

## 4 Effectiveness of unmet need funding

This chapter draws together information on the effectiveness of the unmet need funding, to address the first main project objective:

Assess the effectiveness of the unmet need funding in reducing unmet need for disability services by quantifying and describing additional services provided as a result of unmet need funding and, wherever possible, documenting the impact of these services for individuals receiving support. Effectiveness, in this context, refers to the degree to which stated funding objectives have been achieved.

Chapter 3 began this task, presenting the information obtained from jurisdictions for the study via the Jurisdiction Survey. The present chapter outlines the remaining information relevant to the question of effectiveness, and discusses the combined information.

### 4.1 Scope and outline of the chapter

'Effectiveness' is a challenging topic to investigate for a service program or indeed for any specific service in the disability arena. In a national program such as the CSDA, it would be possible to look at many layers of meaning and many areas of application or effect. Significant new funds have been injected into the CSDA program in recent years, including the unmet need funding in 2000-01 (see Tables 1.3 and 1.4, and Figure 1.1). Effectiveness must be related to stated objectives (for example, AIHW 2000b).

This complexity, as well as the centrality of 'stated objectives', are recognised in the project objective relating to effectiveness quoted above.

#### Objectives of unmet need funding

The principal objectives of the Bilateral Agreements<sup>1</sup> were:

- To help address unmet needs by providing additional services that enable people with disabilities who have ageing carers to remain supported within their families in their local communities.
- The State's (Territory's) new contribution will be used to assist in addressing other priority areas of unmet need.

The breadth of this second objective, where States and Territories may assign a range of purposes to suit their own priorities, means that 'effectiveness' can also be considered against the broad objectives of the CSDA itself (Section 1.2). These are:

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

Objectives are also embedded in the definitions of the service types funded under the CSDA (Box 1.1).

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<sup>1</sup> For more details see Section 1.3 and Chapter 3.

The principal focus on effectiveness will, in the present study, relate mostly to the provision of additional services and, secondly, to the effects on ageing carers. Other evidence for a study of effectiveness could include:

- people living in the community rather than in institutional settings;
- people remaining in stable and satisfactory accommodation arrangements;
- numbers of respite consumers and numbers of episodes of respite;
- numbers of people with a disability working and retaining jobs;
- people gaining skills and 'independence', or having opportunities to do so;
- people participating in various areas of life (see Table 2.1; see AIHW 1999b, 2001b for analysis that is not repeated here);
- service quality – delivering services 'well', with respect to all those involved, and a focus on quality of life.

However, this report is not intended to comprise a full 'evaluation' of the outcomes of CSDA funding and program. The study team has kept the focus on the main objective of 'additional new services' and 'impacts on individuals', and has included other relevant information as a context for that task, and to raise issues.

## **Methods and sources**

The study team, therefore, has drawn on a mix of quantitative, qualitative and 'case story' information that could be compiled in the available time. The main strands of work in this chapter are:

- developing a 'macro' view based on analysis of national CSDA MDS data, in particular trend analysis;
- analysing the information obtained from jurisdictions in particular from section 2 of the Jurisdiction Survey questionnaire on evaluations of the effectiveness of new services or related research (Appendix 2);
- the literature search on the effects and effectiveness of these and similar services, including case studies; and
- peak body discussions.

## **Chapter outline**

Section 4.2 presents national data on the 'additional services' provided in 2000–01 from the CSDA MDS. Evidence on the reduction of unmet need and the achievement of 'other priorities' is then presented in Section 4.3, drawing chiefly on information from the Jurisdictional Survey. What the peak discussions revealed about effectiveness is summarised in Section 4.4. This includes both the significant benefits achieved and the issues still to be resolved. Section 4.5 outlines other information on effectiveness including a literature search. The chapter concludes by combining and summarising the key findings relating to effectiveness (Section 4.6).

## 4.2 Additional services: national trends from the CSDA MDS

The 'unmet need' funding in 2000–01 became available after several years of funding increase in all jurisdictions and, to some extent, is difficult to disentangle from other growth funding (see Table 1.4 and Chapter 3). Thus, analysis of longer term trends in service growth, during these periods of funding growth, provides the context for examining the specific changes between 1999–2000 and 2000–01, as well as providing a general indication of the trends in and effectiveness of new funding, whatever its 'label'.

The national data sets collated by AIHW from jurisdictional snapshot day collections, up to and including 2001, provide valuable information for this purpose.

Trends in this section are examined over recent years, up to and including 2000–01, on:

- service provision (in terms of funding and services received); and
- service intensity (in terms of proportion of consumers needing continual support with at least one ADL)<sup>2</sup>.

Trends in the disability groups receiving services and the living arrangements of consumers are also reviewed.

### Counting 'services received' and 'consumers in a year'

The trend analysis focuses on 'services received on a snapshot day' in the years 1997 to 2001 inclusive. This is the measure that is nationally consistent over these years. From 1999 the introduction of a statistical linkage key into the collections provides a measure of the number of consumers on the snapshot day (that is, double counting of consumers resulting from multiple service use can be removed). This provides a second snapshot measure that is available from the CSDA MDS collection – 'consumers' – but only since 1999. Consumer and services received profiles can differ somewhat, for a particular characteristic, if there is variation in the average number of services received per consumer for that characteristic.

However, this difference becomes much less significant if the data are examined for particular service types separately, as there is much less multiple service use within service types than between service types. For this analysis, it is 'services received' that are of particular interest, as is the monitoring of longer term trends.

Services received on a snapshot day are considered a good indicator of the volume of some service types (for example accommodation places). For service types that follow fairly regular daily patterns (such as day activity and employment programs), the snapshot numbers may be considered useful 'proportional' representations of service volume, although full-year figures on the number of consumers receiving services are higher than daily counts, since not all consumers receive daily services. For service types with more irregular patterns of service provision, such as respite services, the snapshot day data may be less useful for trend analysis.

Table 4.1 illustrates the relationship between snapshot figures and full-year figures for Western Australia, the only State currently able to provide full-year numbers. (After the introduction of the redeveloped CSDA MDS collection, all jurisdictions will have such data.)

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<sup>2</sup> Ideally, data on service volume would also be tabulated, to complete the picture. This could have been indicated by total staff hours by service type but, because of relatively high levels of missing data, trends are unclear; these data will therefore not be included despite their potential value.

**Table 4.1: Comparison of CSDA-funded services received on the 2001 snapshot day and consumers for the full financial year (2000–01) in Western Australia**

<b>Service type</b>	<b>Services received snapshot day</b>	<b>Consumers over the full year</b>	<b>Ratio of full-year consumers: snapshot day services received</b>
<b>Accommodation support</b>			
Institutions/large residentials	391	421	1.08
Hostels	136	155	1.14
Group homes	923	987	1.07
<i>Subtotal residential accommodation</i>	<i>1,450</i>	<i>1,559</i>	<i>1.08</i>
Attendant care	164	649	3.96
Outreach/other 'in-home'/drop-in support	480	817	1.70
Alternative family placement	21	21	1.00
Accommodation support: other/not stated	24	26	1.08
<i>Subtotal community accommodation</i>	<i>689</i>	<i>1,513</i>	<i>2.20</i>
<b>Total accommodation support</b>	<b>2,139</b>	<b>2,740</b>	<b>1.28</b>
<b>Community support</b>			
Early childhood intervention	193	647	3.35
Recreation/holiday programs	538	8,946	16.63
Therapy (PT OT ST)	1,408	6,581	4.67
Family/individual case practice/management	1,145	6,494	5.67
Behaviour/specialist intervention	358	1,225	3.42
Counselling: individual/family/group	258	1,587	6.15
Brokerage/direct funding/ind. supp. pack.	364	2,091	5.74
Mutual support/self-help groups	44	156	3.55
Resource teams/regional teams	0	35	—
Community support: other or not stated	447	1,207	2.70
<b>Total community support</b>	<b>4,755</b>	<b>24,876</b>	<b>5.23</b>
<b>Community access</b>			
Continuing education/independent living training/adult training centre	3	0	0.00
Post-school options/social and community support/community access	455	1,655	3.64
Other community access and day programs	252	502	1.99
<b>Total community access</b>	<b>710</b>	<b>2,053</b>	<b>2.89</b>
<b>Respite</b>			
Own-home respite	25	700	28.00
Respite: centre/respite home	254	1,453	5.72
Respite: host family/peer support	0	0	—
Respite: other/flexible/combination	107	1,543	14.42
<b>Total respite</b>	<b>386</b>	<b>2,682</b>	<b>6.95</b>

Source: AIHW analysis of WA data set kindly provided for this report.

In this chapter and in Chapter 7, it is useful to estimate the increase in numbers of people using CSDA-funded services over a full year, based on an increase in services received figures. The Western Australian ratio of 'full-year consumers: snapshot day services received' (see Table 4.1) is applied to the total services received on the snapshot day to do this. This assumes that the Western Australian ratio would be similar to the national ratio (which is unknown at this stage) and that these are both fairly constant over the years in question.

### **Indicators of service intensity: trends in 'support needs'**

Data on the support needs of consumers in 10 main life areas are collected in the CSDA MDS (overall needs, not just relating to the specific service). The data item provides a framework consistent with international classification standards, into which the common assessment tools can be mapped, and provides data able to be compared to the ABS population data.

As previously discussed, it is important to include consideration of trends in service intensity in the overall consideration of trends in service provision, and these data are useful for this purpose.

For simplicity of analysis, data on the overall support needs of consumers are also grouped into three main areas:

- activities of daily living (ADLs) – including self care, mobility and communication;
- home and social living (HSL) – including home living, social skills, self-direction and managing emotions; and
- education, work and leisure (EWL) – including learning, working and other day activities.

It has been verified by linkage key analysis that these data provide reasonably robust information about support needs, with high inter-rater reliability. For consumers who receive more than one service on the snapshot day there is generally only modest variability between service providers in the recording of frequency of need for support or assistance (that is, between adjacent categories in the scale – none/occasional, occasional/frequent and frequent/continual, AIHW 1999a). Further, linkage key analysis shows that there is little evidence for any systematic variation in the recording of support needed by service type.

### **Overall trends in service groups**

Overall trends are illustrated in Figure 4.1 and tabulated in Table 4.2. The immediately following sections describe these trends, for each service group, along with trends in support needs, as illustrated in Figures 4.2 and 4.3.

Changes between 1999–00 and 2000–01 are set out in Table 4.3, showing estimated increases in the numbers of people receiving services in 2000–01, compared to 1999–00. The estimates are based on adjusting MDS numbers in Table 4.2 with the ratios in Table 4.1. The estimated increases in people over the full year 2000–01 are:

- 180 in residential accommodation (including group homes);
- 740 in community-based accommodation support services;

- 2,350 in community services (includes individualised packages and local area coordination services); and
- 2,425 in community access services.

These numbers provide one estimate of the additional services provided by new funding in 2000–01, alongside the data in Chapter 3.

### **Trends in accommodation support services**

Between 1997 and 2001 there has been a net gain of about 1,800 accommodation support services received on the snapshot day (Table 4.2). This change comprises an increase of some 3,500 community-based accommodation support services (including group homes) offset by the loss of about 1,700 services received (essentially equivalent to places) in institutions, large residentials and hostels. These changes are in line with the national drive to move people out of larger establishments and into the community.

These trends have been fairly steady over the years 1997 to 2001, and the change between 2000 and 2001 is no more marked than any other year (Figure 4.1, Table 4.2). This is perhaps not surprising, given the trends in expenditure reported in Chapter 1 (Figure 1.1 and Tables 1.3, 1.4). Figure 1.1 illustrates that the ‘unmet needs’ funding of 2000–01 was coming into play in the context of rising funding in preceding years, largely related to all jurisdictions’ pre-existing recognition of unmet need as an issue.

A figure of interest in Table 4.2 is the growth from 3,336 in 1997 to 4,835 in 2001 in ‘outreach/other in-home/drop-in support’ service recipients. Using the conversion ratio derived from the Western Australian data (Table 4.1) the additional services can be calculated as an increase of 2,500 clients over the period.

There is also some evidence of slight increases in levels of need among recipients of accommodation services:

- the proportion needing ‘continual support’ in activities of daily living (self care, mobility and communication) increased from 43.3% in 1997 to 46.1% in 2001 (see Table A4.1 and Figure 4.2);
- the proportion needing continual support in home and social living areas increased from 56.5% in 1997 to 58.2% in 2001 (although the high was 61.0% in 2000) (Table A4.1 and Figure 4.2); and
- the proportion needing continual support in the life areas of education, work and leisure increased from 58.0% in 1997 to 64.7% in 2001 (Table A4.1 and Figure 4.2).

