

Unmet need for disability services

**Effectiveness of funding and
remaining shortfalls**

The Australian Institute of Health and Welfare is Australia's national health and welfare statistics and information agency. The Institute's mission is to improve the health and well-being of Australians by informing community discussion and decision making through national leadership in developing and providing health and welfare statistics and information.

DISABILITY SERIES

Unmet need for disability services

Effectiveness of funding and remaining shortfalls

Australian Institute of Health and Welfare

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Abbreviations

ABI	Acquired brain injury
ABS	Australian Bureau of Statistics
ACOSS	Australian Council of Social Service
ACT	Australian Capital Territory
ADD	Attention deficit disorder
ADL	Activities of daily living
AIHW	Australian Institute of Health and Welfare
CAP	Combined Application Process (WA)
CSDA	Commonwealth/State Disability Agreement
DHAC	(Commonwealth) Department of Health and Aged Care
DSQ	Disability Services Queensland
EBA	Enterprise bargaining agreement
EWL	Education, work and leisure
FaCS	(Commonwealth) Department of Family and Community Services
HACC	Home and Community Care (program)
HSL	Home and social living
ICAP	Inventory of Client and Agency Planning
ICF	International Classification of Functioning, Disability and Health
ILT	Independent living training
LAC	Local area coordination
MDS	Minimum data set
NCID	National Council on Intellectual Disability
NDA	National Disability Administrators
NGO	Non-government organisation
NSW	New South Wales
NT	Northern Territory
OECD	Organisation for Economic Co-operation and Development
PDCN	Physical Disability Council of New South Wales
PT/OT/ST	Physiotherapy/occupational therapy/speech therapy
Qld	Queensland
SA	South Australia
SAAP	Supported Accommodation Assistance Program
SAS	Service Access System (NSW)
SCRCSSP	Steering Committee for the Review of Commonwealth/States Service Provision
SNR	Service Needs Register (Vic.)
Tas	Tasmania
Vic	Victoria
WA	Western Australia

Summary

Objectives

This report contains the findings of a project commissioned by the National Disability Administrators (NDA), with two specified objectives, namely to:

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

The outcomes of the project are to inform discussion and negotiations regarding the third Commonwealth/State Disability Agreement (CSDA).

Five areas of work were also specified. In brief, the project team was required to:

- use data from all jurisdictions and 'any other recent relevant data' regarding services provided as a result of unmet need funding in 2000-01;
- carry out secondary analysis of evaluations of services provided as a result of this funding (or of similar services);
- estimate the effectiveness of unmet need funding;
- identify unmet need for the nominated service types; and
- formulate 'recommendations regarding appropriate costing models/approaches to assist in determining the costs of any remaining unmet need for disability services'.

The first four areas of work relate directly to the two project objectives, while the fifth is directed to the consideration of next steps.

Work carried out

The Australian Institute of Health and Welfare (AIHW) has, in the course of the project:

- carried out a Jurisdiction Survey, seeking information on the use and effects of the unmet need funding, on possible remaining shortfalls and the methods of managing and estimating these;
- analysed data from the CSDA Minimum Data Set (MDS) collection and the Australian Survey of Disability, Ageing and Carers;
- undertaken a literature search for information on the costs and effectiveness of disability services of various types; and
- conducted three discussions with peak organisations of non-government service providers, consumers and carers.

This work was carried out and the report prepared between December 2001 and April 2002. A Steering Committee, chaired by Victoria and with representatives from the

Commonwealth and Western Australia, provided guidance throughout. All jurisdictions had opportunities to comment on a progress report in February and a draft final report in April.

The unmet need funding

In recognition of unmet need for disability services, additional funding was made available by Australian governments, totaling \$519 million over the two years 2000–01 and 2001–02, \$210 million of which was available in 2000–01 (Table 1.1). The Commonwealth Government contributed a total of \$152 million over the two years, on the basis that States and Territories would at least match its offer.

Under Bilateral Agreements with the Commonwealth in 2000, all jurisdictions were funded to ‘help address unmet needs by providing additional services which enable people with disabilities who have ageing carers to remain supported within their families in their local communities’. The Bilateral Agreements also noted that the ‘State’s contribution will be used to assist in addressing other priority areas of unmet need’. These ‘other priority areas’ were not specified in the Bilateral Agreements.

The broad objectives and specified target group of the CSDA itself are also relevant (Box S1).

Box S1: The 1998 CSDA objectives and target group

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

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

‘people with a disability attributable to an intellectual, psychiatric, sensory, physical or neurological impairment or acquired brain injury (or some combination of these) which is likely to be permanent and results in substantially reduced capacity in at least one of the following:

- *self care/management*
- *mobility*
- *communication*

requiring ongoing or episodic support’.

Some challenges

Considering effectiveness of and unmet need for disability services

The CSDA is a complex national program, providing supports in many areas of individuals’ lives, interacting with family life and providing a range of other services. It is located in an intricate 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 ‘grey’ areas in relation to eligibility, and these become more complex at the borders with other relevant services. Commonwealth–State relations provide further areas of debate and ‘grey borders’. History and developments in recent decades have played a large part also, in terms of the nature of the services 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 for those, frequently women, who provide much of the informal support on which the 'system' as a whole relies.

Effectiveness is hard to achieve, and to agree on, in a field such as this, where standards and goals are set high by all stakeholders, yet any shortfalls for current or potential recipients generally become very visible. The personal and financial costs to families are high. The potential costs to government, relating to whole-of-life needs, are challenging to contemplate; rationing is essential but can appear at odds with the high standards set and desired by all. The tension between these high standards and on-the-ground realities and possibilities was recognised by the principal consultant evaluating the first CSDA when she titled her report to Administrators, 'Getting real' (Yeatman 1996).

The challenge of considering the effectiveness of the unmet need funding

The task of the current project was to ascertain the effectiveness of the unmet need funding, particularly the funding available in the first year, 2000–01. An ideal evaluation would be planned in advance of change, and conclusions would be drawn some time later, rather than during the roll-out of the two-year funding injection. While there are clear policy needs for some information in early 2002, it should nevertheless be recognised that the timing of this project imposed limitations on the information available and the conclusions that can be drawn.

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

Effectiveness of the unmet need funding

The unmet need funding has been effective in putting additional services on the ground. Estimates of the size of these effects follow, although it is likely that the effects are not yet fully in operation.

These additional services are recognised and appreciated in the field, according to the peak discussions held. 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 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.

A range of quality and infrastructure improvements are also being made by jurisdictions with the unmet need funding; these are detailed in Chapter 3.

Survey of jurisdictions

(See Chapter 3)

It was not easy to quantify, or track the use of, the additional services resulting from the unmet need funding from the Jurisdiction Survey or acquittals to the Commonwealth. Jurisdictions differed in the application of the unmet need funding, the speed and method of rollout, the information they could provide, and the extent to which the unmet need funding and its application were identifiable in administrative systems and processes. The information requested by the AIHW in the Jurisdiction Survey could not be provided by all jurisdictions. The Bilateral Agreements were not accompanied by consistent agreements about acquittal and reporting to the Commonwealth, and some of the reporting agreements have not yet been fulfilled. Those jurisdictions that could provide details of new services received with the unmet need funding accounted for 35% of the total recurrent funding in 2000–01. The combined results for 2000–01 and their estimates of the partial ongoing effect are presented in Table S1 (last two columns).

The full effect of new funding will not be apparent in client outputs until after the two years of additional expenditure have been completed, that is, until 2002–03. However, the estimates of unmet need from the AIHW 1997 report were compared with jurisdictions' estimates of the likely ongoing effect of the unmet need funding in future years. From this 'check', it appears that jurisdictions' expectations of the full-year effects of the unmet need funding are broadly consistent with the 1997 estimates of unmet need made by the AIHW and disability officials (Section 3.9).

CSDA Minimum Data Set (MDS) analysis

(See Chapter 4)

The CSDA MDS allows the annual collation of national data using agreed definitions and processes. The data currently available relate to a snapshot day each year, and the changes between 1999–2000 and 2000–01 have been adjusted using Western Australian full-year numbers, to provide estimates of the numbers of people accessing services with the unmet need funding in 2000–01 (Table S1, first column of numbers).

The redeveloped CSDA MDS collection will produce data even more relevant to these project questions, as there will be full-year data for all service types including respite services, and indications of the ages of carers.

Table S1: Estimates^(a) of effects of unmet need funding

	People in 2000–01: Estimates based on CSDA MDS snapshot data adjusted for full-year ratios ^(b)	People in 2000–01: As reported in jurisdictional survey, equivalent to 35% of recurrent funding ^(c)	People in a full year of ongoing funding: Estimates based on jurisdictional forward estimates equivalent to 38% of recurrent funding ^(c)
Accommodation & respite	180 residential accommodation (including group homes) 740 community-based accommodation support services (respite numbers not used)	887 accommodation support 2,586 respite support	1,196 accommodation support 4,231 respite support
Community support services (including indiv. packages)	2,350 (includes individualised packages and LAC services)	803 individualised packages likely to offer more than one service type	1,409 packages offering more than one service type
Community access	2,425	1,315	2,536
Other	(not estimated)	3,820	3,820

(a) All sets of estimates involve some assumptions and/or extrapolation. All are explained in text in Chapters 3 and 4 and are considered valid for the purpose.

(b) See Tables 4.1 and 4.2, and Section 4.2, for method of adjustment using WA 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).

(c) See Table 3.8. These clients could be new clients or existing ones. Full-year effects may not occur until 2002–03 or later.

Qualitative evidence of the benefits of the new services

(See Chapter 4)

During the peak discussions the AIHW heard numerous examples and stories illustrating the benefits to people of the additional services made available via the unmet need funding. Some of these are included in Box S2.

Box S2: Some case stories of the benefits of unmet need funding

A young man with multiple disabilities who had lived in 18 foster homes, now lives in his own home, and has found employment.

A Local Area Coordinator in a remote area was able to arrange for the return of a baby to a community, overcome various obstacles, and demonstrate to other communities that local support was possible.

A 60 year-old man, now able to attend a day centre, had previously not left his house for five years; this has greatly improved his quality of life and that of his chronically ill mother.

Two mothers in rural areas (over 80 years of age) had been caring for their sons with quadriplegia for many years. After her son received a support package one mother commented 'Now I can die'.

Huge progress was achieved in the middle of one family's crisis by the simple act of acknowledging the complexity and challenge of the situation, and offering to start by cleaning the house – the cost effectiveness of a human, flexible approach.

The study team also heard successful stories of 'roll-out' of new services, for instance, the case of two service providers who, given funding, rapidly got significant numbers of new clients on board.

Source: Section 4.4.

Ageing carers

(See Chapters 3 and 4)

A number of jurisdictions addressed the issue of ageing carers, by providing individualised packages or programs using the Commonwealth unmet needs funds. Most jurisdictions provided data on the number of ageing or long-term carers assisted using these funds, in acquittal reports to the Commonwealth; these numbers totalled nearly 3,000 people for six jurisdictions.

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;
- What is often on ageing carers' minds is 'handing over'. Packages and residential arrangements are greatly valued when they allow the carer to begin withdrawing from the primary role and to be assured of future care arrangements.

The study team heard examples of the effects of long-term caring, and these outcomes are confirmed on a broader scale in population surveys. 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 many ageing carers, mainly parents, are: 'When can I retire? And if I can't, what happens when I die?' For these people, a policy focus on in-home support does not fully meet their needs.

Effectiveness: other issues raised

Other issues were raised in the course of the project, by the analyses carried out, and during the three peak discussions.

'Doing human things well'

Effectiveness, in the words of one participant at the peak discussions, is about 'doing human things well'. This is the prime goal, and no one service type was a guarantee of quality and responsiveness. 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 regarding the nature and timing of the services; consumer autonomy, promoted for instance by involvement in planning; mutual respect; stability of staff and service 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 such as cluster housing, considered acceptable for older people, are not available to younger people with disabilities.

Balancing flexible responses to individual needs and service infrastructure

Flexibility, within any service model, is desired and appreciated.

Flexible services geared to individual needs, often involving individual funding packages, 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. Flexibility, even *within* the individualised funding approaches, was valued; as one participant emphasised—'one size does not fit all'.

Local area coordination seems particularly suited to rural and remote area service planning, particularly where some applicants may find formal written processes difficult.

The initial set-up costs to distribute individual funding packages may sometimes be quite high, and the overheads for some models (and for Local Area Coordination services) may initially be relatively high, in relation to the funding they are distributing.

It was suggested in the peak discussions that the development of flexible 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'. It appeared that those jurisdictions who were also able to allocate funding to existing service providers were able to roll out new funding to new clients quite rapidly.

Management challenges for NGOs

Managing and staffing non-government organisations (NGOs) were considered by people at the peak discussions to be critical factors in the delivery of quality services, and to pose challenges. There was a concern that there was a shortage of suitable staff in the community services field, and that workforce planning should be undertaken nationally, in the interests of promoting service quality.

The general business climate was considered also to pose considerable difficulties, in particular in the area of 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 raised at the peak discussions are:

- Some frustration at the perceived slow speed of roll-out and service increase. Are there questions about the balance 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 policies; for instance, the study team was frequently requested not to forget the extra needs of existing clients. But equally, stories were told about the high costs (some in the order of \$200,000 per year) of supporting some existing clients with very high support needs in the community (for example, those moved from residential institutions, or clients with challenging behaviour and potentially dangerous to other residents); and
- A very strong view that the CSDA program needed to move from 'crisis management' to proactive planning and case management; that is, to move from offering assistance to people only when they reach a crisis, to planning transitions with people, ahead of time.

The 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.

Remaining unmet need for specific services

(See Chapter 7)

The estimation of unmet need for disability support services is also a complex task. The AIHW has used a number of sources to develop and refine the estimates. Population survey data have been used because they focus on people across the community who report specific needs for assistance. As well, data from those jurisdictions that maintain registers of service needs or have holistic application processes (holistic in the sense that they avoid double counting of applicants) have been extrapolated to provide national indications of unmet needs for services. Orders of magnitude have been compared and estimates refined in a process of triangulation.

The resulting estimates of remaining unmet need in 2001 are:

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

The make-up of these estimates is described in Table S2.

Table S2: Estimates of unmet need for specific service types

	Estimate of unmet need	Description of group
Accommodation and respite	12,500 people	People needing assistance at least 3–5 times per day with one ADL ^(a) or less frequent assistance with multiple ADLs, who need assistance from a formal service but cannot get it because no service is available, it costs too much, they are otherwise unable to arrange a service, or it does not provide sufficient hours. <i>Confirmed by:</i> Numbers of people on State registers in three jurisdictions
Community access^(b)	8,200 places	Places for people not in the labour force, aged 18–64 years, who need at least daily assistance with two or more ADLs; they are not studying; the main reason they are not currently looking for a job is their own disability or illness, but they wish to go out more often but are not doing so because of their disability or illness. <i>Confirmed by:</i> Numbers of people on State registers in three jurisdictions
Employment support^(b,c)	5,400 people	Unemployed people who <i>either</i> need at least daily assistance with any ADL <i>or</i> need at least weekly assistance with guidance, PLUS People not in the labour force who could work with special assistance; the main reason they are not currently looking for a job is their own disability or illness; they <i>either</i> need at least daily assistance with any ADL <i>or</i> need at least weekly assistance with guidance.

(a) Activities of daily living (ADLs) are self care, mobility and communication.

(b) Community access and employment estimates exclude people who are currently attending any day program.

(c) Employment estimates were prepared before the 2002–03 Commonwealth budget announcements. These estimates may need to be revised if there is change in assumptions about the expected labour force participation of people currently receiving the Disability Support Pension, or in policy on eligibility for services.

Source: Table 7.1; Section 7.2; Figures 6.1 and 6.2.

The AIHW has made these estimates on a conservative basis, with the aim of providing reliable ‘lower bound’ estimates (see Box S3 for an indication of the approach).

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

Box S3: Some conservative assumptions underlying population-based estimates

Need for CSDA accommodation support services was not inferred on the basis of population estimates of need for assistance alone. Further filters were placed on the analysis, insisting that there was expressed unmet need for formal assistance and some evidence of having tried to obtain it. Reasons for not obtaining formal assistance were examined and some were excluded from the estimates, including people who ‘did not know the service existed’.

The estimates exclude people in ‘health establishments’ including hospitals and aged care homes.

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

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

Source: Chapter 6.

Other evidence on the need for respite

(See Chapter 6)

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

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

(See Chapter 5)

There are other information and data included in the report that provide evidence of needs beyond those estimated:

- Evidence from jurisdictions that they are providing most new services to people with very urgent needs. There appear to be between 6 and 24 times more people seeking services and on jurisdiction registration or waiting lists in 2000–01 than were removed from these lists (usually because they were offered a service). Waiting times reported are long.
- The peak discussions confirmed this and suggested, anecdotally, that community knowledge of this was possibly dampening the numbers of applications.

Pressures at the program boundaries

(See Chapter 7)

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

- People in the CSDA broad target group (those with ongoing needs for assistance in self care, mobility or communication) are **growing in number and ageing**. Between 2000 and 2006, it has been estimated that those aged under 65 years will increase by 9%, those aged 15–64 years by 12%, and the group aged 45–64 years will increase in number by 19.3% or 59,500 people.
- There were almost 6,000 people aged under 65 years living in **residential aged care** on 30 June 2001, 1,014 being aged under 50 years. None of the needs of these people are considered in the estimates in Table S2.
- There are high numbers of people with disabilities using **services for the homeless**, and their need for support services is recorded by these service providers. Disability-related pension recipients accounted for 17% of all Supported Accommodation Assistance Program (SAAP) clients in 1999–00. Repeat use of SAAP services was highest for disability-related pension recipients, with requests for accommodation support (76%) and ‘other’ support (82%) being the primary reasons for seeking assistance.
- The **health system** is another vital interface with the disability services system. The health care of people in residential establishments has been highlighted as a concern during reviews of deaths in residential establishments. But equally there is evidence that the health needs of people with a disability in the community could be improved. The more de-institutionalisation is achieved, the more quality of care in the community, including health care, has to remain visible. There may be groups who are particularly vulnerable, for instance people with psychiatric disabilities, acquired brain injury and complex needs.

- **Insurance** has a triple possible impact on the CSDA program. People excluded from benefits (because of the fault aspects of insurance) create pressures for government schemes (the Disability Support Pension as well as the CSDA). Insurance costs are said to be impacting on the financial viability of NGOs and the resources available for support services. And insurers can be reluctant to insure some high support needs and 'dangerous' clients.
- **Transport** is a need discussed at the peak discussions and elsewhere – viewed as a basic need which, if not met, can preclude participation in the workforce, day programs or community activities generally. It was of concern to some that transport was formerly commonly part of the service (for instance, clients were transported to community access) and now is an extra, with costs attached.
- **Equipment and environmental modifications** were frequent topics at the peak discussions as well as in the peak and consumer literature. These are potentially important for promoting autonomy, as a source of carer assistance and for 'prevention' of high needs for personal assistance. For instance, lifting equipment can sustain a carer's health and ability (and willingness) to provide assistance to a person with significant physical disabilities for many years. Systems for the provision of equipment appear to be nationally fragmented.

Qualitative evidence of unmet needs

(See Chapter 7)

Peak discussions shed limited but supporting light on the quantum of unmet need but, importantly, gave some qualitative picture of its nature and effects.

During the peak discussions the AIHW heard numerous examples and stories illustrating the situation of people and families with unmet needs for disability support services. A small selection is included in Box S4.

Box S4: Case stories of people with unmet needs for disability support services

An individual with a spinal cord injury receives assistance to help him within his home, but not for assistance within the community. For this individual 'getting out of bed, does not mean getting into the community'.

A young woman with high support needs does not receive enough support for her father to return to the labour force.

Inadequate in-home support for a person in a wheelchair has meant that she sleeps in her wheelchair with her head against a table, as she can not get herself in or out of bed.

A mother caring for a 12-year-old child with Down Syndrome and autism had continually broken sleep for 6 weeks, and was dealing with a range of very difficult behaviours during the day. The only respite available to her would have cost \$246 per day during the week and \$310 per day on the weekend. As a result she had no respite.

A funded agency took over the management of two group homes each with four places. Before the agency had an opportunity to advertise the two vacant places, they had 38 applications, the majority from young people with acquired brain injuries.

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

A man is caring for his wife with schizophrenia and multiple sclerosis, and they are looking for a respite service. One service can support her physical needs and another, on the other side of town, can offer respite for people with mental illness but cannot support her physical needs. There is no appropriate respite for them.

Carer: 'In-home support should not be a life sentence ... for 38 years I haven't had a chance to be myself.'

Source: Section 7.3.

Approaches to costing remaining unmet need

(See Chapter 8)

The AIHW was also asked to make 'recommendations regarding appropriate costing models/approaches to assist in determining the costs of any remaining unmet need for disability services'.

In order to cost the remaining unmet need in 2001, a 'building block' or unit cost approach is suggested. This approach is based on the numbers of people estimated to need services, and a suggested approach to distribute their needs across a spectrum (for instance, high, medium and low needs). Policy departments could then relate these needs to service levels, either in terms of hours or places, and then apply the unit costs for these places or hours. The unit costs (cost per hour of service and cost per place) could be estimated either nationally, using data in this report, or estimated for each jurisdiction separately, taking into account jurisdictional variations and plans.

Also suggested is the consideration of:

- differing policy scenarios and how these might significantly affect costs of disability services; and
- different approaches to planning, for example, the possibility of adopting a population 'benchmark' approach developed for the Home and Community Care (HACC) and residential aged care programs.

Finally, it is recommended that further data developments build on the investment already made in the CSDA Minimum Data Set. In particular, if Disability Administrators wish to consider the possibility of producing national data from jurisdictional registers of service needs, then the example should be followed of those jurisdictions who have based their data structures on the CSDA MDS. The CSDA MDS has provided crucial data for this report. The redeveloped collection will have even more depth and analytical power and should be the first option as a basis for further data building.

1 Introduction

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

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

1.1 Project objectives and report outline

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

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

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

Study timeline

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

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

Report outline

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

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

1.2 The Commonwealth/State Disability Agreement (CSDA)

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

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

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

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

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

'people with disabilities' means people with a disability attributable to an intellectual, psychiatric, sensory, physical or neurological impairment or acquired brain injury (or some combination of these) which is likely to be permanent and results in substantially reduced capacity in at least one of the following:

- self care/management
- mobility
- communication

requiring ongoing or episodic support.

Under the second CSDA (1998), it was agreed that the Commonwealth has responsibility for the planning, policy setting and management of employment services, while the States and Territories have these responsibilities for all other specialist disability services. Box 1.1 sets out the purposes of these services. Advocacy, print disability and information services (particular types of community support) are considered shared responsibilities under this agreement.

Box 1.1: Service types covered by the CSDA

<i>Accommodation support</i>	<i>Services that provide accommodation to people with a disability and services that provide the support needed to enable a person with a disability to remain in their existing accommodation.</i>
<i>Community support</i>	<i>Services that provide the support needed for a person with a disability to live in a non-institutional setting (not including support with the basic needs of living such as meal preparation and dressing included under accommodation support).</i>
<i>Community access</i>	<i>Services designed to provide opportunities for people with a disability to gain and use their abilities to enjoy their full potential for social independence. People who do not attend school or who are not employed full-time mainly use these services.</i>
<i>Respite</i>	<i>Respite services provide a short-term and time-limited break for families and other voluntary caregivers of people with disabilities, to assist in supporting and maintaining the primary care-giving relationship, while providing a positive experience for the person with a disability.</i>
<i>Employment</i>	<i>Services that either provide employment assistance to people with a disability in obtaining and/or retaining paid employment in another organisation (open employment), and/or that support or employ people with a disability within the same organisation (supported employment).</i>
<i>Other</i>	<i>Other services include service evaluation and training, research and development, and services provided by peak bodies.</i>

Source: AIHW 2001a.

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

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

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

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

1.3 Bilateral Agreements and unmet need funding

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

The purposes of the Bilateral Agreements are to:

- (a) provide for agreement and action between the Commonwealth and individual States on strategic disability issues within the broad national framework;
- (b) provide a continuing procedure for negotiation and agreement between the Commonwealth and individual States on transfer of responsibility for particular services from one level of government to another; and
- (c) bring into the scope of the Agreement those specialist disability services which are mutually agreed between the Commonwealth and individual States to be important to the national framework for disability services, but which are not yet included in the Agreement.

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

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

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

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

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

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

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

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

Source: Disability Administrators 1999.

Unmet need funding

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

Summary of 2000 bilateral funding objectives

Under Bilateral Agreements with the Commonwealth in 2000, all jurisdictions were funded to 'help address unmet needs by providing additional services which enable people with disabilities who have ageing carers to remain supported within their families in their local communities'. The purpose and some standard key principles of this funding for all jurisdictions are presented in Box 1.3.

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

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

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

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

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

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

Box 1.3: Standard purposes and key principles for all States and Territories, CSDA Bilateral Agreements 2000

FUNDS TO ASSIST THE IN-HOME SUPPORT AND RESPITE CARE NEEDS OF PEOPLE WITH DISABILITIES WITH AGEING CARERS

(a) Purpose:

To help address unmet needs by providing additional services which enable people with disabilities who have ageing carers to remain supported within their families in their local communities.

The State's new contribution will be used to assist in addressing other priority areas of unmet need.

(b) Key principles:

- i Priority will be given to people with a disability whose carer is aged over 65 (or, in the case of Aboriginal people, aged 45 years or over), including older carers in rural and remote regions. Once these most critical needs are met, attention may then be turned to those families where the carer is approaching this age with an emphasis on those who have been caring for over 30 years.*
- ii In supporting families, the new services will focus on a range of supports which respond most appropriately to individual circumstances and provide respite to the carer so as to enable the person with a disability to continue living at home.*
- iii Funding will be allocated statewide, with a focus on support provided to families located in regional areas.*
- iv A focus will be on building and strengthening the capacity of communities.*
- v The new services will not result in cost shifting across jurisdictions or programs.*
- vi Where appropriate, the new services will be integrated with, and supplementary to (and not replace), existing disability and aged care funding, including Carer Respite Centres.*
- vii The Commonwealth funding component of the new services must be publicly acknowledged by the State.*
- viii Wherever possible, existing reporting mechanisms will be utilised.*

Source: Commonwealth Department of Family and Community Services & Department of Human Services Victoria 2000.

Table 1.2: Principles of Bilateral Agreements 2000

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

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

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

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

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

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

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

Expenditure

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

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

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

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

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

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

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

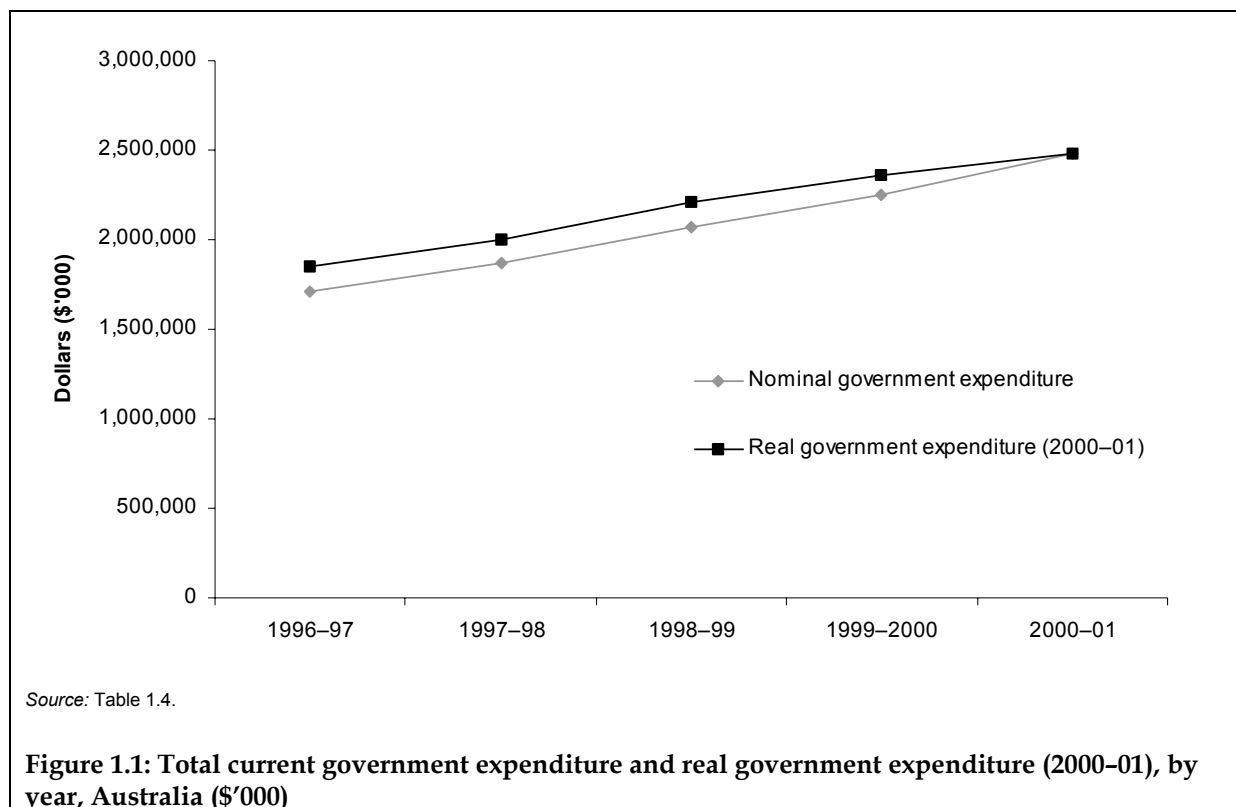
Table 1.4: Current government expenditure and real government expenditure (in 2000–01 prices), by service type, by year, Australia (\$'000)

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

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

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

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



Consumers

State distribution

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

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

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

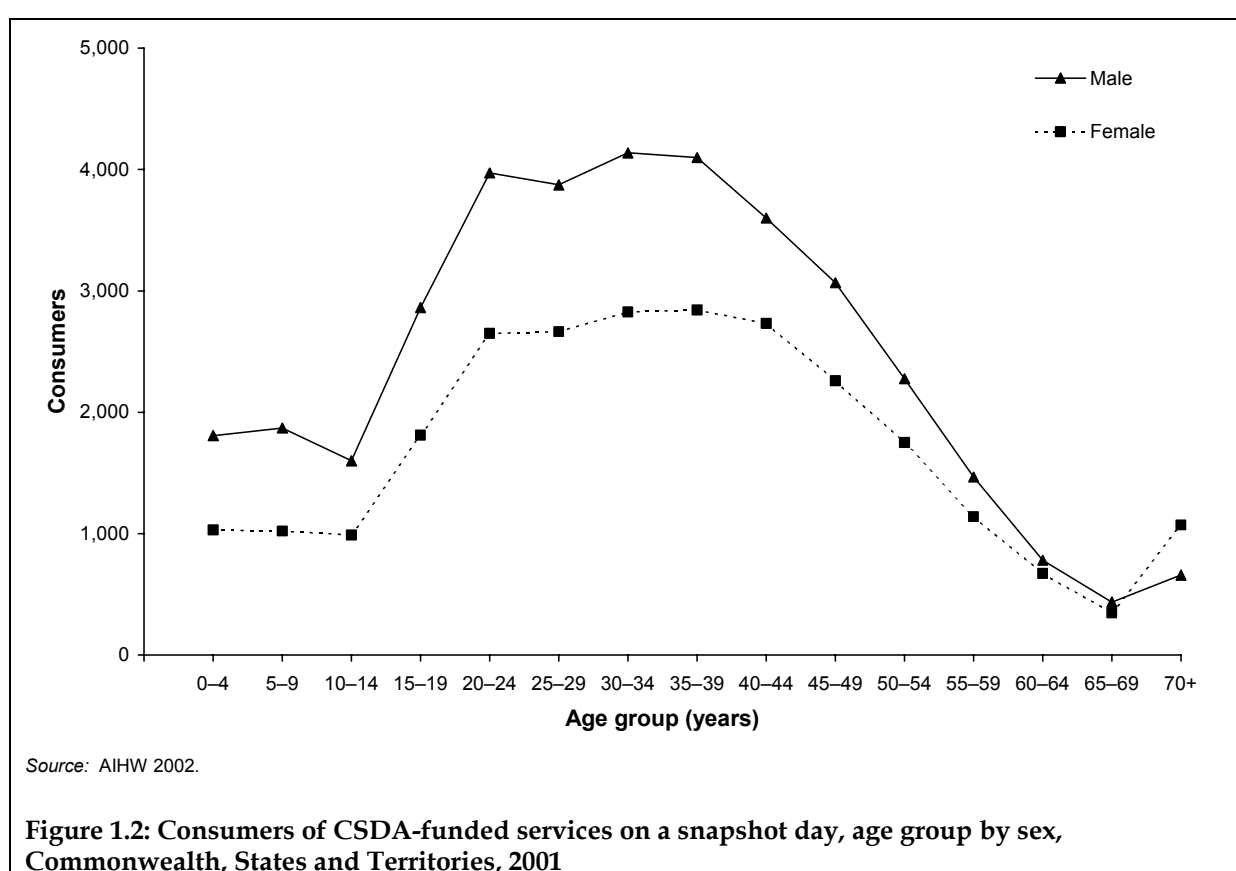
Notes

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

Age and sex

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

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



Disability group

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

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

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

Notes

1. Consumer data are estimates after use of a statistical linkage key to account for individuals who have received more than one service on the snapshot day.
2. Data for consumers of CSDA-funded services with service types Advocacy, Information/referral, Combined advocacy/information, Print disability/alternative formats of communication, Service evaluation/training, Peak bodies, Research/development and Other were not collected.
3. Data provided by the Commonwealth are preliminary and cover 99% of Commonwealth-funded services.

