0	**0.2	**0.2
One ADL lower frequencies	**0.6	9.7	10.3
Two ADLs lower frequencies	**0.2	*4.5	*4.7
<b>Total</b>	<b>**0.8</b>	<b>17.9</b>	<b>18.7</b>
<b>Need for employment services</b>			
<b>Total (A) (B) (C)</b>	<b>0.0</b>	<b>*3.7</b>	<b>*3.7</b>
<b>2001 update (for population growth)</b>			
(A) One ADL at least 1/day	0.0	**0.8	**0.8
(B) Two ADLs at least 1/day	0.0	*2.9	*2.9
(C) Three ADLs at least 1/day	0.0	**0.2	**0.2
One ADL lower frequencies	**0.7	10.3	11.0
Two ADLs lower frequencies	**0.2	*4.8	*5.0
<b>Total</b>	<b>**0.9</b>	<b>19.1</b>	<b>20.0</b>
<b>Need for employment services</b>			
<b>Total (A) (B) (C)</b>	<b>0.0</b>	<b>*4.0</b>	<b>*4.0</b>

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

Source: AIHW analysis of ABS 1998 Survey of Disability, Ageing and Carers confidentialised unit record file; ABS 2001.

**Table 6.8: People aged 15–64 with a severe or profound core activity restriction living in households: who were not in the labour force but could work with special assistance, did not look for job mainly because of their own illness or disability, by number of core activities needing assistance and frequency of need for assistance, by attendance of supervised activity program for disability, 1998 and 2001 ('000)<sup>(a)</sup>**

Number of activity and frequency of need for help	Attendance of supervised day activity		Total
	Yes	No	
<b>1998 survey estimates</b>			
(A) One ADL at least 1/day	**0.6	**1.1	**1.6
(B) Two ADL at least 1/day	0.0	**1.1	**1.1
(C) Three ADL at least 1/day	0.0	**0.8	**0.8
One ADL lower frequencies	0.0	*3.3	*3.3
Two ADL lower frequencies	0.0	**1.3	**1.3
<b>Total</b>	<b>**0.6</b>	<b>*7.7</b>	<b>*8.3</b>
<b>Need for employment services</b>			
<b>Total (A) (B) (C)</b>	<b>**0.6</b>	<b>*3.1</b>	<b>*3.6</b>
<b>2001 update (for population growth)</b>			
(A) One ADL at least 1/day	**0.6	**1.1	**1.7
(B) Two ADL at least 1/day	0.0	**1.2	**1.2
(C) Three ADL at least 1/day	0.0	**0.9	**0.9
One ADL lower frequencies	0.0	*3.6	*3.6
Two ADL lower frequencies	0.0	**1.4	**1.4
<b>Total</b>	<b>**0.6</b>	<b>*8.2</b>	<b>*8.9</b>
<b>Need for employment services</b>			
<b>Total (A) (B) (C)</b>	<b>**0.6</b>	<b>*3.3</b>	<b>*3.9</b>

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

Source: AIHW analysis of ABS 1998 Survey of Disability, Ageing and Carers confidentialised unit record file; ABS 2001.

### *Method 2 (Guidance)*

The second approach to estimating unmet need for employment services focuses more on the need for support with 'guidance' than on the need for support with ADLs. The decision to explore this alternative method relies on two issues:

- first, Table A4.1 illustrates that the current clients of CSDA employment services are less characterised by their need for support with ADLs than by their need for support with other activities;
- second, the ABS questions on the need for help with 'guidance' seemed to provide the best opportunity for looking at these other needs, and also relate most closely to the CSDA MDS support needs questions in the areas where the employment services clients score 'higher' than for ADLs (see Box 6.2 below and Table A4.1).