**Table 4.2: CSDA-funded services received, by service type, by year, on a snapshot day, Commonwealth, States and Territories, 1997–2001**

Service type	Services received <sup>(a)</sup>				
	1997	1998	1999 <sup>(b)</sup>	2000 <sup>(b)</sup>	2001
<b>STATE/TERRITORY</b>					
<b>Accommodation support</b>					
Institutions/large residentials	5,965	5,498	5,148	4,899	4,496
Hostels	1,224	873	878	781	985
<i>Sub-total institutional/large residentials and hostels</i>	<i>7,189</i>	<i>6,371</i>	<i>6,026</i>	<i>5,680</i>	<i>5,481</i>
Group homes	8,522	8,485	8,847	9,522	9,888
Attendant care	588	1,019	1,320	1,115	1,046
Outreach/other 'in-home'/drop-in support	3,336	4,050	4,235	4,466	4,835
Alternative family placement	67	120	121	114	172
Accommodation support: other/not stated	464	624	471	554	531
<i>Sub-total community accommodation and care</i>	<i>12,977</i>	<i>14,298</i>	<i>14,994</i>	<i>15,771</i>	<i>16,472</i>
<i>Total accommodation support</i>	<i>20,166</i>	<i>20,669</i>	<i>21,020</i>	<i>21,451</i>	<i>21,953</i>
<b>Community support</b>					
Early childhood intervention	1,741	2,024	2,235	2,180	2,350
Recreation/holiday programs	1,598	2,051	2,391	2,691	2,559
Therapy (PT OT ST)	2,644	2,832	2,816	3,304	3,622
Family/individual case practice/management	2,240	2,425	3,512	2,762	3,802
Behaviour/specialist intervention	485	564	657	692	946
Counselling: individual/family/group	203	218	277	338	425
Brokerage/direct funding/ind. supp. pack.	656	1,239	1,787	2,883	1,790
Mutual support/self-help groups	238	401	943	879	762
Resource teams/regional teams	1,414	1,610	1,857	1,906	1,557
Community support: other or not stated	474	572	443	602	873
<i>Total community support</i>	<i>11,693</i>	<i>13,936</i>	<i>16,918</i>	<i>18,237</i>	<i>18,686</i>
<b>Community access</b>					
Continuing education/ILT/adult training centre	7,776	3,998	4,326	4,197	8,495
Post-school options/social & comm. support/comm. access	1,978	7,523	8,311	8,287	4,735
Other community access and day programs	2,779	2,157	2,520	2,651	2,744
<i>Total community access</i>	<i>12,533</i>	<i>13,678</i>	<i>15,157</i>	<i>15,135</i>	<i>15,974</i>
<b>Respite</b>					
Own-home respite	366	437	566	373	319
Respite: centre/respite home	922	1,249	1,114	1,147	1,299
Respite: host family/peer support	133	332	392	241	318
Respite: other/flexible/combination	459	709	964	870	801
<i>Total respite</i>	<i>1,880</i>	<i>2,727</i>	<i>3,036</i>	<i>2,631</i>	<i>2,737</i>
Not stated	320	51	0	0	0
<b>Total State/Territory</b>	<b>46,592</b>	<b>51,061</b>	<b>56,131</b>	<b>57,454</b>	<b>59,350</b>

(continued)

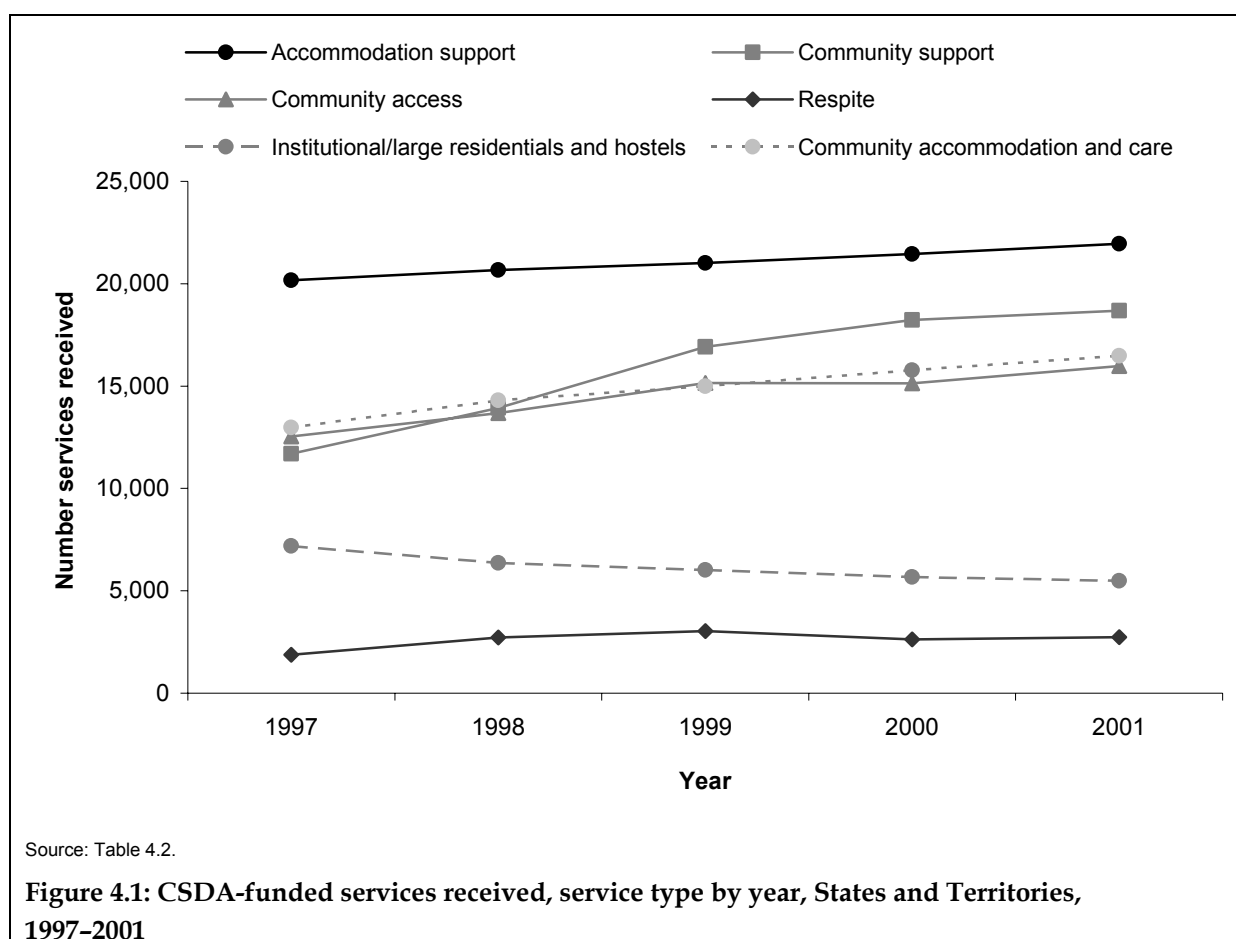
**Table 4.2 (continued): CSDA-funded services received, by service type, by year, on a snapshot day, Commonwealth, States and Territories, 1997–2001**

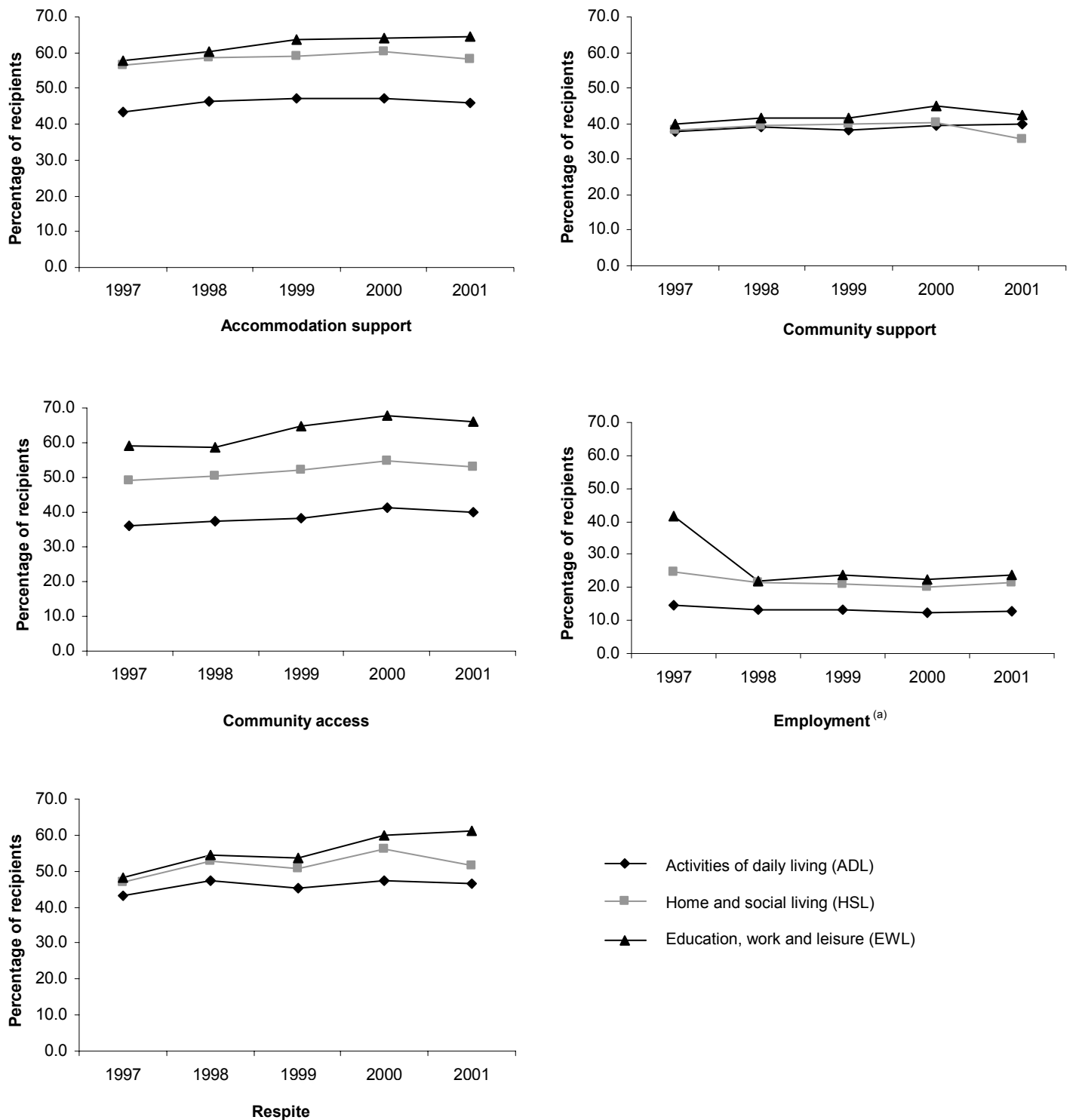
Service type	Services received <sup>(a)</sup>				
	1997	1998	1999 <sup>(b)</sup>	2000 <sup>(b)</sup>	2001
<b>COMMONWEALTH</b>					
<b>Employment</b>					
Open employment	4,541	4,453	3,994	4,286	4,605
Supported employment	12,906	12,883	12,808	11,472	11,502
Open and supported combined	393	658	997	1,717	1,748
Other employment	0	143	52	0	0
<i>Total employment</i>	<i>17,840</i>	<i>18,137</i>	<i>17,851</i>	<i>17,475</i>	<i>17,855</i>
<b>Total services</b>	<b>64,432</b>	<b>69,198</b>	<b>73,982</b>	<b>74,929</b>	<b>77,205</b>

(a) An individual may be counted more than once if more than one service type was accessed on the snapshot day. Consumer numbers, now available because of the introduction of the statistical linkage key, are available from 1999.

(b) Some figures for 1999 and 2000 differ from those previously published (AIHW 1999a, 2000a). This is due to (1) some corrections to service type notified by one jurisdiction for both years, and (2) the deletion of duplicate records for 1999, which were detected due to improved quality control made possible by the introduction of the statistical linkage key. The revised figures have been used in Tables 4.2 and 4.3 and Figures 4.2 and 4.3, but are not yet incorporated in Tables 4.4 and 4.5.

Note: Unmet need funding was not applied to employment services and they are not included in the analysis of effectiveness of this funding.

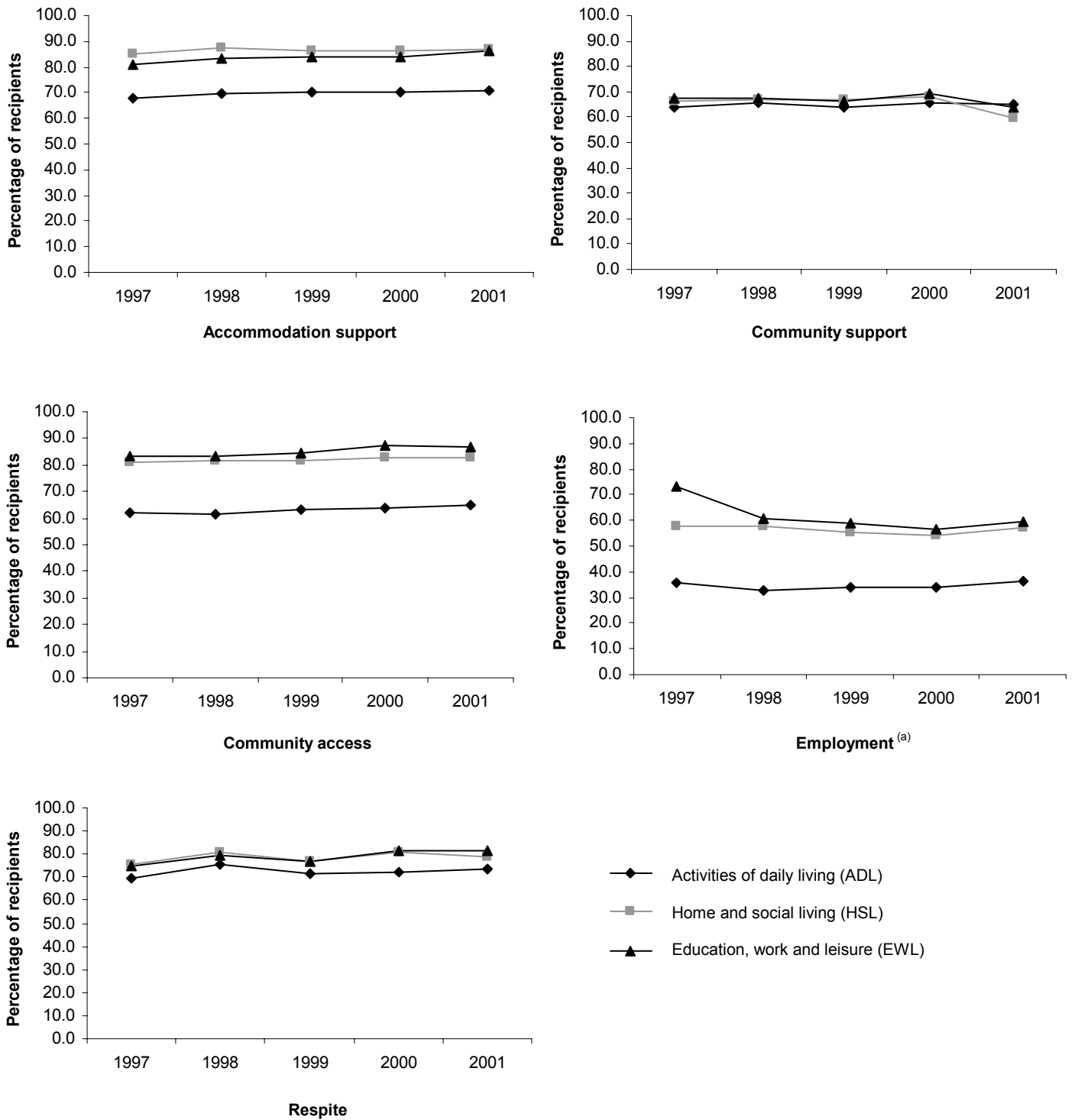




(a) In 1997 the Commonwealth removed the life domain of 'working' from the standard CSDA MDS support needs question and asked about support needs in the area of 'working' in a separate question. In 1998, the 'working' life domain was combined back into the standard CSDA MDS support needs question. Table A4.1 suggests that the varied question format in 1997 affected the responses provided by agencies.