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

Service outlets

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

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

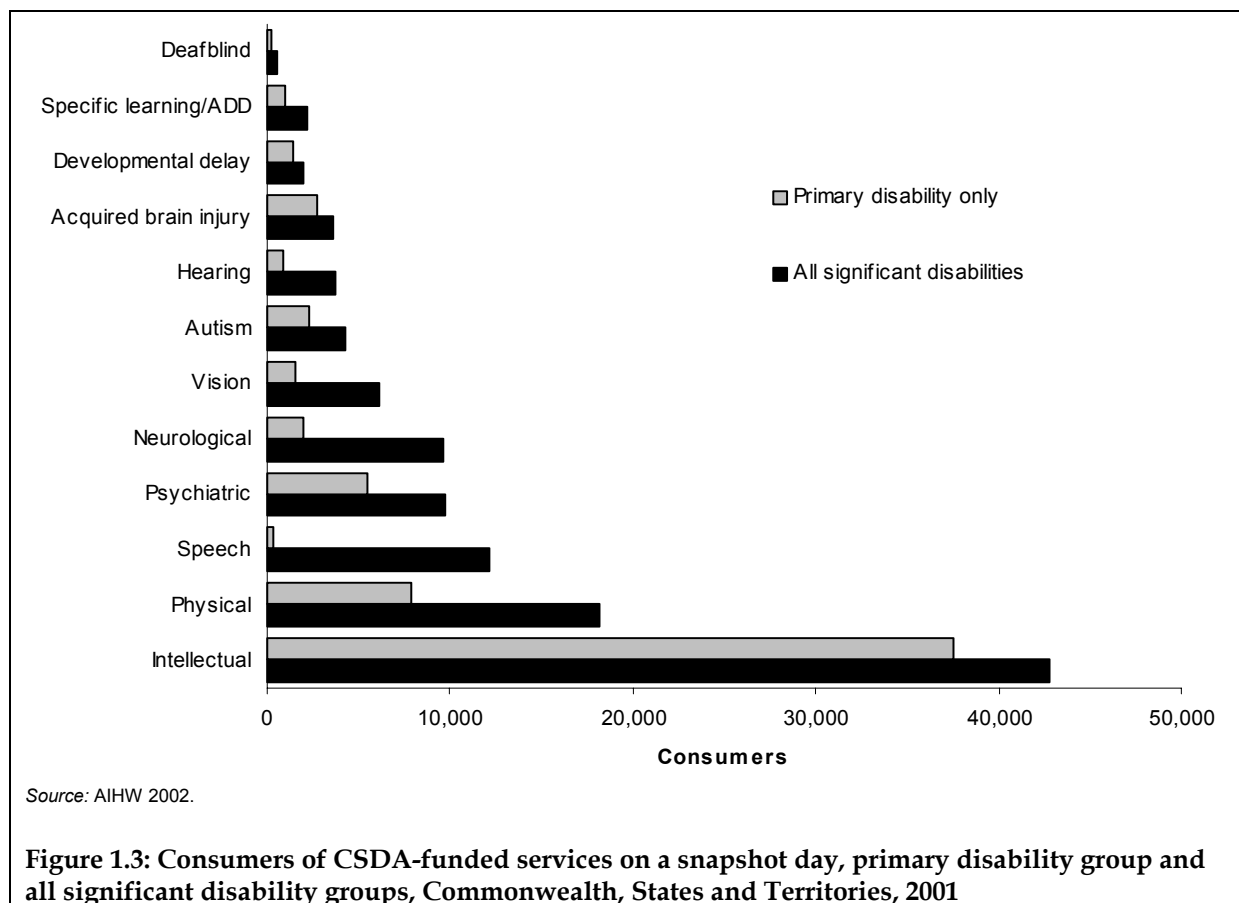


Table 1.7: Outlets of CSDA-funded services on a snapshot day, service type by State and Territory, Commonwealth, States and Territories, 2001

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

Notes

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

2 Framework and method

This chapter describes the key concepts and definitions for the study, relates these to the main data sources to be used, and outlines the overall study method.

2.1 Concepts and definitions for the study

The aims set down for this study require agreement about key underlying ideas, in particular, who needs CSDA disability support services, who receives them and what is the effect of the services for the recipients. These are deceptively simple ideas, and people tend to ‘know’ what they mean, but to ‘know’ differently. This section outlines some concepts and definitions for use in the study, in order to make the analytical process clear.

An extensive theoretical discussion of definitions is not needed, rather an attempt to ensure that terms used are theoretically tidy, in accord with recognised literature, and understandable in the context of national disability services.

Disability and the CSDA target group

Disability is a broad term, and the support services offered under the CSDA target only a subset of people with disabilities in Australia.

The CSDA 1998 is an agreement about services to ‘people with disabilities’:

‘people with disabilities’ means people with a disability attributable to an intellectual, psychiatric, sensory, physical or neurological impairment or acquired brain injury (or some combination of these) which is likely to be permanent and results in substantially reduced capacity in at least one of the following:

- self care/management
- mobility
- communication

requiring ongoing or episodic support.

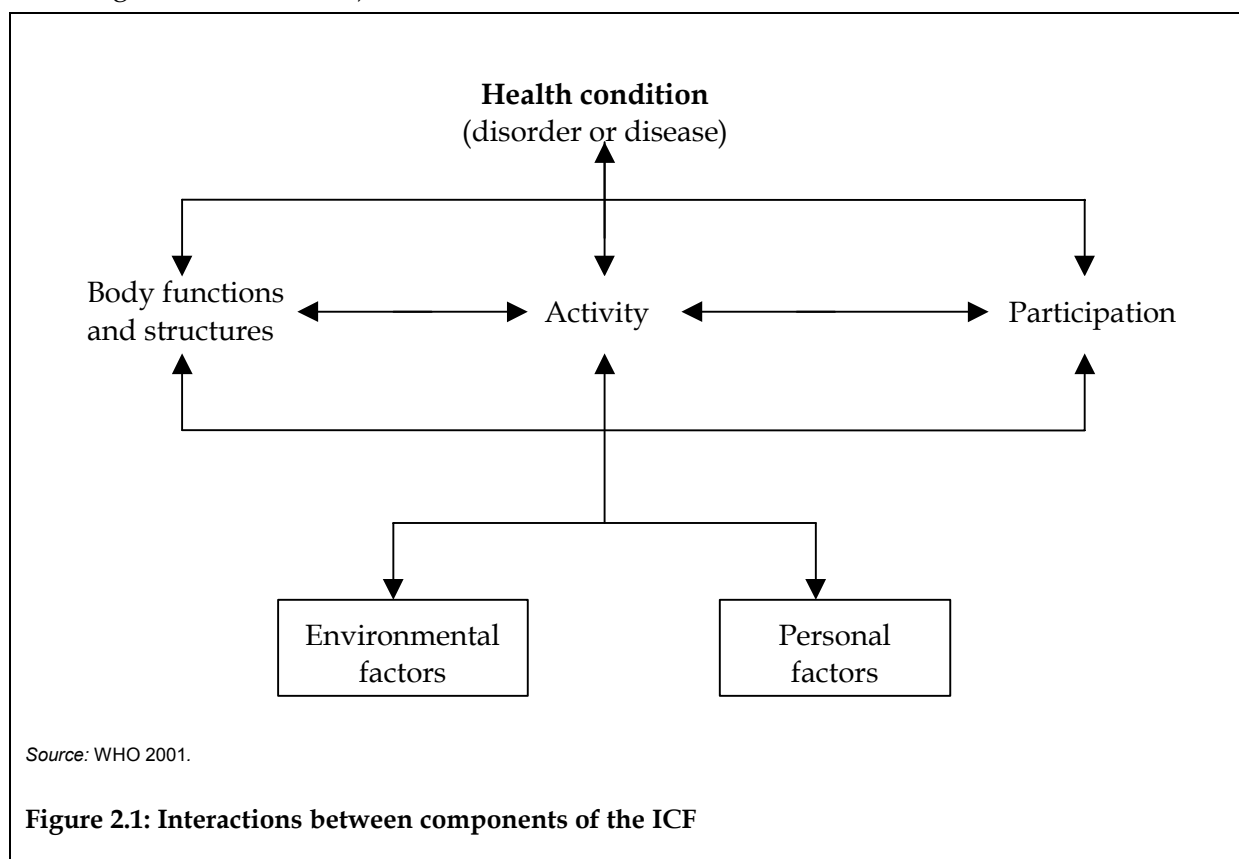
This means that CSDA services are specifically targeted to a group of people who would be regarded as having high levels of disability by most members of the community. Further detail about the CSDA is provided in Chapter 1, but this description of the target group is repeated here, as it underpins much of the consideration of need for services.

Disability and relevant services

Disability is conceptualised as multi-dimensional, relating to the body functions and structures of people, the activities they do, the life areas in which they participate, and factors in their environment which affect these experiences (see Figure 2.1). The disabilities of people for whom CSDA support services are designed can be located in the broad spectrum outlined by the International Classification of Functioning, Disability and Health (ICF – World Health Organization 2001). The ICF provides a framework rather than a universal definition.

CSDA services relate to the ICF framework in a number of ways. For instance, they aim to promote participation – a key ICF concept – classified across defined life domains. They may

do so by providing assistance in any of these major life domains (see Table 2.1 following for a listing of these domains).



Services and assistance of relevance to people with a disability may seek to ameliorate disadvantage associated with any of the components of disability – impairment, activity limitation, participation restriction or environmental barriers – and include:

- formal services and assistance, such as income support, specialist disability services, and relevant generic services;
- equipment or environmental modifications; and
- informal support from family and friends.

Specialist disability support services under the CSDA are thus situated in this mosaic of services and assistance.

The CSDA MDS support need question is framed around the ICF domains for activities and participation, and records the assistance needed in ways that promote comparability with relevant population data and with the common assessment tools in the Australian disability field. The ABS Surveys of Disability, Ageing and Carers have, since starting in 1981, attempted to relate conceptually to the ICF as it emerged, and its predecessor, the International Classification of Impairment, Disabilities and Handicap, for the same comparability purposes. The use of a common framework maximises the comparability of the CSDA MDS data with data from other collections including population surveys.

The relationship of the ICF to the broader conceptualisation of human need and welfare is discussed in a range of documents including, in Australia, AIHW 2001b (Chapter 9) and Madden et al. 1996.

Effectiveness and CSDA service goals

The project brief defined 'effectiveness' as:

Effectiveness, in this context, refers to the degree to which stated funding objectives have been achieved.

This definition is in accord with the usual approach to defining effectiveness (for example, SCRCSSP 2002 and AIHW 2000b) and the study team has focussed on this approach.

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

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

More specific CSDA service goals are tabulated in Box 1.1. These goals, together with the overarching goal statement of the CSDA – relating to participation and quality of life – are the 'goal backdrop' of the study. Into this backdrop the specific goals of the unmet needs funding have been added.

Specific goals of the unmet needs funding for 2000–01 are in the Bilateral Agreements negotiated between the Commonwealth and other individual jurisdictions in 2000 (outlined in Section 1.3). Chapters 3 and 4 also provide more detail on the various stated objectives of CSDA and unmet need funding.

In the available time for this study, the primary focus of the investigation of effectiveness of unmet need funding is the provision of additional services.

Eligibility, needs and demand

Needs and demands are complex, multi-dimensional concepts that may be experienced differently by individuals with a disability, and by carers, communities, service providers or program managers.

In a market economy, demand, supply and price are interconnected. That is, any one of the three is affected by movements in another, and interventions on one factor (for example, price) can affect the other two. The demand for publicly provided resources tends to exceed supply, and the equitable allocation of resources among competing demands can be promoted by clear eligibility criteria and open and accountable administrative processes (Charles & Webb 1986).

Eligibility criteria for government-funded disability services reflect policy decisions about which needs are to be recognised, with community responsibility accepted and resources made available. These eligibility criteria and their supporting administration provide the rationing mechanism for the distribution of resources.

In a tightly defined service program, with highly specific eligibility criteria and related assessment methods, needs quantification and management can, in theory at least, be clearly described.

Administrative definitions of disability, by the creation of eligibility criteria, also have an implicit, and sometimes explicit, relationship to service goals and hence to outcome measures.

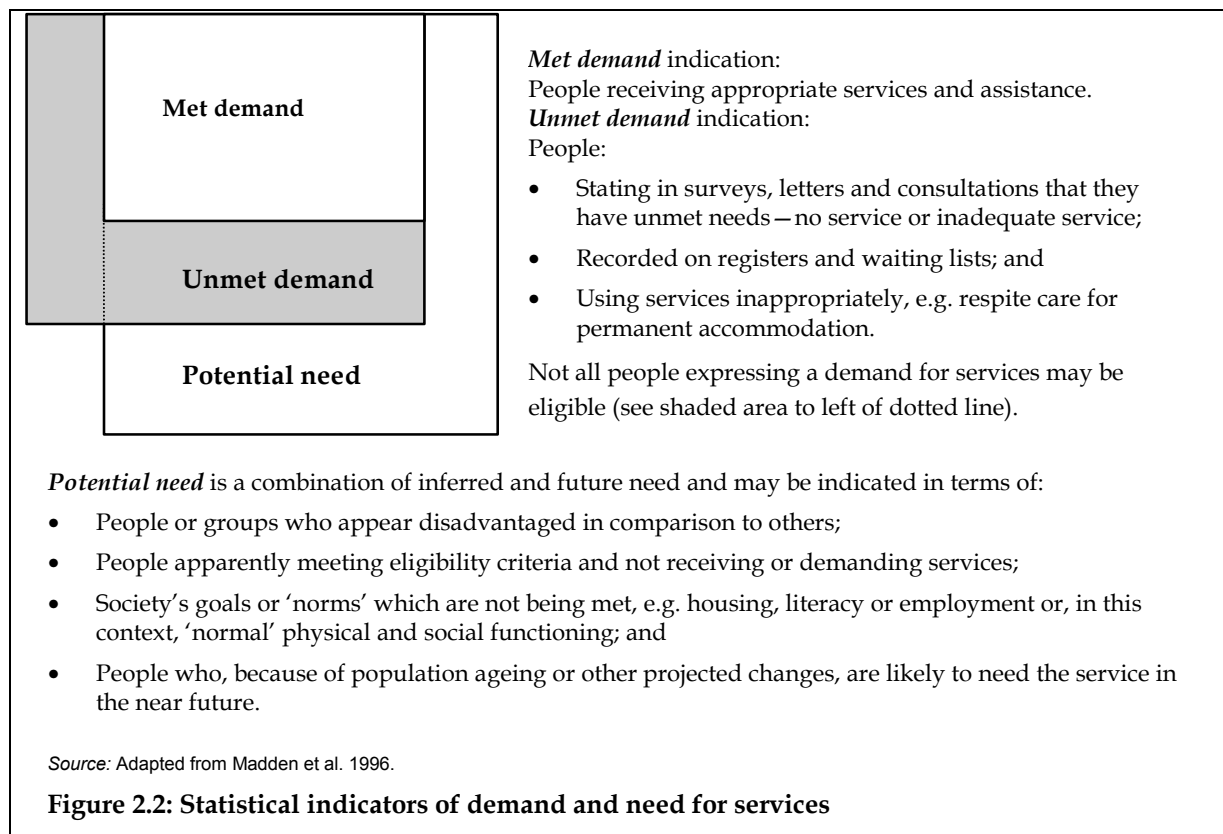
In the strict economic sense, the term 'demand' may not apply to the CSDA program, as the price mechanisms are not 'pure', although there are prices at work. However the term

‘demand’ was the term chosen by Administrators for the 1995–96 and 1997 studies and, as outlined in the following, equates approximately to the notion of ‘expressed need’.

The 1997 AIHW ‘demand study’: relating to data

The 1997 AIHW study of ‘unmet demand’ took the following approach to the use of statistical data for the purpose of the study.

Needs and demands for services or assistance may be indicated by statistical data in a number of different ways. Figure 2.2 illustrates the relationships between met demand, unmet demand and potential need and suggests approaches to the statistical indication of each.



‘Met demand’ is considered, generally, to be people receiving an appropriate service. Data on service users are relevant. However, some people receiving services may be receiving an inadequate level of service, or may be receiving an inappropriate service because the most appropriate service was not available. Indications of these situations were considered, in order to qualify, as necessary and possible, the use of data on service use as directly indicating met demand.

‘Unmet demand’ is indicated by numbers of people expressing the need for a service, but not receiving the service, or receiving inadequate service or an inappropriate service. Need can be expressed through a population survey asking relevant questions, or through administrative means such as waiting lists, application processes or registers. Not all such people will be eligible for CSDA services (but may perhaps be eligible for another type of disability service), and they are represented in Figure 2.2 by the shaded area to the left. Unmet demand, as described in the 1995–96 and 1997 AIHW studies, thus corresponded to the notion of expressed need.

On equity grounds, it is nevertheless important to consider needs for formal services other than those actually expressed. The term 'potential need', as used in the previous AIHW studies, embraced two notions. First, a level of need may be *inferred* by comparing the characteristics of people receiving services, or demanding services, with those in apparently similar circumstances but not expressing the need for services. This approach is often used in service planning. Second, the term 'potential need' also embraces an element of *prediction*. For instance, consider the situation of an adult person with a disability living with ageing carers. Neither the person nor the carers express a need for formal assistance, and they are not on any waiting lists. They are not included as 'unmet demand', but they could be included in data on potential need, as they *may*, in the not too distant future, begin to express the need for assistance. The older the carer, the more likely it is that this need will indeed be expressed as demand in the near future¹.

Estimating 'unmet need' or shortfalls in 2002

The current study team has built further on this earlier work outlined above (see further detail in AIHW 1997a; Madden et al. 1996). In particular, it has been important to allow for and make use of the changes to the ABS Survey of Disability, Ageing and Carers between 1993 and 1998.

To estimate any remaining unmet need for the CSDA service types, operational definitions of unmet need must be developed. This is complex in a program such as the CSDA, which is not an entitlement program and where, moreover, there may be differing emphases among the various jurisdictions, in terms of service priorities, access criteria and relationships with other support programs.

¹ The concepts and terminology used in the AIHW studies (1996 and 1997) referred to were generally consistent with key literature, for example, that of Bradshaw 1972, who suggested four definitions of 'social need'. Bradshaw's four terms correspond to the current discussion as follows:

'Felt need' or want is not considered in the AIHW studies.

'Expressed need' is included in the AIHW studies by this name (also referred to as 'demand' for a non-market service in the 1996 and 1997 AIHW studies). As Bradshaw says, this is 'felt need turned into action'.

'Comparative need' is included in the AIHW concept of 'potential need', chiefly in the idea of 'inferred need'.

'Normative need' is included in this study in so far as the CSDA target group is considered well specified, that is, that the group who 'should be' receiving services is well defined. The use of the 'severe/profound' core activity restriction is relevant, as is its broad acceptance as defining the 'potential population' for CSDA services. Table 2.1 essentially introduces further 'normative' concepts, related to the frequency of need for assistance. These, or related decisions concerning the most appropriate indicators of need for assistance, must be assumed in order to be able to use the population data to best effect. Hence, comment was sought from NDA at the progress report stage, to see if the assumptions were acceptable to policy makers.

It is, further, worth noting that there is considerable debate in the disability field about 'who measures' disability or eligibility for services, and this important aspect is something of a 'sleeper' in the Bradshaw discussion. Recently, for instance, the Commonwealth Government appears to be contemplating splitting its measurement of work ability into the measurement of impairment (by people with medical training) from the measurement of work-related activity limitations and participation restrictions (by other professionals).

The project brief given to prospective tenderers noted the 1997 AIHW work and that:

the terms unmet demand and unmet need are frequently used interchangeably, although strictly speaking the two are not synonymous.

While the study team does not argue that ‘need’ and ‘demand’ should be treated as synonymous, it has not expanded the interpretation of ‘unmet need’ more broadly than the 1997 approach outlined above, relating to expressed need and potential need. In operationalising the definitions in 1997 (so as to be able to use the ABS survey), some evidence of the person trying to obtain a formal service was used to signify ‘demand’ or ‘expressed need’. In retaining a generally conservative approach to any estimation involved in the current study, the team has still sought such evidence. Inclusion of other forms of need, not ‘expressed’, will lead to higher estimates. Nevertheless, as with previous reports, other data indicating need are considered for particular population groups, for example, ageing carers and Indigenous Australians.

Concepts of need and the available data

It is worthwhile briefly to consider the relationship between these broad concepts of need and the available data.

Self-reported need for assistance with activities (ABS surveys)

The need for assistance with self care, mobility and communication—the three broad domains mentioned in the CSDA target group—correspond to the ABS definitions of ‘severe or profound core activity restrictions’. These needs categories and the related ABS data are therefore used in estimating the ‘potential population’ numbers agreed for use in the denominators of performance indicators for the CSDA program. For this purpose the ‘potential population’ estimates adjust the severe/profound numbers for the Aboriginal and Torres Strait Islander population, because of the evidence of their higher disability rates (AIHW 1997b; SCRSP 2002). The potential population concept was later adopted for use in the second CSDA to allocate new funding.

A number of jurisdictions use the ABS data on ‘severe or profound core activity restrictions’ for the basis for regional allocation of funding and monitoring of the equitable spread of program resources. These are now considered basic measures of disability and, in particular, are used as baseline data in calculating measures of ‘potential need’ for CSDA services (or ‘comparative need’ using Bradshaw’s term). They indicate a need for assistance, but not necessarily a need for assistance from a formal service.

A more detailed discussion of the ABS disability survey concepts is included in Chapter 6.

Self-reported need for assistance with activities from formal services (ABS surveys)

These data refer to people with a self-reported need for assistance with one or more activity, who also indicate a need for assistance from a formal service. Data from the ABS survey relating to the self-reported need for formal services are taken in the report as ‘expressed needs’ for formal services, and are used in the estimation of unmet need for CSDA services.

Expressed need for CSDA services specifically

Recipients of CSDA-funded services are, by definition, receiving assistance from formal services. While data are not systematically collected on those who request a service but do not receive it², some such data are increasingly available.

Registers of need or holistic application processes are in place in several jurisdictions, although the scope and process vary. These registers are considered a useful approach to considering long-term needs of stable populations, and potentially yield useful indications of the scope and nature of need in the client population. These data were obtained from jurisdictions during the study as providing a potential complementary source of information, to enable 'triangulation' or corroboration of estimates using data from more than one source (see Chapters 5 and 7).

The balance of measurement

The use of both types of estimates—population based (for equity reasons) and application based (essentially for empowerment reasons)—appears to be an accepted part of the administration and planning of the CSDA program. They reflect the use of the Bradshaw notions of comparative need and expressed need. As previously outlined, both notions were also reflected in the AIHW 1997 demand study, with the terms used being potential (including inferred) need and expressed need or demand.

The approach to estimation in this study is essentially a combination of:

- population-based data; and
- registration-based data.

Carers

While still focusing on people with a disability as the clients for CSDA services, the CSDA program increasingly recognises the primary role of informal care, provided by families in particular. The complementarity and interaction of formal and informal care are important considerations for the program and for this project.

In 1997 the study team had to make assumptions about what was 'expected' of carers (see Appendix 1). In brief, it was assumed that Australian society does not expect people with high support needs to be left to themselves or to the lifelong, 24-hour care of their family. The assumption was especially relevant to the estimation of need for day activity services in 1997. This assumption was supported by subsequent government policy responses, where ageing carers are specifically mentioned in the Bilateral Agreements. Similar assumptions are made in this study (further detailed in Chapter 6). The area is complex and evolving, relating to social expectations about people and families, about the role of the family, and the role of the wider society.

² Such a systematic collection relating to unmet need is undertaken in some other service areas, e.g., the Supported Accommodation Assistance Program (SAAP) Unmet Need Survey.

2.2 Relating key data sources to the key concepts

Data sources to be used must be related to the key concepts outlined in Section 2.1. This section works towards building these relationships, to enable data analysis and other discussion to proceed.

Needs and CSDA service types

The CSDA services offer support in a broad range of activities, with the goal of enabling participation in society by people with disabilities. As noted above, these services are by no means the only ones that can enable this participation.

In previous studies the Institute was urged, in looking at needs, to 'start with the individual'. Several major, recent policy initiatives have reinforced this approach. The approach is:

- in harmony with policy directions in most jurisdictions, attempting to develop flexible person-oriented services, rather than fitting people's needs to existing service types;
- in harmony with disability policy more broadly, where people with disabilities are viewed as people first, with rights to participate as full members of society; and
- consistent with the view that specialist disability support services provide assistance within a potentially broad array of services; people, in order to meet their needs, will 'flow' between categories of similar services, depending on the availability of services. For example, people needing long-term accommodation may accept respite care as the only service available. This displacement effect may not always be 'downwards' to a lower intensity service; people wanting a supported accommodation service may, for example, accept a place in a nursing home.

The relationship between generic and specialist services has recently been clearly set out in the case of employment services. Centrelink provides a broad intake point of entry, and streams potential recipients of employment support via the Job Seeker Classification Instrument; thus people with needs for ongoing assistance are directed to CSDA employment support services and others to the Job Network (see further detail in Chapters 5 and 7).

A person's needs may be met by a variety of means, for example, an individual may be identified as potentially in need of in-home support, supported accommodation and respite. If any one of these is provided, the need for the others may be removed or reduced. The most appropriate of the alternatives can only be assessed on an individual basis, not from broadly indicative national data.

The need for participation and activity across a range of life areas is experienced by people with a disability, their carers and their families. Sometimes one person's need may conflict with another's. For instance, a carer's need for employment may apparently conflict with another person's need for accommodation support: the conflict may be resolved by the provision of appropriate accommodation support and/or day activity in suitable hours.

For all these reasons, services have been grouped, for the purposes of this study, to reflect broad categories of need. For instance, sharp distinctions are not made between categories of accommodation support services, including respite care. People may 'flow' between these

service types and, in some circumstances, they may be in effect somewhat substitutable³. A national data analysis cannot meaningfully distinguish between needs for similar types of services when people may move from one type to another on the basis of availability. When analysing data on the need for assistance, the identification of specific service types required is difficult, not just because of the mix of available services, but also due to the non-exclusiveness of many models of service delivery.

Relating need for assistance with activities to need for CSDA services

To infer expressed need for CSDA services from ABS survey results on need for assistance with activities, a relationship framework must be constructed. This must be, to some extent, a matter of judgment (because CSDA eligibility, perhaps wisely, is not very specifically defined), but experienced practitioners should be able to find consensus around such a framework. The framework set out below was conveyed in draft form to jurisdictions in a progress report on the project, and has been revised in the light of comments received.

Table 2.1 sets out this framework. It is designed to align or relate the CSDA service concepts to the concepts in the ABS survey. The table underpins the data analysis in Chapter 6, and is a 'template' to allow ABS data, CSDA MDS data and the CSDA target group and CSDA service types to be related. The ICF broad domains for activities and participation have been used to guide the construction of the relationship framework. They are not themselves used to estimate need.

To estimate expressed need, a threshold in each ABS question must be applied, that equates with inclusion in the CSDA target group.

Table 2.1 represents a refinement of the 1997 estimation method, made possible by new questions in the 1998 ABS Survey of Disability, Ageing and Carers, on *frequency of need for assistance across all 10 activities* in the survey. The 10 activities are: self care, mobility, communication, health care, housework, meal preparation, property maintenance, transport, guidance and paperwork. The frequency of assistance options are: does not need, <1/month, 1-3/month, 1/week, 2-6/week, 1/day, 2/day, 3-5/day and 6+/day. (See more discussion in Chapter 6.)

The CSDA itself does not specify eligibility criteria for services, other than via the broad target group statement (Section 2.1). In order to use the ABS data, however, these data must be related to *desired or reasonably expected practice on the ground*. Table 2.1 is a key step in doing this.

The table can be used to relate activities to service needs. Thus, the need for accommodation and respite services is principally indicated by the higher frequency need for assistance with the 'core' ADLs (self care, mobility and communication) but may be further indicated by the need for assistance with housework, meal preparation, property maintenance and paperwork. The need for employment services relies less heavily on the core ADLs, and offers two alternative approaches to the indication of need: either still relatively frequent need of assistance with the core ADLs, or less frequent need for assistance accompanied by a need for 'guidance'.

³ Support for the idea of substitutability is found in a New South Wales parliamentary report (New South Wales Legislative Council 2000): 'Respite services are vital to maintaining long-term informal arrangements for people with disability. It is well recognised that investment in respite is a cost-effective and highly desirable way to provide on-going accommodation supports. Adequate provision of respite ensures that demand for permanent accommodation is minimised.'

Via this type of reasoning, the table underpins key estimates in Chapter 6. In preparing the table, and in its overall approach to the project, AIHW has continued its conservative approach to the estimation of unmet need. Thus, while it might be possible that people with lower level needs than those described in the table might access these services, it is intended that the support needs are fairly typical of the intended client group.