### **Box 6.2: ABS 'guidance' questions and related CSDA MDS 'support needs' concept**

#### *Guidance*

*The ABS Survey asks all people aged 15 years or more with a disability if, because of their health condition(s), they have difficulty or need assistance:*

- *making friendships, interacting with others, or maintaining relationships?*
- *coping with feelings or emotions?*
- *making decisions or thinking through problems?*

*These three items relate to the following life domains in the current CSDA MDS support needs question:*

- *social skills (interpersonal interaction) – the ability to, for example, make and keep friends/relationships;*
- *managing emotions and behaviour – the ability to, for example, behave within accepted limits, cope with feelings;*
- *self-direction – the ability to, for example, think through problems, make decisions.*

*Source: ABS 1999b.*

The method still starts with people aged 15–64 with severe or profound core activity restriction, and initially follows through the pathways of Figure 6.2 as follows.

The unemployed group who do not attend day activities (17,900 in Figure 6.2) are split according to those who need guidance rather than according to the level of support needed with ADLs. This results in 4,200 of these people who need at least weekly assistance with guidance (Table 6.9).

The group not in the labour force (8,300 in Figure 6.2) are similarly further split and we find that there are 3,200 who need at least weekly assistance with guidance.

These figures added together provide the baseline estimates for unmet need for employment services in 1998, that is 7,400, which, when updated to 2001, becomes 7,900.

**Table 6.9: People aged 15–64 with a severe or profound core activity restriction living in households: who were unemployed, or who were not in the labour force but could work with special assistance and their main reason for not looking for a job is their own illness or disability, by frequency of need for help with guidance, by attendance of supervised activity program for disability, 1998 and 2001 ('000)<sup>(a)</sup>**

Employment services group type/ frequency of need for help with guidance	Attendance of supervised day activity		Total
	Yes	No	
<b>1998 survey estimates</b>			
<i>Unemployed</i>			
At least once a week	**0.2	*4.2	*4.4
Other lower frequencies or does not need help	**0.6	13.6	14.3
<i>Total</i>	**0.8	17.9	18.7
<i>Not in labour force but could work with special assistance<sup>(b)</sup></i>			
At least once a week	0.0	*3.2	*3.2
Other lower frequencies or does not need help	**0.6	*4.5	*5.1
<i>Total</i>	**0.6	*7.7	*8.3
<b>Total need for help at least once a week</b>	<b>**0.2</b>	<b>*7.4</b>	<b>*7.6</b>
<b>2001 update (for population growth)</b>			
<i>Unemployed</i>			
At least once a week	**0.2	*4.5	*4.7
Other lower frequencies or does not need help	**0.7	14.5	15.2
<i>Total</i>	**0.9	19.1	20.0
<i>Not in labour force but could work with special assistance<sup>(b)</sup></i>			
At least once a week	0.0	*3.4	*3.4
Other lower frequencies or does not need help	**0.6	*4.8	*5.4
<i>Total</i>	**0.6	*8.2	*8.9
<b>Total need for help at least once a week</b>	<b>**0.2</b>	<b>*7.9</b>	<b>*8.1</b>

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

(b) Their main reason for not looking for a job is their own illness or disability.

Source: AIHW analysis of ABS 1998 Survey of Disability, Ageing and Carers confidentialised unit record file; ABS 2001.

## 6.5 Estimates of support needs of ageing primary carers

In 1998, 450,900 people, or 2.4% of the total population, were primary carers. A 'primary carer' is defined as the person who provides the most informal assistance to a person with one or more disabilities (ABS 1999a). Some 247,000 primary carers were caring for a main recipient aged less than 65 years (AIHW 1999b, table A7.6).

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 17,100 who had received it at some stage but needed more (AIHW 2001b:301).

The analysis of population survey data in this section provides a range of estimates related to support needs of ageing carers. As was mentioned in Section 6.1, the estimates are related to the purpose and key principles of the new unmet need funding agreed in the 2000 CSDA Bilateral Agreements. Particular attention focused on two groups identified in the

agreements. Based on available data items from the ABS 1998 disability survey, estimates are provided for two groups of ageing primary carers (Table 6.10):

- Group A – 15,600 primary carers aged 65 or more with a co-resident main recipient aged under 65;
- Group B – 15,300 primary carers aged under 65 with a co-resident main recipient aged under 65, who either had been caring for 30 years or more or were aged 60–64 living in a non-capital city.

In 1998, 1,400 primary carers in Group A and 700 in Group B reported that they needed assistance but did not receive any, and 3,700 in Group A and 2,700 in Group B needed more assistance than they currently received (Table 6.10).