Source: Table A4.1.

**Figure 4.2: Percentage of recipients needing continual support in the areas of activities of daily living (ADL), home and social living (HSL) and education, work and leisure (EWL) by service group, 1997–2001**



(a) In 1997 the Commonwealth removed the life domain of 'working' from the standard CSDA MDS support needs question and asked about support needs in the area of 'working' in a separate question. In 1998, the 'working' life domain was combined back into the standard CSDA MDS support needs question. Table A4.1 suggests that the varied question format in 1997 affected the responses provided by agencies.

Source: Table A4.1.

**Figure 4.3: Percentage of recipients needing continual or frequent support in the areas of activities of daily living (ADL), home and social living (HSL) and education, work and leisure (EWL) by service group, 1997-2001**

**Table 4.3: Estimates of effects of unmet need funding: additional services in 2000–01**

	<b>People in 2000–01: Estimates based on CSDA MDS snapshot data adjusted for full-year ratios <sup>(a)</sup></b>
<b>Accommodation &amp; respite</b>	180 residential accommodation (including group homes) 740 community-based accommodation support services (respite numbers not used)
<b>Community support services</b>	2,350 (includes individualised packages and local area coordination services)
<b>Community access</b>	2,425

(a) See Tables 4.1 and 4.2 for method of adjustment using Western Australia full-year data. The snapshot day respite numbers were not considered reliable enough to be adjusted for this purpose (being subject to high daily fluctuations).

### **Trends in community support services**

This service group has seen the largest increases over the years from 1997 – almost 7,000 services received – although the change from 2000 to 2001 is smaller than in previous years. This is the service group where local area coordination, brokerage and individual funding are recorded, and the pattern in these newer service types is interesting. Marked increases over these years have occurred in family and individual case management services received (from 2,240 in 1997 to 3,802 in 2001), and in the category ‘brokerage/direct funding/individual support package’ (from 656 in 1997 to 1,790 in 2001). Some instability in classification/distinction between these two groups is apparent (see the apparent ‘exchanges’ in the years 1999, 2000, 2001). Grouping these two categories together, in order to avoid this problem, it can be seen that little of the increase occurred in 2000–01.

Interestingly, therapy services received have also increased in number steadily over these years (from 2,644 to 3,622 services on the snapshot day in 2001). Behaviour/specialist interventions have also increased (from 485 in 1997 to 946 in 2001), particularly in 2000–01.

There is mixed evidence about trends in levels of need among recipients of community support services, with relatively small changes between 1997 and 2001.

### **Trends in community access services**

Over the years since 1997 there has been an increase of almost 3,500 in community access services received on the snapshot day (Table 4.2, Figure 4.1). There appears to be some ‘exchange’ of classification between the two main categories over these years (continuing education/Independent Living Training/adult training centre and post-school options/social & community support/community access), so working with the total number seems most useful. If we assume that there is a fixed number of ‘places’ and that the places are filled each day, we could further assume that the increased snapshot day count represents approximately the same number of new places, that is, 3,500. These ‘places’ are probably being used by more than 3,500 ‘new’ people, since many people may not receive full-time services (according to Table 4.1, the number of people in a full year may be three times the number of services on a snapshot day).

As with accommodation services, there is some evidence of modest increases in levels of need among recipients of community access services, with:

- growing proportions needing 'continual support' in activities of daily living (self care, mobility and communication) from 36.3% in 1997 to 39.9% in 2001 (see Table A4.1 and Figure 4.2);
- some growth in the proportion needing continual support in home living and social living areas, from 49.1% in 1997 to 53.3% in 2001 (Table A4.1 and Figure 4.2); and
- growing proportions needing continual support in the life areas of education, work and leisure, from 59.0% in 1997 to 66.3% in 2001 (Table A4.1 and Figure 4.2).

It is not known whether or not these possible trends in support needs are related to the ageing of CSDA clients.

### **Trends in respite services**

The number of respite services received on the snapshot day in 2001 was 2,737, in comparison with 1,880 in 1997, an increase of about 850 (Table 4.2 and Figure 4.1). Snapshot day numbers for respite services are considered perhaps the least reliable indicators of what occurs on a typical day or in a full year, because the weekly or monthly pattern of service provision is variable (for example, weekend services being common).

As with accommodation services, there is some evidence of modest increases in levels of need among recipients of respite services, with:

- growing proportions needing 'continual support' in activities of daily living (self care, mobility and communication) from 43.1% in 1997 to 46.4% in 2001 (see Table A4.1 and Figure 4.2);
- some growth in the proportion needing continual support in home living and social living areas, from 47.0% in 1997 to 51.4% in 2001 (Table A4.1 and Figure 4.2); and
- growing proportions needing continual support in the life areas of education, work and leisure, from 48.0% in 1997 to 61.1% in 2001 (Table A4.1 and Figure 4.2).

Recipients of respite services have aged in the years 1997 to 2001, in two ways. First, the median age of consumers rose from 21.3 in 1999 to 22.5 in 2001 (AIHW 2002). Second, there have been gradual increases in the proportion of recipients in all age groups 40 years and older (AIHW 200, Figure 3.6), consistent with the focus on ageing carers.

### **Employment services**

Employment services are the responsibility of the Commonwealth Government and were not the subject of bilateral negotiation or unmet need funding. Accordingly they are not included in the 'effectiveness' objective of this study. The data are included here for later reference.

## Trends in characteristics of service recipients

### Trends in service groups and living arrangements

The CSDA MDS collections include a question on the 'living arrangements' of clients, as an indication both of their housing arrangements but also as an indirect indicator of their potential in-home support. Trends are presented in Table 4.4 and are discussed separately for the various services types.

**Accommodation support:** Most people receiving CSDA accommodation support services (over 70% in 2001) lived in either 'disability community accommodation' such as group homes, or in 'other institutional accommodation'. This overall percentage has been fairly stable over the years since 1997, but with a change of emphasis towards community-based accommodation (see also Figure 4.1 above). Almost 10% lived alone and another 10% with families. These numbers are consistent with (but of course cannot prove) the possibility that resources have been directed to de-institutionalisation efforts and that there remains more scope for growth in less resource-intensive community-based and in-home support. (See also following section on de-institutionalisation.)

**Community support:** 72% of these service recipients lived with family, about 10% lived alone and another 10% in 'disability community accommodation'. The proportion of people living with families has tended to rise, related to a decrease in the proportion living in 'disability community' and 'institutional' accommodation.

**Community access:** About 43% of community access services on the snapshot day in 2001 were received by people who lived with family, and 36% by people living in 'disability community accommodation'. This confirms statements about the importance of community access services in supporting families as well as in offering activities to people with disabilities.

**Respite:** Not surprisingly, 81% of respite services received on the snapshot day in 2001 were received by people who lived with their family.

**Employment:** 60% of people receiving employment support on the snapshot day in 2001 lived with families, 16% lived alone (lower than in 1997) and 15% lived in 'disability community accommodation' (higher than in 1997). These numbers may indicate the importance of supportive living arrangements for people seeking work. They may also indicate an increasing focus on people with higher levels of support, in that those living alone tend to have lower levels of support (AIHW 2002, CSDA MDS report, Table 3.22).

There were very few people receiving CSDA services in 2001 living in aged care homes (less than 1% of recipients (Table 4.4).

**Table 4.4: Percentage of recipients in each living arrangement/accommodation type by service group on a snapshot day, 1997–2001**

<b>Service group</b>	<b>1997</b>	<b>1998</b>	<b>1999</b>	<b>2000</b>	<b>2001</b>
<b>Accommodation support</b>					
Lives alone	7.9	8.9	9.5	9.5	9.8
With family	9.0	9.3	10.2	10.1	10.0
Disability community	47.3	49.6	49.4	50.8	52.3
Other community	4.8	5.6	5.2	5.5	5.5
Aged care home	1.1	1.0	1.4	1.0	1.1
Hospital	0.9	0.7	1.3	0.7	0.5
Other institutional accommodation	28.9	24.9	22.8	22.4	20.7
No usual residence	0.0	0.0	0.1	0.0	0.1
<i>Total</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>
<b>Community support</b>					
Lives alone	9.1	8.7	9.6	8.9	9.6
With family	66.3	69.5	71.0	71.1	71.5
Disability community	13.7	12.4	10.9	11.0	10.4
Other community	2.7	2.9	2.8	3.2	3.2
Aged care home	0.7	1.3	1.2	0.9	0.9
Hospital	0.4	0.4	0.6	0.4	0.3
Other institutional accommodation	7.1	4.7	3.9	4.4	4.2
No usual residence	0.1	0.1	0.1	0.1	0.1
<i>Total</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>
<b>Community access</b>					
Lives alone	6.1	8.6	8.8	7.0	6.4
With family	38.7	40.7	41.4	41.6	43.0
Disability community	35.8	34.0	33.2	35.2	35.5
Other community	2.9	3.0	2.8	2.8	3.2
Aged care home	1.0	1.0	1.1	1.1	0.9
Hospital	0.4	0.6	0.5	0.4	0.4
Other institutional accommodation	15.2	12.1	12.1	12.0	10.6
No usual residence	0.1	0.1	0.1	0.0	0.0
<i>Total</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>
<b>Respite</b>					
Lives alone	5.8	4.4	4.2	4.9	6.2
With family	78.2	83.1	83.8	82.7	80.9
Disability community	10.1	7.9	7.0	8.0	7.3
Other community	2.7	1.7	1.5	2.3	2.1
Aged care home	0.4	0.9	0.6	0.3	0.6
Hospital	0.1	0.2	0.4	0.4	0.2
Other institutional accommodation	2.4	1.0	2.1	1.2	2.3
No usual residence	0.3	0.8	0.4	0.2	0.4
<i>Total</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>

(continued)

**Table 4.4 (continued): Percentage of recipients in each living arrangement/accommodation type by service group on a snapshot day, 1997–2001**

<b>Service group</b>	<b>1997</b>	<b>1998</b>	<b>1999</b>	<b>2000</b>	<b>2001</b>
<b>Employment</b>					
Lives alone	14.6	15.4	15.0	15.6	15.5
With family	58.1	59.3	59.1	58.9	60.0
Disability community	19.7	15.9	15.8	15.7	15.4
Other community	2.8	6.5	6.1	5.4	4.9
Aged care home	0.4	0.3	0.3	0.2	0.3
Hospital	0.2	0.1	0.1	0.2	0.1
Other institutional accommodation	4.3	2.5	3.7	3.9	3.8
No usual residence	0.1	0.1	0.1	0.1	0.0
<i>Total</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>
<b>All service groups</b>					
Lives alone	9.6	10.3	10.5	10.1	10.3
With family	40.9	43.7	45.2	45.1	45.7
Disability community	30.2	28.5	27.5	28.3	28.6
Other community	3.4	4.6	4.2	4.3	4.2
Aged care home	0.8	0.9	1.0	0.8	0.8
Hospital	0.5	0.4	0.7	0.4	0.3
Other institutional accommodation	14.6	11.4	10.9	10.9	10.1
No usual residence	0.1	0.1	0.1	0.1	0.1
<b>Total</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>
<i>Total number</i>	<i>63,488</i>	<i>67,748</i>	<i>72,185</i>	<i>73,421</i>	<i>75,679</i>

*Notes*

1. Percentages exclude recipients whose living arrangements were missing ('not stated' or 'not known'). Total numbers vary from totals in Table 4.2 because they exclude these missing data.
2. Percentages exclude 292 recipients in 1997 and 42 recipients in 1998 whose service group was missing.
3. Data provided by the Commonwealth are preliminary and cover less than 100% of Commonwealth-funded services.

### **Trends in the disability groups receiving CSDA services**

The CSDA MDS collections include a number of questions on the disability status of clients, including 'primary' disability group, 'presence of other disability' and the identification of 'other significant' disability group(s). When 'primary' and 'other significant' disability groups are combined, they are reported as 'all significant' disability groups. The trends for 'all significant' disability groups are presented in Table 4.5 and discussed separately for the various service groups.