It is important to note at this stage:

- Table 2.1 does not represent a full picture of the approach to the ABS survey analysis. Questions other than support with activities will also be used to 'drill' through the population data. Figure 2.3 is included to illustrate the process of 'drilling' through population data to determine baseline estimates of unmet need, using the example of need for accommodation and respite services. This process is described in more detail in Chapter 6.
- The approach in the table is compared to the profile of support needs for clients of each CSDA service type (Table 6.1). While it will not be assumed that current client profiles should be perfectly aligned with 'potential clients' based on analysis of the population data, differences should be noted.

The importance of triangulation of estimates

A range of sources has been used, both to ensure that all available information is brought to bear on this important project, and also to seek opportunities for confirming findings using data from different sources and differing perspectives. Sources include jurisdictional databases, national data sets, literature on service evaluation and costing, recent published information on unmet need, and discussions with peak bodies.

It must be emphasised that the ABS survey data are not the sole foundation of the final estimates of unmet need. The ABS survey data provide the source of the baseline estimates in Chapter 6. The data from jurisdictions' registers of unmet need for services are used more directly, in Chapters 5 and 7, as a parallel source of data to estimate unmet need.

In Chapter 7, these two primary sources, together with other data, are compared and combined to arrive at consolidated estimates of unmet need. This process of cross-checking and corroboration using multiple data sources, for estimation purposes, is frequently referred to as 'triangulation' in the social and physical sciences. This term recurs in this report, as data from multiple sources are brought to bear on the complex questions considered in the report.

Table 2.1: Relating ABS data to the need for CSDA services

Individual's life areas ^(a)	Disability support services (CSDA)	Relevant 'activities' questions in ABS survey	Relationship between frequency of need for assistance in ADLs ^(b) and CSDA services	Relationship between other support needs (as indicators, not essentials) and CSDA services
Learning and applying knowledge	Community support, Community access, Employment	Guidance, communication	Community support possible.	
General tasks and demands	Community support, Accommodation, Respite	Guidance, property maintenance, mobility , paperwork, communication	Accommodation & respite if at least 3–5 times per day, or less frequent if other ADL needs present	Other activities are supplementary indicators of need for these services Community support if lower frequency needs
Communication	Community support, Accommodation, Respite	Communication	Accommodation & respite if at least 3–5 times per day, or less frequent if other ADL needs present	Community support if lower frequency needs, and as a possible supplementary service
Mobility	Community support, Accommodation, Respite	Mobility , transport	Accommodation & respite if at least 3–5 times per day, or less frequent if other ADL needs present	Community support if lower frequency needs
Self care	Accommodation, Respite	Self care , health care	Accommodation & respite if at least 3–5 times per day, or less frequent if other ADL needs present	
Domestic life	Accommodation, Respite	Housework, meal preparation	Accommodation & respite if at least 3–5 times per day, and other ADL needs present.	Note: if domestic life the only area of need, HACC may be used
Interpersonal interactions and relationships	Community support, Community access, Respite	Guidance, communication		Supplementary indicators for all service types (if high frequency)
Major life areas (education, work, economic life)	Employment, Community access	Communication, self care, mobility , guidance, paperwork	Employment if needs: – at least daily support in any ADL, or – some assistance with at least one ADL and 'guidance' at least weekly Community access if once daily or more for two or more ADLs	Other activities are supplementary indicators of need for these services
Community, social and civic life	Community access, Community support	Communication, self care, mobility , guidance, paperwork	Community access if twice daily or more	Community support if lower frequency needs, and as a possible supplementary service

(a) The life domains in the left-hand column are as listed in the ICF, the International Classification of Functioning, Disability and Health (World Health Organization 2001).

(b) Activities of daily living (ADLs), as mentioned in CSDA target group definition, are highlighted in bold.

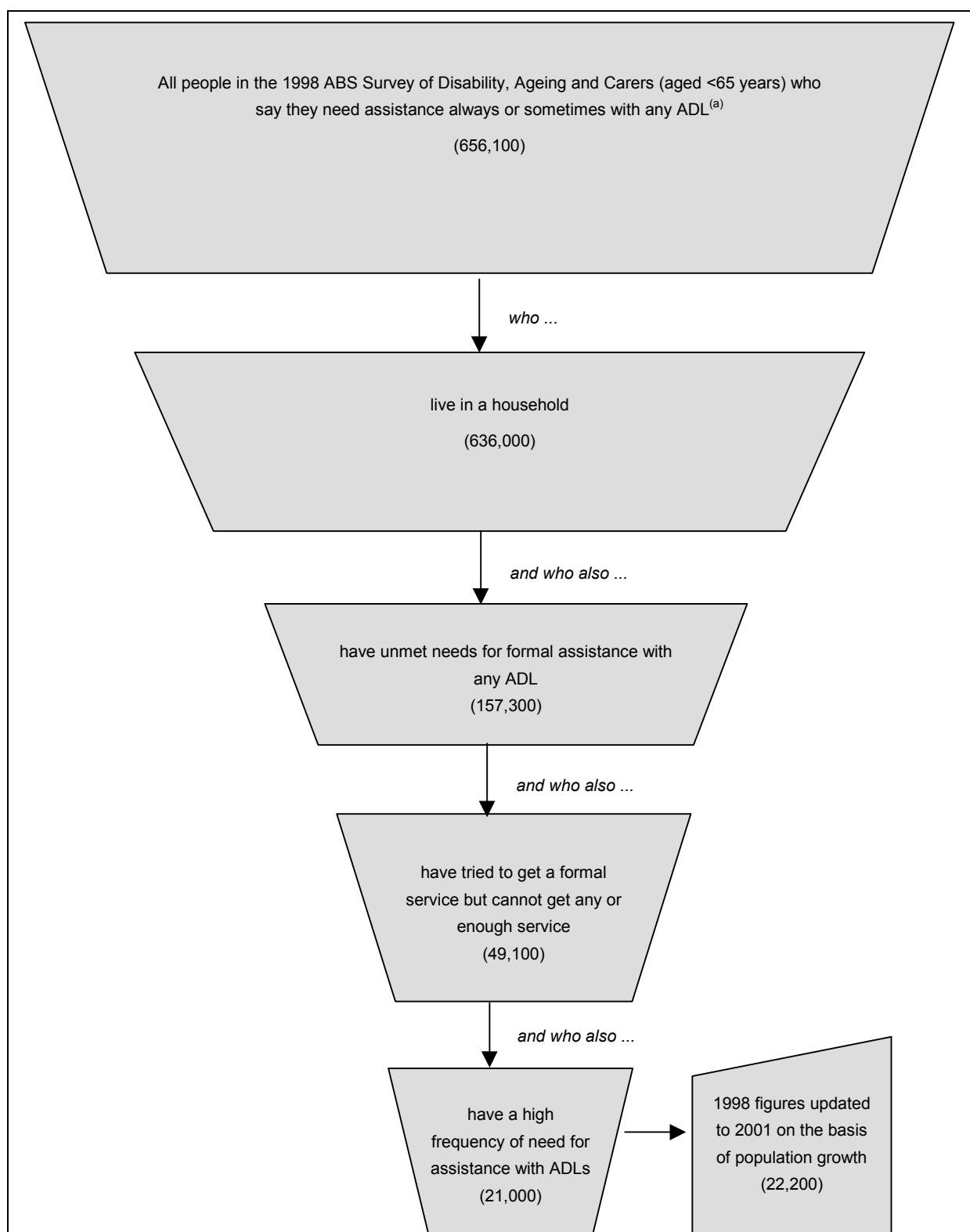


Figure 2.3: The process of 'drilling down' through population data to develop baseline estimates of unmet need for accommodation and respite services in 2001

(a) ADLs are activities of daily living: self care, mobility and communication.

Source: Figure 6.1.

2.3 Study method

Five project components (or areas of work) were set down as the 'scope of work' required by the NDA. This section describes how the Institute carried out each of these areas of work.

Area 1: Collation and analysis of data provided by the Commonwealth, States and Territories, together with any other recent data available from relevant sources, regarding services provided as a result of unmet need funding provided in 2000–01.

Tasks for this project component included the following.

First, the Bilateral Agreements were reviewed for statements about funding objectives and jurisdictional obligations to report to the Commonwealth. The aims were to discover:

- what information the Commonwealth has received from the States and Territories;
- the extent of Commonwealth analysis already done relating to reports received from States and Territories; and
- the processes generally followed.

Second, a detailed questionnaire was sent to all jurisdictions (see Appendix 2), requesting information on:

- 'new money' and its objectives;
- detailed information about the use of the new money, including numbers of services and clients, and their profiles;
- effectiveness of this funding; and
- possible remaining shortfalls and the method of estimating these.

All jurisdictions responded, though not all within the requested timeline. Two study team members were assigned to each jurisdiction to analyse the information and follow up as required. In some cases extensive follow-up was needed to clarify data, seek missing information and resolve apparent discrepancies.

Third, likely sources of relevant data were searched, including peak body publications and web sites, AIHW publications, and other literature.

Area 2: Secondary analysis of any study or evaluation conducted regarding the impact of services provided as a result of unmet (need) funding or of the impact of similar services provided with other funds.

This area of work involved obtaining relevant evaluative information from jurisdictions, peak bodies and other relevant organisations, and via a literature review. Of particular interest were questions on special innovative projects, and lessons learnt from their use including individual funding packages – their effectiveness and profile of target group and users.

A search for literature and other information on the effectiveness of other similar service types was carried out. An extensive literature review was not possible within the constraints imposed by the study time frame. Moreover, the study team was aware of, and had the opportunity to interact with, the team carrying out a related NDA project (to 'Review current responses to meeting service needs of people with a disability and the effectiveness of strategies to support families').

Area 3: Estimation of the effectiveness of unmet need funding in reducing unmet need for services, using an appropriate methodology.

This was a key and challenging aspect of the project. In addition to the information obtained in Areas 1 and 2, the following analyses were carried out.

Macro data analysis

The AIHW made relevant use of the CSDA MDS national data sets for recent years, up to and including the data set for 2000–01. Areas investigated included:

- Service growth: trends in service types of interest in recent years.
- Service trends: investigating a possibly changing profile of service provision and service users (numbers and characteristics).
- Analysis of the profile of services resulting from unmet need funding (assuming these can be identified – this proved not possible, as most jurisdictions could not provide the required information in the available time).

AIHW also carried out extensive analysis of the ABS Disability, Ageing and Carers surveys (see Chapter 6).

These two major national data sources help provide a national, quantitative context in which to place the other information gathered.

Analysis of data concerning related services

Because of the context in which specialist disability services operate, their operation is affected by other service trends, and information on the following service systems was also sought:

- the profile of people with long-term disabilities, aged under 65, in residential aged care;
- use of HACC and other community services;
- the health and rehabilitation systems;
- employment, education and training systems;
- variation among jurisdictions in the use of housing services; use of services for homeless people by people with disabilities; boarding house closure and what has happened to former residents;
- trends in income security payments; insurance, as it affects the entitlements of different people in different ways, and as it affects the operation of non-government service providers; and
- transport systems and equipment and environmental modification services.

Other information

The consideration of effectiveness also relied on information collected in relation to Areas 1, 2 and 4.

Area 4: Identification of any remaining unmet need for disability accommodation, in-home support, day programs, respite services, and disability employment services, using both qualitative and quantitative measures to obtain an understanding of shortfalls in services (if any).

This component of the specified work related to the second main project objective, and relied on assembling information from a range of sources. Three levels of analysis supported this component.

Population data analysis

Analysis of ABS population surveys was carried out (see especially Chapter 6).

Analysis of data from individual jurisdictions

Analysis of data from jurisdictions on remaining unmet need was carried out, including information from service registers (for example, in Victoria and Queensland) and local area planning mechanisms (Western Australia and South Australia) and any other statewide methods of recording unmet need.

Qualitative analysis: the nature of unmet need.

Recent and reliable accounts of the existence and experience of any unmet need were sought, for example in articles, peak body newsletters, government and peak body reports on consumer consultations.

Discussions with peak organisations

The disability field is a highly committed one, and one where differing views are often expressed as to how to move towards common goals.

Three discussions with peak and community organisations took place in Canberra, Brisbane and Melbourne during February and March 2002.

The purpose was to:

- explore aspects of the new or innovative services, the process of introducing them and the effectiveness for clients (ideally, the individual experience of reduced unmet need);
- explore ideas of effectiveness and outcomes achieved, timelines for achieving outcomes and objectives, and difficulties encountered;
- explore the experience of clients who have benefited from new funding;
- discuss costs with service providers; and
- explore the experience of unmet need.

The agenda for these discussions, the participant list and other details about the process are at Appendix 3. Chapters 4 and 7 have special sections (Sections 4.4 and 7.3) devoted to the issues raised in these discussions.

Area 5: Formulation of recommendations regarding appropriate costing models/approaches to assist in determining the costs of any remaining unmet need for disability services.

In the fifth and final area of work specified for the project, the project team built on the approach used in the 1997 study, and:

- briefly reviewed literature about cost factors and cost models, so as to understand some of the key factors influencing costs 'on the ground';
- synthesised the understanding gained from the project research about costing methods and models in use; and
- developed some broad, feasible and practical national approaches to costing large numbers of services.

3 The use of the unmet need funding

3.1 Introduction

This chapter considers how the unmet need funding contributed by the Commonwealth and each State and Territory was applied in 2000–01 and is being applied in 2001–02. It outlines:

- the data used for the analysis and their limitations;
- the actual quantum of funds made available by jurisdictions;
- the application of that funding considering jurisdictions' objectives, allocations to and/or expenditure on specific service types;
- the expected number of people to benefit from the funding;
- the average government funding per person assisted;
- cost factors, literature on the cost of disability services and the development of funding mechanisms based on different levels of individuals' assessed needs; and
- achievements of the unmet needs funding compared with expectations.

Unmet need funding

Table 1.1 shows the contributions of each jurisdiction as indicated in the 2000 Bilateral Agreements. Using the Commonwealth's counting convention, total funds offered over the two-year period amount to \$519 million. This includes the 2000–01 allocation of \$210 million by all jurisdictions, which is recurrent and is extended by a further \$99 million in 2001–02 to \$309 million.

In the Bilateral Agreements over the two-year period, all jurisdictions agreed to broadly match or exceed the Commonwealth's contribution. The New South Wales offer was the most significant, accounting for 44% of total unmet need funding offered by State and Territory jurisdictions in 2000–01 and 39% in 2001–02. The New South Wales offer exceeded that of the Commonwealth by more than fivefold in 2000–01, and more than threefold in 2001–02. Victoria's 2000–01 offer exceeded the Commonwealth's offer by more than threefold.

3.2 Data sources and limitations

This chapter draws on three main sources of data:

- responses provided by States and Territories to the Commonwealth as part of the acquittal of funds for 2000–01;
- responses provided by each jurisdiction to the survey conducted by AIHW for this study (referred to as the Jurisdiction Survey); and
- data published in the 2002 Report of the Commonwealth/State Steering Committee on Service Provision (referred to as the Productivity Commission data).

Acquittal data

The 2000 Bilateral Agreements included reporting requirements for each jurisdiction regarding the use of the Commonwealth's funds. All agreements state that, wherever possible, existing reporting mechanisms will be utilised. However, the data items requested do not always align specifically with CSDA MDS data items (the main statistical collection mechanism common to all jurisdictions) and are in some cases not available from current MDS data. This is the case for the age of carers, a data item required by the terms of reference for this study; this will be available in the redeveloped collection.

Furthermore, while most jurisdictions are required to report on the number and type of services provided, the number of ageing carers assisted and the geographic distribution of the funds, the actual data items requested are defined differently in each jurisdiction's Bilateral Agreement. For example, the number of people assisted is counted in the following ways across jurisdictions:

- New South Wales agreed to report on the number of people who received immediate response packages;
- Queensland, South Australia, Tasmania and the Australian Capital Territory agreed to report on the number of persons with ageing carers assisted;
- Western Australia and the Northern Territory agreed to provide:
 - CSDA MDS data on the total number of additional people with disabilities aged 35 years and over living at home and in receipt of respite, recreation or day support; as well as
 - Local Area Coordination data, including number of carers provided with new or added services; and
- Victoria agreed to report on the number and type of new services provided to the target group.

Partly as a result of the varied reporting requirements of the Bilateral Agreements, acquittal data provided to the Commonwealth in relation to services to ageing carers are neither comparable nor able to be combined at a national level.

In July 2001, following the completion of the first year of the unmet need funding, the Commonwealth asked jurisdictions to report on the application of its contributions. Most responses were made in October 2001.

Some jurisdictions indicated that services were not fully operational during 2000-01 or that while allocations had been completed not all the funding had been rolled out. This appears to be due to a combination of lead times for establishing new service strategies or initiatives and the signing of some Bilateral Agreements not occurring until after the commencement of the 2000-01 financial year. New South Wales also mentioned the Olympics as having disrupted the schedule for their tendering process.

Therefore the acquittal responses of jurisdictions to the Commonwealth provide only some preliminary data in relation to the application of the Commonwealth's \$50 million allocated for use in 2000-01.

Jurisdiction Survey

Given the limitations in the data provided to the Commonwealth, the Jurisdiction Survey¹ conducted by the AIHW for this study needed to clarify the application of the Commonwealth funds for 2000–01, seek estimates of their use for 2001–02, and request predictions about the ongoing impact of the funds. Similar information on the contributions made by States and Territories, which represent over two-thirds of the unmet need funding, was also needed.

In particular, sections 1 and 5 of the survey (see Appendix 2) requested the following information from States and Territories:

- whether the Commonwealth’s contribution could be distinguished from their own and from other disability funding;
- the objectives for their own contributions to unmet needs funding;
- the policy processes for selecting service types;
- the strategy for service provision for ageing carers;
- the contract and accountability arrangements and any costing models used;
- audited financial statements indicating the purpose and extent of jurisdictional expenditure;
- expenditure on each of the service types or program areas to which unmet need funding was directed; and
- for each of these service types or sub-programs:
 - a brief description of its aims;
 - its offerings;
 - the number of clients assisted;
 - the proportion of new and existing clients assisted;
 - targeting;
 - estimates of demographic groups supported;
 - counts of units of service provision; and
 - the basis for funding whether by service, client or package.

Productivity Commission data

All jurisdictions referred the project team to the data they had provided to successive Productivity Commission reports (SCRSSP 2002) as the source of consistent historical information to provide the broad expenditure context for the unmet need funding. This context shows the different bases on top of which jurisdictions applied unmet need funding.

Financial data

Throughout this chapter, three major financial figures are referred to: reported estimated expenditure in 2000–01, expected expenditure in 2001–02 and expected full-year recurrent expenditure (based on 2001–02 costs).

¹ Unless otherwise stated, most of the funding data in this chapter come from jurisdictional responses to the Jurisdiction Survey.

The first two figures may include recurrent, capital and other one-off expenditure.

The last term requires additional explanation. It represents the estimated full-year recurrent effect of the initiatives instigated with unmet need funding over the two-year period 2000–02, based on 2001–02 prices. For most jurisdictions, their full-year recurrent expenditure is the same as their estimated expenditure for 2001–02, less any capital or one-off expenditure. However, for some it is not, where the full recurrent effect of their unmet need initiatives had not yet impacted in 2001–02. This is discussed in more detail in Section 3.5.

Other data limitations

No jurisdiction provided audited expenditure statements for their own contributions to unmet need funding for 2000–01 as most do not separate this expenditure from total disability expenditure for audit purposes.

A number of jurisdictions, who do not separately record the impact of their unmet need expenditure from the impact of their other funding, needed to estimate the numbers of clients supported or expected to be supported with unmet need funding.

This study is taking place during the second financial year of the funding (2001–02) and so the results for that year are estimates.

The Jurisdiction Survey also asked jurisdictions to provide service type outlet identifiers for all outlets provided with unmet needs funding. The purpose of this request was to enable analysis of national CSDA MDS data to describe characteristics of service type outlets benefiting from the new funding (for example, funded service type, staffing levels, opening hours) and their consumers (for example, number of consumers on the snapshot day, support needs, disability groups). Only two jurisdictions (Victoria and South Australia) were able to provide this information, and the analysis did not proceed.

3.3 The quantum of funds

Table 3.1 compares the amounts offered in the Bilateral Agreements to those reported on by jurisdictions in their survey responses.

The quantum of funds reported by jurisdictions as expended on unmet needs actually exceeds the expected \$210 million for 2000–01 by \$10 million and the planned \$309 million for 2001–02 by \$42 million. This is explained by:

- Victoria providing an additional \$12 million in capital funds in 2000–01 and a further \$5 million in capital funding and \$13.45 million accommodation support and community access initiatives in 2001–02;
- New South Wales estimating it will exceed its offer by \$29 million in 2001–02; and
- the Australian Capital Territory reporting that it will contribute \$1 million more than had been agreed over the two years.

Several jurisdictions reported somewhat less expenditure than their offer amounts.

Table 3.1: Expenditure reported by jurisdictions compared with offers in 2000 Bilateral Agreements (\$m)

		Commonwealth	State	Total
State/Territory		2000–01		
New South Wales	Agreed unmet need funding	16.840	93.410	110.250
	Amount reported	16.840	93.410	110.250
Victoria	Agreed unmet need funding	12.290	38.400	50.690
	Amount reported	12.300	50.400	62.700
Queensland	Agreed unmet need funding	9.155	9.000	18.155
	Amount reported	9.100	9.000	18.100
Western Australia	Agreed unmet need funding	4.905	9.500	14.405
	Amount reported	4.905	9.538	14.443
South Australia	Agreed unmet need funding	4.045	6.000	10.045
	Amount reported	3.625	4.842	8.468
Tasmania	Agreed unmet need funding	1.315	1.500	2.815
	Amount reported	1.315	1.500	2.815
ACT	Agreed unmet need funding	0.845	1.500	2.345
	Amount reported	0.131	1.832	1.963
Northern Territory	Agreed unmet need funding	0.605	0.652	1.257
	Amount reported	0.605	0.652	1.257
Total	Agreed unmet need funding	50.000	159.962	209.962
	Amount reported	48.821	171.174	219.996
2001–02^(a)				
New South Wales	Agreed unmet need funding	34.450	119.308	153.758
	Amount reported	33.680	148.491	182.171
Victoria	Agreed unmet need funding	25.140	38.400	63.540
	Amount reported	25.150	56.850	82.000
Queensland	Agreed unmet need funding	18.730	18.000	36.730
	Amount reported	18.300	18.000	36.300
Western Australia	Agreed unmet need funding	10.040	15.970	26.010
	Amount reported	9.810	16.008	25.818
South Australia	Agreed unmet need funding	8.280	6.000	14.280
	Amount reported	8.276	6.000	14.276
Tasmania	Agreed unmet need funding	2.690	6.132	8.822
	Amount reported	2.690	4.800	7.490
ACT	Agreed unmet need funding	1.730	1.500	3.230
	Amount reported	2.333	2.300	4.633
Northern Territory	Agreed unmet need funding	1.240	1.230	2.470
	Amount reported	1.224	1.210	2.434
Total	Agreed unmet need funding	102.300	206.540	308.840
	Amount reported	101.463	253.659	355.122

(a) The 2001–02 Commonwealth offer figure includes an amount for indexation. A non-indexed amount was included in the initial Bilateral Agreements. This difference explains some of the situations where offered funds slightly exceed actual expenditure in 2001–02.

The unmet need funding was introduced within a context of steady growth in expenditure on disability services. Table 3.2 shows the growth in disability expenditure since 1995–96. With the exception of two jurisdictions (Tasmania and the Northern Territory), all jurisdictions consistently increased their expenditure on CSDA services over this five-year period.

Given that the unmet need funding was an additional effort over and above expected growth to cover population increase and inflation, one would expect the growth in funds from 1999–00 to 2000–01 to exceed the unmet need funding expenditure in 2000–01. This is the case in total; that is, the growth over that year exceeds the agreed \$210 million or the reported expenditure of \$220 million in 2000–01, although not in all jurisdictions.

However when consideration is given to each jurisdiction, it is apparent that the funding growth in New South Wales and South Australia is less than the unmet need expenditure in those States. New South Wales explained that the creation of the new Department of Ageing, Disability and Home Care in March 2001 involved merging three different financial systems and bringing all New South Wales Government expenditure on disability services under the auspice of the new agency. The accounts for the new Department have not yet been audited. South Australia advised that the current expenditure figures in Table 3.2 include funding for once-off items such as workers' compensation lump sum payments. As a result the base figures are inflated. South Australia reported that growth between 1999–00 to 2000–01 was in fact approximately \$8.65 million, which is more than the unmet need expenditure of \$8.468 million.

Table 3.2: Current expenditure on CSDA services, by Commonwealth, State and Territory Governments, 1995–96 to 2000–01 (\$'000)

Jurisdiction	Current expenditure (\$'000)						Increase between 1999–00 & 2000–01	Reported unmet need expenditure 2000–01
	1995–96	1996–97	1997–98	1998–99	1999–2000	2000–01		
New South Wales	395,397	470,995	508,535	591,060	660,750	731,966	71,216	110,250
Victoria	427,671	466,892	506,060	559,565	613,292	705,674	92,382	62,700
Queensland	158,529	168,770	199,409	217,824	246,621	268,016	21,395	18,100
Western Australia	129,990	147,224	170,450	176,055	187,253	204,010	16,757	14,443
South Australia	127,466	131,586	143,586	153,237	163,360	170,298	6,938	8,468
Tasmania	53,469	59,054	59,237	57,936	59,948	63,242	3,294	2,815
ACT	18,200	21,894	22,118	23,882	28,940	30,904	1,964	1,963
Northern Territory	10,413	9,715	13,384	12,666	14,034	17,877	3,843	1,257
Commonwealth ^(a)	224,183	231,782	246,903	274,688	276,113	289,493	13,380	—
Total	1,545,318	1,707,911	1,869,682	2,066,914	2,250,310	2,481,480	231,170	219,996
Annual increase		162,593	161,771	197,232	183,396	231,170	—	—

(a) Commonwealth funds to States and Territories are shown within State and Territory totals in this table. Commonwealth funds increased by \$72.115 million between 1999–2000 and 2000–01 due to unmet need funds, indexation and other growth funding.

Source: SCRCSSP 2002 and AIHW Jurisdiction Survey responses.

At the time the Bilateral Agreements were signed, several jurisdictions were also in the process of redesigning and/or implementing significant changes to program arrangements and service delivery strategies. These included:

- new purchasing arrangements for services;
- individualised support arrangements; and
- revisions to assessment tools and related individual resource levels.

It is possible that these strategic developments contributed to the unmet need funding in 2000–01 being rolled out late in the financial year, services not being fully operational and the estimated under-expenditure predicted by some jurisdictions in 2001–02.

3.4 Application of the unmet need funding

Funding objectives: State and Territory contributions

Under the 2000 Bilateral Agreements, all jurisdictions were funded by the Commonwealth to provide additional services to enable people with disabilities who have ageing carers to remain supported by their families in their local communities. General principles which applied to this funding in all jurisdictions were outlined in Chapter 1 (Section 1.3).

The States' and Territories' contributions to unmet need funding were to be used to assist in addressing 'other priority areas of unmet need'.

The Jurisdiction Survey asked States and Territories to outline the objectives for the use of their contributions to unmet need funding. Most reported that their funds were being used to enhance the shifts in service delivery they were pursuing through growth funds generally and indicated the priority areas for the use of their contributions as follows.

New South Wales

- To support its efforts in more strategic resource management, including:
 - the management of community-based living arrangements post-devolution;
 - improving the availability of respite services;
 - developing a more flexible process for supporting people at risk and, in particular, the creation of the Service Access System;
 - increasing service access in New South Wales through regional capacity building;
 - building community support for people with a disability through local support coordination; and
 - extending early childhood intervention to children with a disability aged 6 to 18 years.

Victoria

- To address identified unmet needs and Victoria's vision outlined in its State DisAbility Plan; and
- To support re-development of the disability support system from funding of 'places' in specific service types to provision of individualised support packages to promote community inclusion and self-determination of people with a disability. This involved the consolidation of a number of service activities into broadly two types of

individualised support packages, namely Community Support Packages (for day program and community participation) and Personal Support Packages (for personal and accommodation support). These packages were said to be underpinned and based on broad, individual, whole-of-life plans, as well as individualised support delivery.

Queensland

- To meet the support needs of people with a disability and their families, and to reduce unmet need, within the strategies outlined in the Queensland *Business Plan 2000–2002* (Disability Services Queensland 2000a). The funds were to be used to focus on services supporting families not the target of Commonwealth funding. These included programs that supported individuals, families who have a child with a disability, post-school services, institutional reform and service development.

Western Australia

- To support services that complement the Disability Services Commission's *Business Plan 2000–2005* which aims to make a difference:
 - 'to the lives of individuals by being flexible and responsive to changing needs as they arise;
 - to families by providing them with the support they need, when they need it; and
 - to the level of understanding and support provided by the community, which also has an essential role to play in improving the quality of life for people with disabilities'. (Disability Services Commission 2000:8)

Funding was allocated to:

- accommodation support, which aims to provide assistance to people with disabilities who are in immediate need of accommodation support outside their family home;
- professional and therapy services, which aim to help support individuals to minimise the impact of their disability and maximise their ability to function effectively in their daily lives;
- respite and family care, aimed at improving access of families to both small and intensive amounts of support as they need it;
- post-school options, which aims to provide developmental opportunities for school leavers with severe and profound disabilities who cannot realistically pursue full-time employment;
- alternatives to employment, which aims to provide developmental opportunities for adults with severe and profound disabilities who are unable to pursue full-time employment;
- Local Area Coordination; and
- aids and equipment.

South Australia

- To support services that aligned with the State's *Disability Services Planning and Funding Framework 2000–2003* (Department of Human Services 2000). This included funding to young carers for respite, individual packages, supported accommodation, day options, early intervention and equipment.

Tasmania

- 'To ease the pressures in demand for permanent accommodation options (group homes) and day options programs. Demand in this area was ascertained using disability services monthly statistical data and existing waiting lists. These clearly indicated that demand was increasing with a number of clients occupying respite beds on a permanent basis.'²

Australian Capital Territory

- To 'increase capacity in the sector through funding of individual support packages and other unmet need applications from funded agencies and individuals'.³ Priority areas included therapy services for children, post-school options for youth graduating from school and unable to find full-time employment, and quality improvement and assessment in the sector.

Northern Territory

- To assist reforms supporting families who care for people with disabilities and avoid the movement of clients to large urban areas, away from their family and community. A key feature of the reforms was the introduction of the Local Area Coordination model in five service regions throughout the Northern Territory.

In recognition of the huge unmet need across the Northern Territory a consumer focused-funding model was also implemented. The Disability Program aims to provide consumers with more choice and control over their own care and support needs. Consumers have the choice as to whether they wish to manage their own funds, and in doing so assume responsibility for the purchasing and acquittal functions attached to this money.⁴

To achieve these ends, the government directed its unmet need contribution in 2001 to:

- individual funding packages;
- implementation of Local Area Coordination and Individual Funding Packages;
- a policy officer for information planning and data development; and
- service development.

² Extract from the Tasmanian Jurisdiction Survey response.

³ Extract from the Australian Capital Territory Jurisdiction Survey response.

⁴ Extract from the Northern Territory Jurisdiction Survey response.