About 6,800 in Group A and 4,200 in Group B reported that they did not have a fall-back carer.

Most primary carers (12,200 Group A and 12,200 Group B) had never received respite care services, and the majority of them (8,400 Group A and 8,800 Group B) stated that they did not need such services. However, 1,700 in Group A and 1,500 in Group B said that they needed respite services but had never received them.

Of primary carers who had used respite services in the last three months 1,900 primary carers (1,300 Group A and 600 Group B) needed more assistance.

Around 10,000 primary carers in each of the groups reported that their main recipient could not manage at home alone for a few days. Some 5,500 recipients in Group A and 4,200 recipients in Group B could not manage at home alone for a few hours; and 3,800 recipients in Group A and 2,600 in Group B could not manage at home alone even for less than one hour.

About 5,500 primary carers in Group A and 8,300 in Group B had been in a caring role for 30 years or over; and 7,200 primary carers in Group A and 7,800 in Group B spent, on average, 40 hours or more per week providing care.

When the estimates are updated to 2001, the data indicate (Table 6.11):

- 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.

**Table 6.10: Support needs of ageing primary carers with a co-resident main recipient aged under 65, 1998 ('000)<sup>(a)(b)</sup>**

	Group A <sup>(c)</sup>		Group B <sup>(d)</sup>	
	Number	%	Number	%
<b>Geographic location</b>				
Capital city	10.0	64.2	*6.2	40.2
Balance of State/Territory	*5.6	35.8	9.2	59.8
<b>Total</b>	<b>15.6</b>	<b>100.0</b>	<b>15.3</b>	<b>100.0</b>
<b>Disability status</b>				
Severe or profound restriction	**0.9	5.9	**2.2	14.1
No severe or profound restriction	*6.4	41.1	*7.8	50.6
No disability	*8.3	52.9	*5.4	35.4
<b>Whether has been diagnosed with a stress-related illness</b>				
Yes	**1.3	8.1	**1.5	10.1
No	13.1	84.0	13.8	89.9
Not stated	**1.2	7.8	0.0	0.0
<b>Relationship to the main recipient</b>				
Spouse/partner	*4.9	31.3	*7.9	51.5
Parent	*8.9	56.8	*6.4	41.9
Children	0.0	0.0	**0.7	4.8
Other family member/friend	**1.9	11.9	**0.3	1.7
<b>Primary carer's need for and receipt of assistance to care for main recipient</b>				
Receives assistance:				
Does not need further assistance	*4.6	29.5	*4.3	27.9
Needs further assistance	*3.7	23.8	*2.7	17.9
Does not receive assistance:				
Does not need assistance	*5.9	37.6	*7.6	49.4
Needs assistance	**1.4	9.2	**0.7	4.8
<b>Availability of a fall-back carer</b>				
Available	*7.7	49.3	*7.7	50.4
Not available	*6.8	43.3	*4.2	27.3
Don't know if available	**1.2	7.5	*3.4	22.3

(continued)

**Table 6.10 (continued): Support needs of ageing primary carers with a co-resident main recipient aged under 65, 1998 ('000)<sup>(a)(b)</sup>**