**Accommodation support:** The category 'intellectual' disability was the most frequently reported disability group of people receiving CSDA accommodation support services (over 78% in 2001). This proportion has remained stable since 1997, decreasing only slightly from just over 80% in 1997. The majority of disability groups have remained somewhat stable since 1997, except for increased reporting of psychiatric disability (from 14% in 1997 to 20% in 2001) and neurological disability (18% in 1997 to 22% in 2001).

**Community support:** 'Intellectual' disability was again the most frequently reported disability group, for people receiving CSDA community support services. The proportion of people reporting 'intellectual' disability was significantly lower for community support services (53% in 2001) than for accommodation support services (78% in 2001). The proportions of people reporting having an intellectual disability, receiving community support has decreased from 59% in 1997 to 53% in 2001. People reporting 'physical'

disability were the next highest represented group receiving community support services (36% in 2001). Both 'autism' and 'psychiatric' disability groups experienced slight relative increases in proportions since 1997 (from 6% to 10% for autism, and from 7% to 10% for psychiatric). The proportion of people receiving CSDA community support services reporting 'vision' has decreased from 16% in 1997 to 11% in 2001.

**Community access:** 81% of people receiving CSDA community access services on the snapshot day in 2001 reported having an 'intellectual' disability, followed by 'physical' disability (29%) and 'speech' disability (26%). The proportion of most disability groups receiving community support services remained stable between 1997 to 2001, except for 'psychiatric' disability which increased from 11% to 17%, and 'autism' (from 5% to 9%).

**Respite:** As with all other CSDA service groups, 'intellectual' disability was once again reported as the most prevalent disability group for people receiving CSDA respite services (62% in 2001). This was followed by 'physical' disability, reported by 39% of people in 2001. The disability groups that have increased in proportion from 1997 to 2001 are 'acquired brain injury' (from 5% to 11%), 'neurological' disability (16% to 20%) and 'autism' (8% to 13%).

**Employment:** The proportion of people reporting 'intellectual' disability has decreased from 79% in 1997 to 74% in 2001, for people receiving CSDA employment services, yet remains as the most commonly reported disability group. The proportion of other disability groups has remained stable for the majority of disability groups, except for slight growths in 'psychiatric' disability (from 11% in 1997 to 15% in 2001), and 'specific learning/ADD' (from 2% in 1997 to 5% in 2001).

**Table 4.5: Percentage of recipients reporting all significant disability groups by service group on a snapshot day, 1997–2001**

<b>Service group</b>	<b>1997</b>	<b>1998</b>	<b>1999</b>	<b>2000</b>	<b>2001</b>
<b>Accommodation support</b>					
Developmental delay	0.2	0.2	0.2	0.2	0.1
Intellectual	80.5	78.6	78.5	79.1	78.4
Specific learning/ADD	1.7	1.9	2.3	1.6	1.9
Autism	4.1	5.5	6.1	7.0	7.0
Physical	33.1	32.0	34.7	35.2	33.4
ABI	4.7	5.0	4.9	5.2	6.1
Deafblind	0.8	1.0	1.0	1.1	1.2
Vision	12.1	10.2	10.8	11.1	11.0
Hearing	6.0	5.9	6.3	6.7	6.6
Speech	25.9	24.8	29.0	29.6	28.4
Psychiatric	14.3	16.2	18.4	18.4	20.1
Neurological	17.6	18.0	20.9	21.5	22.2
<b>Community support</b>					
Developmental delay	13.0	11.9	11.6	13.2	11.7
Intellectual	59.0	56.5	54.5	55.7	53.2
Specific learning/ADD	5.6	4.7	4.8	5.1	5.2
Autism	5.9	7.9	9.6	10.2	10.1
Physical	35.9	33.0	32.0	33.4	36.1
ABI	4.8	5.5	5.4	6.0	6.7
Deafblind	0.9	0.9	1.1	1.1	1.1
Vision	15.7	14.0	10.5	10.6	11.2
Hearing	4.6	4.3	4.3	4.0	4.1
Speech	24.1	22.1	21.1	24.0	22.3
Psychiatric	6.9	6.9	10.7	10.6	9.7
Neurological	16.9	13.9	14.5	16.4	17.9
<b>Community access</b>					
Developmental delay	0.1	0.0	0.0	0.0	0.0
Intellectual	82.6	77.8	78.1	81.6	81.4
Specific learning/ADD	1.4	1.6	2.2	2.1	2.4
Autism	5.4	6.9	7.1	7.7	8.5
Physical	30.3	26.9	30.4	30.3	29.2
ABI	3.4	3.4	4.2	4.2	5.1
Deafblind	0.9	1.3	1.1	1.0	1.0
Vision	14.7	13.9	14.2	12.6	11.9
Hearing	5.6	5.7	7.0	6.1	5.6
Speech	28.8	22.4	25.2	28.3	26.3
Psychiatric	11.4	14.8	16.7	17.8	17.0
Neurological	15.9	12.4	17.3	18.5	18.9

*(continued)*

**Table 4.5 (continued): Percentage of recipients reporting all significant disability groups by service group on a snapshot day, 1997–2001**

<b>Service group</b>	<b>1997</b>	<b>1998</b>	<b>1999</b>	<b>2000</b>	<b>2001</b>
<b>Respite</b>					
Developmental delay	2.5	2.7	2.3	2.8	1.5
Intellectual	62.0	67.5	62.8	62.4	61.6
Specific learning/ADD	3.7	4.5	4.6	5.0	5.0
Autism	8.0	12.4	12.6	14.3	12.5
Physical	41.5	38.2	37.6	41.8	39.0
ABI	5.4	5.4	5.7	7.7	11.1
Deafblind	1.4	1.4	1.0	1.5	1.3
Vision	12.7	9.9	9.9	12.0	11.9
Hearing	5.8	4.7	4.8	5.2	4.1
Speech	21.1	18.4	18.9	23.3	22.8
Psychiatric	7.9	5.3	7.3	8.8	9.4
Neurological	15.5	14.6	14.9	20.5	20.2
<b>Employment</b>					
Developmental delay	0.0	0.0	0.0	0.0	0.0
Intellectual	79.0	74.8	76.4	74.1	73.7
Specific learning/ADD	2.0	3.2	3.9	4.1	4.6
Autism	1.8	2.1	2.2	2.5	2.6
Physical	16.9	16.9	18.5	19.2	19.0
ABI	3.6	4.0	3.7	3.9	3.8
Deafblind	0.2	0.4	0.5	0.5	0.5
Vision	6.7	6.3	6.9	6.9	6.4
Hearing	3.9	3.4	4.0	3.9	3.9
Speech	8.4	7.7	9.2	8.6	8.9
Psychiatric	11.3	14.1	12.8	14.2	14.6
Neurological	7.8	5.8	8.1	7.4	7.2
<b>All service groups</b>					
Developmental delay	2.5	2.6	2.8	3.3	2.9
Intellectual	75.8	72.6	71.8	72.2	71.3
Specific learning/ADD	2.5	2.8	3.3	3.3	3.5
Autism	4.2	5.7	6.4	7.1	7.2
Physical	28.9	27.5	29.4	30.3	30.1
ABI	4.2	4.5	4.6	5.0	5.7
Deafblind	0.7	0.9	0.9	1.0	0.9
Vision	11.7	10.7	10.5	10.3	10.2
Hearing	5.1	4.8	5.4	5.2	5.1
Speech	21.1	19.1	21.3	22.9	21.8
Psychiatric	11.3	13.1	14.5	15.1	15.3
Neurological	14.5	12.7	15.4	16.4	16.9

**Notes**

1. Percentages are based on all significant disability groups reported, that is, primary disability groups and 'other significant' disability groups. These percentages add to more than 100% because a recipient may be counted in more than one disability group.
2. Percentages exclude recipients whose disability group was not stated.
3. Percentages exclude 292 recipients in 1997 and 42 recipients in 1998 whose service group was missing.
4. Data provided by the Commonwealth are preliminary and cover less than 100% of Commonwealth-funded services.

### **4.3 In what other ways has the level of unmet need been reduced?**

The reduction of unmet need was perhaps the key and over-arching objective of the unmet need funding. The provision of 'additional services', discussed in the previous section and in Chapter 3, was one of the key methods of delivering on this objective and was itself reflected in the Bilateral Agreements.

This section will briefly discuss other ways in which unmet need has been addressed by the funding, drawing on information provided by the jurisdictions in response to the study questionnaire. Needs can be 'unmet' because appropriate service models do not exist, the service mix is historically based rather than suited to current needs, or because the quality of services means that only part of a person's overall needs are recognised. Further, government administrations may recognise that assessment and allocation processes are not efficiently or effectively detecting and deciding on which needs to meet. There is evidence that all these approaches to unmet needs have been taken.

#### **Innovative programs and their evaluations**

The Jurisdiction Survey for States/Territories (Q2, Appendix 2a) asked jurisdictions for information about:

- innovative services or projects undertaken with the unmet need funding;
- evaluations or relevant literature to indicate the effectiveness of these or similar services; and
- information on jurisdiction-specific cost factors – see Chapter 3.

All jurisdictions have established new programs and new methods of allocating funding during the recent years of growth and in particular during 2000–01. The study team received a large amount of information about policies, plans, new programs and allocation methods. It is not possible to summarise all this material in detail, and examples will be provided to illustrate the following overall picture (see also Section 3.4 for further detail).

#### **Overall picture**

There is strong evidence that all jurisdictions are taking very seriously the responsibility to:

- respond to the community's desire for more flexible funding arrangements;
- develop a range of new service responses capable of responding to high and complex support needs, while also making assistance available to people with lower levels of need;
- develop service responses specifically addressing the needs of ageing carers;
- continue the national de-institutionalisation effort, in terms of shifting resources towards community accommodation options;
- develop regionally and locally responsive coordinating mechanisms; and
- improve administrative infrastructure for the allocation of funds.

There is also evidence that these initiatives are, in many instances, informed by:

- investigation of successful models and methods in other Australian jurisdictions or in the literature; and
- community consultation;

and are:

- subject to business or other planning processes; and
- open to review and evaluation of some kind.

The following examples illustrate this overall picture.

### **New South Wales**

New South Wales commenced a major new initiative in September 2000, with its Service Access System, designed to provide more flexible packages in the following way. The target group is people with identified risk factors who have been unable to obtain suitable supports when attempting to access services under the existing disability services program. These people are referred to 'support planners' to help them develop a suitable package of supports from across the CSDA range. New South Wales reported that 35% of recipients of these packages had ageing carers (see Chapter 3).

A Local Support Coordination program and an Early Childhood Intervention program were also introduced in 2001, based on Western Australian and Queensland models.

Other services further developed using New South Wales growth funding (indistinguishable from unmet needs funding) include:

- Attendant care;
- ATLAS and day programs generally; and
- Special initiatives relating to institutional 'devolution', crisis support and accommodation, boarding house relocation.

### **Victoria**

Victoria has developed several new programs to address various (published) policy and funding priorities:

- HomeFirst is described as an 'alternative, proactive and lower cost service response to shared supported accommodation' and was introduced in 2000-01.
- Flexible respite options have been introduced to 'enhance/maintain existing care arrangements and delay or avoid higher cost services'; this initiative is relevant to the agreed policy priority on ageing carers.
- 'Lower cost and one-off' packages have been introduced within the Making a Difference program.
- Rural Access has been introduced 'to build and strengthen the community's capacity to provide support for people with disability and their families ...'.

A number of evaluations of these programs are in process.

Another recent initiative, Futures for Young Adults, is also being evaluated. In its questionnaire response, Victoria noted that the evaluation has found that the 'program was well regarded by participants, with each young person obtaining the post-school option of their choice'.

### **Queensland**

Queensland reports that its unmet need funding was used to build on and enhance existing programs, following their recent development with the State's own growth funding. These

programs were developed after 'extensive interstate and international research', and include:

- Local Area Coordination where previous pilots have now been consolidated into a recurrent program;
- the Family Support Program offering flexible support to families; and
- individualised services offered in the Adult Lifestyle Packages and the Post School Options Program.

Funds to support ageing carers were predominantly expended through the Adult Lifestyle Support Program. Funds have also been allocated to assist non-government organisations to support residents moving from institutionalised accommodation to community based living. A service development program has also provided funds for issues related to service infrastructure and viability.

### **Western Australia**

Western Australia has been the pioneer of the local area coordination model, now adopted and adapted in several jurisdictions. Recent developments are focusing on several of the other areas highlighted above in the overall picture, with specific initiatives being:

- a new Combined Application Process;
- Family Support and Respite: Flexible Family Support;
- Family Support and Respite: Intensive Family Support.

Ageing carers were predominantly supported through Family Support and Respite services. The Flexible Family Support program is undergoing evaluation. Development processes in WA are guided by the Disability Services Commission Board consisting of nine members, at least five of whom either have a disability, have a relative with a disability, or have recent experience as a carer or advocate.

### **South Australia**

Commonwealth funding was provided to the five lead Options Coordination Agencies to purchase respite services for ageing carers (usually by developing individual care packages). State funding was provided to young carers for respite, with individual packages, supported accommodation, day options, early intervention and equipment.

### **Tasmania**

Tasmania has established the Individual Options Project which is described as 'an innovative individualised funding program consistent with the national movement towards a more client-focused approach to assessment and service delivery'. The Individual Options Program assists people with disabilities to identify their support needs, negotiate their own contracts of service delivery with service providers and monitor service standards on an ongoing basis. Funding is fully portable and clients can move from one provider to another within agreed guidelines. The program covers a wide range of support services including personal support, day support, respite and equipment. Currently approximately 320 people receive individual packages with the average allocation being \$8,400. The Tasmanian response noted that the program has been 'well received by clients, families, service providers and advocates' and has 'empowered clients to maximise choice and control'.