The translation of objectives into funding

Total unmet needs funding

When total Commonwealth and State/Territory unmet need funding is considered:

- The majority of unmet need funds was used for accommodation support, for individualised funding packages (which incorporate accommodation support and funding for other service types) and/or for respite (around 66% over the two-year period 2000–02, comprising about 46% accommodation, 9% packages and 11% respite; Table 3.3a and b). Expenditure in these three major areas is expected to form 71% of ongoing funding (Table 3.5).
- Only two States (Victoria and South Australia) provided information about the division of their accommodation support funding between group homes and other accommodation support. In both these States, other accommodation support exceeded group home funding, which over the two-year period formed 34% of accommodation support funding in Victoria and 11% in South Australia.
- In addition to individualised packages which incorporate services from a number of service types, some jurisdictions also have individualised packages within a service type. For example, Victoria spends \$8.2 million on Making a Difference packages which offer a flexible range of supports to assist families and carers, via case management and individualised community support funding. Western Australia spends \$5.3 million on Flexible and Intensive Family Support Packages which provide individualised respite packages.
- The three previous points reflect a growing move in Australia away from residential to community support, involving funding packages designed around the individual needs of recipients.
- In 2000–01, 9.5% of total unmet need funding was used for capital or one-off projects (possibly a result of the up-front capital and equipment costs and delays in commencement of new recurrent initiatives). In 2001–02, this is expected to fall to 6.4% of funding (Table 3.3b).
- Noting that package funding may incorporate funding across all service types, specific funding to service types reported by jurisdictions:
 - averaged just over 12% for community support over 2000–02 (which included funding for therapy services, specialist services, early intervention, local area coordination and/or intake and assessment services); and
 - averaged nearly 9% for community access services (post-school options or day care services) in 2000–02 and is expected to be slightly higher in full-year recurrent estimates (Tables 3.3a, b and 3.5).
- Just over 3% of funding was allocated to service infrastructure or quality development initiatives over the two-year period, representing initiatives in Victoria, Queensland, Western Australia, the Australian Capital Territory and Northern Territory (Tables 3.3a and b).

Jurisdictions were asked whether the additional funding had assisted new or existing clients. Some reported difficulties providing this information, as information systems did not necessarily distinguish, or allow analysis of, whether a client was new to disability support

or to support from within a particular service type and no definition was included in the Jurisdiction Survey.

However, bearing in mind this ambiguity, estimates were provided by six jurisdictions for each of their sub-programs. Particular initiatives ranged from wholly supporting new clients to wholly supporting existing clients. Generally:

- on average, 25% of clients supported by Victoria's initiatives were existing clients (ranging from 0% to 100% for individual initiatives);
- Queensland reported that all of its unmet need money went to new clients;
- Western Australia said its initiatives mainly supported new clients, although up to 32% of one program's clients were existing;
- South Australia's initiatives almost entirely supported existing clients (this may reflect a different method of cross-matching clients within its data system than that possible in other jurisdictions);
- Tasmania indicated 80% of its unmet need funding clients were existing clients; and
- on average, 30% of clients supported by the Australian Capital Territory's initiatives were existing clients (within a range of 0–60% for individual initiatives).

Tables 3.3a and b show actual unmet need funding expenditure in 2000–01 and estimated expenditure in 2001–02.

Table 3.3(a): Use of unmet need funds by major service types, packages and service development, by States and Territories, 2000–01 (\$'000)

	NSW ^(c)	Vic ^(d)	Qld	WA	SA	Tas	ACT ^(e)	NT	Total ^(f)	% of total
	Estimated ^(a)									
Group homes		6,300			144				6,444	2.9
Other accommodation support		15,300			1603				16,903	7.7
<i>Subtotal: Accommodation support</i>	<i>77,285</i>	<i>21,600</i>		<i>5,130</i>	<i>1,746</i>			<i>947</i>	<i>105,761</i>	<i>48.1</i>
<i>Subtotal: Packages offering more than one service type ^(a)</i>			<i>11,500</i>			<i>2,815</i>	<i>291</i>		<i>15,553</i>	<i>7.1</i>
<i>Subtotal: Respite</i>	<i>7,641</i>	<i>4,000</i>	<i>2,300</i>	<i>3,848</i>	<i>4,241</i>				<i>22,029</i>	<i>10.0</i>
Therapy services		1,000		1,550			250		2,800	1.3
Specialist services		3,200			217				3,417	1.6
Early intervention					13				13	0.0
Local area coordination/intake & assessment	1,040	2,000	300	150					3,490	1.6
Other community support	12,580	5,000	900		50				18,530	8.4
<i>Subtotal: Community support</i>	<i>13,620</i>	<i>11,200</i>	<i>1,200</i>	<i>1,700</i>	<i>279</i>		<i>250</i>		<i>28,249</i>	<i>12.8</i>
Day programs		1,000		1,695	84				2,779	1.3
Post-school options		6,900	1,200	850	361				9,311	4.2
<i>Subtotal: Community access</i>	<i>3,005</i>	<i>7,900</i>	<i>1,200</i>	<i>2,545</i>	<i>445</i>				<i>15,095</i>	<i>6.9</i>
<i>Subtotal: Other (including equipment)</i>	<i>1,700</i>	<i>3,000</i>			<i>408</i>				<i>5,108</i>	<i>2.3</i>
<i>Subtotal: Service/infrastructure/quality development ^(b)</i>		<i>3,000</i>	<i>1,900</i>	<i>1,220</i>			<i>1,081</i>	<i>10</i>	<i>7,211</i>	<i>3.3</i>
<i>Subtotal: Capital or one-off expenditure</i>	<i>7,000</i>	<i>12,000</i>			<i>1,348</i>		<i>341</i>	<i>300</i>	<i>20,989</i>	<i>9.5</i>
Total	110,250	62,700	18,100	14,443	8,467	2,815	1,963	1,257	219,995	100.0

(a) Queensland, Tasmania, the Australian Capital Territory and the Northern Territory had packages with a general target group involving \$7.2 million, \$1.315 million, \$0.290 million and \$0.947 million respectively. Queensland had two other package programs (one for children and families involving \$1 million and one for adults moving from institutional care involving \$3.3 million). Tasmania had an additional package program which could also include group home support costing \$1.5 million.

(b) This development category includes all service development, quality, infrastructure and viability initiatives for which there are no direct client outputs, only indirect benefit.

(c) In New South Wales, \$5 million in 2000–01 and \$15 million in 2001–02 was estimated to have been spent on capital for accommodation support and \$2 million in both 2000–01 and 2001–02 on transport capital.

(d) Victorian capital expenditure was all on group homes. Development funds were spent on accommodation support training, quality improvement and rural disability access.

(e) The Australian Capital Territory allocated \$0.131 million one-off funds in 2000–01 and \$0.693 million one-off funds in 2001–02 to their Mature Carers Program and \$0.210 million one-off funds to their Post School Options Program in 2000–01.

(f) Insufficient information was available to report the allocation of funds within all sub-categories of service types for all jurisdictions. Thus some sub-categories do not add to their service type sub-total (within the total column).

(g) Although these figures represent 2000–01 expenditure, the figures are estimated as some jurisdictions did not maintain separate unmet need funding and other CSDA funding details in their records.

Table 3.3(b): Use of unmet need funds by major service types, packages and service development, by States and Territories, 2001–02 (\$'000)

	NSW ^(c)	Vic ^(d)	Qld	WA	SA	Tas	ACT ^(e)	NT	Total ^(f)	% of total
Group homes		12,800			337				13,137	3.7
Other accommodation support		21,590			2,278				23,868	6.7
Subtotal: Accommodation support	117,234	34,390		6,730	2,615			100	161,069	45.4
Subtotal: Packages offering more than one service type ^(a)			23,000			7,490	2,131	1,682	34,303	9.7
Subtotal: Respite	15,102	7,390	2,600	7,138	9,466			100	41,796	11.8
Therapy services		1,000		3,200			256		4,456	1.3
Specialist services		3,200			355				3,555	1.0
Early intervention					450				450	0.1
Local area coordination/intake & assessment		2,000	1,500	700					4,200	1.2
Other community support		8,170	1,800		220				10,190	2.9
Subtotal: Community support	19,784	14,370	3,300	3,900	1,025		256		42,635	12.0
Day programs		1,000		3,330	110				4,440	1.3
Post-school options		13,850	3,600	1,810	652		500	82	20,494	5.8
Subtotal: Community access	9,351	14,850	3,600	5,140	762		500	82	34,285	9.7
Subtotal: Other	3,700	3,000			408				7,108	2.0
Subtotal: Service/infrastructure/quality development ^(b)		3,000	3,800	2,910			1,053	430	11,193	3.2
Subtotal: Capital or one-off expenditure	17,000	5,000					693	40	22,733	6.4
Total	182,171	82,000	36,300	25,818	14,276	7,490	4,633	2,434	355,122	100.0

(a) Queensland, Tasmania, the Australian Capital Territory and the Northern Territory had packages with a general target group involving \$13.5 million, \$2.69 million, \$0.491 million and \$1.682 million respectively. Queensland had two other package programs (one for children and families involving \$3.5 million and one for adults moving from institutional care involving \$6 million). Tasmania had an additional package program which could also include group home support costing \$4.8 million.

(b) This development category includes all service development, quality, infrastructure and viability initiatives for which there are no direct client outputs, only indirect benefit.

(c) In New South Wales, \$5 million in 2000–01 and \$15 million in 2001–02 was estimated to have been spent on capital for accommodation support and \$2 million in both 2000–01 and 2001–02 on transport capital.

(d) Victorian capital expenditure was all on group homes. Development funds were spent on accommodation support training, quality improvement and rural disability access.

(e) The Australian Capital Territory allocated \$0.131 million one-off funds in 2000–01 and \$0.693 million one-off funds in 2001–02 to their Mature Carers Program and \$0.210 million one-off funds to their Post School Options Program in 2000–01.

(f) Insufficient information was available to report the allocation of funds within all sub-categories of service types for all jurisdictions. Thus some sub-categories do not add to their service type sub-total (within the total column).

The Commonwealth contribution

In acquittal reports to the Commonwealth for the year 2000–01, States and Territories reported on their use of Commonwealth unmet need funds. A summary of these reports follows:

- New South Wales used the allocated funds in three ways, although not all funds were ‘rolled out’ in the year:
 - \$2 million was included in the new Service Access System (SAS) which addresses the needs of people who are in crisis. It was reported that 35% of people supported through SAS by the time of the report had ageing carers;
 - \$14.3 million was allocated to ‘growing broad regional capacity in service to better respond to’ the whole cohort of ageing carers, not just those in crisis. Allocations were made to 110 ‘ageing carer service types across New South Wales’, involving 406 individuals; and
 - \$0.5 million was used for project administration.

Additional principles applied in the New South Wales Bilateral Agreement included that:

- special attention would be paid to those who registered an urgent need by providing an immediate response (a package of intensive in-home supports and other non-residential options to maintain the family at home); and
 - service providers would be contracted through a competitive selection process.
- The Victorian acquittal only covered client figures and did not provide any expenditure breakdown for the three sub-programs funded. It was reported that, to 30 June 2001, 205 people had been supported via home support, 828 people had received respite and 549 flexible care packages had been allocated. These acquittal figures relate to people ‘from the target group’ (namely, people with a disability whose carer was over 65 years or who had been caring for 30 years or more).
 - Queensland reported that it allocated its Commonwealth \$9.1 million funding to five areas:
 - \$5.7 million was allocated to supporting adults with a disability through the Adult Lifestyle Support Initiative. Combined with a \$1.5 million State contribution, funds were allocated to 297 people, of whom 173 had ageing carers, six had carers who had been caring for 30 years or more, 20 lived in rural or remote areas and 34 were Indigenous people with disabilities;
 - \$1.2 million to 21 services to provide respite, in combination with State funds;
 - \$0.3 million to eight Local Area Coordination services (with three more to be funded in 2001–02);
 - \$1 million for service development via four statewide and 33 local initiatives; and
 - \$0.9 million for program support via increased Disability Services Queensland program support facilitators providing direct community support services to individuals.

In relation to the funding for respite and Local Area Coordination services it was said that, as many of the funded services were new and not fully operational during 2000–01, a breakdown of data for people with disabilities supported by these services would only

be available for 2001–02. However it was anticipated that when fully operational the services would support 400 and 750 individuals and families respectively.

- Western Australia reported that it had allocated the Commonwealth funding of \$4.9 million to four programs:
 - \$0.7 million to Flexible Family Support Packages;
 - \$1.92 million to Intensive Family Support Packages;
 - \$0.75 million to new or expanded respite and family support programs and services; and
 - \$1.51 million to day options.

Western Australia's total funding had increased by \$13.7 million, involving increased support to 1,517 people.

The jurisdiction reported that 47 families included carers aged over 65 years (or over 45 years for Indigenous carers), and a further 27 carers had cared for the person with a disability for more than 30 years.

- South Australia reported that, prior to 1 July 2001, Commonwealth unmet need funding was allocated to 474 people with ageing carers and 23 Indigenous people with disabilities.
- Tasmania allocated Commonwealth unmet need funding via its Individual Options Program. Similar to the Victorian report, the acquittal included client figures but no financial breakdown. There were 68 people with carers aged 65 years and over who were said to have been supported, as well as 34 people with long-term carers.
- The Australian Capital Territory reported that it had funded two pilot services to ageing carers in 2000–01, which assisted 65 people with ageing carers, two of whom were of Indigenous origin and 10 of whom came from culturally diverse backgrounds.
- The Northern Territory reported that it had allocated the \$0.6 million Commonwealth unmet need funding over its Darwin, Top End and Central Australian regions. The jurisdiction reported that the CSDA MDS showed 12 additional people with disabilities aged 35 years and over living at home and in receipt of respite, recreation or day support. Local Area Coordination data showed 41 carers (of whom 25 were of Indigenous origin) receiving new or additional services.

The sum of the acquittal data available from States and Territories suggests that nearly 3,000 people with a disability who had carers aged 65 years or more or carers who had been caring for 30 years or more, were assisted via the Commonwealth unmet needs funding.

Tables 3.4a and b summarise the actual or estimated expenditure of Commonwealth unmet needs funding by jurisdiction by service type for 2000–01 and 2001–02.

These responses show that, over 2000–01 and 2001–02, the bulk of Commonwealth funding (67%) was spent on accommodation support and/or individual packages and/or respite (comprising in order around 21% accommodation support, 31% respite and 16% individualised packages). Around 19% was spent on community support and around 11% on community access services.

Table 3.4(a): Use of Commonwealth unmet need funds by major service types, packages and service development, by States and Territories, 2000–01 (\$'000)

	NSW	Vic	Qld	WA	SA	Tas	ACT ^(b)	NT	Total ^(c)	% of total
	Estimated ^(d)									
Group homes										—
Other accommodation support		7,800							7,800	16.0
<i>Subtotal: Accommodation support</i>	2,981	7,800							10,781	22.1
<i>Subtotal: Packages offering more than one service type</i>			5,700			1,315		605	7,620	15.6
<i>Subtotal: Respite</i>	5,341	2,000	1,200	3,400	3,465				15,406	31.6
Therapy services										—
Specialist services										—
Early intervention										—
Local area coordination/intake & assessment	555		300						855	1.8
Other community support	4,959	2,500	900						8,359	17.1
<i>Subtotal: Community support</i>	5,514	2,500	1,200						9,214	18.9
Day programs				1,505					1,505	3.1
Post-school options										—
<i>Subtotal: Community access</i>	3,005			1,505					4,510	9.2
<i>Subtotal: Other</i>										—
<i>Subtotal: Service/infrastructure/quality development ^(a)</i>			1,000							0.0
<i>Subtotal: Capital or one-off expenditure</i>					160		131		291	0.6
Total	16,841	12,300	9,100	4,905	3,625	1,315	131	605	48,822	100.0

(a) This development category includes all service development, quality, infrastructure and viability initiatives for which there are no direct client outputs, only indirect benefit.

(b) The Australian Capital Territory allocated \$0.131 million one-off funds in 2000–01 and \$0.693 million one-off funds in 2001–02 to their Mature Carers Program.

(c) Insufficient information was available to report the allocation of funds within all sub-categories of service types for all jurisdictions. Thus some sub-categories do not add to their service type sub-total (within the total column).

(d) Although these figures represent 2000–01 expenditure, the figures are estimated as some jurisdictions did not maintain separate unmet need funding and other CSDA funding details in their records.

Table 3.4(b): Use of Commonwealth unmet need funds by major service types, packages and service development, by States and Territories, 2001–02 (\$'000)

	NSW	Vic	Qld	WA	SA	Tas	ACT ^(b)	NT	Total ^(c)	% of total
Estimated										
Group homes									—	
Other accommodation support		14,090							14,090	13.9%
<i>Subtotal: Accommodation support</i>	5,849	14,090						100	20,039	19.8%
<i>Subtotal: Packages offering more than one service type</i>			11,500			2,690	1,640	902	16,732	16.5%
<i>Subtotal: Respite</i>	8,802	5,390	1,500	6,390	8,276			100	30,458	30.0%
Therapy services									—	
Specialist services									—	
Early intervention									—	
Local area coordination/intake & assessment			1,500						—	
Other community support		5,670	1,800						7,470	7.4%
<i>Subtotal: Community support</i>	9,678	5,670	3,300						18,648	18.4%
Day programs				3,010					3,010	3.0%
Post-school options								82	82	0.1%
<i>Subtotal: Community access</i>	9,351			3,010				82	12,443	12.3%
<i>Subtotal: Other</i>									—	
<i>Subtotal: Service/infrastructure/quality development ^(a)</i>			2,000	410					2,410	2.4%
<i>Subtotal: Capital or one-off expenditure</i>							693	40	733	0.7%
Total	33,680	25,150	18,300	9,810	8,276	2,690	2,333	1,224	101,463	100.0%

(a) This development category includes all service development, quality, infrastructure and viability initiatives for which there are no direct client outputs, only indirect benefit.

(b) The Australian Capital Territory allocated \$0.131 million one-off funds in 2000–01 and \$0.693 million one-off funds in 2001–02 to their Mature Carers Program.

(c) Insufficient information was available to report the allocation of funds within all sub-categories of service types for all jurisdictions. Thus some sub-categories do not add to their service type sub-total (within the total column).

3.5 Ongoing effect of unmet need funding

Table 3.5 shows States' and Territories' estimated full-year recurrent expenditure arising from unmet need funding. This represents the estimated full-year recurrent effect of the initiatives instigated with unmet need funding, based on 2001–02 prices. This is generally the same as 2001–02 expenditure, less any capital or one-off expenditure, except for a small number of jurisdictions, which reported that the full recurrent impact of their initiatives was not felt in 2001–02.

For seven jurisdictions the figures are the same as their expected 2001–02 expenditure, less any capital expenditure in that year. For the Northern Territory, total funding matches expected 2001–02 expenditure, but the allocation between service types varies. This is explained by the completion of one-off funding to some initiatives allowing those funds to be allocated to other initiatives as recurrent funding.

Table 3.5 indicates that accommodation support is the major area for ongoing spending in all jurisdictions, either as a distinct service type or as part of a package, respectively comprising 49% and 10% of total expected expenditure. In combination, accommodation support (either as a distinct service type or as part of a package) and respite account for 71% of estimated full year recurrent expenditure. This percentage ranges between 54% of jurisdiction expenditure in Victoria, Western Australia and the Australian Capital Territory and 100% in Tasmania.

Table 3.5: Estimated full-year recurrent expenditure from unmet need funding initiatives, by States and Territories, at 2001–02 prices ^(a)

	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Total
Accommodation support (\$'000) ^(b)	117,234	34,390		6,730	2,615			150	161,119
% of ongoing expenditure	71.0%	44.7%		26.1%	18.3%			6.2%	48.5%
Packages (\$'000)			23,000			7,490	2,131	1,734	34,355
% of ongoing expenditure			63.4%			100.0%	54.1%	71.2%	10.3%
Respite (\$'000)	15,102	7,394	2,600	7,138	9,466			100	41,800
% of ongoing expenditure	9.1%	9.6%	7.2%	27.6%	66.3%			4.1%	12.6%
<i>Subtotal—accommodation, package & respite support as % of ongoing expenditure</i>	80.1%	54.3%	70.6%	53.7%	84.6%	100.0%	54.1%	81.5%	71.4%
Community support (\$'000)	19,784	14,369	3,300	3,900	1,025		256	200	42,834
% of ongoing expenditure	12.0%	18.7%	9.1%	15.1%	7.2%		6.5%	8.2%	12.9%
Community access (\$'000)	9,351	14,850	3,600	5,140	762		500	250	34,453
% of ongoing expenditure	5.7%	19.3%	9.9%	19.9%	5.3%		12.7%	10.3%	10.4%
Other (incl. equipment) (\$'000)	3,700	3,000			408				7,108
% of ongoing expenditure	2.2%	3.9%							2.1%
Service/infrastructure/quality development (\$'000) ^(c)		3,000	3,800	2,910			1,053		10,763
% of ongoing expenditure		3.9%	10.5%	11.3%			26.7%		3.2%
Total (\$'000)	165,171	77,003	36,300	25,818	14,276	7,490	3,940	2,434	332,432
% of ongoing expenditure	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%

(a) Some jurisdictions also provided information which would allow calculation of average funding costs for sub-categories within each of these service types. This information is not presented here, although some of the results are reported in Table 3.9.

(b) Expenditure shown against particular service types may be in the form of packages funding, e.g., packages for accommodation support in New South Wales and Victoria.

(c) This development category includes all service development, quality, infrastructure and viability initiatives for which there are no direct client outputs, only indirect benefit.

3.6 Service delivery from the unmet need funding

Table 3.6 summarises the numbers of clients supported by the unmet need funding in 2000–01 as reported by jurisdictions. These figures suggest that, *at least*:

- 887 clients received accommodation support, of whom the bulk were supported in their own homes in the community, rather than in group homes;
- 803 received individualised packages likely to incorporate more than one service type;
- 2,586 received respite support; and
- 1,323 received community access support.

However, these figures under-report the total number of clients supported, as not all jurisdictions were able to provide information about the number of clients supported. This means it is not possible from the information provided to state the likely total number of clients supported by the unmet need funding. In particular, the gaps in data for New South Wales, which accounts for half of the estimated expenditure of all jurisdictions, limit the national analysis. Difficulties were generally experienced with the provision of accurate information about whether clients supported were new or existing clients (see Section 3.4).

In the Jurisdiction Survey, States and Territories were asked to provide information about how funding levels were calculated and about how many service outputs (for example, hours) were expected to be provided for these funding levels. Generally, jurisdictions were unable to provide this level of detail and mainly reported on the total number of clients to be assisted with the funding or group home places to be provided, without detail of service outputs.

In addition, as noted above, there was a frequent use of individualised funding packages, which combine support across a range of service types to address an individual's needs. Generally, information was not available about the proportion of service types within these packages, although the number of clients receiving them was usually available as well as the range of possible service types which could be included in packages within programs⁵.

This means that reporting on service delivery in this chapter is restricted largely to a financial and client number analysis.

Table 3.7 shows the number of clients reported as expected to be supported by the ongoing effect of the unmet need funding. Similar significant data gaps occur in Table 3.7 as in Table 3.6, so that the full number of clients likely to be supported cannot be estimated.

The table suggests that *at least* some:

- 1,200 clients are expected to receive accommodation support, of whom the bulk will be in their own homes, rather than in group homes;
- 1,400 are expected to receive individualised packages likely to incorporate more than one service type;
- 4,200 are expected to receive respite support; and
- 2,500 are expected to receive community access support.

⁵ For example, the Australian Capital Territory's Mature Carers Program provides respite care, in-home support, networking and skill acquisition services. It differs from many of the other packages programs which target families in crisis or at risk, in that it aims to assist families with mature carers to proactively plan for the time when current support arrangements may become untenable.

Table 3.6: Number of clients supported by unmet need expenditure, by service type and States and Territories, 2000–01

	NSW ^(c)	Vic	Qld	WA ^(c)	SA ^(d)	Tas	ACT ^(e)	NT	Total excluding 'Not provided' or incomplete figures
Group homes		113			7				120
Other accommodation support	155+++	519			110				629
<i>Subtotal: Accommodation support</i>	155+++	632		138	117				887
<i>Subtotal: Packages offering more than one service type</i>			465			242	43	53	803
<i>Subtotal: Respite</i>	Not provided	1,655	150	394+++	781				2,586
Therapy services		500		769			50		1,319
Specialist services		230			296				526
Early intervention					Not provided			Not provided	NA
Local area coordination/intake & assessment	34	1,638	150	83					1,905
Other community support	Not provided	1,098	297		Not provided				1,395
<i>Subtotal: Community support ^(a)</i>	NA	NA	NA		NA		50	Not provided	NA
Day programs		66		141	Not provided				207
Post-school options		877	160	71	49		8		1,165
<i>Subtotal: Community access</i>	Not provided	943	160	212	Not provided		8		1,323
<i>Subtotal: Other (including equipment)</i>	Not provided	3,820			Not provided				3,820
<i>Subtotal: Service/infrastructure/quality development ^(b)</i>		NA	NA	NA			NA	NA	NA

(a) Clients in the community support sub-categories cannot be added as a client may receive support from more than one sub-category.

(b) The development category includes all service development, quality, infrastructure and viability initiatives for which there are no direct client outputs, only indirect benefit.

(c) +++ symbols have been used where an entry within a service type for a jurisdiction does not cover the total number of clients supported with the funds reported in Table 3.3(a). In New South Wales, this is the case as no expected client figures are available for the Service Access System. Western Australia provided client figures for two of their four respite sub-programs (representing \$2.650 million of its \$3.848 million respite expenditure). The cells are shaded as the figures are not included in row totals.

(d) Brokerage clients for accommodation support are included in other accommodation support in South Australia, rather than within other community support.

(e) In the Australian Capital Territory, 30 Mature Carers Program clients (of their 43 package clients) and eight Post School Options program clients were reported as receiving benefit from one-off 'set-up' costs.

Table 3.7: Anticipated number of clients to be supported by full-year recurrent unmet need expenditure, by service type and States and Territories, at 2001–02 prices

	NSW ^(c)	Vic	Qld	WA ^(c)	SA ^(d)	Tas	ACT	NT	Total excluding 'Not provided' or incomplete figures
Group homes		213			7				220
Other accommodation support	203+++	668			110				778
<i>Subtotal: Accommodation support</i>	203+++	881		198	117			<i>Not provided</i>	1,196
<i>Subtotal: Packages offering more than one service type</i>		889				366	75	79	1,409
<i>Subtotal: Respite</i>	<i>Not provided</i>	3,000	400	780+++	781			50	4,231
Therapy services		500		1,588			50		2,138
Specialist services		230			296				526
Early intervention					Not provided			Not provided	NA
Local area coordination/intake & assessment	400	1,600	750	389					3,139
Other community support		1,700	562		Not provided				2,262
<i>Subtotal: Community support ^(a)</i>	NA	NA	NA	NA	NA		50	<i>Not provided</i>	NA
Day programs		66		277	Not provided				343
Post-school options		1,680	320	151	49		30	12	2,242
<i>Subtotal: Community access</i>	<i>Not provided</i>	1,746	320	428	<i>Not provided</i>		30	12	2,536
<i>Subtotal: Other (including equipment)</i>	<i>Not provided</i>	3,820			<i>Not provided</i>				3,820
<i>Subtotal: Service/infrastructure/quality development ^(b)</i>		NA	NA	NA	NA	NA	NA	NA	NA

(a) Clients in the community support sub-categories cannot be added as a client may receive support from more than one sub-category.

(b) The development category includes all service development, quality, infrastructure and viability initiatives for which there are no direct client outputs, only indirect benefit.

(c) +++ symbols have been used where an entry within a service type for a jurisdiction does not cover the total number of clients supported with the funds reported in Table 3.5. In New South Wales, this is the case as no expected client figures are available for the Service Access System. Western Australia provided client figures for two of their four respite sub-programs (representing \$5.3 million of its \$7.138 million respite expenditure). The cells are shaded as the figures are not included in row totals.

(d) Brokerage clients for accommodation support are included in other accommodation support in South Australia, rather than within other community support.

3.7 Costing and funding of services

The literature

Cost of services

The 1997 AIHW report outlined relevant disability cost literature to that date (AIHW 1997a). This suggested that cost was related to a range of variables, including location, facility size, facility type and ownership, client characteristics, client mix, and operational, staffing and service quality.

A position paper, 'Regional Center Budget Issues – Purchase of Service Budget' (attached to a letter from Lewis Braxton of the Association of Regional Center Agencies, California, 2001), listed a range of reasons why operational costs of disability services were increasing over time. Some of the reasons which could apply to Australia include:

- significantly increased expectations of both government and clients about service delivery, affecting both the quality and quantity of service to be delivered with available funds and choices to be offered, including expectations that service delivery will:
 - be increasingly individualised (thereby incurring higher planning and developmental and skills costs);
 - have increased staff:client ratios;
 - move away from segregated sites; and
 - involve a more sophisticated range of day activities and possibly transport between a range of sites.
- changes in the proportion of people with particular disabilities or characteristics requiring revised program, support and behaviour management structures and therefore costs. (The article reports a 138% growth of persons diagnosed with autism spectrum disorder over eight years, compared with an overall client population growth of 27%, an increase in the birth of more medically frail, smaller babies as a result of advances in medical technology and an increasing incidence of clients from non-English-speaking backgrounds); and
- changed support models.

The paper also discusses other changes that have possibly had a stronger impact in California, but which may be increasingly relevant in Australia, particularly related to alternative or extended care requirements resulting from the workforce participation of carers.

Other recent costing research has largely focused on accommodation models. This literature suggests that moves for enhanced service quality and choice are occurring throughout the world, and this can come at a higher cost. However, higher costs can be moderated with careful program design which carefully matches resources and models to unmet needs of clients.

In summary, the research (which is outlined and referenced below) suggests that there are trade-offs between cost and quality, although higher costs do not always indicate improved outcomes for clients. The data suggest higher average costs for community care than for institutional care in Britain and the reverse in one area of the United States. An Australian

study suggests higher costs for group homes than for semi-independent, community-based accommodation support. All suggest that outcomes for clients are generally better in community-based than institutional settings, with the Australian study suggesting this also for semi-independent, community-based support compared with group homes.

Felce et al. (2000) considered housing support to 36 adults with severe intellectual disabilities and the most severe challenging behaviour. The housing was of two types: traditional hospital institutional services and specialist community housing where all residents were regarded as having challenging behaviour. For these two broad service models and for this group of clients with very high support needs, the researchers found:

Higher accommodation costs were associated with lower resident ability and community services. Costs were inversely associated with setting size when the variable representing service model was omitted, but setting size did not otherwise add to the explanation ... Variation in accommodation costs did not contribute to the explanation of the level of staff:resident interaction or quality of life, neither did staff:resident ratios, after control for service model.

An earlier Felce paper concluded that community services were to be preferred to traditional services in terms of quality of life, 'but that they were considerably more expensive and there was doubt as to whether their greater quality could be linked to their greater cost' (Felce 1998, quoted in Felce et al. 2000:323). Higher costs of community than institutional services was also found in two other British studies, another by Felce focusing on people with more severe or profound intellectual disabilities (Felce 1986, quoted in Felce et al. 2000) and one by Knapp et al. which analysed costs for people with a wider ability spectrum (Knapp et al. 1992, quoted in Felce et al. 2000). Felce et al. (2000) suggest tenuous links between resource input and service quality. Their research suggests that the notion that the level of staff input can be taken as a proxy for quality of life of residents requires revision 'except in terms of more staff having a negative impact on resident autonomy'. They suggest that achieving the ideal staff input is a balance between under- and over-allocation.