	Group A <sup>(c)</sup>		Group B <sup>(d)</sup>	
	Number	%	Number	%
<b>Need for and receipt of respite care</b>				
Received in the last three months:				
Does not need further care	0.0	0.0	**1.9	12.2
Needs further care	**1.3	8.1	**0.6	4.1
Did not receive in the last three months:				
Does not need care	**2.1	13.6	**0.4	2.7
Needs care	0.0	0.0	**0.2	1.1
Never received respite care:				
Does not need/want care	10.6	67.7	10.8	70.1
Needs care	**1.7	10.6	**1.5	9.6
<b>Use of respite care services</b>				
Used in the last three months	**1.3	8.1	**2.5	16.3
Used not in the last three months	**2.1	13.6	**0.6	3.9
Never used respite care	12.2	78.3	12.2	79.8
<b>Main reason primary carer has never used respite care</b>				
Does not need respite care	*8.4	54.1	*8.8	57.2
Does not know enough about it	0.0	0.0	**0.9	6.0
Availability barriers to respite care	**1.2	7.7	0.0	0.0
Main recipient does not want it	0.0	0.0	**0.7	4.8
Primary carer does not want respite care	**1.4	9.0	**1.1	7.3
Has not heard of it	**0.4	2.7	0.0	0.0
Other	**0.7	4.8	**0.7	4.5
Has used respite care	*3.4	21.7	*3.1	20.2
<b>Whether main recipient can manage at home alone for less than one hour</b>				
Not applicable	**2.2	14.3	**0.3	1.7
Could and with no difficulty	*7.7	49.1	10.4	67.9
Could but with difficulty	**1.9	12.3	**2.1	13.4
Could not manage	*3.8	24.4	*2.6	16.9
<b>Whether main recipient can manage at home alone for a few hours</b>				
Not applicable	**2.2	14.3	**0.3	1.7
Could and with no difficulty	*5.6	36.2	*7.5	49.2
Could but with difficulty	**2.2	14.4	*3.4	22.0
Could not manage	*5.5	35.1	*4.2	27.1

(continued)

**Table 6.10 (continued): Support needs of ageing primary carers with a co-resident main recipient aged under 65, 1998 ('000)<sup>(a)(b)</sup>**

	Group A <sup>(c)</sup>		Group B <sup>(d)</sup>	
	Number	%	Number	%
<b>Whether main recipient can manage at home alone for a few days</b>				
Not applicable	**2.2	14.3	**0.3	1.7
Could and with no difficulty	**1.9	12.1	*2.7	17.7
Could but with difficulty	**1.6	10.6	**1.8	11.8
Could not manage	9.8	63.1	10.5	68.7
<b>Years in caring role</b>				
1–4	**1.2	7.4	*3.1	19.9
5–9	**1.8	11.3	**2.0	13.3
10–14	**0.8	5.2	**0.2	1.2
15–19	**1.7	10.6	**0.6	4.1
20–24	*2.6	16.4	**0.6	3.6
25–29	**2.1	13.7	**0.6	4.1
30–34	**1.6	9.9	5.9	38.7
35–39	**0.7	4.5	**1.2	7.5
39 or more	*3.3	21.0	**1.2	7.5
<b>Hours per week spent actively caring or supervising</b>				
Less than 20	*5.1	32.7	*4.8	31.5
20–39 hours	**2.0	13.1	*2.7	17.6
40 hours or more	*7.2	46.4	*7.8	50.9
Not stated	**1.2	7.8	0.0	0.0
<b>Whether primary carer has unmet need for weekday respite care once/month</b>				
Need respite care on weekdays at least once a month	**1.7	11.0	**2.1	13.7
Need respite care on weekdays less than once a month	**0.6	3.9	**0.2	1.1
Need respite care but not on weekdays	**0.6	3.8	0.0	0.0
Does not need/want respite care	12.7	81.3	13.1	85.1
<b>Whether primary carer has unmet need for weeknights respite care once/month</b>				
Need respite care on weeknights at least once a month	**0.4	2.9	**0.3	1.9
Need respite care on weeknights less than once a month	0.0	0.0	0.0	0.0
Need respite care but not on weeknights	**2.5	15.9	**2.0	13.0
Does not need/want respite care	12.7	81.3	13.1	85.1
<b>Whether primary carer has unmet need for weekend respite care once/month</b>				
Need respite care on weekends at least once a month	**1.0	6.7	**1.1	7.1
Need respite care on weekends less than once a month	**0.6	3.9	0.0	0.0
Need respite care but not on weekends	**1.3	8.1	**1.2	7.7
Does not need/want respite care	12.7	81.3	13.1	85.1

(continued)

**Table 6.10 (continued): Support needs of ageing primary carers with a co-resident main recipient aged under 65, 1998 ('000)<sup>(a)(b)</sup>**

	Group A <sup>(c)</sup>		Group B <sup>(d)</sup>	
	Number	%	Number	%
<b>Whether primary carer has unmet need for respite care at short notice or on an irregular basis</b>				
Need respite care at short notice or on an irregular basis	**2.3	14.9	**1.4	8.9
Need respite care but not at short notice or on an irregular basis	**0.6	3.8	**0.9	6.0
Does not need/want respite care	12.7	81.3	13.1	85.1

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

(b) Each section of the table (within lines) adds up to the total: 15,600 for Group A and 15,300 for Group B.