## **Australian Capital Territory**

The Territory's growth funding has gone to initiatives such as the Post School Options program and therapy services for children. A service improvement scheme has involved assessing quality of service provision against the Disability Service Standards.

A pilot Mature Carers Program assists individuals and families to plan proactively for the time when current support arrangements become untenable. Three agencies are involved and should be providing new services, such as accommodation support and respite, according to these plans in 2002.

## **Northern Territory**

The Unmet Needs process in 2000-01 highlighted the need for further policy and service development in the areas of:

- early childhood intervention
- post-school options
- respite
- remote area services
- accommodation support.

The unmet need funding enabled the introduction of a Local Area Coordination model across the Northern Territory, based on the model of Local Area Coordination in Western Australia.

The unmet need funding was also instrumental in the implementation of the Northern Territory consumer-focused funding model. This model aims to provide consumers with more choice and control over their own care and support needs by the provision of individualised support packages of funds. The Local Area Coordinators played a key role in the provision of individualised support packages to consumers via the development of Individual Lifestyle Options Plans.

In one remote community in central Australia, some individuals received individualised funding through the 2000-01 Unmet Need funding round. These funds were used to part-employ a support worker and provide respite care. Funding for the support worker is met through a three-way agreement between the Department of Health and Community Services, Community Development Employment Program (CDEP) and Catholic Education. According to the Department:

This innovative approach to funding and the development of services in remote areas has produced positive outcomes including:

- improvements in behaviour management;
- increases in school attendance;
- improvements in community acceptance, e.g., the community no longer want children with challenging behaviours removed from the community;
- prevention of the removal of several people with challenging behaviours from their community and consequently avoiding the need for long-term supported accommodation or other long-term, high-support needs services (Northern Territory Survey response, page 12).

No formal evaluations of these quite recent initiatives have yet taken place.

## **4.4 Effectiveness of new funding: views from the peak discussions**

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

This section summarises the key issues raised and discussed in relation to 'effectiveness'. (Material from these discussions relating to 'unmet need' is contained in Chapter 7.)

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

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

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

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

Outside of the discussion sessions, a number of service providers and carers took the time and effort to provide the study team with further information relating to the numbers and effectiveness of new services. For example, one service provider identified and listed the service types and program areas that, they understood, had attracted or benefited from unmet needs funding.

### **Rollout, spread and allocation**

#### **How identifiable was the unmet need funding?**

One of the challenges for the discussion with the peak groups was the degree of uncertainty about whether developments and new services in 2000–01 had relied on 'unmet need' funding or 'growth funding'. This issue generally had to be resolved by keeping the discussion focused on new developments in 2000–01 and assuming that the 'effectiveness' (or otherwise) of these new developments and services established probable effectiveness (or otherwise) of unmet need funding. New developments for 'ageing carers' were generally assumed to be related to unmet need funding.

In at least one jurisdiction, however, there was uncertainty amongst participants as to the recurrent nature of the unmet needs funding, and whether it was available for forward funding. These participants had the impression that the funding had been directed to non-recurrent expenditure (such as various quality improvements and de-institutionalisation efforts) rather than taking on new clients for whom future funding was uncertain.

### Processes

There was considerable variation among jurisdictions in the processes used to allocate new funding in 2000–01.

Advertisements targeted agencies in some cases. Some jurisdictions then took a great deal of time to bring the funding on stream (for instance, over six months). Where much of the unmet need funding had been directed to agencies there was a perception that ‘the new money went to service providers and staff, not to clients’. There were also instances cited where some agencies and programs were slow in starting up new services for new clients, after receiving funding. Yet another story concerned an agency who was asked (by the funding department) not to advertise new services as the department considered there was such unmet need that the agency would be ‘knocked over in the rush’; it was asked to do something about the people with unmet needs of whom it was already aware.

Despite this, the study team heard about specific examples where agencies given significant funding boosts were able to bring services to large numbers of new clients (see, for instance, Box 4.1).

#### **Box 4.1: Success stories with allocating funding through agencies**

*1. One service provider received funding for a respite coordination model. The agency reached a lot of new people, who had not been accessing the service system at all, by advertising through GPs, community centres, etc. Families wanted to know what was available and then be linked in (and to avoid multiple assessments). A single support plan is prepared, to reduce the number of times the person and their family need to be assessed. The agency has far exceeded its targets for ageing carers; the target was 25 families in the first 6 months; it assisted 46 families in this period, and a total of 68 families in 8 months since set-up.*

*2. Additional funding has enabled one employment agency to take 140 people (of a total of 150) off their waiting list and into the open employment service. Many of these people are now in employment. This is in addition to 16 extra people from growth funds. (This funding was actually provided under the Commonwealth’s Case Based Funding trial; while it was not part of the unmet needs funding, it was considered to illustrate the benefits of devolving some responsibilities to agencies.)*

Other jurisdictions, focusing on individual funding strategies, advertised for applications from individuals.

There were positive views that, despite its ‘warts’, the process of advertising for individual funding in one jurisdiction is ‘better and fairer than it was ... it used to be who you knew and how articulate you were’. In another jurisdiction it was pointed out that the needs register provides information on ‘the minimum number of people requiring assistance’ and this is of value.

While many people favour the individualised funding approach, the study team did hear stories of dissatisfaction about the process of application and allocation. Families may, for instance, underestimate the amount of care needed, especially when they have been providing care for a long time.

The registration process could be a laborious and even painful process for many people (see Box 4.2 for case stories). Many families have constructed their lives around the paradigm of the person with a disability being a loved and valued member of the family. These people had to force themselves to reveal private information and to portray a loved family member as a 'burden'. They then found the rejection of their application all the more disturbing and difficult to accept.

**Box 4.2: The painful process of application: weakening positive paradigms**

*1. During the registration process for an individual package, a mother recalls completing the forms on her own at home. The process of completing the forms forced her to look at her child with a disability in a different way. She had to describe her child as being a burden to her, and she felt a sense of betraying her son in putting his private and sensitive information into the public forum. There was no support from the funding department in completing the forms and the mother 'felt abandoned' with the process illustrating the 'vulnerability of families'.*

*2. In one rural area, a group of 20 people got together to complete the registration form and to provide support to each other while doing so. Of these 20 people, only six managed to complete the forms and send them to the department. The group also required four subsequent sessions to debrief and to overcome the trauma of exposing individual situations and those of their families. The registration process was made worse when some of the group received rejection letters with no acknowledgment of unmet need.*

The decision making could be very impersonal and was seen by some as arriving at 'wrong' decisions. In one jurisdiction people applied and decisions were made by a panel, with no reference to the local area coordinator; it was believed that people with lower literacy skills and high needs missed out, particularly Indigenous people in remote communities. This view was echoed in another form. It was recognised that assessment is complex and, in a service field so diverse, assessment tools can rapidly become cumbersome and repetitive. Related to this was concern expressed by a panel member in one jurisdiction that criteria and guidelines could be 'too rigid' and that some panels regretted the people they had to reject in favour of some who more closely met the criteria. There was a view among some participants that an overly impersonal application process could not work, and that a service provider (for example, a local area coordinator) should assist in developing ideas about supports, after getting to know the person and any related family and support network. This can result in a more effective and sometimes less costly solution (Box 4.3).

The topic of assessment was raised by participants at all discussion groups. While consumers and carers were often concerned that multiple assessments (for various CSDA service types) are intrusive and time consuming, they recognised the potential threat of introducing standardised assessment across the disability sector. That is, standardised assessment across this complex field may not meet all individuals' needs and may exacerbate their belief that individuals are often being forced into service boxes that do not meet their needs. In other words, the issue of assessment is perceived as a 'double-edged sword'.

#### **Box 4.3: Working together towards less costly solutions (and not)**

1. A child with high support needs and incontinence required a lot of attention and assistance from his parents. The family washing machine broke and there was great difficulty keeping up with the child's washing. The pile of soiled clothes requiring washing grew. The family was able to receive in-home respite, but the respite worker was not willing or allowed to do the family's washing, and the family went into a crisis situation. The family asked the respite service for a new washing machine. The service advised the family that it did not provide that type of support, and continued to offer the family 10 hours of respite per week rather than a washing machine.

2. A family was in a crisis situation. The service provider did not know how best to support the family's complex needs or which of several possible services to offer. The agency admitted this to the family, and offered to start by cleaning the family's house. This made a dramatic change to the family's situation, as it provided clear evidence of the service's desire to support the family. This action seemed immediately to reduce the stress on the family and its overall need for service. The support and the changed situation which resulted provided a basis for further dialogue.

#### **Leadership and balance**

Jurisdictions differed in the extent to which they had been seen to 'lead' the development and spread of new services and the degree to which they had relied more heavily on a submission-based model. There were positives and negatives of both approaches reported to the study team.

One view was that the submission process (after advertising to agencies and individuals) had to be balanced by leadership from government. Not all new initiatives should come from the non-government sector. Not all new initiatives need new funding and vice versa: not all new funding has to go to new initiatives, but could go to existing services to help them expand. There was also concern that, without some overall plan, service infrastructure could be whittled away, and people and brokers might actually have trouble finding the services they wanted to buy with their packages.

Some service providers are questioning whether brokerage has been pushed beyond its capacity to be meaningful. Service provision should be made flexible by brokerage, but when there are no services to buy, it fails as a service model. Recently innovation in service delivery has come from brokers, therefore providers tend to stay with what they are doing and do not feel the need to innovate. Purchasing has been shifted from a government responsibility to brokers.

In another jurisdiction, where new service models had been developed by government, there was considerable recognition and appreciation of these models and the new services emanating from them.

#### **More effective use of funding – and carers**

The value of informal care was a recurring theme at all discussions, and the costs of not adequately supporting carers were illustrated in various case stories (see Box 4.4).

#### **Box 4.4: The costs of not supporting carers**

1. According to one participant's calculation, it would cost \$2,600 per week (with penalties) on the Social and Community Services Award to replace a mother's care of her two sons. This equates to employing 4.5 full-time workers.

2. A young person with quadriplegia and high functional support needs has a job but requires 3 hours of support a day, for instance to help him out of bed in the morning. As the individual could not get this support, the person's mother quit her job and left her community to live with him, to provide the support required. In the time taken to get this support the individual lost his job. For 21 hours of support per week, two people became unemployed. 'People may have high support needs, but may not need a lot of support...'

Economies of scale were suggested as a possible way of obtaining more value from the funding dollar. There was a concern expressed by some carers and clients that too many service providers are funded for too little, and that there has been a proliferation of programs and providers. That is, there could be some economies in funding larger services. (The down-side of the possible lack of flexibility and choice this might bring was recognised.)

Different cost structures for government and non-government services were recounted as an example of potentially more effective use of funding. One service provider noted that clients with complex needs, associated with psychiatric disability and challenging behaviours, can be managed with fewer staff when managed with a *consistent support model*. This provider gave the example of a situation where one client had previously had three staff allocated to them and five staff at 'handover time', but could now be managed safely with a 1:1, staff:client ratio in the non-government service.

#### **Geographic inequity**

The unequal access to services among different regions was of concern to a number of participants. One family who moved house to another local government area in the one State found that they were eligible for 2.5 hours of support, where previously they had been receiving 15 hours per week

Eligibility itself can vary, from region to region. This means that families in which someone has a disability are unable to move around the State or country. This is particularly difficult for people with mobile jobs but also very difficult for people who would, for example, like to move back to their home State but cannot risk losing access to services.

#### **Effectiveness: 'additional services' for new and existing clients**

Typical of the perhaps cautious recognition and appreciation of the new services available was the comment of one service provider that he '*now felt more confident that there was a chance of some assistance in areas where there was virtually none*'.

It is recognised that there are new places in a range of programs and that new people are accessing flexible packages of services.

Nevertheless in all discussions there was still some concern expressed that the system was still crisis driven. In one jurisdiction it was stated by a panel member that only people in 'horrendous circumstances' were receiving new services.

And it was firmly stated that the unmet need situation could not be seen to be a thing of the past until 'we have planned transitions at each major stage of the life cycle'.

### **Effectiveness: stories of successful outcomes for clients**

A range of examples was given in the discussions about the effective use of new funding (whether growth or unmet need funding) and the positive difference that support services made to people's lives. Typical case stories best illustrate these positive outcomes, and these follow immediately. It was repeatedly pointed out that positive outcomes did not always involve expensive solutions, and that the best results were achieved when people themselves were truly involved in planning their lives.

### **Ageing carers: a range of positive outcomes but with a sobering message ...**

Discussion participants spoke of positive outcomes for ageing carers, via the provision of either out-of-home or in-home accommodation or respite support. However, there were also stories of carers who had been providing full-time support to a family member for decades, with little hope of receiving formal assistance (see Box 4.5 and also Box 4.1).

#### **Box 4.5: Positive outcomes for ageing carers ...**

*1. One project funded with unmet needs funding targeted four clients with ageing carers. While a house was being built for them, the agency worked with the families in providing recreation services, etc. The four clients elected to do a lot of activities as a group. The idea was that the agency would provide support to the families during the transition from home to group home. However it became clear that the families and the clients did not want in-home support, they wanted a permanent out-of-home solution. Hence, when the house was ready, all of the clients moved in straight away. Overall the program was viewed as a success, with the major lesson learned that more consultation with the families early on would have revealed the exact nature of the service they were seeking.*

*2. Funding was used successfully to support a young person with intellectual disability – initially supporting the person to stay living with his grandmother who was terminally ill. Support was progressively increased and funding then used to continue to support the person to stay in his grandmother's house after she died. The independent living skill focus of this initiative suited this situation (although it may not suit all).*

#### **... but with a sobering message**

*3. Two mothers in rural areas (over 80 years of age) had been caring for their sons with quadriplegia for many years. Both sons are now receiving support packages. One mother said 'Now I can die' because her son is now being provided for.*

### **Respite: some positive stories and the balancing views**

There were positive stories about the benefits of new respite programs and flexible packages (Box 4.6). However, the positive accounts of new respite services were balanced by stories of families receiving respite services that did not really meet their needs. For example, in-home respite when they really needed out-of-home respite, 'recreation' support at times that do not suit the carer, respite of insufficient duration to enable the family to have a real break.