This work is reinforced by Emerson et al. (2000a) who analysed residential support to 20 adults with severe and complex disabilities. These researchers found that residents living in dispersed housing schemes 'enjoyed a significantly greater quality of care and quality of life than participants living in residential campuses. The total costs of provision in dispersed housing schemes were significantly greater than the total costs of provision in residential campuses' (Emerson et al. 2000a:263). Cost differences were explained by significantly greater direct staffing costs in the community-based services.

Another study led by Emerson et al. (2000b) compared 86 people with intellectual disabilities living in 'village communities', newly built residential campuses and dispersed housing schemes. This work found that dispersed housing schemes cost 15% more than residential campuses and 20% more than village communities. However it also found that dispersed housing schemes and village communities offered significantly greater quality of care and quality of life than did residential campuses.

Felce et al. (2000) reported that their findings were consistent with other UK research that community services are more expensive than institutional services. However they also noted that this may differ between countries, recognising that a study by Stancliffe and Lakin (1998) in one State of the USA found that community services for people with severe or profound intellectual disabilities were less costly than institutional services. Felce et al. hypothesise that this could relate to different policy and funding settings, and funding histories, between countries.

A paper by Stancliffe and Keane compared matched groups of Australian adults with intellectual disability living in group homes or semi-independently. This comparison of non-traditional models found that outcomes did not differ significantly by group, although where significant differences did occur, people living semi-independently experienced better outcomes. There were no outcomes which were significantly better for group home residents. 'The lower level of staffing provided to semi-independent participants was not associated with poorer outcomes. Per-person expenditure was substantially higher for group home participants' (Stancliffe & Keane 2000:281).

Costing services

The costing exercise undertaken for the present study drew on and further developed the methodology employed in the 1997 study of unmet demand (AIHW 1997a).

The costing exercise undertaken for the 1997 AIHW study of unmet demand was underpinned by the first three of Knapp's four basic principles for cost research (Knapp 1995):

1. Comprehensiveness measure: costs broadly to cover all relevant services and other financial implications.
2. Recognise that there will be cost and outcome variations between service users, facilities and geographical locations.
3. Only make like with like comparisons.
4. Integrate cost information with information on user and other outcomes.

The fourth principle, which was beyond the scope of the 1997 study, is relevant to the present study in considerations of effectiveness in Chapter 4. The other three principles have been borne in mind in the requests for data from jurisdictions and in the subsequent analysis. However the general absence of quarantining of (or separately tracking the use of) the unmet need funding reduces the robustness of the cost estimates presented below (Table 3.9).

Cost data from States and Territories

The unmet need funding can be viewed as an increment of funding to a major service program. The question which follows is 'what is the cost of the increment of outputs achieved with that funding?'. In this case, the outputs are the number of clients supported.

As described above, jurisdictions agreed to specific reporting requirements about the use of the unmet needs funding in each of their Bilateral Agreements. There was no explicit requirement for States and Territories to report their expenditure of unmet need funds separately from other expenditure, nor to adopt a consistent method of reporting clients using services funded with unmet need funds by service type. This, along with the requirement to conclude the present study prior to the completion of the two-year funding period; and so before the full impact of unmet need funding can be observed, directly constrained the capacity of this study to provide a clear picture of funding levels and directions.

As a result, jurisdictions were only able to provide *both* expected client and expenditure figures in respect of 35% of 2000–01 recurrent expenditure, and 38% of ongoing full-year expenditure (Table 3.8).

Table 3.8: Analysis of recurrent expenditure and clients by service type, for jurisdictions where both expenditure and client data provided, compared with total expected recurrent expenditure for all jurisdictions^(a)

	2000–01 recurrent ^(b)		Full-year recurrent ^(c)	
	Clients supported	Expenditure (\$'000)	Clients supported	Full-year expenditure (\$'000)
Accommodation support	887	28,476	1,196	43,735
Community access	1,315	11,645	2,536	24,340
Respite	2,586	10,541	4,231	19,560
Other	3,820	3,000	3,820	3,000
Packages offering more than one service type	803	15,553	1,409	34,355
Total recurrent expenditure for which client figures are available:		69,215		124,990
<i>Total expected recurrent expenditure:</i>		<i>199,006</i>		<i>332,432</i>
% of expected recurrent expenditure for which client figures are available:		34.8%		37.6%

(a) The table does not include community support as it is not possible to add client figures across sub-categories within this service type (12% of expenditure in 2000–01). It also excludes service/infrastructure/quality development as there are no direct clients of this service type, only indirect support to clients (involving 9.5% of 2000–01 expenditure in 2000–01).

(b) For 2000–01, complete expenditure and client figures were not provided by New South Wales for any of the five service type categories and by Western Australia for respite. Further, in 2000–01 in the Australian Capital Territory, 30 Mature Carers Program clients (of their 43 package clients) and eight Post School Options program clients received benefit from one-off pilot funding in 2000–01 and so are not included in this table.

(c) For full-year recurrent funding, complete expenditure and client figures were not provided by New South Wales for any of the five service type categories, by the Northern Territory for accommodation support and by Western Australia for respite.

Source: Tables 3.6 and 3.7.

Average annual costs to government

For the data provided, average annual recurrent funding costs⁶ to government (based on 2001–02 costs) can be calculated by dividing the estimated full-year recurrent expenditure by the estimated number of clients who are reported as likely to benefit.

The estimated full-year recurrent expenditure is the appropriate expenditure figure for this calculation as it excludes the costs of set-up and other one-off costs that may have been incurred in the first year of the initiative.

Average rather than marginal cost is relevant here, for a number of reasons. In many instances, services funded were new initiatives (so that their costs may differ from established services). Furthermore average costs have been found to be most relevant to the issue of service costs in areas where unit costs of community care have been monitored over time⁷.

⁶ 'Funding cost to government' indicates the size of government contributions to services—it does not include administration costs nor does it indicate total cost of services.

⁷ See annual reports of the Unit Costs of Health and Social Care by the Personal Social Services Research Unit.

Table 3.9 provides the results of these calculations:

- as suggested by the literature, the average funding cost of supporting clients in a group home setting (just under \$60,000) was larger than that incurred in providing in-home accommodation support (at under \$31,000), although this may reflect a higher average client dependency level where the group home model is used;
- the average funding per client of accommodation support in Victoria, Western Australia and South Australia was \$36,568;
- the average funding per client of packages offering support in more than one service type (including accommodation support) in Queensland, Tasmania, the Australian Capital Territory and the Northern Territory was \$24,383;
- the overall average funding of accommodation support and multi-service type packages in these jurisdictions was just under \$30,000 (calculated by averaging the client and expenditure figures for jurisdictions with complete data returns in Tables 3.5 and 3.7);
- funding to respite clients on average was \$4,600; and
- funding for community access clients on average was just over \$12,500 for day program support and \$9,000 for post-school options support. This almost certainly reflects the higher average dependency level of day program clients.

In reading these figures, it should be noted that little is known about the composition of the costs reported here. From discussions with jurisdictions, the costs contain a different mix of direct and indirect service delivery costs. It is generally assumed that funding to non-government service deliverers, who deliver the bulk of services provided by unmet need funding, would incorporate an allowance for their indirect administrative costs.

It must also be stressed that the figures represent what the jurisdictions, on average, have been prepared to fund for these service types. The funding cost to government may not cover all the costs incurred by providers. Further, funding cost to government does not include additional costs borne by informal carers and clients in relation to their use of services and/or to complement what the services offer.

Further, as reinforced by the literature, costs will vary according to the standard or quality of care to be delivered. Lower costs do not necessarily imply cost effectiveness nor, according to the literature, do higher costs always mean enhanced outcomes for consumers.

Again reflecting on one of Knapp's principles, summaries of diverse information must try to ensure that like with like comparisons are being made, although the diversity and richness of program design and delivery may not be retained. Every attempt has been made to summarise and group the data provided by jurisdictions in a way that reflects what is being provided and how it is being delivered.

Table 3.9: Expected average recurrent funding per client, by service type and States and Territories, at 2001–02 prices ^(a)

	NSW	Vic	Qld	WA ^(d)	SA ^(e)	Tas ^(f)	ACT	NT	Average of jurisdictions with complete data ^(g)
Group homes		60,094			48,094				59,712
Other accommodation support		32,320			20,712				30,679
<i>Subtotal: Accommodation support</i>	NA	39,035		33,990	22,350			NA	36,568
<i>Subtotal: Packages offering more than one service type</i>			25,872			20,464	28,413	21,949	24,383
<i>Subtotal: Respite</i>	NA	2,465	6,500	Note 4	12,120			2,000	4,623
Therapy services		2,000		2,015			5,120		2,084
Specialist services		13,913			1,199				6,759
Early intervention					NA			NA	NA
Local area coordination/intake & assessment	NA	1,250	2,000	1,799					1,533
Other community support		4,805	3,203		NA				4,504
<i>Subtotal: Community support ^(b)</i>	NA	NA	NA	NA	NA		NA	NA	NA
Day programs		15,152		12,022	NA				12,624
Post-school options		8,244	11,250	11,987	13,306		16,667	20,833	9,216
<i>Subtotal: Community access</i>	NA	8,505	11,250	12,009	NA		16,667	20,833	9,598
<i>Subtotal: Other (including equipment)</i>	NA	785							785
<i>Subtotal: Service/infrastructure/quality development ^(c)</i>	NA	NA	NA	NA	NA	NA	NA	NA	NA

(a) Some jurisdictions provided information which would allow calculation of average funding costs for sub-categories within each of these service types, but this information was not presented in Table 3.5. It is, however, reported in this table.

(b) Clients in the community support sub-categories cannot be added as a client may receive support from more than one sub-category.

(c) This category includes all service development, quality, infrastructure and viability initiatives for which there are no direct client outputs, only indirect benefit. So an average funding cost cannot be calculated.

(d) Western Australia reported on four respite sub-programs. The average cost of two of these sub-programs is \$6,795 per client, representing an estimated full-year recurrent cost of \$5.3 million and an estimated 780 clients.

(e) Average funding for brokerage of accommodation support in South Australia is included in other accommodation support, rather than within other community support.

(f) Tasmania had two package programs—one which could include group home accommodation support (which had an average funding cost of \$106,667 per client) and the other which did not (with an average funding cost of \$8,380 per client).

(g) Insufficient information was available to report the average funding within all sub-totals for all jurisdictions. Thus some row totals are not the averages of their service type sub-totals.

Another source of information from which average funding costs can be calculated is the information compiled for a number of service types by the Productivity Commission (SCRCSSP). In Table 3.10 this information is compared with data from Table 3.9.

The Productivity Commission figures show average funding levels for all Commonwealth/State Disability Agreement services, including but well beyond the scope of 2000–01 unmet need funding service enhancements. These figures therefore largely represent the legacy of past funding practices, whereas the unmet need funding figures represent the expected average results of funding strategies employed by the jurisdictions during 2000–02.

The figures in Table 3.10 show that, on average, funding costs to government were higher for places run by government. Interestingly, average funding costs were lowest for large, non-government institutional places. While this could reflect historically lower levels of funding, it may also reflect, to a degree, British research that for some clients, institutional care may be delivered at lower cost, although it results in lower outcomes for residents than care in the community (Felce et al. 1998, 2000; Emerson et al. 2000a, 2000b).

Table 3.10 demonstrates that, for the service types and jurisdictions for which comparable data are available, these jurisdictions have utilised lower funding cost strategies in their distribution of unmet need funding than have been used on average in the past. In relation to the average funding cost of accommodation support and multi-service type packages, this probably largely reflects the absence of government-delivered places, in favour of group home and in-home accommodation models delivered mainly by non-government agencies.

The lower average costs for community access from unmet need funding reflect a higher proportion of post-school options funding in the unmet need funding than in the CSDA Productivity Commission figures, combined with the much lower post-school funding level of Victoria.

Table 3.10: Average funding per client for accommodation support and community access services, by States and Territories, comparing unmet need funding with average funding costs derived from tables from the Report on Government Services (\$) ^(a)

Source	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Average of jurisdictions reported in Table 3.9
Accommodation Support									
<i>Productivity Commission figures ^(b)</i>									
Average per govt inst./large residential place 2000–01 ^(b)	97,079	72,977	106,503	69,731	64,181	—	—	—	79,725
Average per govt community accomm. & care place 2000–01 ^(b)	95,649	72,305	83,597	81,230	44,401	61,322	75,483	—	73,324
Average per non-govt inst./large residential place 2000–01 ^(b)	35,024	39,517	21,743	25,089	23,281	31,421	—	—	30,701
Average per non-govt community accomm. & care place 2000–01 ^(b)	60,145	53,226	29,771	55,551	25,820	48,797	22,728	72,800	46,208
Average govt \$ per client 2000–01 ^(c)	77,062	67,272	47,775	61,492	45,234	50,616	61,765	68,612	63,856
<i>Jurisdiction Survey figures ^(d)</i>									
Average per shared supported accomm. or group home client ^(d)		60,094			48,094				59,712
Average per other accomm. support client ^(d)		32,320			20,712				30,679
Average estimated funding cost for accommodation support per client ^(d)		39,035		33,990	22,350				36,568
Average funding cost for packages offering more than one service type per client ^(d)			25,872			20,464	28,413	21,949	24,383
Community Access									
<i>Productivity Commission figures: Average govt \$ per client 2000–01 ^(e)</i>									
	16,986	17,339	14,274	24,342	10,444	18,583	12,510	34,615	16,956
<i>Jurisdiction Survey figures: Average estimated cost ^(d)</i>									
		8,505	11,250	12,009			16,667	20,833	9,598

(a) Accommodation support and community access are the only two service types for which sufficient data are published by the Productivity Commission to calculate average funding cost.

(b) SCRCSSP 2002, table 13A.19.

(c) Calculated from SCRCSSP 2002, tables 13A.7 & 13A.11.

(d) These figures are the estimated full-year recurrent effect of unmet need funding initiatives (at 2001–02 prices) divided by the anticipated number of clients to benefit from the expenditure (as shown in Table 3.9).

(e) Calculated from SCRCSSP 2002, tables 13A.7 & 13A.13(B).

3.8 Unmet need funding cost experience

Just as the expected average costs per client from unmet need funding have differed from historic average costs (Table 3.10), it is assumed that future average costs may also vary, as the experiences of jurisdictions with new service initiatives and strategies are followed by review and analysis, leading to revised funding and support models. Further, there is some information from a number of jurisdictions which suggests that this initial unmet need funding initiative selected clients most in crisis or with the highest needs⁸. However, with time it is possible that more funding will be allocated to proactive rather than reactive support. This will almost certainly affect cost structures and will be a challenge for future costing exercises. This issue is explored in Chapter 8.

A number of jurisdictions provided contextual information in relation to the average annual funding costs expected in the unmet need funding initiative. Some of this information suggests that future costs could vary from unmet need full-year average costs which in turn varied from historical costs.

Four jurisdictions commented on their average individual support package costs, three saying that they expected they could in the future be larger than suggested by their average need experience:

- Queensland suggested that its future average funding costs per place for Adult Lifestyle Support packages may be as high as \$35,000, although the unmet need funding average is expected to be \$24,000.
- Western Australia reported an average individual support package cost of \$45,000 in its survey response, compared to the average of \$34,000 expected to be the case from unmet need funding. This variation was thought to result from a greater proportion of historical funding including residential care, whereas all unmet need funding was for support in the community or in clients' homes. A large range in actual client funding packages is based on self-reporting (by agency or outlet), with some packages (for example, for people with multiple sclerosis) being as low as \$500 per annum.
- Northern Territory expected its average funding cost for individualised packages could be as high as \$30,000 (rather than the \$21,949 in Table 3.9). This was because a number of clients were likely to be requiring much higher funding levels than initially approved. They also reported that there were another 20 people funded outside the unmet need funding initiatives whose package were costing an average of \$95,000.

⁸ This is said to be not the case in Western Australia which reported that specialist disability services 'are based on a preventive strategy that is designed to avoid the need for more crisis-orientated and costly interventions at later stages; included in this strategy are:

- early intervention services and support for people with disabilities and their families and carers;
- supports for people to live within their own local communities rather than residential facilities;
- Local Area Coordination that has State-wide coverage and helps facilitate the mobilisation of community capacity.

The results of this strategy can be illustrated by the age distribution of service users in Western Australia as compared with other jurisdictions. The significantly higher proportion of service users in the under 16 age group is largely the result of Local Area Coordination'. (Western Australian survey response, page 4)

- The Social and Community Services Award increase in New South Wales will significantly increase costs of service provision in the non-government sector. The current annual estimate of the cost of this increase is in the order of \$29 million recurrent.

Western Australia reported higher Local Area Coordination (LAC) costs for all CSDA clients than was the case for those supported with unmet need funds (which had an average coordination cost of \$1,800). In 2001–02, it has been estimated that for all Western Australian clients, the average LAC cost was \$2,278 per client, with direct grants of \$8,112 per client.

The average client cost for the Australian Capital Territory Post School Options program suggests that a higher proportion of initial clients were in the high funding band than was expected from applications, as lower need school graduates have other alternatives to work, or work options available to them. The Australian Capital Territory Post School Options program provides flexibility to explore options beyond the standard funded programs, while retaining a level of control as to how far the interpretation of ‘alternative to work activities’ is taken. The Australian Capital Territory expects that the availability of Commonwealth employment programs will continue to influence the level of applications at the lower level to the Post School Options program in the Australian Capital Territory.

Jurisdictional comments on cost factors

Jurisdictions were also asked about any cost factors which they felt applied particularly in their jurisdiction and about the costs of supporting clients with a disability with additional needs (from Indigenous or other cultural or language backgrounds, or from rural or remote areas). While some of the cost factors mentioned by the jurisdictions are addressed by the Commonwealth Grants Commission in its equalisation process, jurisdictions’ comments are outlined here as reported.

A number of jurisdictions reported that weightings are included in their planning systems for clients with a disability with additional needs. New South Wales considers rurality and Indigenous status in its Population Group Planning and Queensland includes a 10% weighting for residents living in rural or remote areas and a 100% weighting for Indigenous people in its regional funding formula. The Commonwealth is currently considering whether a higher funding level should be applied to providers of support to people in rural and remote areas.

Higher costs were reported as being associated with:

- *supporting a highly decentralised or dispersed population*, in jurisdictions with large regional, rural and remote areas (mentioned by Queensland, Western Australia, Tasmania, the Northern Territory and the Commonwealth). Tasmania noted that this dispersion results in a greater reliance on individualised or small group service options, with increased operational costs such as transport. The Northern Territory noted that there were few disability service providers in remote areas, with basic services being provided to people with a disability via the HACC program. Many urban-based services were reported as having their staff travel out to remote area communities, with its associated travel costs. ‘During the wet season some communities are only accessible by air charter which increases the associated costs of travel.’⁹ Staff recruitment, retention and training costs were seen to be higher in rural and remote areas.

⁹ Northern Territory Survey response, page 13.

The Northern Territory quoted a report of Thomson Goodall (2001) on employment services:

Although based on a limited number of cases, the data suggests that input costs for disability employment services in rural and remote locations are 10–20% higher than in urban areas, mainly due to higher travel and communication costs. Salaries and wages may also be slightly higher. The Commonwealth Grants Commission has information which supports these estimates, indicating even higher relative costs in very remote locations... In addition to higher input costs, staff productivity in rural and remote open employment services is often relatively low due to longer travel times (especially where services are provided on an outreach basis), and lower ‘throughput’ of job seekers with disabilities, the result of weak and/or seasonal labour markets. (Thomson Goodall 2001:viii–ix)

The Northern Territory also noted that, based on the work of the Grants Commission, the Thomson Goodall report estimated that disability services in the Northern Territory require nearly twice the average Australian expenditure due to the dispersed nature of the population, the higher proportion of Indigenous people and other factors (Thomson Goodall quoted in the Northern Territory Survey response);

- *the support of people from other cultural and language backgrounds* (mentioned by New South Wales, the Northern Territory and the Commonwealth). The Northern Territory quoted a report by the Australian Bureau of Statistics (2000), commissioned by the Commonwealth Grants Commission Indigenous Funding Inquiry, which estimated that providing culturally appropriate services for Aboriginal people increased service delivery costs by 10%¹⁰;
- *high population growth* (mentioned by Queensland and New South Wales);
- *support of a different profile of disabilities between jurisdictions*. The Northern Territory noted that it had the highest proportion of clients with a profound core activity restriction utilising CSDA services;
- *higher housing and rental costs of Sydney* (as shown in the Australian Bureau of Statistics CPI Quarterly Review);
- *higher costs of living in non-metropolitan areas* (mentioned by Queensland, Western Australia and the Northern Territory)¹¹. The Northern Territory noted the additional transportation costs of bringing goods to Northern Territory communities, with remote areas being especially disadvantaged by paying higher costs to have goods delivered to them;
- *different salary rates* between jurisdictions (mentioned by New South Wales and Victoria);
- *high rates of ageing* in certain areas (for example, mentioned by New South Wales (in relation to its northern region), Queensland and the Commonwealth); and
- *higher cost margins* in the Northern Territory and the Australian Capital Territory as fixed costs are not as easily spread amongst their limited number of service providers with smaller providers being unable to benefit from economies of scale.

Funding and service delivery difficulties were reported to arise from:

- the high level of *unmet need* (mentioned by Queensland);

¹⁰ Australian Bureau of Statistics 2000, quoted in the Northern Territory Survey response.

¹¹ Western Australia and the Northern Territory both referred to the work of the Grants Commission.

- the historic cost and service provision *balance between government and non-government provided care* and the associated salary, conditions, models, cost and ability differentials of the two sectors, which may vary by region within jurisdictions (mentioned by New South Wales, Victoria, Queensland, the Northern Territory and the Commonwealth);
- historic *service provision and resource allocation differences* between jurisdictions and between geographic areas, which do not necessarily match current demography or future trends (for example, historic resource deficiencies were mentioned as occurring in northern New South Wales; a lower current level of service provision was reported in Queensland; and Western Australia noted that its medical and specialist services were unique);
- 'historic *underfunding of the disability sector* resulting in large numbers of extremely high-cost clients due to crisis situations' (Queensland);
- the amount of *congregate care* still being provided within a jurisdiction (mentioned by Victoria);
- different average costs of service deliverers (mentioned by Queensland); and
- a *limited number of service providers* in the Australian Capital Territory and the Northern Territory to compete for potential contracts, which limits these jurisdictions' capacity to negotiate a best price. The Northern Territory also noted that this affected the provider network's ability to lobby for cost reductions (for example, in terms of reduced workers' compensation premiums).

Queensland and the Northern Territory reported difficulties in establishing new service responses in areas with limited existing infrastructure and few, if any, service purchase options. The Northern Territory also noted that the absence of appropriate infrastructure resulted in some people with a disability being inappropriately relocated to major centres.

The Northern Territory reported the results of Disability Community Consultation forums, which were held in Darwin (30 October 2001) and Alice Springs (13 November 2001):

Participants acknowledged the need for a combination of individual funding and funding to service providers.

For a wholly individualised model to work properly, a wide range of services need to be on offer. In the Northern Territory, particularly in rural and remote areas there is a small, limited service network, which means that there is little choice in the spectrum of services which consumers are able to purchase their care and support services from.

The unmet need funding round 2000–01 was acknowledged as a starting point but it was recognised that for many people who did receive funding there were limited or no services to purchase, particularly in remote areas.

Sustainability of services in remote areas was recognised as an on-going concern, e.g. funding for the administrative component of their work, cost of vehicles, staff training etc. Overheads impacted on the services that could be provided. Innovative service models were required. Pooling of funding was seen as one way to maximise the purchasing power.

Anecdotal feedback has highlighted that for individuals living in remote areas there were some cultural difficulties associated with the receipt of individualised funding, i.e. issues pertaining to the payment of family members to provide services, e.g. Who is allowed to do what for whom, who the payment goes to etc.¹²

¹² Northern Territory Survey response, pages 18–19.

Queensland also reported concerns about:

- ‘the “cost” of disability, both in terms of the cost of aids and equipment, and the GST which is placed on some essentials such as air conditioners (required for temperature control for people with severe physical disability). These issues are not taken into account in the Commonwealth’s income support system’¹³; and
- ‘Commonwealth Tax Reform – compliance with the new requirements is time-consuming and often beyond the expertise of volunteer management committees. Service providers’ operating/administrative budgets are unable to meet these requirements, resulting in funds being diverted from service provision budgets and therefore less service to clients. Some are having to purchase specialist accounting and other financial expertise. For States this is a cost-shifting exercise both in terms of the diversion of funds away from service provision, and of having to “bail out” providers when they have reached critical points in terms of their viability, often for millions of dollars.’

Developments in funding or purchasing arrangements and costing approaches

A development in most jurisdictions since the 1997 study is the expansion of resource allocation and funding or purchasing arrangements used, including systems based on:

- *individual assessments* of applicants which lead to support strategies which are then costed according to predetermined funding increments or unit costs. This system is largely used for accommodation support and individual packages;
- *categorisation* of applicants into broad bands of support need, to which predetermined funding levels apply. This is most often used for post-school option services but is also being used for packages, day services, community support and local area coordination, in some jurisdictions. The post-school option systems used include:
 - in Victoria, six funding bands are used related to client need, from the lowest level which is funded at a rate of \$7,014 per annum (which is assumed will support 20–30% of clients), to the second level of \$8,317 (20–30% of clients), third level of \$10,751 (10–20% of clients), fourth level \$15,809 (10–20% of clients), fifth level \$17,513 (<10% of clients) to level 5.5 \$20,166 (<5% of clients);
 - Queensland uses two funding bands: low which provides less than \$14,500 (for possibly 61% of clients) and high which funds between \$14,500 and \$18,500 per annum (for possibly 39% of clients);
 - the Australian Capital Territory uses four funding bands: low – \$6,000 per client per annum, based on 200 hours (for some 24% of clients); medium – \$10,000 per client per annum based on 333 hours (7% of clients); high – \$14,000 per client per annum based on 466 hours (23% of clients); and very high – \$20,000 per client per annum based on 666 hours (46% of clients);

The very different distribution of clients supported across the fairly similar funding bands in Victoria and the Australian Capital Territory would suggest that the Australian Capital Territory would incur higher average government funding per person supported. This is demonstrated in the figures in Table 3.9 for the unmet need funding;

¹³ In relation to this point, Queensland referred to the web sites of the Physical Disability Council and of QCOSS.

- *resource allocation formulae* related to demographic, socioeconomic, geographic and other characteristics of areas, which may include weightings for particular target groups and/or goals of ensuring geographic coverage of all catchment areas. This system is most often used for service development and intake, assessment and/or local area coordination projects.

Contracting of service providers to provide prescribed services (which may be in relation to specific individuals) is becoming increasingly common, although Queensland, the Northern Territory and the Australian Capital Territory each mentioned difficulties associated with contracting (outlined above).

3.9 Unmet need funding: comparisons with past estimates

The study team also set out to answer the question: How does the quantum of new service provision compare with what might have been anticipated, based on the estimates of need and cost contained in the AIHW 1997 report and the Administrators' paper of 1999? This section compares the estimates of need from the AIHW 1997 report with jurisdictions' estimates of the effect of the unmet need funding in future years. In order to make these comparisons various assumptions are needed, for example to deal with missing data.

The AIHW report conservatively estimated that, in 1996, there could be some 13,400 people who had expressed unmet demand for accommodation and respite support and another 12,000 for day programs (AIHW 1997a). It was estimated that these may cost \$178.29 million and \$115.79 million to meet respectively. The funding cost method used was built up from the estimated need of individuals within each of these groups and from predicted appropriate service response levels (see also Appendix 1).

In 1999, Disability Administrators considered the Institute's estimates and (as reported in Chapter 1) recommended to Ministers that:

- 750 clients with profound disabilities be provided accommodation support, at an average cost of \$50,000 each;
- 16,760 ageing carers be supported with either or both respite or day programs, at an average cost of \$10,400 for each service component per client; and
- 7,890 younger families be supported with either or both respite or day programs, at an average cost of \$10,400 for each service component per client.

Table 3.11 places the 1997 AIHW estimates of unmet need for disability services (namely the estimated number of clients and the estimated cost of supporting them) alongside jurisdiction-based figures of the possible future effects of the unmet need funding provided in 2000-01 and 2001-02 (namely the number of clients that may be supported with unmet needs funding when it is fully operational). Caution is needed when interpreting the jurisdiction-based figures because they were derived by:

- taking the expected full-year recurrent expenditure provided by jurisdictions for each service type (see Table 3.5);
- considering the expected number of clients to be supported with this expenditure, provided by some jurisdictions for some service types (see Table 3.7); and
- deriving possible client numbers where client figures were not provided by jurisdictions (by dividing expected full-year recurrent expenditure for these jurisdictions and service

types, by the average funding costs derived for these service types by information provided by other jurisdictions).

Because of missing data, this comparison or checking process does not provide reliable estimates. For instance, it uses estimated projections of some jurisdictions and applies average funding costs from other jurisdictions to fill gaps.

This process broadly suggests that the ongoing impact of the unmet need funding *could* be that (Table 3.11):

- some 14,800 clients *may* receive accommodation support, multi-service packages or respite support (4,400, 1,400 and 9,000 respectively), which is higher than initially recommended; and
- some 3,500 clients *may* receive day programs support, which is lower than initially recommended¹⁴.

In addition, the jurisdiction-based estimates show that jurisdictions used the funds for purposes beyond accommodation, respite and day programs. An additional number of clients will also receive community support or other (mainly equipment) assistance. Clients can also be expected to receive indirect benefits from funded quality and service infrastructure development projects.

The analysis also suggests that overall average costs for accommodation and respite and for day programs, depending upon the New South Wales results, *may* approximate those predicted. However, New South Wales has indicated a range of factors as to why it believes its costs are greater. So the client extrapolations outlined above may be on the high side, that is, fewer clients may realistically be assisted, and the average cost figures on the low side, that is, funding cost per client may in reality be greater.

Further, it must be noted that the grouping of accommodation and respite costs camouflages a considerable range in delivery costs, and allows high client numbers for lower cost respite services to offset lower client numbers for higher cost accommodation services. Separation of these service types in future estimates may better reflect expenditure goals and client needs. This issue, and the methodology used, is discussed in Chapters 2 and 8.

¹⁴ In some jurisdictions clients may receive day support as part of their multi-service packages, which could extend the number, to perhaps a maximum of 4,900 clients, which is still below the level initially recommended.