(c) Group A includes primary carers aged 65 or more with a co-resident main recipient aged under 65.

(d) Group B includes primary carers aged under 65 with a co-resident main recipient aged under 65, who either had been caring for 30 years or more or was aged 60–64 living in non-capital city.

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

**Table 6.11: Support needs of ageing primary carers with a co-resident main recipient aged under 65, 2001 ('000)<sup>(a)(b)</sup>**

	Group A <sup>(c)</sup>		Group B <sup>(d)</sup>	
	Number	%	Number	%
<b>Geographic location</b>				
Capital city	10.6	64.2	*6.5	40.2
Balance of State/Territory	*5.9	35.8	9.7	59.8
Total	16.5	100.0	16.2	100.0
<b>Disability status</b>				
Severe or profound restriction	**1.0	5.9	**2.3	14.1
No severe or profound restriction	*6.8	41.1	*8.2	50.6
No disability	*8.7	52.9	*5.7	35.4
<b>Whether has been diagnosed with a stress-related illness</b>				
Yes	**1.3	8.1	**1.6	10.1
No	13.8	84.0	14.5	89.9
Not stated	**1.3	7.8	0.0	0.0
<b>Relationship to the main recipient</b>				
Spouse/partner	*5.1	31.3	*8.3	51.5
Parent	9.3	56.8	*6.8	41.9
Children	0.0	0.0	**0.8	4.8
Other family member/friend	**2.0	11.9	**0.3	1.7

(continued)

**Table 6.11 (continued): Support needs of ageing primary carers with a co-resident main recipient aged under 65, 2001 ('000)<sup>(a)(b)</sup>**

	Group A <sup>(c)</sup>		Group B <sup>(d)</sup>	
	Number	%	Number	%
<b>Primary carer's need for and receipt of assistance to care for main recipient</b>				
Receives assistance:				
Does not need further assistance	*4.9	29.5	*4.5	27.9
Needs further assistance	*3.9	23.8	*2.9	17.9
Does not receive assistance:				
Does not need assistance	*6.2	37.6	*8.0	49.4
Needs assistance	**1.5	9.2	**0.8	4.8
<b>Availability of a fall-back carer</b>				
Available	*8.1	49.3	*8.2	50.4
Not available	*7.1	43.3	*4.4	27.3
Don't know if available	**1.2	7.5	*3.6	22.3
<b>Need for and receipt of respite care</b>				
Received in the last three months:				
Does not need further care	0.0	0.0	**2.0	12.2
Needs further care	**1.3	8.1	**0.7	4.1
Did not receive in the last three months:				
Does not need care	**2.2	13.6	**0.4	2.7
Needs care	0.0	0.0	**0.2	1.1
Never received respite care:				
Does not need/want care	11.1	67.7	11.3	70.1
Needs care	**1.7	10.6	**1.6	9.6
<b>Use of respite care services</b>				
Used in the last three months	**1.3	8.1	*2.6	16.3
Used not in the last three months	**2.2	13.6	**0.6	3.9
Never used respite care	12.9	78.3	12.9	79.8
<b>Main reason primary carer has never used respite care</b>				
Does not need respite care	*8.9	54.1	9.3	57.2
Does not know enough about it	0.0	0.0	**1.0	6.0
Availability barriers to respite care	**1.3	7.7	0.0	0.0
Main recipient does not want it	0.0	0.0	**0.8	4.8
Primary carer does not want respite care	**1.5	9.0	**1.2	7.3
Has not heard of it	**0.4	2.7	0.0	0.0
Other	**0.8	4.8	**0.7	4.5
Has used respite care	*3.6	21.7	*3.3	20.2

(continued)

**Table 6.11 (continued): Support needs of ageing primary carers with a co-resident main recipient aged under 65, 2001 ('000)<sup>(a)(b)</sup>**