#### **Box 4.6: Outcomes of new respite initiatives**

*1. One peak body has had a significant number of reports from families who have benefited from a new respite initiative using unmet needs funding. For example, one group of isolated rural families with adult sons/daughters was funded for the young people to go away together for a weekend holiday at the beach with familiar workers. 'They had a wonderful time doing things that they haven't done before or don't do often.'*

#### **Box 4.6 (continued): Outcomes of new respite initiatives**

2. By combining elements of two different funding programs, a family was able to develop a flexible respite package that suited its needs. A one-week residential respite placement was arranged for the young man with intellectual disability while his mother was supported in purchasing an airfare to fly to another city to visit her new (first) grandchild. This package was particularly successful as the family had previously been reluctant to use respite due to cultural values, background and the young man's voiced opposition. Unfortunately, subsequent program guidelines have excluded airfares as part of such flexible respite packages.

#### **Flexible packages: value and cost effectiveness**

Discussion participants spoke of the life-changing impacts of individual packages (Box 4.7). The most favoured types of individual package appeared to be those that were flexible and allowed families maximum autonomy in selecting appropriate services (Box 4.8). Such flexible approaches often resulted in cost-effective solutions (Box 4.9).

#### **Box 4.7: Positive stories of individual packages**

1. A young male with various disabilities, having lived in 18 foster homes as a child, now receives a package of 10 hours of support per week from unmet need funding (as well as funding through a post-school option program), enabling him to live in his own home. In doing so, his behaviour has stabilised and he has a sense of security for the first time in his life. He has obtained employment, is studying and has an active social life.

2. One service provider wrote of a man in his 60s living with his mother. Until he recently received a very small flexible support package of 11 hours per week, **he had not left his home for 5 years**. His elderly mother has a chronic illness and, prior to receiving the support package, the two of them would often spend days in bed without any support. This man now attends a respite centre once a week, goes out on a community activity once a week and receives weekday support in his own home. This minimal amount of support has significantly improved the quality of life for both the man and his elderly mother.

3. A woman who received a flexible support package was finally able to move from a permanent respite situation into her own home (prior to 'permanent' respite, she spent many years in an institution). 'I can't even begin to explain the positive impact of this on her life. She is in her 50s and for the first time in her life she feels she is in control of her life.' Examples of changes are that the woman now works and attends TAFE, controls what she eats, what she wears and where she goes. The woman believes that her life has turned around completely.

#### **Box 4.8: Positive stories of highly flexible individual packages**

1. A family with three children with disabilities needed respite after 'burn-out' and exhaustion. This was found to be related to features of the house design that required constant vigilance on their part to save the children from serious injury. Home modifications solved a number of problems. In the second year of service the family has been able to **plan**, and to 'picture a real life', and their need for respite has been reduced.

2. An individual receiving a package through a state government organisation managed to negotiate some assistance from an employment agency to help support her in unpaid work experience. The two agencies, working together, were able to identify and arrange paid work options for the individual, who was now at the job search stage and ready to enter the workforce. In doing this, the individual has been able to sort out other areas of her life.

3. One family has benefited from the flexible way in which they have been able to use their funding to directly employ a support worker – obtaining best value for money. This has enabled one parent to continue in the workforce; significantly improved the quality of the marriage; and allowed the parents to go on their first holiday in 10 years, while the support worker looked after the child through a flexible family respite option.

**Box 4.9: A positive story of a flexible and cost-effective individual package**

*One funding package enabled a person with a disability to access holiday accommodation for respite purposes. The place accommodated six people, at no extra cost. The result was that a total of two carers and four people with disabilities had a real holiday, for the cost of respite for one person. This outcome maximised the benefits of funding usage and supported a greater number of people in need.*

Positive accounts were balanced by stories of lack of flexibility in some individual packages (Box 4.10). Similarly it was said that some 'respite' services are in fact recreation services and only available at fixed times, not when a break might most suit the person concerned or the carer.

**Box 4.10: 'Flexible' packages that are not flexible enough**

*1. In one sole parent family where there are two young adults with disabilities the younger became eligible for a particular package but the elder was not, as the type of package did not exist when she finished school. The mother is required to ensure that all the funding goes to support the younger adult, even though her view is that the family as a whole would function better if she could make more flexible use of the support, and sometimes include her daughter in the arrangements.*

*2. If a service user receiving support through block funding of a service type leaves a town or the area, the funding does not go with them. Packages do not always overcome this problem.*

**Local area coordination and brokerage: value and cost effectiveness**

The value of local area coordination, case management and brokerage approaches was also raised by discussion participants. As with individual funding packages, these approaches are often viewed as producing cost-effective outcomes for families (Box 4.11).

**Box 4.11: Positive stories of local area coordination, case management and brokerage**

*1. A mother (75+ years old) lived together with her disabled son (late 40s), with no extended family and received no services. The mother became seriously ill, was admitted to hospital and soon died. During this time the son had engaged a broker, one of whose roles ended up being to keep the assessors, disability specialists and occupational therapist out of his life, as the man's wish was to resist the pressure to be in the specialist system. Now (2.5 years later) the man is still living alone in his family home, and working within the community on a volunteer basis, helping people and working in an area he is familiar with. The outcome in the case involved minimal cost to the government, and high satisfaction for the individual. If the specialist system had been allowed to take over the individual's life, the cost could have been significant.*

*2. A baby was born with severe disabilities into an Indigenous community in remote Australia and was taken to hospital, originally not expected to live. The baby and her family were subsequently helped over a number of hurdles and challenges, to get her home and accepted into the community. The family received 5–6 visits from a LAC worker, who over that time noticed a marked change in the attitudes of the people within the community. When the community saw that, through the use of LAC emergency funds, the child was able to remain at home, they rallied around to help. The LAC support given to the child meant that she could live a 'normal' life and did not require extra services. This one case opened the door for other children with disabilities, in similar situations, to move back into the community – there was a demonstration effect for other individuals and communities.*

*3. A mother and her disabled son were living together in the family home until she fell ill and went to hospital. With support, the son remained in the family home, and has been able to remain there after his mother's death. With ongoing help from a support worker he has, for two years, been renting some of the rooms out to other people within the community. The cost to the government in this case has been 'minimal', the person with the disability has remained within the community and has maintained his community networks.*

## **Effectiveness: ‘doing human things well’**

One of the participants at the peak discussions said that delivering good disability support services ‘is not rocket science; it’s about doing human things well’. This statement captured a theme of the discussions on effectiveness, namely that almost any service type could work well or badly, depending on the management of the service and the staff interacting with clients. Services were very highly regarded when they respected people as individuals, consulted about key matters such as staffing, timing and nature of services and negotiated with clients and carers about key personal needs and wishes. Services where people were treated as routine tasks to be done were viewed negatively, with emotions ranging through pain, anger, frustration and scorn.

Thus, while efforts to develop new service types are appreciated, and the move towards more person-centred services welcomed, there is a perception, in some quarters at least, that effort would be better directed to improving service quality and standards, in particular service management and, in turn, service staffing.

## **Quality, flexibility and types of services**

One participant argued that it is the wrong question to focus on what service types people need. The real question should be ‘what support do people need to live satisfying lives? Society needs to realise that this is everyone’s problem. Disability is an inevitable part of life and humanness. Investment in people with disabilities is the responsibility of all of us’.

This comment related to a range of issues, one of which is the capacity of the disability sector to provide truly flexible packages to meet individual needs. As previously stated (above, under ‘Leadership and balance’) advantages and disadvantages were reported in both flexible packages and in more specified programs. Examples of participants’ concerns regarding the provision of fixed service type approaches are included in Box 4.12.

### **Box 4.12: The limitations of in-home respite, according to peak discussions**

- 1. ‘Ideology’ appears to some people to be promoting in-home respite over centre-based respite, and in-home care over residential options such as group homes or cluster housing. This means that carers may be supported, but are never relieved of the care, irrespective of their age.*
- 2. The move to in-home respite means the support worker comes into the home, is fed, uses the utilities, bed etc., which is all paid for by the carer or the family, while the carer has to leave the house in order to capitalise on the respite.*
- 3. By focusing on in-home support, staff impact increasingly on the family home – ‘workers intrude in my space’ – and carers cannot choose ‘just to veg out’ in their own homes as a form of break.*

Individualised funding is often seen as the solution to individuals’ service needs, rather than the provision of flexible, innovative service types and service delivery practices. It was said that many service users are pushing for individual funding packages because they have given up hope that the service system can be adapted to meet their needs by service providers. If services were responsive and/or reflective of the service users’ desires, the demand for individual funding would be reduced.

However it was noted that individual funding is ‘good if there are enough dollars’. If there are not, some services ‘top up’ funding from block grants. For example, brokerage services that deal with respite ‘were said to often cobble together packages from a range of sources’

including CSDA and HACC. This typifies the 'keeping the ship afloat' service model where, in order to get appropriate and flexible services for service users, service providers stitch together services from across and outside the field. It is often the case that carers will search together with brokers for appropriate services, and may give up because of the inflexibility of the service system.

In making service provision more flexible for individuals, governments need to ensure that non-government organisations remain viable and infrastructure is supported. It was suggested that an accommodation service that is half funded by the government is still required to pay full rent, electricity etc. even when service users leave their service and take their funding with them – this affects service viability. Further, it was noted that the flexibility/creativity of brokerage must be traded off against the increased coordination costs of providing these services. Some participants felt that administration costs have reduced the amount of money available for direct service provision (particularly when services are sub-contracted a number of times).

### **Staffing**

Positive examples were given of workers who were highly appreciated – again, people who established good relations with their clients and who worked with them to provide services that were wanted and needed. A number of the success stories recounted above clearly had, as a critical element, a thoughtful, creative and caring service provider.

Nevertheless, the study team heard a number of complaints from consumers and carers about the poor skill level of workers in the disability services sector. Examples included staff treating carers as if their views are not important (when they consider themselves to have a great deal of expertise), not consulting adequately with carers, insisting on providing what they think is needed, or not arriving for work consistently or on time. As one carer summed up: 'A whole barrage of ignorant women come into my home, each with their own ideas about how to manage a 22-year-old with the mind of an 8-year-old'.

A service provider noted that there is a shortage of trained staff in this sector, across the country. This relates to a number of factors including:

- the increase in funding to the sector in the context of a limited and relatively static pool of workers;
- the fact that government employees earn 23% more on average than non-government employees;
- the nature of home-based services where employees are reluctant to work the required 1-2 hour shifts, the travel time involved and the need to keep 'moving on' throughout the day; and
- the lack of career structure for workers who are successful and appreciated.

In this context, examples of poor practice were given to the study team: respite staff arriving late, causing carers to have to cancel important appointments scheduled for their brief break; families' rights to privacy not being respected, with family details being shared among unrelated staff; new staff arriving with their own fixed ideas about what might constitute a treat, when the person with the disability had hoped for quite specific and different activities. High turnover in staff, when it occurs, can mean that carers have to 'train' new staff within the normal respite hours – that is, the carer loses respite hours.

In response to the issues raised about lack of qualified staff, one carer point out that 'there are currently large numbers of fully trained and experienced' unpaid family carers who are unable to work (either as carers for their own family member or in the paid labour force).

Suggestions relating to this point included: consider accrediting carers; involve carers in selection of staff; enable carers to join the paid work force by providing long day care of at least standard work hours for people with disabilities (9 a.m.-3 p.m. day activities programs are not enough).

One discussion group called for a national strategy to improve the skilled workforce in disability services.

### **General methodological issues of the study**

Several participants were interested in the study methodology. In relation to 'effectiveness' the following issues were raised:

- This study is asking ambitious questions. Findings need to be qualified where appropriate. Where it is not possible to resolve a given question, the AIHW was urged to provide advice on the appropriate process for doing so in the future.
- It was suggested that it is not possible to fully measure unmet need and is therefore not possible to quantify the whole cost.
- It was suggested that performance indicators agreed by the NDA are needed for use across the disability sector before we can have a sensible discussion of effectiveness.

### **4.5 Other indications of effectiveness**

Literature and other information was sought for evidence about the effectiveness of service types similar to those receiving unmet need funding. As noted in Chapter 2, an extensive literature review was not possible within the study time frame and much of the information relevant to the study questions was found in literature produced by peak organisations and other researchers – available via websites, newsletters, conference proceedings and personal communication. The key points raised in the literature are detailed below.

Little information came from jurisdictions regarding evaluations of the specific services provided as a result of unmet needs funding, or of similar service types. Several studies are in train in some jurisdictions but the timing is such (new funding in 2000–01) that it is not surprising that the results are not yet available. (See some discussion in Chapter 3.)

The concurrent study reviewing *Current Responses to Meeting Service Needs of People with a Disability and the Effectiveness of Strategies to Support Families* is understood to have found evidence of support for the effectiveness of:

- individual packages;
- local area coordination mechanisms; and
- care coordination in Indigenous communities.

### **Overall satisfaction**

The consideration of effectiveness is taking place in a context of reasonably high satisfaction among those who do get these services. For instance, a national client satisfaction survey

sponsored by disability administrators, indicated an overall satisfaction level of 75–85% among CSDA clients and 65–76% among their families (E-Qual & Donovan Research 2000).