Table 3.11: Comparison (check) of AIHW 1997 estimates with jurisdiction estimates of future effects of unmet need funding

a. Numbers estimated by AIHW and reflected in Administrators' paper 1999			
Unmet needs	Number	Total funding cost	Average funding cost (AIHW)
Accommodation and respite	13,400 people	\$ 178,290,000	\$ 13,305
Day programs	12,000 places	\$ 115,500,000	\$ 9,625
Total		\$ 293,790,000	
b. Jurisdiction-based figures: Possible effect of unmet need funding (based on estimated full-year recurrent expenditure and clients supported from Tables 3.5 and 3.7)			
Unmet needs	Possible number of clients supported	Expenditure provided by jurisdictions	Possible average costs
Accommodation support	4,400	\$ 161,119,000	\$ 36,618
Multi-service type packages	1,400	\$ 34,355,000	\$ 24,539
Respite	9,000	\$ 41,800,000	\$ 4,644
Community support	not available	\$ 41,034,000	not available
Community access	3,500	\$ 34,453,000	\$ 9,844
Other	8,500	\$ 7,108,000	\$ 836
Service/infrastructure/quality development	not available	\$ 12,563,000	not available
Total		\$ 332,432,000	
<i>Subtotal accommodation, respite or multi-service type packages:</i>	<i>14,800 people</i>		<i>\$ 16,032</i>
<i>Subtotal day programs:</i>	<i>3,500 people</i>		<i>\$ 9,844</i>
<i>Subtotal other:</i>	<i>not available</i>		<i>not available</i>

Sources: AIHW 1997a and NDA 1999.

3.10 Summary: use of the funding

Quantum

Bilateral Agreements in 2000 between the Commonwealth and all other jurisdictions covered unmet need funding of \$519 million over two years, 2000–01 and 2001–02. Through the survey for this study, jurisdictions reported on estimated expenditure totalling \$575 million.

New South Wales, Victoria and the Australian Capital Territory reported applying more funds over 2000–01 and 2001–02 than were required under the Bilateral Agreements with the Commonwealth.

Expenditure in New South Wales dominates unmet need funding—50% of the \$220 million reported on in 2000–01 and 51% of the \$355 million estimated in 2001–02.

Growth in disability expenditure in 2000–01 exceeded Bilateral Agreement offers by all jurisdictions except New South Wales (see Section 3.3).

Constraints on national expenditure analysis

The unmet need funding is a national initiative that has been translated differently in each jurisdiction, including the application of the Commonwealth funding, which targets ageing carers.

The unmet need funding has not always been 'quarantined' within disability expenditure and so in many cases its size and client impact had to be estimated. Furthermore, the unmet need funding is a two-year initiative being considered after 18 months and with only one year of data.

Some jurisdictions reported they were not able to fully roll out the 2000–01 funding within the 2000–01 financial year. Consultations with other jurisdictions suggest they had similar problems although their figures do not show under-expenditure for 2000–01.

New service models are still evolving (with expenditure including set-up costs) so actual recurrent funding costs are not yet available.

Given these circumstances, all expenditure figures should be considered estimates and must be used with caution.

Application of the unmet need funding

Over the two years of funding, around 66% of both Commonwealth and State funding is estimated to be directed towards accommodation support, multi-service packages and respite. Around 31% of Commonwealth funds are expected to be allocated to respite compared to 11% of States' and Territories' contributed funds.

The ongoing effect of unmet need funding is expected to be an even greater emphasis on accommodation support, multi-service packages and respite, with 71% of funds directed to those service types (Table 3.5).

Clients supported and funding amounts

Client numbers provided by jurisdictions are incomplete. These incomplete reports suggest that, on an ongoing basis, at least 1,200 clients will receive accommodation support, 1,400 are expected to receive individualised packages (containing more than one service type), 4,200 are expected to receive respite support and 2,500 are expected to receive community access support. The incompleteness of these figures is apparent when it is noted that the estimates of clients supported relate to only 35% of 2000–01 funding (Table 3.6) and 38% of ongoing recurrent funding (Tables 3.7 and 3.8).

For accommodation support, average funding per client from unmet need funding is lower than historic CSDA costs as reported to the Productivity Commission (Table 3.10). This probably reflects the absence of government-delivered accommodation services and the lower representation of group homes in the new funding.

For community access, the average funding per client from unmet need funding is lower in four jurisdictions than historic costs as reported to the Productivity Commission and higher in one (Australian Capital Territory) (Table 3.10).

Jurisdictions reported new service initiatives for ageing carers (see Section 3.4) although the variety of reporting methods does not readily allow aggregation of the data supplied.

Achievements compared with expectations

The full effect of funding will not be apparent in client outputs until after the two years of additional expenditure have been completed, that is, until 2002–03. Given the incompleteness of the data currently available on the effect of the unmet need funding, it is too early to judge the extent to which it may achieve the service needs identified by National Disability Administrators in 1999. However, an exercise was undertaken to compare the estimates of unmet need from the AIHW 1997 report with jurisdictions' expectations of the effect of the unmet need funding in future years. From this exercise, it appears that jurisdictions' expectations of the full-year effects of the unmet need funding may be broadly consistent with the 1997 estimates of the AIHW and disability Administrators (Section 3.9).

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 Agreements¹ 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).

¹ 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)².

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.)

² 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

Service type	Services received snapshot day	Consumers over the full year	Ratio of full-year consumers: snapshot day services received
Accommodation support			
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>
Total accommodation support	2,139	2,740	1.28
Community support			
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
Total community support	4,755	24,876	5.23
Community access			
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
Total community access	710	2,053	2.89
Respite			
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
Total respite	386	2,682	6.95

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 ^(a)				
	1997	1998	1999 ^(b)	2000 ^(b)	2001
STATE/TERRITORY					
Accommodation support					
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>
Community support					
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>
Community access					
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>
Respite					
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
Total State/Territory	46,592	51,061	56,131	57,454	59,350

(continued)

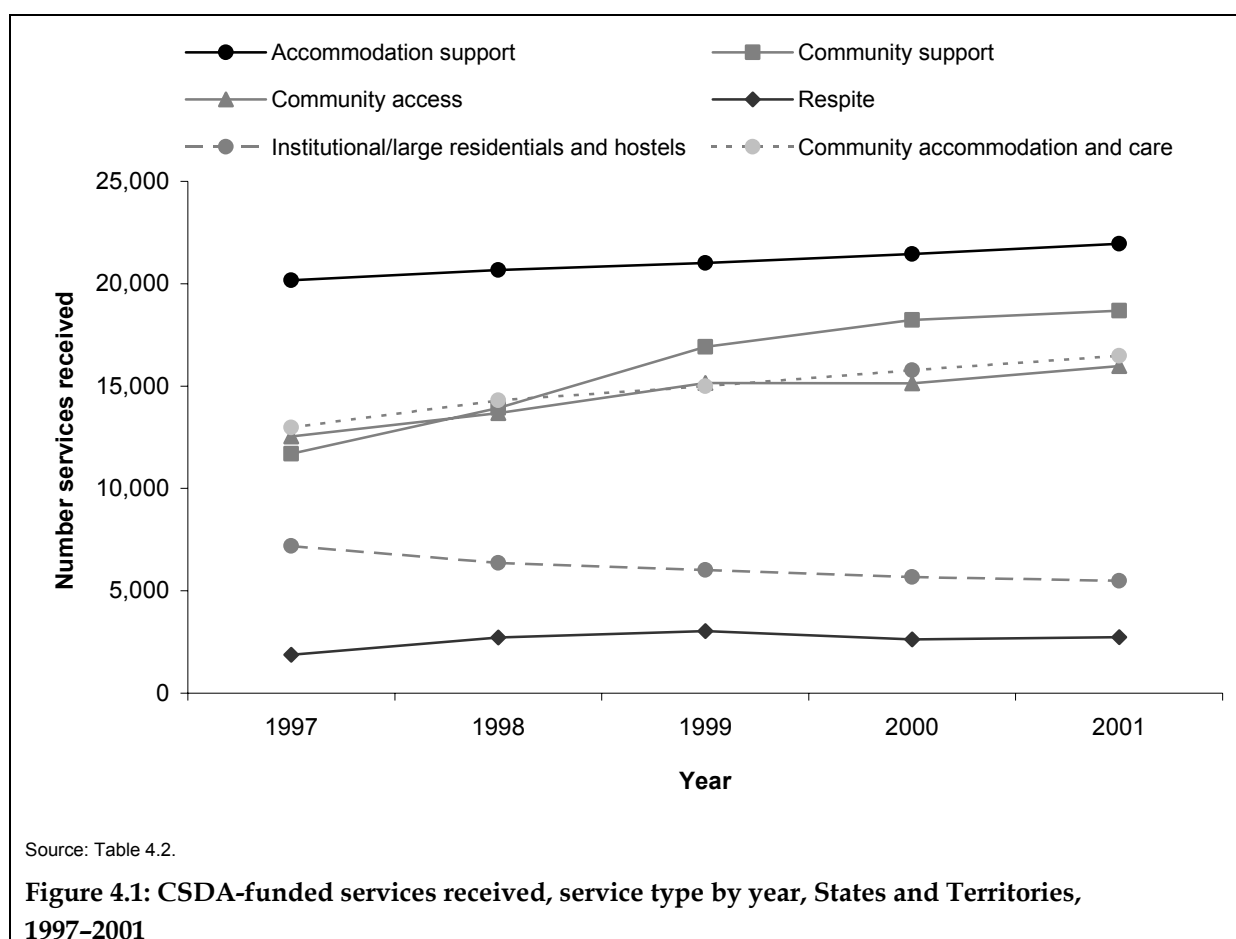
Table 4.2 (continued): CSDA-funded services received, by service type, by year, on a snapshot day, Commonwealth, States and Territories, 1997–2001

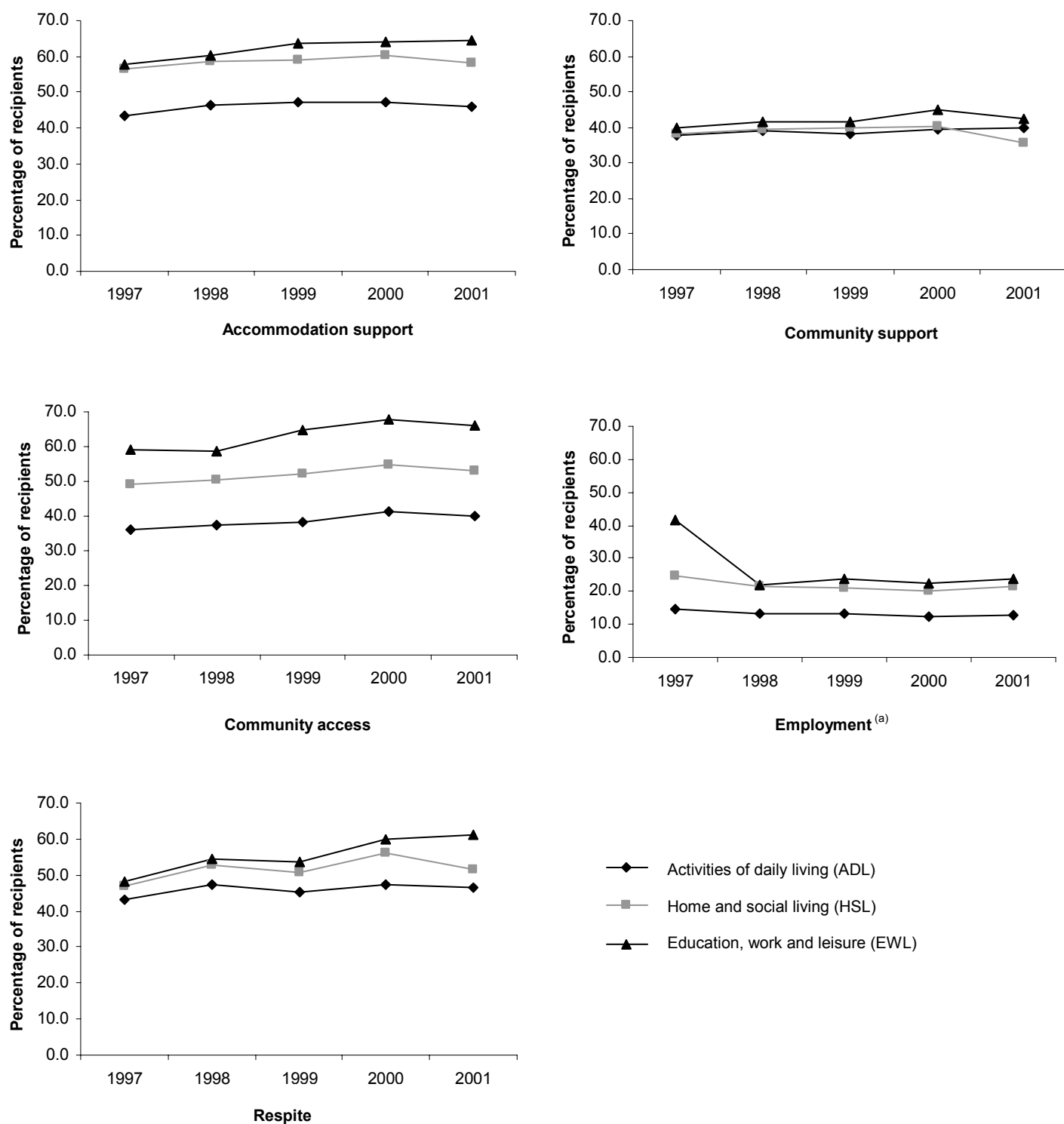
Service type	Services received ^(a)				
	1997	1998	1999 ^(b)	2000 ^(b)	2001
COMMONWEALTH					
Employment					
Open employment	4,541	4,453	3,994	4,286	4,605
Supported employment	12,906	12,883	12,808	11,472	11,502
Open and supported combined	393	658	997	1,717	1,748
Other employment	0	143	52	0	0
<i>Total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

(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.

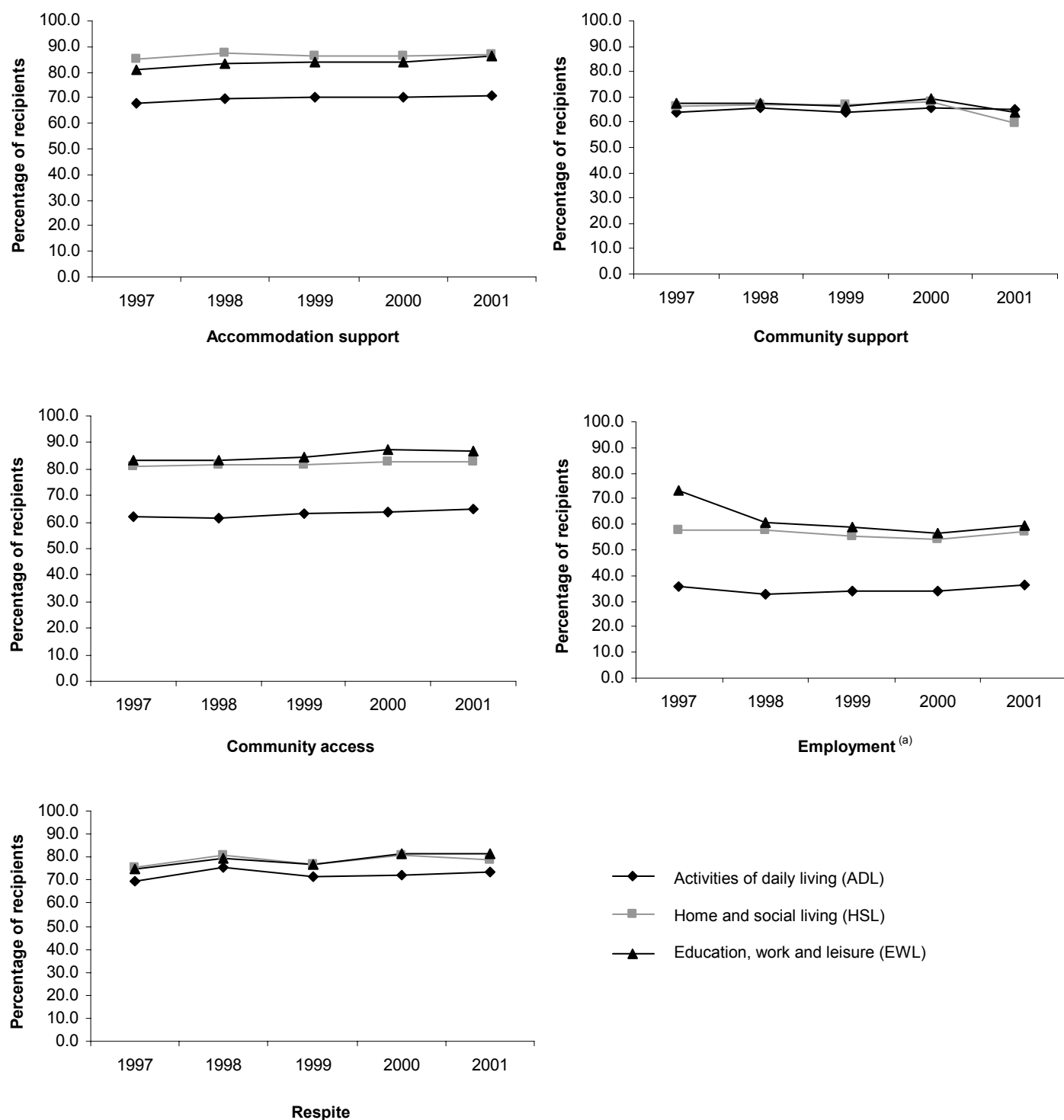




(a) In 1997 the Commonwealth removed the life domain of 'working' from the standard CSDA MDS support needs question and asked about support needs in the area of 'working' in a separate question. In 1998, the 'working' life domain was combined back into the standard CSDA MDS support needs question. Table 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

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

Service group	1997	1998	1999	2000	2001
Accommodation support					
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>
Community support					
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>
Community access					
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>
Respite					
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

Service group	1997	1998	1999	2000	2001
Employment					
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>
All service groups					
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
Total	100.0	100.0	100.0	100.0	100.0
<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

Service group	1997	1998	1999	2000	2001
Accommodation support					
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
Community support					
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
Community access					
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

Service group	1997	1998	1999	2000	2001
Respite					
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
Employment					
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
All service groups					
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 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.

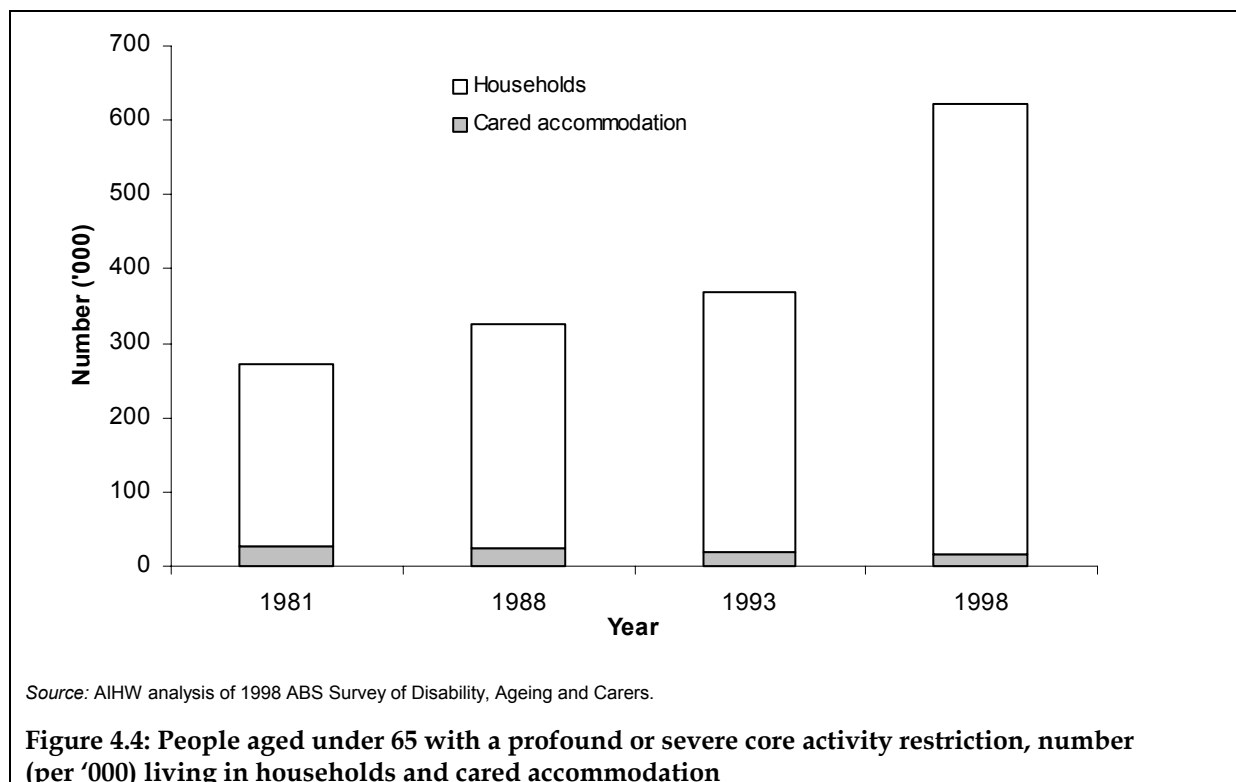
De-institutionalisation

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 households³. 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).

³ 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.

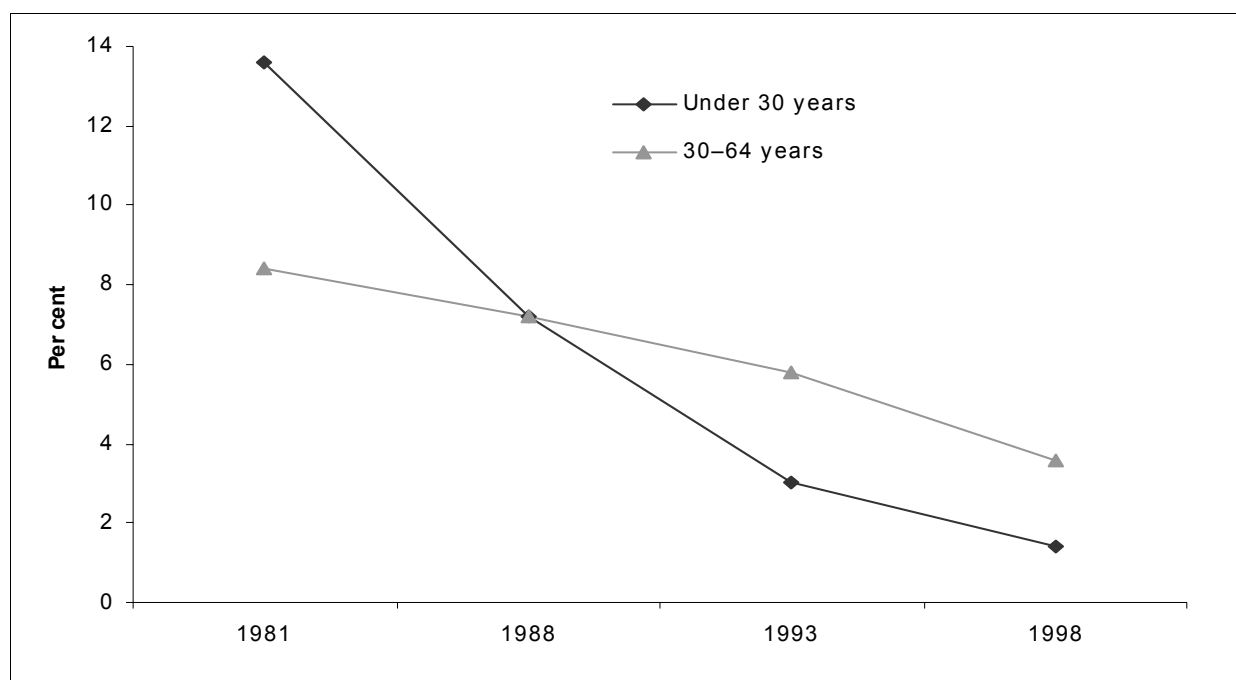


- For people living in institutions, there was a decrease in the percentage of the population aged under 15, from 13% in 1981 to 2% in 1998. A similar decrease was observed for people aged 15–29, from 27% in 1981 to 13% in 1998. In contrast, an increase from 42% to 56% occurred for people aged 45–64.

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.

5 Jurisdiction methods for managing ‘need’

5.1 Introduction

Chapter 5 examines methods for managing ‘need’ in each jurisdiction and the information available from these processes. Information in this chapter is drawn from material provided by funding departments in response to the Jurisdiction Survey (Appendix 2). Information gathered from peak discussions, relating to methods of managing need, is presented in Chapters 4 and 7.

Section 5.2 discusses the main jurisdiction-wide method used in each jurisdiction to manage expressed need, Section 5.3 then presents analysis of what these processes tell us about need and unmet need and Section 5.4 provides a brief summary and discussion of the main issues raised in the chapter.

5.2 How jurisdictions manage ‘need’

Target group of CSDA-funded services

The CSDA target group is defined and discussed in Chapters 1 and 2 and relates to people with specified disabilities that are likely to be permanent and result in substantially reduced capacity in at least one of: self care/management; mobility; or communication. Most policy and program documents provided by jurisdictions refer to the broad target group included in the Disability Services Acts and other relevant legislation (for example, the *Victorian Disability Services Act 1991* and the *Victorian Intellectually Disabled Persons Services Act 1986*), with which the CSDA target group is broadly aligned¹.

Most programs also have further eligibility criteria but these are generally very broad and still relate to the CSDA definition of disability.

Most jurisdictions continue to grapple with historical funding practices, which tended to focus on the needs of people with intellectual disability and on service models such as institutional care. This means that many of the current client population of CSDA-funded services have been receiving services for many years and are not necessarily representative of the newer client population.

¹ The *Queensland Disability Services Act 1992* refers to substantially reduced capacity for communication, social interaction, learning or mobility; the *South Australian Disability Services Act 1993* refers to reduced capacity for social interaction, communication, learning, mobility, decision making or self care; the *Commonwealth Disability Services Act 1986*, the *Australian Capital Territory Disability Services Act 1991* and the *Victorian Disability Services Act 1991* refer to substantially reduced capacity of the person for communication, learning or mobility.

Planning models

Many jurisdictions have regional or State-based planning models to plan around *potential* need for support (see Box 5.1 for examples). These models provide the information essential to planning the distribution and funding of new and existing services. Generally, their purpose is to promote equity in distribution of resources, that is, they often focus on comparative need.

Box 5.1: Examples of jurisdiction planning methods

New South Wales

Funding objectives are determined through a two-tier planning model. This model has been developed to facilitate equitable resource distribution to meet the identified needs of population groups, rather than focusing on programs. The model is applied in determining priorities for distribution of resources, which are not otherwise targeted to meet specific budget or system reform initiatives.

- *Regional Planning Framework and Plans: Regional Planning Officers in each of the Department's six regions work with service providers, service users, carers and local interest groups to establish local needs and priorities and to make annual recommendations for priority targeting of resources.*
- *Population Group Planning (PGP) statistical data model: PGP determines resource distribution on indicators such as current service supply, population demographics and identified needs, including those of particular groups such as non-English-speaking background, Aboriginal and Torres Strait Islander, and rural and remote populations.*

Victoria

The Victorian Policy and Funding Plan identifies target groups and criteria for priority of access to services for all service specifications or types. Estimates of the potential target group or 'client profile' are developed using disability (or synthetic) estimates based on the ABS Survey of Disability, Ageing and Carers and the Population Census. These data are adjusted for client profile factors such as Victorian population size and structure (e.g. age composition), socioeconomic disadvantage across regions, characteristics and service user patterns of existing clients (based on the Commonwealth/State Disability Agreement Minimum Data Set collection), and the current service provider environment.

Source: Jurisdiction Survey response for New South Wales; DisAbility Services Policy and Funding Plan 2001–02, Department of Human Services, Victoria 2001.

Developments in funding and assessment models

Significant work has been undertaken in most jurisdictions in relation to funding and assessment methods. Examples are presented in Box 5.2 for Victoria and Queensland. These examples mostly relate to methods for managing the needs of people who have been accepted into the CSDA service system.

The focus of this chapter is on methods for managing 'unmet need', specifically *expressed* need for support via processes such as needs registers and application processes.

Box 5.2 Examples of recent developments in funding and assessment models

Victoria

Significant re-development work is under way to shift the disability support system from funding of 'places' in specific service types to provision of individualised support packages to promote community inclusion and self-determination of people with a disability. This will involve the consolidation of a number of service activities into broadly two types of individualised support packages, namely Community Support Packages (day program and community participation) and Personal Support Packages (for personal and accommodation support).

The development of these packages will be underpinned and based on broad individual whole-of-life plans, as well as developing individualised support delivery. The new Individualised Funding and Support Framework focuses on working in partnership with people with a disability and their families to identify their needs and aspirations, plans the support for their choice of lifestyle, coordinates support from both formal and informal networks and provides ongoing monitoring and review of the implementation of the individual's package of support. The new framework will also shift the current crisis-driven focus of case management to one of proactive early intervention and targeting people at major life transitions such as transition from early childhood to school, young adults leaving school and people moving from home to supported accommodation options.

Whilst the new framework will provide person-centred, needs-based assessment and planning, a project to develop a mechanism to integrate assessment, planning, priority determination and resource allocation for clients will be undertaken in 2002.

Queensland

Disability Services Queensland (DSQ) has recently commenced a major 18-month project on funding reform. The project aims to:

- *address the viability of non-government organisations to ensure that reliable infrastructure exists to deliver services;*
- *develop a funding framework to accurately forecast future demand and cost models of support;*
- *develop a program framework to provide a coherent and consistent approach to DSQ's funding programs;*

The outputs of this project may include new or revised service and funding models, an assessment of the quantum of funding needed in the long term, revised service level agreements (contracts) and a 'life stages' model of support.

Source: Jurisdiction Survey responses for Victoria and Queensland.

Needs registers and other application processes

There is variation across jurisdictions in the mechanisms used to manage and record expressed need and unmet need. Methods include full registers, partial registers, annual application cycles and local or service-based application processes. Table 5.1 summarises some important aspects of the *main* jurisdiction-wide or holistic methods currently used in each jurisdiction to manage need and unmet need. The issues and implications of the material presented in Table 5.1 are discussed in Section 5.3.

Table 5.1: Jurisdiction-wide method for managing need and unmet need in each State/Territory

	Name of method and commencement date	Who is eligible for inclusion on register/application or submission process?	Which service types does the register/application or submission process cover?	What does the form/assessment look like (plus any tools referred to)?	How is urgency/priority established?	What is the vacancy coordination process?
NSW	Service Access System (SAS) Commenced September 2000	People with a disability as defined under the <i>Disability Services Act 1993</i> who have identified risk factors and whose needs are unable to be met by attempting to access services provided under the Disability Services Program.	All CSDA service types	Not provided	SAS looks at whether the individual's current situation places: <ul style="list-style-type: none"> • them at significant risk; • their current support arrangements at risk; or • their current level of independence at risk. 	Those people who are assessed as eligible to be provided with support under the SAS are referred to support planners to have a support plan developed. The plan identifies the types of supports that would alleviate the risk factors for the individual and their carer(s).
Victoria	Service Needs Register (SNR) Commenced 1996	People who are eligible for services under the <i>Intellectually Disabled Persons Services Act 1986</i> or eligible for services under the <i>Disability Services Act 1991</i> .	Accommodation support and community access (day activity support)	The SNR application form includes, for example, client demographics, carer details, support needs and services requested. A number of assessment tools including Support Need Assessment and Inventory of Client and Agency Planning have been developed or adopted to enable grouping of clients with similar support needs and resource banding. Whilst these assessment tools can be used as objective and reliable benchmarking tools, they cannot be used as the only mechanism to determine the level of funding required by the individual as they do not account for individual needs or the formal or informal support network established.	The SNR application includes an Application for Consideration of Urgency. Applicants are asked to tick any of nine possible factors: <ul style="list-style-type: none"> • homelessness • recent death of primary care-giver • violence or abuse • age and/or health of primary carer • physical demands of caring for someone with high/complex support needs • significant skill loss impacting on applicant's current care/living arrangements • imminent family breakdown • current care/living arrangements placing the applicant and/or others at risk of abuse or significant harm (financial, physical, emotional) • significant family stresses such as the number of dependents. 	When a vacancy arises, Department of Human Services regional staff consider all urgent applications on the SNR and identify a list of clients compatible with the vacancy profile. In most cases, a shortlist of clients ranging from three to seven is developed and presented to the Vacancy Coordination Panel. The client who is considered most suitable for the vacancy and is the most urgent is allocated the vacancy.