	Group A <sup>(c)</sup>		Group B <sup>(d)</sup>	
	Number	%	Number	%
<b>Whether main recipient can manage at home alone for less than one hour</b>				
Not applicable	**2.4	14.3	**0.3	1.7
Could and with no difficulty	*8.1	49.1	11.0	67.9
Could but with difficulty	**2.0	12.3	**2.2	13.4
Could not manage	*4.0	24.4	*2.7	16.9
<b>Whether main recipient can manage at home alone for a few hours</b>				
Not applicable	**2.4	14.3	**0.3	1.7
Could and with no difficulty	*6.0	36.2	*8.0	49.2
Could but with difficulty	**2.4	14.4	*3.6	22.0
Could not manage	*5.8	35.1	*4.4	27.1
<b>Whether main recipient can manage at home alone for a few days</b>				
Not applicable	**2.4	14.3	**0.3	1.7
Could and with no difficulty	**2.0	12.1	*2.9	17.7
Could but with difficulty	**1.7	10.6	**1.9	11.8
Could not manage	10.4	63.1	11.1	68.7
<b>Years in caring role</b>				
1–4	**1.2	7.4	*3.2	19.9
5–9	**1.9	11.3	**2.1	13.3
10–14	**0.9	5.2	**0.2	1.2
15–19	**1.7	10.6	**0.7	4.1
20–24	*2.7	16.4	**0.6	3.6
25–29	**2.3	13.7	**0.7	4.1
30–34	**1.6	9.9	*6.3	38.7
35–39	**0.7	4.5	**1.2	7.5
39 or more	*3.4	21.0	**1.2	7.5
<b>Hours per week spent actively caring or supervising</b>				
Less than 20	*5.4	32.7	*5.1	31.5
20–39 hours	**2.1	13.1	*2.8	17.6
40 hours or more	*7.6	46.4	*8.2	50.9
Not stated	**1.3	7.8	0.0	0.0
<b>Whether primary carer has unmet need for weekday respite care once/month</b>				
Need respite care on weekdays at least once a month	**1.8	11.0	**2.2	13.7
Need respite care on weekdays less than once a month	**0.6	3.9	**0.2	1.1
Need respite care but not on weekdays	**0.6	3.8	0.0	0.0
Does not need/want respite care	13.4	81.3	13.8	85.1

(continued)

**Table 6.11 (continued): Support needs of ageing primary carers with a co-resident main recipient aged under 65, 2001 ('000)<sup>(a)(b)</sup>**

	Group A <sup>(c)</sup>		Group B <sup>(d)</sup>	
	Number	%	Number	%
<b>Whether primary carer has unmet need for weeknights respite care once/month</b>				
Need respite care on weeknights at least once a month	**0.5	2.9	**0.3	1.9
Need respite care on weeknights less than once a month	0.0	0.0	0.0	0.0
Need respite care but not on weeknights	*2.6	15.9	**2.1	13.0
Does not need/want respite care	13.4	81.3	13.8	85.1
<b>Whether primary carer has unmet need for weekend respite care once/month</b>				
Need respite care on weekends at least once a month	**1.1	6.7	**1.2	7.1
Need respite care on weekends less than once a month	**0.6	3.9	0.0	0.0
Need respite care but not on weekends	**1.3	8.1	**1.3	7.7
Does not need/want respite care	13.4	81.3	13.8	85.1
<b>Whether primary carer has unmet need for respite care at short notice or on an irregular basis</b>				
Need respite care at short notice or on an irregular basis	**2.5	14.9	**1.4	8.9
Need respite care but not at short notice or on an irregular basis	**0.6	3.8	**1.0	6.0
Does not need/want respite care	13.4	81.3	13.8	85.1

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

(b) Each section of the table (within lines) adds up to the total: 16,500 for Group A and 16,200 for Group B.

(c) Group A includes primary carers aged 65 or more with a co-resident main recipient aged under 65.

(d) Group B includes primary carers aged under 65 with a co-resident main recipient aged under 65, who either had been caring for 30 years or more or was aged 60–64 living in non-capital city.

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