Some jurisdictions also conduct client satisfaction surveys, either of specific service types or across the sector. For example, the Victorian Department of Human Services has conducted client satisfaction surveys among users of the Aids and Equipment Program (formerly the Program of Aids for Disabled People) each year since 1998–99. The 2000–01 report noted that ‘the levels of satisfaction continue to be high though, as in previous reports, these levels need to be understood in the context of the expected norm (85–95% in the health sector)’. Overall, 87% of clients were satisfied with program, 86% were satisfied with the process of getting the equipment/repair and 91% were satisfied with the equipment. Of those clients who were not satisfied with an aspect of the program, 43% were dissatisfied with the waiting time and 33% with the degree to which they were kept informed during the waiting period (Acuity Consulting Pty Ltd 2001).

Disability Services Queensland conducted a consumer satisfaction survey in 2001 to:

- establish consumer and family views on the delivery of quality services;
- provide all staff with information that will enable them to improve services;
- establish baseline data; and
- refine the survey process to provide a framework for future research.

Results from this process are soon to be made public.

## **De-institutionalisation**

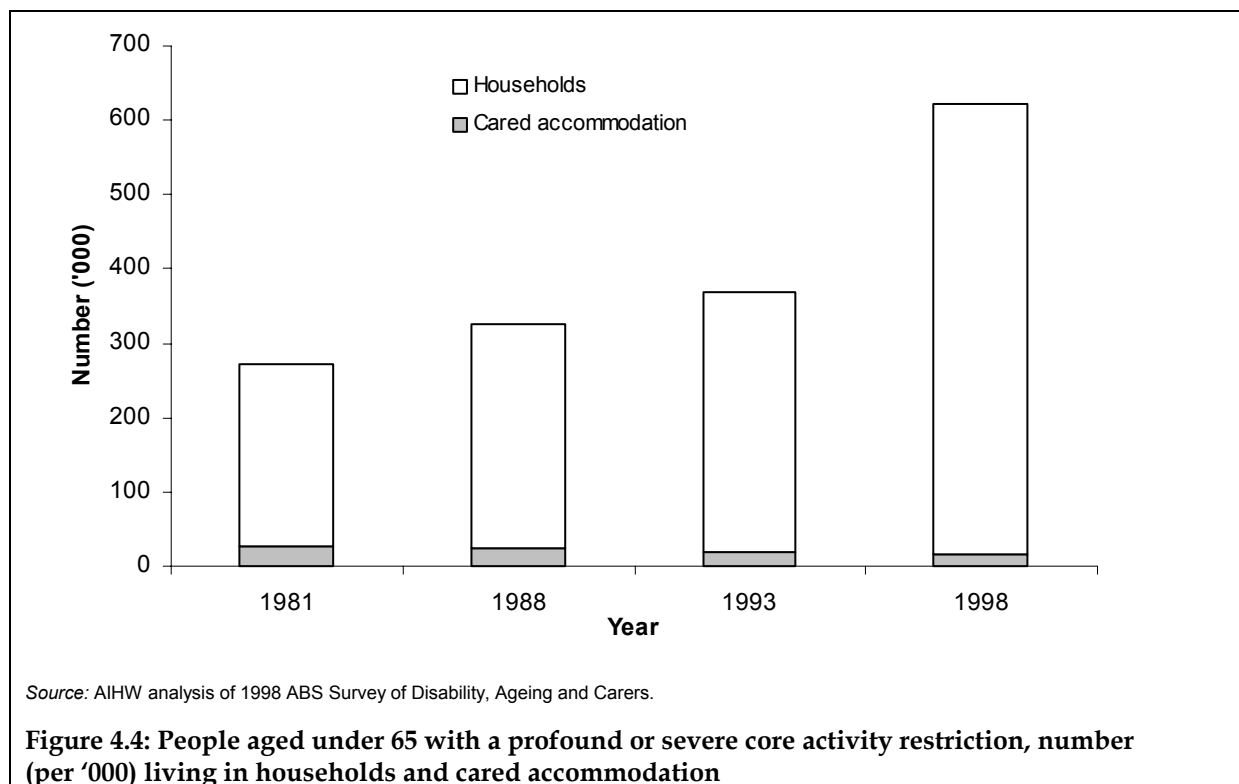
It has already been observed that there has been a trend in CSDA services away from large institutions, over several years (in the discussion of accommodation services in Section 4.2).

De-institutionalisation programs more broadly have been in process in Australia since the 1980s. What do the available data tell us about patterns of change and, in particular, the context in which the CSDA services operate?

- The number of people aged between 5 and 64 years with a severe or profound core activity restriction living in households increased from 244,100 in 1981 to 644,700 in 1998 (Figure 4.4). The increase was particularly marked between 1993 and 1998 with an additional 271,400 people living in households<sup>3</sup>. Most of the people in households live with family members.
- A corresponding decrease has occurred in cared accommodation living, declining from 27,000 in 1981 to 19,100 in 1993 (Figures 4.4 and 4.5).

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<sup>3</sup> In the ABS survey, ‘profound’ means unable to perform a core activity or always needing assistance and ‘severe’ means sometimes needing assistance to perform a core activity. Technical and other modifications to the ABS survey have resulted in an increased ‘capture’ of response relating to severe or profound restrictions. This means that changes between 1993 and 1998 need to be interpreted carefully.

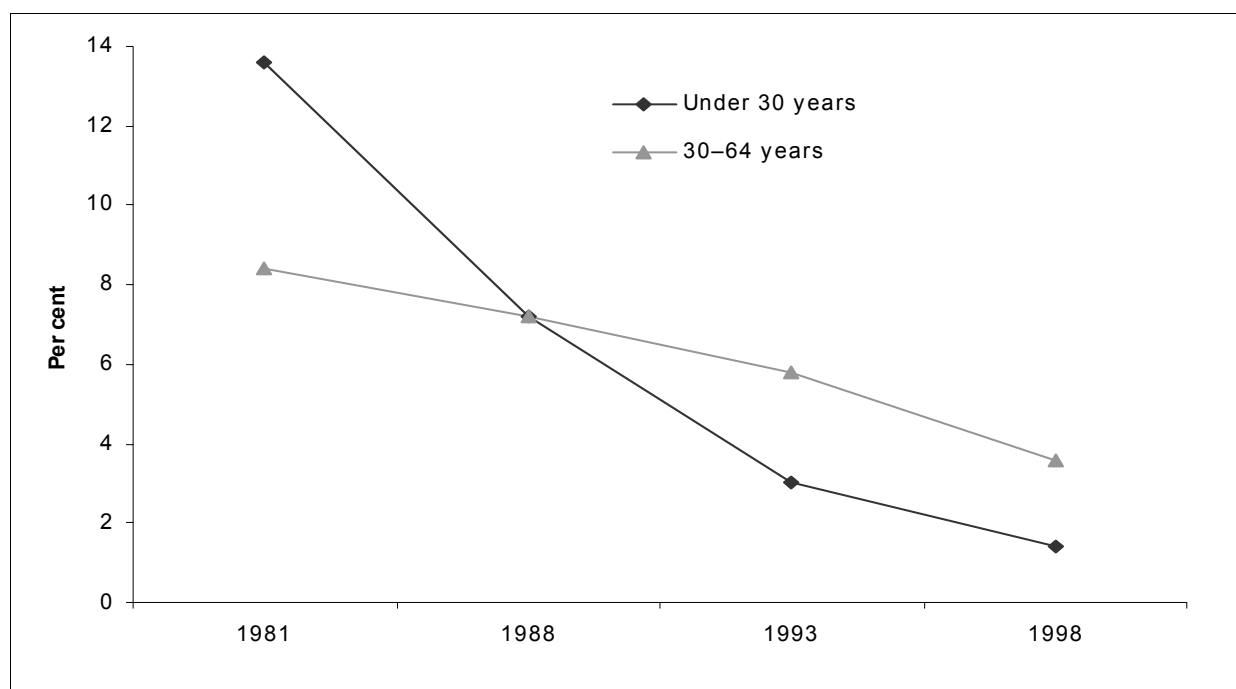


- For people living in institutions, there was a decrease in the percentage of the population aged under 15, from 13% in 1981 to 2% in 1998. A similar decrease was observed for people aged 15–29, from 27% in 1981 to 13% in 1998. In contrast, an increase from 42% to 56% occurred for people aged 45–64.

These results suggest that:

- Observed changes in institutional and community living are mainly driven by ‘non-institutionalisation’, that is, people with ongoing support needs remaining in the community rather than going into institutions.
- The institutionalised population is ageing, primarily as a result of younger people with high support needs staying in the community.

Informal carers provide a considerable proportion of the support required by non-institutionalised people with disabilities. In 1998, 1,648,880 or 87% of people who required assistance received it from an informal carer (AIHW 1999b, page 250). Only 48% (74,100) of people received formal services.



Source: AIHW 2001b, Table 7.22.

**Figure 4.5. People aged under 65 with a profound or severe core activity restriction, proportion living in cared accommodation, 1981-98**

## Individualised funding

Available literature suggests that while individualised funding models are generally viewed favourably in terms of improving the sense of control or empowerment of individuals with disability, caution needs to be exercised in terms of the way these models are implemented. That is, the effectiveness of various individualised funding models depends in part on factors such as the environment in which they are being implemented, funding levels associated with packages, portability of packages, and the viability and accountability of service providers. These issues, outlined below, echo those raised at all three peak discussions.

A succinct summary of individualised funding and principles of self-determination is contained in a paper by Carmel Laragy of the Victorian Department of Human Services, presented at the 2001 Social Policy Research Centre Conference (Laragy 2001). The paper cites a range of cautionary literature on the complexity of moving towards individualised funding (for example, concern about viability of existing services, government abdication of responsibility for individual support and service development). The paper also examines the extent to which these principles have been applied in the Victorian 'post-school options' program, Futures for Young Adults. The author suggests that the program was a bold initiative that has greatly benefited the small number of families who have been able to take on full control of their funding. She also notes the significant challenges for a system moving from block funding arrangements towards a system that is responsive to individual needs.

The Paraplegic and Quadriplegic Association of Queensland prepared a paper on individualised funding in the broader context of reform of funding policies and practices, for the ACROD Convention in 2000 (Porter 2000). The paper noted the trend towards the use of individualised or self-managed funding in Queensland and the positive reasons this trend

has occurred (for example, 'to provide the person with a disability with greater "purchasing power" and control over the use of "their" funding; to directly involve the person with a disability in the negotiation of funding and support levels'). While they applauded the Queensland Government's focus on individualised funding they note that this type of funding is not suitable for all service types or situations. That is, self-managed funding, individualised funding and block grant funding are each appropriate in various situations and one should not be used to the exclusion of all others. The paper notes the issues surrounding individualised funding that require clear policy directions. These are:

- portability – how to support an individual's choice in moving to different providers with their direct support funding, without affecting the viability of the provider...;
- flexibility – how to take account of the effect of changing circumstances on an individual's funding (short term and long term);
- accountability – how to ensure providers are accountable to individuals for the quality and level of support provided; and
- meeting the reasonable costs of service provision. (Porter 2000)

The Accommodation Support Network (South Coast Region) raised similar concerns to those discussed above in relation to the effectiveness of Adult Lifestyle Support Packages in meeting the community accommodation needs in Queensland (Accommodation Support Network 2001).

### **Choice and empowerment: doing human things well**

The large body of literature on self-determination and empowerment is not reviewed here. However, a number of illustrative examples is provided, of literature outlining the importance of choice, empowerment and 'doing human things well'. These were also strong themes at the peak discussions.

The Alternative Living Service Improvement Project investigated national and international literature and identified lack of choice as one of the major issues faced by people with an intellectual disability living in Disability Services Queensland (DSQ) group homes (DSQ 2001). The research found that successful independent living depended on a range of factors, including that individuals need to make choices based on their own needs rather than on those of the group. The report findings were confirmed by community consultation done by DSQ throughout Queensland.

The importance of individual choice in terms of quality of life and health is discussed by Morrell (2000), who proposes draft principles for good assessment methods. These principles advocate methods that: support the personal autonomy, integrity and contributions an individual with a disability can make to the community; focus on the client, their family, their knowledge and unique experience of disability; and provide opportunities for meaningful involvement by the client and his/her family at all stages.

A carer consultation in Victoria noted that carers requested that case worker positions be 'filled by a worker with an empathic attitude and an understanding of the carer/family needs as well as those of the person with a disability. This would introduce a more preventative focus, reduce the responsibility of carers having to fight for services and minimise delays and duplication of assessment procedures' (Nankervis & Rebeiro 2000, page 29).

Involvement of the consumer is an increasingly well-recognised principle in the human service literature. In health services, for instance, it is considered that a 'consumer focus' is important when providing information: 'you need to meet them on their own ground' and include them in decision making (OECD 2002, page 108).

### **Innovation and new service models**

Current funding and management models are viewed variously as facilitating or hindering innovation and flexibility in the disability service sector.

The Gold Coast Disability Task Force is an example of an innovative management model, working effectively in conjunction with current government funding models. The Task Force developed from a case-based response to individual unmet needs and grew into 'a sophisticated planning group', involving all the main service providers and funding agencies in the area (Edwards 2001). The Task Force identifies service gaps and the preferred options to address them, and then works within an agreed model of integrated family support and a strategic plan. They have successfully influenced the flow and direction of funding in the region, as well as bringing together funding from several sources to achieve identified goals (Edwards 2001).

In contrast, the current purchaser-provider system of management has been criticised, with one academic noting that the service providers' requirements to meet the 'bureaucratic' requirements specified in purchasing agreements inhibit their ability to be as responsive to clients as they would like (Stewart 2002). It was noted that 'the constant harping in the Gallop report on the need to be "innovative", when simply keeping the group houses running was difficult enough, must have grated on many managers'.