(continued)

Table 5.1 (continued): Jurisdiction-wide method for managing need and unmet need in each State/Territory

	Name of method and commencement date	Who is eligible for inclusion on register/application or submission process?	Which service types does the register/application or submission process cover?	What does the form/assessment look like (plus any tools referred to)?	How is urgency/priority established?	What is the vacancy coordination process?
Qld	Registration, Application and Funding database Commenced November 1998 (formerly known as the Registration of Need database)	People with a disability who are aged 0–65 years, a resident of Queensland, and who need support.	All CSDA service types including flexible packages and individualised approaches under the Adult Lifestyle Support Program, Family Support Program and Post School Services.	The Registration, Application and Funding database and the application forms for programs included in the database (e.g. Adult Lifestyle Support) incorporate the majority of CSDA MDS data items.	<p>Priority rating is based on the following criteria:</p> <ul style="list-style-type: none"> • violence, abuse or neglect • no carer, age/health of primary carer, capacity of carer • person is homeless or has temporary accommodation in a respite facility or alternative emergency accommodation or is inappropriately placed in institutional care (or will be) • an impoverished environment resulting in significant deterioration of abilities. <p>Three other indicators are considered:</p> <ul style="list-style-type: none"> • involvement in criminal justice system • identified need for development or maintenance of the carer's ability to support the person with a disability • an identified need for significant development and improvement in the person's cognitive, physical, behavioural, social and communication abilities. <p>The priority rating is then weighted based on the number of critical indicators and the immediacy of the risk to the person.</p>	Regional priority panels operate across a number of DSQ programs as a means of prioritising individuals applying for support in a fair, equitable and transparent manner. Priority panels comprise both departmental and community representatives with a range of skills and expertise in supporting people with disabilities. Panel members consider the information supplied by each eligible individual against key criteria to determine a priority rating. Outcomes of the priority determination process directly inform the support and funding decisions made by the Department.

(continued)

Table 5.1 (continued): Jurisdiction-wide method for managing need and unmet need in each State/Territory

	Name of method and commencement date	Who is eligible for inclusion on register/application or submission process?	Which service types does the register/ submission process cover?	What does the form/assessment look like (plus any tools referred to)?	How is urgency/priority established?	What is the vacancy coordination process?
WA	Combined Application Process (CAP) Commenced October 2000	The person with a disability must: have a significant long-term disability; be in need of ongoing help or supervision; be in receipt of, or eligible for, the Disability Support Pension or the Carers Allowance unless the child has formally been assessed as having an intellectual disability; and be under the age of 60 when they first apply for services.	Accommodation support Community access (Alternatives to employment (AEP)) Community support (Intensive family support (IFS) packages —individual support packages where funding is allocated to families either through LAC or agencies depending upon the individual's choice)	The CAP form includes individual and carer information (demographics, supports needed, risk factors (e.g. risk of abuse); current supports; proposed use of funding), i.e. the CAP incorporates the majority of CSDA MDS data items. The Estimate of Requirement for Staff Support Instrument is used in certain circumstances to ensure that funding levels are consistent across people with similar support needs. The Inventory of Client and Agency Planning is currently being investigated for this purpose (see Tasmania).	Applicants are prioritised by Priority Panels and Options Panels using the information provided in the CAP form (i.e. on risks, current supports etc.).	Priority Panel and Options Panel. New applications are considered every 3 months (CAP form). If the person is allocated to AEP they meet with Disability Services Commission staff for a meeting called an Individual Needs Assessment (to determine appropriate level of funding and ways it can be utilised). If the person is allocated to IFS they will be contacted by their service provider (or LAC) to finalise a service/funding plan for consideration by the Commission. An appropriate funding level will then be determined. If the person is allocated to Accommodation Support they will also be contacted via their service provider (or LAC) to finalise a service/funding plan for consideration by the Commission. If the total amount sought is greater than \$30,000, a comparative assessment form, known as the Estimate of Requirement for Staff Support Instrument will also be completed to ensure that the total funding does not exceed maximum levels set for others with similar support characteristics.

(continued)

Table 5.1 (continued): Jurisdiction-wide method for managing need and unmet need in each State/Territory

	Name of method and commencement date	Who is eligible for inclusion on register/application or submission process?	Which service types does the register/application or submission process cover?	What does the form/assessment look like (plus any tools referred to)?	How is urgency/priority established?	What is the vacancy coordination process?
SA	Options Coordination Planning Process Commenced 1996	Each Options Coordination agency focuses on people from particular disability groups (e.g. Sensory Options Coordination only assists people with a sensory disability and complex needs). Some Options Coordination agencies have particular age restrictions to their eligibility criteria (e.g. the Crippled Children's Association Options Coordination agency only assists children under 18 years of age with a physical or neurological disability or an acquired brain injury)	May vary slightly across the five Options Coordination agencies but tends to cover all CSDA service types.	Options Coordination framework and policy guidelines agencies. No assessment tools were provided.	Priority of access guidelines state that the following should be considered in prioritising eligible applicants: <ul style="list-style-type: none"> abilities (e.g. physical, behavioural/social, cognitive and communication); other factors (e.g. non-English-speaking background; Aboriginal or Torres Strait Islander descent; age of person with disability; financial disadvantage); situation (e.g. homelessness; no carer; involvement in the criminal justice system; social or physical isolation; no access to services; dependent child(ren); health, capacity or age of carer; impoverished environment) 	Where a vacancy arises in a funded service that matches a client's assessed needs, the client will be offered the vacancy before a new resource allocation. Options Coordination agencies are responsible for establishing needs, matching them to vacancies and purchasing services (as per the Options Planning Process principles and Options Coordination Purchasing Client Supports Policy).
Tasmania	Statewide register of unmet need Commenced 1999–00 (although similar format statewide information from 1996–97)	All clients on the register have already been assessed as being eligible for services. They may already be receiving some services funded by the Tasmanian department.	All service types	Day Options support is based on the Inventory of Client and Agency Planning tool, which scores the client's ability to perform a variety of self care and independent living functions. The tool does not map directly to funding levels as it provides support hours ranges.	Not provided	Not provided
ACT	Operates a partial register based on submissions received at any time.	Not provided	All service types	Not applicable	Three-level priority rating system	Not provided

(continued)

Table 5.1(continued): Jurisdiction-wide method for managing need and unmet need in each State/Territory

	Name of method and commencement date	Who is eligible for inclusion on register/application or submission process?	Which service types does the register/ application or submission process cover?	What does the form/assessment look like (plus any tools referred to)?	How is urgency/priority established?	What is the vacancy coordination process?
NT	An unmet needs funding round was conducted in 2000–01. The details of applicants who applied for unmet need funding in 2000–01 were entered onto the Department of Health and Community Services Community Care Information System.	People with disabilities, their families and/or service providers were encouraged to complete applications for new or additional funding. If the applicant identified as being Aboriginal or Torres Strait Islander s/he had to be aged under 50 years at the time of onset of the disability. If non-Indigenous the applicant had to be aged under 65 years at the onset of the disability.	All service types	The application for funding form asks individuals about their current situation and support and what is required to assist them to be able to live the lifestyle of their choice. Availability of this funding was consumer-focused allowing for the first time people with disabilities, their families and guardians to apply for funding on their own behalf.	<p>Priority rating is based on the following critical indicators:</p> <ul style="list-style-type: none"> • Current living and support arrangements including homeless and without support; living in temporary accommodation; will be inappropriately incarcerated, institutionalised or removed from family and/or community. • Risk or harm including abuse, violence, exploitation or neglect; deterioration in functioning and/or wellbeing. • Carer circumstances including: high and/or complex support needs of the person with disability; ageing carer; ill-health or stress of carer; sole carer; caring for more than one dependent person. 	An independent panel was appointed with the specific task of assessing and prioritising applications. Panel members were provided with training to undertake this task. The panel included people with disabilities, a representative from a peak disability organisation, a remote area service provider and a senior Departmental officer. In considering each application the panel members were not provided with the applicant's name or residential address to ensure impartiality and confidentiality. The panel prioritised each application against strict criteria and made no recommendations regarding funding allocations.

(continued)

Table 5.1 (continued): Jurisdiction-wide method for managing need and unmet need in each State/Territory

	Name of method and commencement date	Who is eligible for inclusion on register/application or submission process?	Which service types does the register/application or submission process cover?	What does the form/assessment look like (plus any tools referred to)?	How is urgency/priority established?	What is the vacancy coordination process?
Commonwealth	Employment Assistance for People with Disabilities Database—Centrelink referrals system Commenced 1 May 1998	From 1 May 1998 Centrelink became responsible for assessing and referring all eligible job seekers to appropriate employment assistance services.	Disability employment services (i.e. open employment and supported employment) and access to rehabilitation services (not CSDA-funded) and Job Network.	Centrelink staff primarily use the Work Ability Tables, or WATs, in the process of referring job seekers to disability employment services, versus other services. A minority of job seekers may have completed the Job Seeker Classification Instrument as a precursor to the WATS.	Service providers manage priority of access. Eligibility guidelines require priority to be given to people aged 15–24 who can work a minimum of 8 hours per week. 'When a consumer reaches a service provider, they may be rejected if there is insufficient funding or if the service provider considers the consumer does not have sufficient work capacity or that the service cannot offer the appropriate type of assistance. These consumers are encouraged to try another service, including gaining another referral from Centrelink. The Centrelink process is one of streaming between services, with service providers actually determining final eligibility.'	Not applicable (there is no vacancy coordination for open and supported employment). Vacancy coordination does not apply in the same sense as for State/Territory services types as all eligible job seekers are referred for assistance and service providers then manage priority of access.

Source: Jurisdiction Surveys, follow up and program guidelines (where available).

5.3 What do these processes tell us about need and unmet need?

Data limitations

Limited data were initially provided from jurisdictions in response to the Jurisdiction Survey (see Appendix 2) in relation to registers, waiting lists or application processes. In an effort to obtain information in a comparable format, the AIHW then sought the following information from all jurisdictions:

Numbers of people on the register/waiting list or making fairly 'centralised' applications as at:

- 30 June 2000; and
- 30 June 2001;

(or over specified relevant time periods).

Characteristics of people on the list at 30 June 2000 and 30 June 2001 as well as characteristics of people coming off the lists in 2000–01:

- age and sex
- disability groups
- support needs
- what they say they need (what list they are on/what they applied for)
- carer age (other details?)
- indigenous status
- priority rating (of the jurisdiction – with interpretation if not already sent to AIHW)
- what services the person received (if anything) (that is, to estimate total number of people who were on the list prior to July 2000 and started receiving services in 2000–01).

Some information was received from nearly all jurisdictions in response to this request. Only Queensland was able to provide all of the information in the requested format.

Table 5.1 reveals that, for a number of reasons, it is not possible to simply pool data provided from the various jurisdictions in relation to their main jurisdiction-wide method for managing need in order to indicate *unmet need* in the broad service type areas at a national level. These reasons include:

- **Registration/application processes and their scope vary.** Queensland has a full register for all service types funded under the CSDA. That is, access to any service funded by Disability Services Queensland must be obtained via the Disability Services Queensland (DSQ) Register and associated Registration, Application and Funding database. New South Wales, Victoria, Western Australia, South Australia and Tasmania have established processes for registering need for certain service types. The Northern Territory ran a submission process for unmet needs funding in 2000–01. The Australian Capital Territory has a partial register that records applications from service providers for additional funds. The Commonwealth, through Centrelink, has records of all people referred by Centrelink to specialist disability employment services (that is, supported or open employment services).

- **Eligibility for inclusion on the 'lists' (or to apply for funding) varies.** In Tasmania, a person has already been assessed as eligible for service before they are included on the statewide register of unmet need. In the Commonwealth process, applicants referred to disability employment services by Centrelink have already been assessed for eligibility for a CSDA employment service via the Work Ability Tables (if ineligible for disability employment services, applicants are referred to other suitable services such as the Job Network). In New South Wales, only people with a disability defined under the Disability Services Act who have identified risk factors *and* whose needs are unable to be met by attempting to access services provided under the Disability Services Program are eligible for inclusion on the Service Access System database.

Data from Queensland and the Northern Territory include people who have been or may be at some point judged as ineligible for CSDA services. Ineligible people also appear to be included on the main 'list' in the remaining jurisdictions with available data in this area (that is, New South Wales, Victoria, and the Australian Capital Territory).

Thus, the data provided by Tasmania and New South Wales from their main registration or application process include a restricted number of applicants compared with the available data from other jurisdictions. The Commonwealth data presented are different from other jurisdictions as they represent only those jobseekers referred for disability employment assistance (following eligibility assessment using the Working Ability Tables (WATs)) and do not include those jobseekers who were referred to other services such as Job Network. In this sense, these figures also represent a restricted number of applicants, compared with available data from other jurisdictions (that is, applicants on some State/Territory registers may eventually be judged as being ineligible for CSDA services but eligible for other services such as HACC).

- **Assessment processes vary.** A range of assessment tools is used within jurisdictions, depending on factors such as service type and agency preference. Apart from the application forms developed by jurisdictions, it appears rare for jurisdictions to recommend the use of particular assessment tools across the sector. For example, the following assessment tools were the only ones referred to in response to the Jurisdiction Survey:
 - the Inventory of Client and Agency Planning (ICAP), used for day options in Tasmania to provide a score around clients' ability to perform a variety of self care and independent living functions (the tool does not map directly to funding levels as it does not relate to an actual number of hours of support required but rather a range of hours);
 - the Estimate of Requirement for Staff Support Instrument (ERSSI), used in Western Australia as part of the process of estimating accommodation support costs (Western Australia is also investigating the ICAP);
 - the Support Needs Assessment and the ICAP, used in relation to some individualised packages in Victoria (for people eligible under the *Intellectually Disabled Persons Services Act 1986* only) to enable grouping of clients with similar support needs and resource banding;
 - the WATS, used by Centrelink on behalf of the Commonwealth, to determine which jobseekers are referred to specialist disability employment services; and
 - the Disability Pre-employment Instrument and the Disability Maintenance Instrument used by the Commonwealth (in conjunction with the Job Seeker

Classification Instrument administered by Centrelink) in the Case Based Funding Trial for employment services, to determine funding levels.

The tools mentioned are generally designed for use in quite specific circumstances. They are often used by funding departments to enable grouping of clients with similar support needs to ensure that clients with similar needs receive similar levels of funding.

There is therefore little standardisation across jurisdictions in assessment tools or application processes, except where CSDA MDS data items are included in application forms. The practice of including CSDA MDS data items in application forms varies across jurisdictions but appears to be considered most important in Queensland and Western Australia.

- **Methods for prioritising applicants and managing vacancies vary.** Many application forms advise applicants that eligibility alone will not ensure access to services, that is, that access to services also depends on priority or urgency of need. All jurisdictions have established mechanisms for prioritising applicants, generally based on urgency of need rather than need alone. Criteria used to establish urgency are very similar across the country and generally include factors such as: age or health risks to the primary carer; homelessness; risk of abuse or neglect; risk of diminishing abilities due to an unsatisfactory environment; and contact with the criminal justice system. Most jurisdictions use a system of priority committees or panels, usually at a regional level, to establish priority (for example, Queensland, Victoria, New South Wales, Tasmania and Western Australia).

Data available from jurisdictions

A selection of the data provided by jurisdictions in response to the above information request is presented in Tables 5.2, 5.3 and 5.4. Some caution should be exercised in comparing the data provided from each jurisdiction as the process, scope and eligibility arrangements for each process vary widely (see above and Table 5.1). In addition, some jurisdictions expressed concern about using waiting list data to indicate unmet need (for example, the Northern Territory was concerned that not all potential applicants such as people living in rural areas and Indigenous people had access to the unmet needs funding process). Finally not all people on registers are necessarily eligible for CSDA-funded services and not all people who need support will apply for inclusion on registers.

With these data limitations in mind, the following tables are presented to illustrate both the type of information that is currently available from unmet need registration and application processes and the type of information that could be available if consistent methods for managing need were employed across jurisdictions. Jurisdiction-specific data from Table 5.4 are extrapolated to the Australian population in the process of 'triangulating' estimates of unmet need developed using other data sources (see Chapter 7).

Numbers of applicants

Table 5.2 presents available data on the number of people included in the jurisdiction's main register or application process at 30 June 2000 and 30 June 2001, along with the number and percentage of people that were moved off the 'list' in this period. The table reveals the following:

- Baseline information about the number of people on 'lists' at 30 June 2000 (that is, prior to the injection of 'unmet needs' funding) is only available for Victoria, Queensland and one South Australian Options Coordination agency. Information is not available for other

jurisdictions either because the main method is a relatively new phenomenon or because data are not routinely available from their current systems in the requested format.

- Substantially more information was available in relation to people on 'lists' at 30 June 2001. The number of people on the lists varies widely across jurisdictions.
- About half the jurisdictions were able to provide some information on the number of people moved off the 'list' in 2000–01. It is difficult to comment with confidence on the proportion of people moved off lists during 2000–01 as there are definitional differences across States. For example, in Queensland and the Northern Territory, the number of people removed from the list in 2000–01 only includes people who were assessed as eligible and received funding. In Victoria, in addition to these people, a small number of those moved off the list may have withdrawn from the list due to change in circumstances, moving, death or inappropriate assessment, etc. The New South Wales figure of 523 applicants moved off the list in 2000–01 is not included in the table as it specifically includes all those judged as eligible, rather than those who had received funding at 30 June 2001. Finally, it should be noted that people who are 'moved off a list' are not necessarily having all of their needs for formal service being met (that is, in the Northern Territory, although a person received some service in 2000–01 they may appear on the 'list' in 2001–02).
- Nevertheless, for State/Territory services, the registers or application processes indicate that there were between six and 24 times more people seeking services in 2000–01 than were removed from the list (usually because they were offered a service). While cross-jurisdiction comparisons are not sensible, jurisdiction-specific figures suggest that unmet needs still exist and that long waiting times are likely. This is consistent with the information provided at peak discussions (see Chapter 7) and some additional information provided by jurisdictions. For example, the Victorian response directed the AIHW to a question in the Victorian parliament in October 2001 (VICHANSARD 2001). The official record of the question states that 'for the year ending 30 June 2001, 234 people waiting for a Shared Supported Accommodation place, were removed from the Service Needs Register. These people either received a place in a Shared Supported Accommodation facility or a package of tailored services which met their accommodation needs. People who received a Shared Supported Accommodation place or package of tailored service waited an average of 810 days. One person was relocated from an institutional to a community-based option'.
- Data from the Commonwealth registration process for employment services indicate that people who apply to Centrelink for employment assistance *and* who are subsequently referred to specialist disability employment services are very likely to receive a service (around 80%). This is at least partly because people who are referred to specialist disability employment services have already undergone a streaming process in order to obtain that referral (that is, their eligibility has been assessed via the Job Seeker Classification Instrument, Work Ability Tables and involvement of a Centrelink Disability Officer or Disability and Carer Team member).

Priority ratings of applicants

Table 5.3 provides details of the priority ratings for applicants on 'lists' at June 2001. It is clear that stringent priority criteria apply in all States and Territories, relating to the risk of immediate family or informal support systems breaking down. These strict priority criteria appear to be designed to lower the expectations of applicants and/or to genuinely reflect a

system that can only deal with the most urgent cases. The data presented in Table 5.3 show that, for example:

- 29% of people on the Queensland Registration, Application and Funding database are rated as being priority 1 (the highest rating, requiring immediate intervention);
- 42% of people on the South Australian Adult Physical and Neurological Options Coordination database have priority 1 (the highest rating, indicating immediate and high risk);
- 36% of people on the South Australian Intellectual Disability Services Council Options Coordination database are rated as having urgent priority (the highest rating); and
- 65% of people on the Victorian Service Needs Register for accommodation support (HomeFirst) are rated as urgent priority (the highest rating).

Where available, priority ratings are also presented for people coming off 'lists' in 2000–01. The data show that:

- in Queensland, of the people coming off the register in 2000–01, 71% (138 from 194 people) had the highest priority rating '1'; and
- in South Australia, the Intellectual Disability Services Council Options Coordination data indicate that, of the people coming off the 'list' in 2000–01, 71% (48 from 68 people) had the highest priority rating 'urgent'.

In both Queensland and South Australia, a person's chance of being moved off the list during the 2000–01 year diminished as their priority rating decreased.

The limited data in Table 5.3 strongly suggest both that there are remaining unmet needs for CSDA services and that these unmet needs are often experienced by people and families who have been judged as having the jurisdiction's highest possible rating (for example, critical, urgent, immediate).

Service types or supports requested by applicants

Table 5.4 details the type of service requested by applicants on the main jurisdiction-wide 'list' at 30 June 2001. The table shows that in most cases data cannot be used to indicate unmet need in each of the broad CSDA service type categories at a jurisdiction level. This is because needs are not described consistently across jurisdictions, nor in terms of CSDA MDS service types. Although data are incomplete or missing for some jurisdictions, the table suggests that there are substantial levels of need in most of the major service type areas, particularly accommodation support and community access.

The data in Table 5.4 should not be compared across jurisdictions for the reasons outlined above. However, the data are used in Chapter 7 to compare with other estimates of unmet need for specific service types. This is achieved by extrapolating jurisdiction-specific figures for the number of people requesting a specific service type to the entire Australian population.

Table 5.2: Main jurisdiction-wide method for managing need: people on 'lists' and people moved off 'lists' 2000, 2001 – available data

State/Territory	People on list at 30 June 2000	People on list at 30 June 2001	People moved off the list in 2000–01 ^(a)	% of people moved off list/all people on list at 30 June 2001
NSW (SAS)	Not applicable ^(b)	1,470	— ^(c)	—
Vic (SNR)	3,567	4,381	764	17%
Qld (Registration, Application and Funding database)	4,153 ^(d)	4,589 ^(d)	194 ^(e)	4%
WA (CAP)	Not applicable	Not applicable	Not applicable	Not applicable
SA (Options Coordination)^(f)				
<i>Sensory Options Coordination</i>	<i>No register</i>	<i>No register</i>	<i>No register</i>	<i>Not available</i>
<i>Adult Physical and Neurological Options Coordination^(g)</i>	<i>Not provided</i>	310	<i>Not provided</i>	<i>Not available</i>
<i>Brain Injury Options Coordination^(h)</i>	97	24	<i>Not provided</i>	<i>Not available</i>
<i>Crippled Children's Association Options Coordination⁽ⁱ⁾</i>	<i>Not provided</i>	57	<i>Not provided</i>	<i>Not available</i>
<i>Intellectual Disability Services Council</i>	<i>Not provided</i>	495	68	14%
<i>Total available data</i>	<i>Not available</i>	886 ^(l)	<i>Not available</i>	<i>Not available</i>
Tas (statewide unmet needs register)	Not provided	Not provided	Not provided	Not available
ACT (unadvertised application process)	Not provided	29	Not provided	Not available
NT (advertised application process)	Not applicable	359	53 ^(k)	15%
Commonwealth (Centrelink data)				
<i>Open employment</i>	<i>Not provided</i>	16,413 ^(l)	13,074 ^(m)	80%
<i>Supported employment</i>	<i>Not provided</i>	2,206 ^(l)	1,806 ⁽ⁿ⁾	82%

(a) It is not always clear from information provided if people moved off lists have actually received services yet or have only formally been judged as eligible and high priority.

(b) The New South Wales mechanism for recording unmet need (SAS) had not commenced operation at June 2000.

(c) 523 applicants had been assessed as eligible at 30 June 2001. By 18 December 2001, 147 Support Plans had been approved and quality assured. In most cases an endorsed Support Plan is required before supports can be purchased. Data are limited as Support Plans only began to be developed and returned to SAS in September 2001 (New South Wales Jurisdiction Survey response).

(d) Total unfunded applicants on the Registration, Application and Funding database.

(e) Funded people coming off lists refers to those unfunded individuals who were registered prior to June 2000, who then received funding during 2000–01. It does not include those individuals who registered during 2000–01 who also received funding.

(f) Options Coordination agencies do not have a centralised registration or application process. Data are presented for the five Options Coordination agencies separately, where available.

Table 5.2 notes (continued)

- (g) Adult Physical and Neurological Options Coordination data are for August 2001, rather than June 2001.
- (h) Brain Injury Options Coordination data are for October 2001, rather than June 2001. The figures are for Priority 1 clients only and do not include a number of people in hospitals, aged care homes and institutions who have high support needs and are inappropriately placed. The number also does not include a number of people awaiting the availability of shared accommodation in the community with the support hours attached. These people are currently living with family who provide a large degree of support.
- (i) Crippled Children's Association Options Coordination data are the remaining clients on the unmet needs register following allocation of 2000–01 unmet needs funding.
- (j) Note that this total does not include data from all five Options Coordination agencies.
- (k) 79 people were assessed as eligible for support but only 53 received funding in 2000–01 and moved to an active care phase.
- (l) Referrals to Centrelink for open employment and supported employment in 2000–01.
- (m) Of the customers whose referrals to open employment were not accepted by 30 June 2001, 2,249 (14%) were outstanding and 1,090 (7%) were not accepted (by the service provider). Of those not accepted 396 (36%) were not accepted because there was 'no vacancy'. However, some customers have more than one referral and while one of their referrals may not be successful because of 'no vacancy' they may have been accepted by another service. This could mean that the number of 'no vacancies' is overestimated. Referrals marked 'outstanding' may include consumers who will ultimately be accepted.
- (n) Of the customers whose referrals to supported employment were not accepted by 30 June 2001, 312 (14%) were outstanding and 88 (4%) were not accepted (by the service provider). Of those not accepted 28 (32%) were not accepted because there was 'no vacancy'. However, some customers have more than one referral and while one of their referrals may not be successful because of 'no vacancy' they may have been accepted by another service. This could mean that the number of 'no vacancies' is overestimated. Referrals marked 'outstanding' may include consumers who will ultimately be accepted.

Note: The processes used in each jurisdiction to register need (or unmet need) vary in terms of who is eligible to be included on the list, which service types the list is used to manage demand for, the comprehensiveness of the approach etc. See Table 5.1, summarising the main methods used in each jurisdiction, for accompanying detail.

Source: Jurisdiction Survey responses and additional information requested from jurisdictions.

Table 5.3: Main jurisdiction-wide method for managing need: priority ratings for applicants on 'lists' at June 2001 and coming off lists in 2000-01 – available data

	Priority rating	Applicants with specified priority rating at June 2001	Applicants with specified rating coming off the list in 2000-01
NSW	Not available	Not available	Not available
Victoria^(a)	U = Urgent	<i>Day activities</i> (ATSS—Adult Training and Support Service)	Not available
	H = High	U = 82%	
	L = Low	H = 16%	
		L = 2%	
		<i>Accommodation support</i> (SSA—Shared Supported Accommodation)	Not available
		U = 33%	
		H = 20%	
		L = 47%	
Qld		Accommodation support (HomeFirst)	Not available
		U = 65%	
		H = 22%	
		L = 13%	
	1 = people in extremely critical and urgent need who require some form of immediate intervention for there to be any likelihood of the situation improving.	1 = 1,347 (29%)	1 = 138 (71%)
		2 = 694 (15%)	2 = 38 (20%)
	2 = people who are very likely to be in this situation in the near future.	3 = 1,312 (29%)	3 = 12 (6%)
	3 = people who have a potential risk of experiencing critical and urgent need in the longer term.	4 = 922 (20%)	4 = 6 (3%)
		I = 191 (4%)	I = 0
	4 = people with acknowledged need for support that will enhance their general quality of life.	N = 121 (3%)	N = 0
	I = Ineligible	W = 2 (0%)	W = 0
	N = Not rated		
	W = Withdrawn		

(continued)

Table 5.3 (continued): Main jurisdiction-wide method for managing need: priority ratings for applicants on ‘lists’ at June 2001 and coming off lists in 2000-01 – available data

	Priority rating	Applicants with specified priority rating at June 2001	Applicants with specified priority rating off the list in 2000-01
WA	Not applicable	Not applicable	Not applicable
SA			
<i>Sensory Options Coordination</i>	Not available	Not available	Not available
<i>Adult Physical and Neurological Options Coordination</i> ^(b)	Crisis = needs immediate response 1 = Immediate and high risk in any of the six specified areas. ^(c) 2 = High to moderate risk in the near future in areas 1-6, and/or immediate need for development of maintenance of carer's ability to support the person with the disability. 3 = Potential moderate to low risk in the long term in areas 1-6 and/or a (future) need for development and improvement in cognitive, physical, behavioural, social, communication abilities. 4 = Enhancement of general quality of life.	Crisis = 0 1 = 131 (42%) 2 = 140 (45%) 3 = 34 (11%) 4 = 5 (2%)	Not available
<i>Brain Injury Options Coordination</i>		Not available	Not available
<i>Crippled Children's Association Options Coordination</i>		Not available	Not available
<i>Intellectual Disability Services Council</i>	U = Urgent I = Immediate P = Planned L = Low priority	U = 180 (36%) I = 176 (36%) P = 104 (21%) L = 34 (7%)	U = 48 (71%) I = 9 (13%) P = 10 (15%) L = 1 (1%)

(continued)

Table 5.3 (continued): Main jurisdiction-wide method for managing need: priority ratings for applicants on ‘lists’ at June 2001 and coming off lists in 2000–01 – available data

	Priority rating	Applicants with specified priority rating at June 2001	Applicants with specified rating coming off the list in 2000–01
Tasmania	Not available	Not available	Not available
ACT	1 = urgent/critical/political (harm/homelessness almost certain if not implemented, crisis) 2 = important (potential for crisis/harm/homelessness in next 12 months or significant level of unmet need causing significant restriction to wellbeing or lifestyle) 3 = desirable (adding to current services, will not cause harm if not implemented)	1 = 13 (72%) 1–2 = 1 (6%) 2 = 4 (22%) 3 = 0 (0%)	Not available
NT	1 = immediate—experiencing situation now 2 = short term—likely to experience situation within next 12 months 3 = long term—likely to experience situation in next 12 months or more 4 = all other applications No priority All priority 1 applications are then assessed on their capacity to cope with their overall situation without funding support. A = none B = minimal C = some D = sufficient E = significant	1A = 20 (6%) 1B = 36 (10%) 1C = 56 (16%) 1D = 16 (4%) 1E = 7 (2%) 2 = 88 (25%) 3 = 43 (12%) 4 = 89 (25%) No priority = 4 (1%)	Not provided
Commonwealth	Not available	Not available	Not available

(a) Percentages are of current referrals to the Service Needs Register (i.e. at February 2002).