The Physical Disability Council of New South Wales 2002 made a range of recommendations on developing new models of holistic personal assistance services in their 2002 discussion paper 'Living on our own terms'. They also referred to the 2000 Review of the Home Care Service High Needs (Virtual) Pool (see PDCN 2002). This was an innovative pilot, established from existing Home Care funds to attempt to better meet the personal care needs of clients with complex needs and to assist the access of lower needs clients to Home Care services. The pool is a mechanism to spread the cost of a small number of people, with above average support needs, across the whole system. In some respects, the pilot has been viewed as effective. For instance, the funding is portable for each individual (that is, they can use it around the State as it is not tied to a particular region) and it is said that the pool has enabled the provision of assistance to more people. However, the paper notes that there has been no 'flow through' of clients and there are limited 'exit points', the pool has a growing waiting list (that is, no waiting list in August 2000 and 46 people by October 2000) and has been inadequate in meeting the needs of some people.

A large Victorian non-government service provider has identified a number of factors which have the potential to significantly impact on the long-term relevance of one of their service types (accommodation). These include:

- younger people are clear in their preference for smaller or individually focused services;
- ageing with a disability is creating a demand for age-appropriate services;
- residents of the service are growing older and experiencing the impact of ageing, including increasing support needs.

The service provider has addressed these issues by developing a new service approach to better accommodate the service users' needs, including for improving the bridge between disability and aged services (Sheridan 2000).

## **Processes**

Disability Services Queensland (DSQ) established regional priority panels to decide who should get individual funding packages (DSQ 2000b). DSQ has conducted a two-phase evaluation of its regional priority determination process (DSQ 1998). The first stage of the evaluation examined the process of implementing the new interim measures and confirmed that overall the new approach was considered consistent and reliable. The second stage of the evaluation examined the impacts and outcomes of the new process. The report details findings and recommendations in terms of: awareness of the process; priority panel membership; registration of need process; priority determination process; follow-up processes; public perception; prioritisation and funding processes; prevention/early intervention; and registration of need database. Overall, the regional priority determination process appears to be achieving its intended aims. The report identifies key areas for further development and improvement.

## **4.6 Effectiveness: summary and discussion**

The CSDA is a complex national program, providing supports in many areas of individuals' lives, interacting with family life and a range of other services. It is located in a complex structure of family and social supports and expectations; it must address needs over whole lifetimes. It is not an entitlement system. While it has high-level goals, relating to participation and quality of life, and while it provides descriptions of the services it funds and of the population target group, there are many 'grey' areas. Commonwealth-State relations provide further areas of debate and 'grey borders'. The field is passionate and ambitious, and the administrative challenges are considerable. History and developments in recent decades have played a large part also, in terms of the services that are available, the role families have played in establishing some of these services, and the changing expectations among all the players – people with disabilities, governments, non-government service providers and families. The impact of human rights philosophy relating to people with disabilities has been considerable, as it has been also for those, frequently women, who provide much of the informal support on which the 'system' as a whole relies.

To ascertain the effectiveness of a single injection of new funds, even if large, for a service program such as this, is a potentially lengthy and complex task. In the time available, the study team has attempted to delineate between conclusions it considers justified, and other matters that are better raised as questions or issues for further consideration.

## **Overview**

The additional CSDA funding provided over recent years, including the unmet need funding, has been effective in putting additional services on the ground.

These additional services are recognised and appreciated in the field. The views of the field, as heard in the course of the study, could be summed up by the following quote from the peak discussions: 'I now feel more confident that there is a chance of some assistance in areas where there was virtually none.'

Further, the nature of some of the additional services – particularly the focus on flexibility, the use of individual packages and local area coordination mechanisms – is positively viewed. Where there is genuine flexibility and responsiveness, there are stories of consumers, carers and service providers working together to achieve good outcomes, and often cost-effective ones. The effectiveness of these newer services is supported by the literature, and jurisdictions have drawn on this knowledge in developing new approaches.

### **Survey of jurisdictions (Chapter 3)**

It is not easy to quantify or track the use of the additional services resulting from the unmet needs funding. Jurisdictions differed in the application of the unmet need funding, the speed and method of rollout, and the extent to which their contribution to unmet need funding was distinguishable from other growth funding. The Bilateral Agreements were not accompanied by consistent agreements about acquittal and reporting to the Commonwealth, and many of the reporting agreements were not, in any case, fulfilled. The information requested by the AIHW in the Jurisdiction Survey could not be provided by all jurisdictions. In particular, because a large jurisdiction (New South Wales) could not provide certain key data, and because it represented such a large proportion of the unmet need funding, the AIHW questionnaire did not yield the quality of national data hoped for. Chapter 3 reflects this challenge, and the impact of the problems in the available data on the ability to draw the conclusions required by the study brief. Nevertheless Chapter 3 reaches some conclusions about the use of the unmet need funding:

- Over the two years 2000–01 and 2001–02 it is expected by jurisdictions that about 66% of the unmet need funding (Commonwealth and State combined) would be directed to accommodation support, multi-service packages and respite. Considering the Commonwealth contribution alone, it is expected that about 35% would be allocated to respite.
- Client numbers provided by jurisdictions are incomplete and cannot be reliably combined to provide national totals. For the 35% of 2000–01 unmet need funding, for which funding and client numbers are available, it was reported that, in 2000–01:
  - 887 clients received accommodation support;
  - 773 received individualised packages likely to incorporate more than one service type;
  - 2,586 received respite support; and
  - 1,315 received community access support.

Jurisdictions estimated that the full-year effects of the new funding would be higher than this (Table 3.8).

### **CSDA MDS analysis (Section 4.2)**

The CSDA MDS collections provide trend data over several years that illustrate the growth in services, thus enabling aspects of effectiveness to be gauged (see Section 4.2). This national collection has acknowledged limitations for some service types because of its snapshot nature. The decision by NDA and the AIHW to invest resources in improving the collection is very useful, indeed essential, if this important national data resource is to provide the kind of data required for an analysis such as the present one. Other data collections and agreements should always, in the first instance, at least consider using CSDA

MDS and *National Community Services Data Dictionary* data concepts. The resulting consistency between specific data collections and the CSDA national minimum data set would enable the effectiveness of national programs and initiatives to be monitored more surely.

Estimated increases in the numbers of people receiving services in 2000–01, compared to 1999–00, are:

- 180 in residential accommodation (including group homes);
- 740 in community-based accommodation support services;
- 2,350 in community services (includes individualised packages and local area coordination services); and
- 2,425 in community access services.

These numbers provide one estimate of the additional services provided by new funding in 2000–01, alongside the data in Chapter 3.

These increases have occurred in a longer-term trend in service growth. Since 1997, there have been the following increases in services received on the snapshot day:

- 1,800 accommodation support services, with clear evidence of greater emphasis on community-based options within this number; annual figures would be much higher in some community-based categories (see Chapter 7 regarding estimated increases in supply);
- almost 7,000 additional community support services received; and
- 3,500 community access services.

These increases have been generally accompanied by growing levels of need for support among service recipients.

### **Qualitative evidence of the benefits of the new services**

During the peak discussions the study team heard numerous examples and stories illustrating the benefits to people of the additional services made available via the unmet need funding, for instance:

- The progress achieved by the simple act of recognising the complexity of a family's crisis situation, and offering to start by cleaning the house (Box 4.3).
- A young man with multiple disabilities who had lived in 18 foster homes, now lives in his own home, and has found employment (Box 4.7).
- A local area coordinator in a remote area who was able to arrange for the return of a baby to a community, overcome obstacles, and demonstrate to other communities that local support was possible (Box 4.11).
- A 60-year-old man who is now able to attend a day centre, previously had not left the house for five years; this has greatly improved his quality of life and that of his chronically ill mother (Box 4.7).

The study team also heard successful stories of 'roll-out' of new services, that provide a more detailed and human picture of the data in Chapter 3: for instance the successes of two service providers who quite rapidly got significant numbers of new clients on board (Box 4.1).

## Ageing carers

Commonwealth funding under the 2000 Bilateral Agreements with each State and Territory was 'to assist the in-home support and respite care needs of people with disabilities with ageing carers'. Thus the purpose of the funding was 'to help address unmet needs by providing additional services which enable people with disabilities who have ageing carers to remain supported within their families in their local communities' (see Section 1.3). A number of jurisdictions addressed the issue of ageing carers, by providing individualised packages or programs using the Commonwealth unmet needs funds. The available data from jurisdictions on the number of people with disabilities who have ageing carers (or carers who have been caring for over 30 years) and who were assisted using Commonwealth unmet needs funding is outlined in Section 3.4. From these available data it appears that at least 2,900 people benefited from the Commonwealth funding contribution in this area. This estimate does not include data for Northern Territory and is incomplete for New South Wales. Furthermore, not all jurisdictions reported comprehensively and consistently on ageing carers.

The focus of Commonwealth funding, on in-home support, was the subject of considerable comment in the peak discussions.

### Issues from peak discussions:

The main messages from the peak consultations regarding ageing carers were:

- respite is useful and appreciated;
- centre-based respite is needed as well as in-home respite; but
- what is often on ageing carers' minds is 'handing over'.

The study team heard examples of the effects of long-term caring, and these outcomes are confirmed on a broader scale in the ABS surveys (see for example, Table 6.10). There are many positive aspects to caring, and high levels of commitment are clearly apparent. But health may suffer, as may family relationships and cohesion. Exhaustion and bitterness may be long-term effects for the long-term caregivers – and a sense of abandonment by the wider community. Some carers are looking 'over the fence' at the aged care system and believe there are more choices and options for people (both clients and carers) in that system.

The fundamental questions for ageing carers, mainly parents, are: 'When can I "retire"? And if I can't, what happens when I die?'

### Effectiveness: issues raised

Other issues were raised by the analysis in Chapters 3 and 4, and during the three peak discussions (Section 4.4); many of these issues are also in evidence in the relevant literature. The following issues appear to the study team to bear consideration by national policy makers.

#### 'Doing human things well'

Effectiveness, in the words of one participant at the peak discussions, is about 'doing human things well'. Around this principle further issues were raised:

- How services are delivered may matter as much as what is delivered. Themes from the peak discussions included: *choice*, not only regarding the nature of the services but also

the timing; services that promote consumer *autonomy*, and *involvement* in planning; *respect* as a theme; *stability* as an ingredient of cost effectiveness.

- 'Choice' may involve asking for services that are not 'on the policy agenda'; this may include residential respite and residential accommodation for adults with ageing carers. Some participants asked why services that are considered acceptable for older people, such as cluster housing, are not available to younger people with disabilities.

### **Individualised funding and 'one size does not fit all'**

Flexible funding packages, geared to individual needs, are undoubtedly appreciated in the community. Further, the processes established in some jurisdictions to allocate this funding seem to have been successful in distributing new funding perhaps further and wider than otherwise.

Nevertheless, it was pointed out that the development of these funding models needed to be balanced with maintaining support of service infrastructure. Otherwise, it was said, purchasers and brokers 'may have nothing suitable to buy'.

The initial set-up costs may sometimes be quite high, and the overheads for some models (and LACs) may initially be relatively high, in relation to the funding they are distributing.

One discussion group considered that 'doing human things well' was the highest level criterion, and no one service type was a guarantee of quality and responsiveness. Flexibility even within the individualised funding approaches was valued; as one participant emphasised: 'one size does not fit all'.

### **Management challenges for NGOs**

Management and staffing issues for NGOs were considered to be crucial to the delivery of quality services, but to pose challenges. In particular one group believed that there was a serious shortage of suitable staff in the community services field. This group believed that workforce planning should be undertaken in the interests of promoting service quality.

The general business climate was considered to pose considerable challenges also, in particular, insurance. As well as the general current concern with public liability insurance, it was reported that agencies cannot insure 'dangerous' clients.

### **Program management issues raised by peak discussions**

A number of the issues raised above have implications for program management. Three further issues that should be reported are:

- some frustration at the perceived slow speed of change and service increase; are there questions about the speed and balance of roll-out? How conscious has the balance been between achieving large infrastructure changes compared to the possible benefits of directing some funds to agencies that can get services to new clients rapidly?
- the cost implications of some policy directions; for instance, the study team was frequently requested at the discussions not to forget the extra needs of existing clients. But equally we were challenged by stories about the costs of moving very high needs people into the community (that is, the high costs of improving quality of service for some existing clients). Clients with challenging behaviour and who are potentially dangerous to other residents were a case in point – \$180,000 was a figure quoted publicly (Campbell 2002) and the study team heard anecdotal evidence of similar amounts in other jurisdictions.

- a very strong view that the program needed to move from ‘crisis management’ to proactive planning and case management; that is, to move from only offering assistance to people when they reach a crisis, to planning transitions with people ahead of time.

These issues raised in the peak discussions must be seen in the context of major changes being effected in most jurisdictions – significant changes to infrastructure and application processes, and other reforms including the completion of de-institutionalisation.

### **Families, carers and ageing**

The future of informal care cannot be assumed. The peak discussions raised the issue of changing community expectations regarding the intensity and duration of informal care. Workforce issues also pose a conundrum. In discussing the staffing challenges for community services, they pointed out that informal carers were a potential workforce in the community service field – but that carers cannot both care for someone with high support needs and go out and earn money. They noted that the community does not expect to pay carers to look after their own family member, and voiced understandable caution about ‘paying’ people to look after their own family.

Informal care provides most support to people with disabilities in the wider community. Most recipients of CSDA services live with their families. Informal care is crucial to all types of service provision and to de-institutionalisation initiatives.