(b) Adult Physical and Neurological Options Coordination data are for August 2001, rather than June 2001.

(c) Immediate and high risk in any of the following areas: safety to others (particularly carer); health of self or others (particularly carer); breakdown of family; physical or emotional abuse; institutionalisation; and deterioration of cognitive, physical, behavioural, communication abilities.

Source: Jurisdiction Survey responses and additional information requested from jurisdictions.

Table 5.4: Main jurisdiction-wide method of managing need: service types requested by applicants on 'lists' at June 2001 – available data

	Accommodation support	Community support	Community access	Respite	Other	Employment	Total (applicants)
NSW^(a)	303 (supported accommodation) 166 (in-home support)	137 (behaviour support)	—	231 (flexible respite)	89 (transport) 7 (support dependents) 3 (other)	Not applicable	Not provided
Victoria (recommended service type)	3,605 (supported accommodation)	Not applicable	776 (ATSS)	Not applicable	Not applicable	Not applicable	4,381 ^(b)
Qld	2,347 (personal care) 2,770 (household management)	3,143 (recreation)	2,623 (using local facilities and services) 3,427 (community access)	—	—	Not applicable	4,589
WA	Not available	Not available	Not available	Not available	Not available	Not applicable	Not available
SA							
<i>Sensory Options Coordination</i>	Not provided	Not provided	Not provided	Not provided	Not provided	Not applicable	Not provided
<i>Adult Physical and Neurological Options Coordination</i>	164 (personal care) 196 (domestic assistance)	47 (recreation)	10 (day options)	62 (respite)	—	Not applicable	310
<i>Brain Injury Options Coordination</i>	Not provided	Not provided	Not provided	Not provided	Not provided	Not applicable	24
<i>Crippled Children's Association Options Coordination</i>	Not provided	Not provided	Not provided	Not provided	Not provided	Not applicable	57
<i>Intellectual Disability Services Council</i>	375 (accommodation) 59 (day options and accommodation)	—	61 (day options) 59 (day options and accommodation)	—	—	Not applicable	495
Tasmania	Not provided	Not provided	Not provided	Not provided	Not provided	Not applicable	Not provided

(continued)

Table 5.4 (continued): Main jurisdiction-wide method of managing need: service types requested by applicants on 'lists' at June 2001 – available data

	Accommodation support	Community support	Community access	Respite	Other	Employment	Total (applicants)
ACT	9 (supported accommodation) 1 (residential accommodation) 1 (accommodation support)	1 (structured support and case management) 1 (service coordination)	1 (day programs)	2 (respite care) 1 (replacement respite care)		Not applicable	17 ^(b)
NT	30 (supported accommodation only) 97 (combined supported accommodation and community support)	97 (combined supported accommodation and community support)	65 (community access in combination with other supports) 60 (community access only)	123 (respite)		Not applicable	375
Commonwealth	Not applicable	Not applicable	Not applicable	Not applicable	Not applicable	16,413 (open employment) 2,206 (supported employment)	18,619

(a) Information on supports requested is not recorded in the SAS database. The information in Table 5.4 was from information provided by New South Wales from SAS eligibility and support plan quality assurance reports (i.e., it relates to a sub-set of total applicants). Information was not provided to show how many applicants the supports information relates to.

(b) This total differs slightly from that provided in Table 5.2.

Note: The number of supports requested may exceed the number of people on lists (where supports are recorded for all people on lists) or be far less than the number of people (where supports are only recorded for approved applicants).

Source: Jurisdiction Survey responses and additional information requested from jurisdictions.

5.4 Summary and discussion

Jurisdiction methods for managing expressed need generally exist alongside planning mechanisms around potential need (usually based on population data) and developments in assessment and funding methods. Only the main method for managing expressed need is discussed in detail in this chapter.

Processes for managing expressed need vary across jurisdictions in terms of the process, scope, application and assessment methods. Across all jurisdictions, except the Commonwealth, there is a theme of managing according to urgency of need rather than need alone. That is, all States/Territories have priority rating systems and generally acknowledge in application processes that there may be more people eligible than will immediately be able to receive services. The Commonwealth, on the other hand, is dealing with a specific service type (employment), and only considers for its service those passing a service eligibility test.

Jurisdictions thus employ different processes for managing expressed need, record the associated data in different ways and have varied capacity for retrieving and collating such data. Some jurisdictions have concerns about the limitations of their available data. Their concerns include that not all people on the lists are necessarily eligible, some people who would be eligible will not be on the list because they have been discouraged, do not have access due to language, or geographical barriers, and so on. In combination, these factors mean that data must be analysed with caution.

Nevertheless, the data from registration lists provide very useful information to support some of the other data sources used in this study. In particular, the data on service types requested by people on the jurisdiction 'lists', when extrapolated to the national level, can be used to 'triangulate' the estimates of remaining shortfalls (see Chapter 7).

It is promising to note that two jurisdictions have incorporated the vast majority of CSDA MDS items into their main registration or application processes (Queensland and Western Australia). If other jurisdictions made more use of the CSDA MDS data set (recently redeveloped by the AIHW in cooperation with the National Disability Administrators), it is possible that registration data could be more readily comparable in future. This could enable jurisdictions to share information relatively easily and allow the regular compilation of national data on unmet need. The development of needs registers and processes in recent years is generally a welcome development and, if coordinated across jurisdictions more closely in future, could provide very useful information on which to base ongoing monitoring of unmet need.

The value in using CSDA MDS data items is particularly notable in relation to the 'support needs' data item. This data item asks agencies to describe the level of support a person requires in a range of life domains, including self care, mobility, communication, interpersonal interactions and relationships, working, education and domestic life. These life domains and the associated scale have been developed to be consistent with the International Classification of Functioning, Disability and Health (ICF) and the ABS Survey of Disability, Ageing and Carers. Previous AIHW work on the CSDA MDS support needs question (commissioned by the National Disability Administrators) found that most assessment tools used in CSDA-funded agencies can be mapped to the life domains described in the ICF, and related to some of the measures in the ABS Survey of Disability, Ageing and Carers. One jurisdiction noted in their response that 'the real issue with costing is assessment of support needs and until there is national consistency in that it will be

difficult to develop a funding formula acceptable to all jurisdictions'. As jurisdictions strive to increase consistency in the way applicants and clients are assessed for services, it should be noted that a consistent framework into which a range of assessment tools can be mapped already exists in the redeveloped CSDA MDS. Support needs information will be available for all CSDA clients in 2003.

In conclusion, the numbers of people on lists, in combination with information about their priority rating and limited information about the priority rating of people actually moved off lists, strongly suggest remaining unmet needs in the sector. This is consistent with peak discussions.

6 Population estimates of need

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

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

6.1 Approach and sources for population data analysis

Main population data sources

Estimates of unmet demand for accommodation and respite and day activity services in the 1997 demand study were based mainly on data from the 1993 ABS Survey of Disability, Ageing and Carers. The decision to rely on this source was made after an intensive review of other data sources. These other sources were subsequently used to confirm the magnitude and conservatism of the main estimates (Madden et al. 1996; AIHW 1997a).

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

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

Reported changes in prevalence of disability, 1993 and 1998

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

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

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

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

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

Approach to population estimates of unmet need

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

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

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

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

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

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

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

Methods of updating population growth from 1998 to 2001

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

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

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

Detailed steps for adjustments were as follows:

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

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

Main relevant data items from the 1998 ABS survey

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

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

Activity restrictions and their severity

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

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

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

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

Specific restrictions are:

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

Core activities are:

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

A core activity restriction may be:

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

Source: ABS 1999a.

The age of the person

While the CSDA does not specifically exclude people above a certain age, many services do so in practice. While people who age ‘in the service’ can in practice remain, services do not generally take on new clients who are aged 65 or more. In addition, the overall approach of this study, of seeking to minimise debate about the lower end of the estimated range, weighs against including people who may be eligible for aged care services. The age range considered was therefore 0–64 years.

Whether the person is living in a household

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

Activities in which help was needed

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

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

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

Frequency of need for assistance because of disability

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

Whether or not there was a stated unmet need for help

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

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

The possible categories into which responses were allocated by the ABS interviewers were:

- the person did not know of the service;
- the person did not consider their need important enough;
- the person would not ask for the service, for reasons of pride;
- the person was unable to arrange a service;
- no service was available;
- not eligible for service (additional category in the 1998 survey);
- service costs too much (additional category in the 1998 survey);
- service does not provide sufficient hours (additional category in the 1998 survey); and
- other.

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

Views were put to the study team that there are very good reasons for including some people from other categories. In the income security field, for example, lack of knowledge of a service is seen to be a failing of the service rather than a lack of demand for it. Similarly, people may not consider their need important enough only because they have low expectations that they will be eligible for the sorts of services that are available. Any of these considerations could lead to an increase in the estimates of unmet need (Madden et al. 1996; AIHW 1997a).

CSDA MDS and ABS data—and Table 2.1

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

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

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

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

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

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

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

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

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

Some data limitations related to the comparison should be noted:

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

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

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

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

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

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

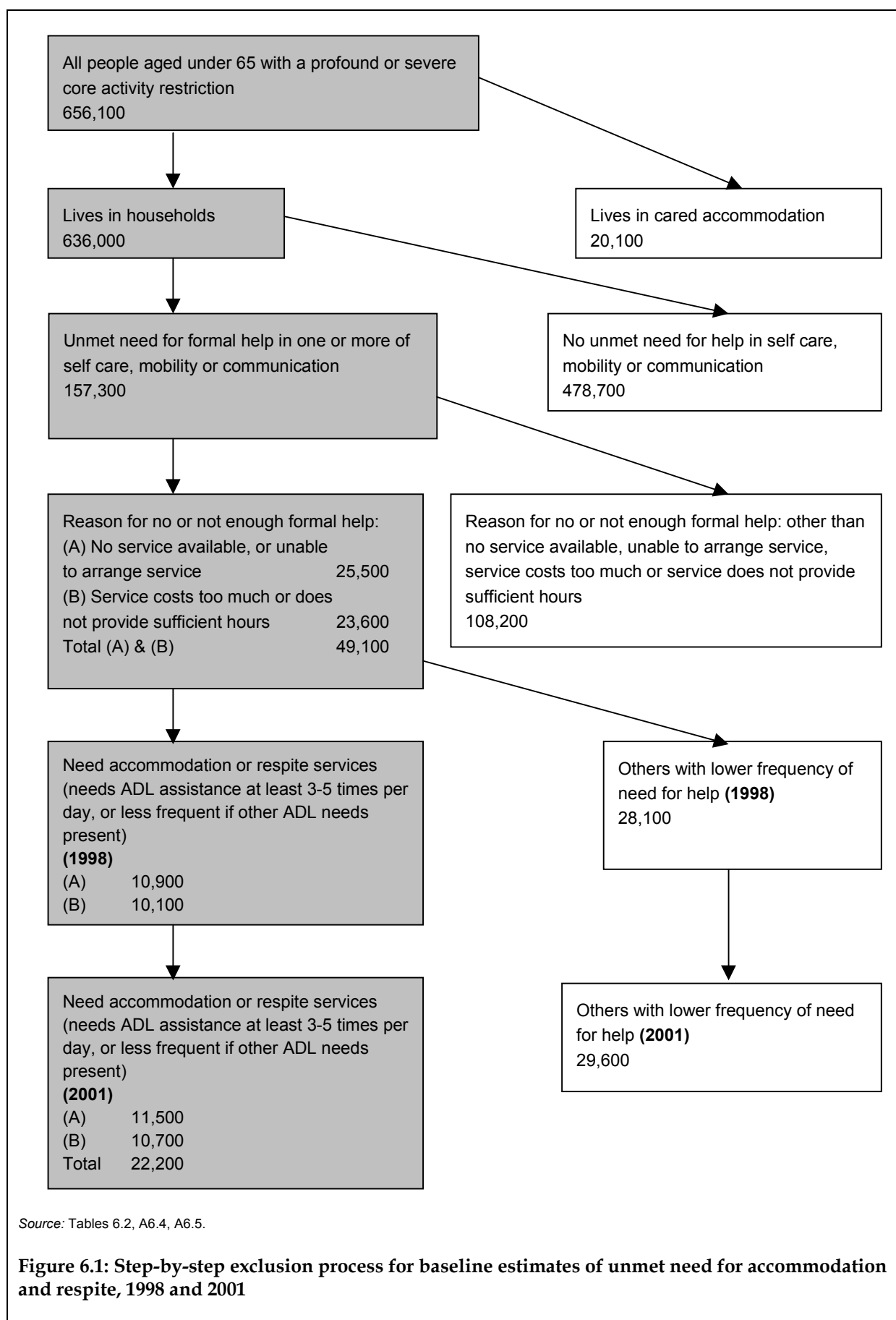
6.2 Accommodation and respite services: estimates of unmet need

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

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

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

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



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

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

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

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

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

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

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

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

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

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

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

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

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

6.3 Community access services: estimates of unmet need

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

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

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

It was stated then that: ‘day programs should be provided at such a level that family carers are not obliged to provide 24-hour care for people with high support needs on a lifelong basis. That is, from the time people with high-level support needs are 18 years old and have left school, they may still be receiving accommodation support from their families, but should not be reliant on them for the equivalent of “day programs”’ (AIHW 1997a). The study team in 2001 continues this assumption. It should be noted, however, that the assumption (not critical to these particular estimates) that family carers might continue care for the children all their lives is questionable (see description of the 1997 estimates in Appendix 1).

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

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

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

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

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

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

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

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

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

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

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

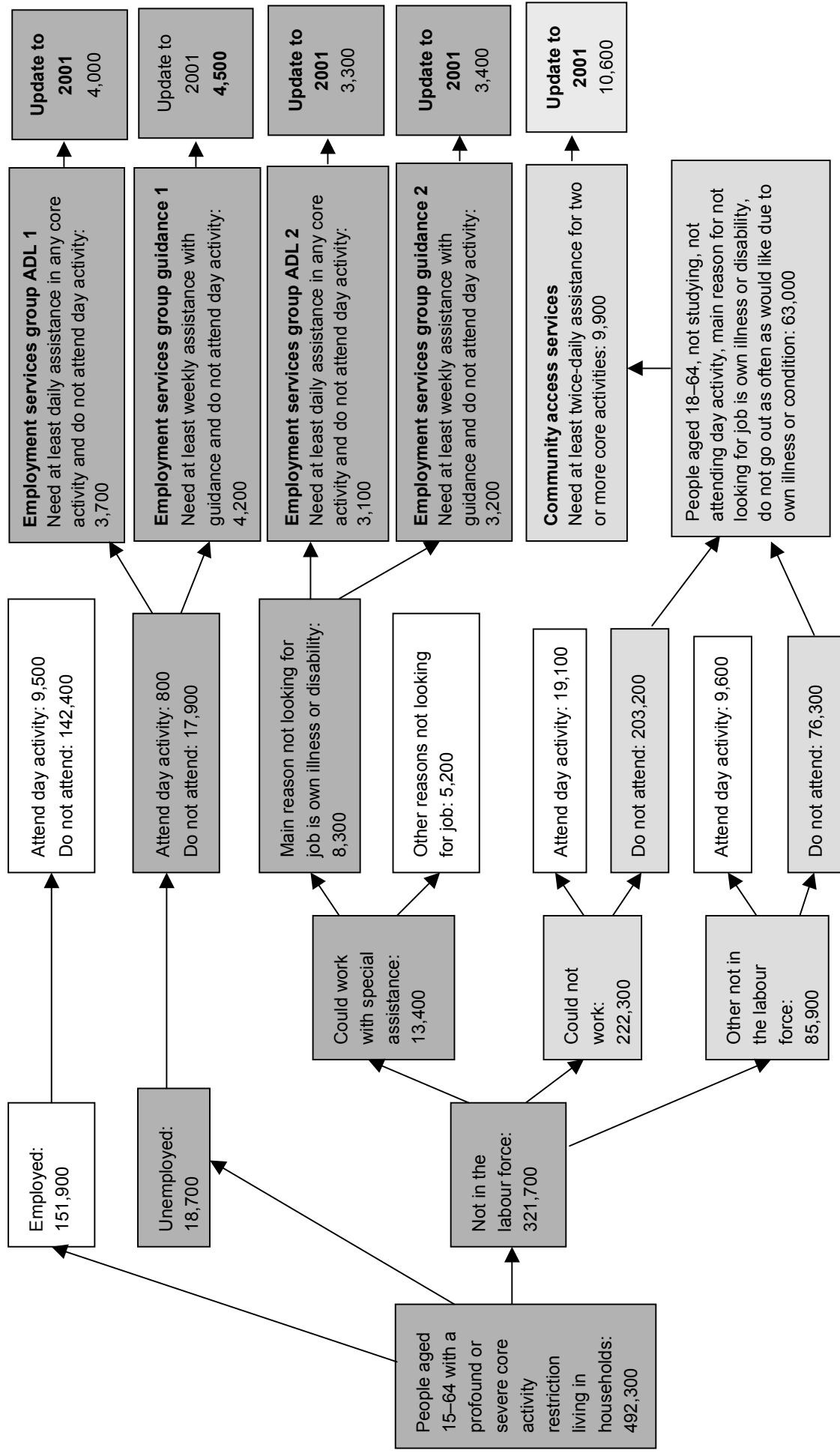
It should be noted that the estimates make no specific allowance for possibly higher rates of use of post-school options services by people aged 18–20 years whereas some jurisdictions do attempt to provide post-school options services to a wider group of 18–20 year-olds.

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

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

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

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



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

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

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

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

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

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

6.4 Disability employment services: baseline estimates of unmet need

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

Employment restrictions and need for assistance

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

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

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

- are permanently unable to work;

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

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

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

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

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

(continued)

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

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

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

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

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

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

Unmet needs for disability employment services

Two alternative approaches are used in estimating unmet needs for CSDA employment services. The first approach ties itself to the CSDA target group definition, focusing on the need for assistance with self care, mobility and communication; in line with the approach to accommodation services, some evidence of relatively high support needs is used to screen people into the estimates: people are included in the estimates only if they need at least daily assistance with at least one of these core activities (see Table 2.1).

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

Method 1 Activities of daily living (ADL)

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

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

Group ADL2 consists of people who:

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

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

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

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

It is also important to consider a proportion of people not in the labour force. This is an accepted approach to ‘mainstream’ labour market analysis, and is in line with current welfare reforms that seek to assist people to participate in the workforce, where possible, or in other community activities (see, for example, Newman 1999). It is especially important for people with disabilities, whose labour market experience is not as good as that of the overall community (see, for example, AIHW 1999b & 2001b).

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

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

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

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

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

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

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

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

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

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

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

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

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

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

Method 2 (Guidance)

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

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

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

Guidance

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

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

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

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

Source: ABS 1999b.

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

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

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

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

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

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

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

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

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

6.5 Estimates of support needs of ageing primary carers

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

In 1998 there were 23,600 primary carers of people with disabilities aged under 65 who reported that they had never received respite but needed it, and a further 17,100 who had received it at some stage but needed more (AIHW 2001b:301).

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

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

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

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

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

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

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

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

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

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

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

Table 6.10: Support needs of ageing primary carers with a co-resident main recipient aged under 65, 1998 ('000)^{(a)(b)}

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

(continued)

Table 6.10 (continued): Support needs of ageing primary carers with a co-resident main recipient aged under 65, 1998 ('000)^{(a)(b)}

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

(continued)

Table 6.10 (continued): Support needs of ageing primary carers with a co-resident main recipient aged under 65, 1998 ('000)^{(a)(b)}

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

(continued)

Table 6.10 (continued): Support needs of ageing primary carers with a co-resident main recipient aged under 65, 1998 ('000)^{(a)(b)}

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

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

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

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

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

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

Table 6.11: Support needs of ageing primary carers with a co-resident main recipient aged under 65, 2001 ('000)^{(a)(b)}

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

(continued)

Table 6.11 (continued): Support needs of ageing primary carers with a co-resident main recipient aged under 65, 2001 ('000)^{(a)(b)}

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

(continued)

Table 6.11 (continued): Support needs of ageing primary carers with a co-resident main recipient aged under 65, 2001 ('000)^{(a)(b)}

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

(continued)

Table 6.11 (continued): Support needs of ageing primary carers with a co-resident main recipient aged under 65, 2001 ('000)^{(a)(b)}

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

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

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

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

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

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

7 Shortfalls—remaining unmet needs

7.1 The approach in this chapter

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

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

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

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

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

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

7.2 Consolidating the estimates of unmet need

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

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

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

Accommodation and respite

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

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

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

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

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

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

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

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

Table 7.1: Consolidated estimates of unmet need, 2001

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

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

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

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

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

(e) Employment estimates were prepared before the 2002–03 Commonwealth budget announcements. These estimates may need to be revised if there is change in assumptions about the expected labour force participation of people currently receiving the Disability Support Pension, or in policy on eligibility for services.

Community access

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

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

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

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

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

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

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

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

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

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

Source: CSDA MDS data, 1998 and 2001.

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

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

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

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

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

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

Employment services

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

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

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

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

Commonwealth data and definitions

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

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

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

Box 7.1: Selected consumer ‘count’ definitions for Commonwealth employment support services 1998–2001

Commonwealth census definitions of ‘on the books’, 1998–2001

Data Guide 1998, 1999

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

Data Guide 2000, 2001

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

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

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

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

Data Guide 2000, 2001

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

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

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

Table 7.3: Employment services: various counts

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

7.3 Unmet needs: views from peak discussions

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

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

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

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

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

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

Unmet needs of existing clients: ‘under-met need’

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

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

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

Fees and contributions

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

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

Needs of people who are receiving nothing

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

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

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

Groups missing out

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

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

Psychiatric disability

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

Acquired brain injury (ABI)

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

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

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

Physical disabilities

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

High support needs and 'high risk' clients

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

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

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

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

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

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

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

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

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

People of Indigenous origin

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

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

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

People from culturally and linguistically diverse backgrounds

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

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

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

Rural and remote areas

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

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

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

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

Border issues—other service areas

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

Nursing homes

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

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

HACC

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

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

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

Transport

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

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

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

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

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

Equipment

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

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

Education

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

Disability, ageing and service borders

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

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

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

The interface between employment services and other CSDA-funded services

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

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

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

Service types

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

Respite, including centre-based respite

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

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

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

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

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

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

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

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

Siblings

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

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

Quality respite

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

Inadequate early intervention services for children

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

Employment

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

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

Attendant care in the workforce

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

Carers and ageing

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

As one participant put it:

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

In the meantime:

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

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

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

On carer outcomes:

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

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

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

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

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

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

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

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

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

Funding, infrastructure and planning life transitions

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

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

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

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

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

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

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

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

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

7.4 Unmet needs: literature and other sources

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

Accounts of remaining unmet needs

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

Equipment and therapy

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

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

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

For adults especially:

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

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

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

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

Attendant care

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

Appropriate residential accommodation support and respite

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

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

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

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

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

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

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

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

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

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

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

Day activities

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

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

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

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

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

Transport

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

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

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

Interface issues and planning for life transitions

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

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

Costs of disability

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

The mutual support of the formal and informal care systems

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

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

7.5 Evidence from analysis of 'other services' data

Disability and ageing

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

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

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

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

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

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

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

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

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

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

— Nil or rounded to zero.

Source: AIHW 2000c, Table 19.2.

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

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

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

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

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

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

Use of HACC services

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

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

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

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

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

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

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

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

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

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

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

Notes

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

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

Use of SAAP services by people with disabilities

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

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

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

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

Housing

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

Impact of boarding house closures

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

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

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

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

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

Health

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

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

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

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

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

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

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

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

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

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

Insurance

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

Equipment and environmental modifications

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

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

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

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

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

7.6 Conclusions on remaining unmet need for specific services

The estimation of unmet need for disability support services is a complex task. The AIHW has used a number of sources, both quantitative and qualitative, to develop and refine the estimates. Population survey data have been used because they focus on people across the community who report specific needs for assistance. As well, data from those jurisdictions that maintain registers of service needs or have holistic application processes (holistic in the sense that they avoid double counting of applicants) have been extrapolated to provide national indications of unmet needs for services. Orders of magnitude have been compared and estimates refined in a process of triangulation.

The resulting estimates of remaining unmet need in 2001 are:

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

Conservative basis of estimates

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

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

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

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

While the accommodation and respite unmet needs estimates may include some people who are receiving some services² the community access and employment services estimates do not. That is, for the latter service types there is no inclusion of people with possibly 'under met' need.

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

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

Other evidence on the need for respite

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

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

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

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

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

Pressures at the program boundaries

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

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

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

Qualitative evidence of unmet needs

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

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

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

8 Approaches to costing remaining unmet need

As well as the two main objectives of the study, the project brief specified five areas of work to be carried out in the course of the project (see Sections 1.1 and 2.3 of this report). The first four areas of work related directly to the two main objectives – effectiveness and remaining unmet need – and is described in the preceding chapters. This chapter discusses the fifth area of work, namely:

formulation of recommendations regarding appropriate costing models/approaches to assist in determining the cost of any remaining unmet need for disability services.

The study is, thus, required to recommend approaches to the costing task, rather than to provide an estimate of the cost of meeting unmet need nationally.

Section 8.1 of the chapter provides an overview of available information on costing. Section 8.2 suggests a ‘building block’ or unit cost approach to cost estimation, the building blocks being related to the components of the unmet need estimates. Sections 8.3 and 8.4 contain discussion of other costing and planning options. Section 8.5 discusses the possible further development of jurisdictional registers of need, in line with CSDA MDS data standards.

8.1 Overview of information

The 1997 AIHW study, after a brief and focused literature review, identified several key factors likely to affect service costs to government. This provided essential underpinning to the national estimation methods then used. This review has been updated for this study. Three key data sources are available, as follows.

Cost information from jurisdictions

Information was requested from jurisdictions in the Jurisdiction Survey (Appendix 2). All jurisdictions were asked to provide information about costing models, as well as specific data on costs incurred in providing these services generally and to specific groups (for example, rural and remote communities, Indigenous Australians and people of diverse cultural or language backgrounds). All jurisdictions were also asked to identify any special features of their jurisdiction that should be considered in understanding cost differentials between jurisdictions. Finally, where States and Territories indicated that they provided funding by level of need, they were asked to provide details. Specifically, they were asked to provide the unit for which this funding is paid; the amount of funding per unit; the average hours of support anticipated to be provided with this funding (if unit is not per hour); the percentage of clients expected to receive this funding level; and a description of how the funding levels were determined.

Each jurisdiction is administering the CSDA program somewhat differently, using sub-programs with different profiles (as well as different names). As a result, there are different cost profiles.

Local factors differ among jurisdictions, not only the factors identified in jurisdiction questionnaires (for example, rural and remote disadvantage, cultural and linguistic diversity issues, historical funding levels) but also interrelationships with other State-based service systems including health, transport, local government and so on, and the related charging regimes.

Chapter 3 reports in detail on the information provided by jurisdictions.

Government expenditure and cost information from the *Report on Government Services 2002*

The annual reports on government services contain national data on government expenditure on services provided under the CSDA (SCRCSSP 2002). These data are prepared each year by each jurisdiction, in line with nationally agreed definitions and in accord with the CSDA MDS data definitions and service categories, and are collated by the Productivity Commission.

Government expenditure and costs to government per place are published for the major CSDA service types (see Tables 1.3 and 1.4 for data from recent years).

These data were used in the 1997 AIHW demand study, combined with supplementary information supplied to AIHW by the jurisdictions, to estimate national average cost components of disability support services (see Appendix 1, AIHW 1997a and Section 8.2 following). The supplementary information from jurisdictions was particularly useful in guarding against the unquestioning use of current average costs to estimate the total national costs of new services. Information on emerging service costing and funding trends, and discussion of marginal costs of new services, were vital information to the estimation process.

Cost information from the literature

A preliminary focused literature search produced material on the costing of services to individuals, including packages of service, and cost comparisons across alternative service approaches, such as institutional, group home or in-home accommodation support.

Knapp (1998: 7-11) defines three different levels at which care costs may be considered:

- micro – the individual user;
- mezzo – the facility level; and
- macro – the system level.

He indicates that historically the most common cost analyses have been at the mezzo level. He also suggests that macro analyses are rare 'and generally less informative because of the problems of aggregation bias and distortions, a mix of very different facilities within the aggregation'. Knapp is referring to both the British and other European experience here.

The UK literature focuses on estimating unit costs both at the micro level, in terms of packages of support, and at the mezzo level, according to different service types and care workers. A key building block in these costing efforts is a census of service users to assist in building up an understanding of service usage for different client characteristics (see, for example, the annual unit cost reports of the Personal Social Services Research Unit). An array of unit costs is reported so that resource needs can be built up from the user level across the country. However it appears a major use of the unit costs is for benchmarking and 'value for money' scrutiny rather than resource allocation.

The 1997 study provided a macro level estimate of costs. Alternative approaches could be considered by the NDA.

8.2 The 'building block' approach to costing unmet need in 2001

The previous study of unmet demand (AIHW 1997a) used the following components of cost to transform the estimates of unmet need (in terms of people and day program places) into national estimates of costs to Australian governments. The cost estimates were based on data, provided by jurisdictions, relating to the costs of existing and new services for:

- group homes per place;
- in-home accommodation support and respite per client; and
- day programs per client.

It was not possible, on the basis of available data, simply to prepare weighted averages of new service cost estimates ... It was not the purpose of this study to attempt to explain the inter-jurisdictional and other variations in detail, but rather to combine the various estimates judiciously, with explanation, to arrive at national cost estimates. (AIHW 1997a; see also summary at Appendix 1)

The main cost estimates used related to:

- costs per group home place per year (net cost to government);
- costs per hour per client for in-home accommodation support or respite;
- costs per client per year for day programs; these varied according to whether the support needs of clients were 'low, medium or high'.

These three sets of data were the 'building blocks' of the national costs estimates in 1997. The profile of people estimated to need accommodation or respite, or day program places was analysed to estimate the intensity of service needed, so as to be able to apply the 'building blocks'. For instance, certain people were assumed to need a group home place whereas, at the other end of the spectrum, some people were assumed to need perhaps three hours of support per week (AIHW 1997a; see also summary at Appendix 1).

One option for costing remaining unmet needs in 2001 is to take a similar 'building block' or unit cost approach to national or State-by-State cost estimates.

The steps involved would be as follows.

Step 1: Decide on the units for which costs can feasibly be estimated. Based on AIHW experience in 1997 and in discussions of indicators during the CSDA MDS redevelopment, it is considered that, once again, the key components will probably be:

- hours of service for community-based accommodation, respite, and individualised packages; hours of service could well be the right approach for open employment services also; and
- places for residential accommodation and community access; if new clients are being placed in supported employment, places could well be a suitable unit cost component.

Cost data for employment services were not obtained in this study. Those published in SCRCSSP 2002 relate to cost per person 'receiving assistance during the financial year'. It is not clear how these figures relate to the definitions in Box 7.1, and hence how they relate to the estimates of unmet need. Employment services are the responsibility of a single jurisdiction (the Commonwealth) who could carry out the costing of unmet need for these services.

Step 2: Decide on measures of service intensity for places – measures that can feasibly be estimated (for example, places in group homes with varying levels of supervision, and community access places for clients with varying levels of support needs).

Step 3: Decide how to relate these unit cost components to the unmet needs estimates in Table 7.1. Estimates for accommodation support need to be split into those receiving some support and those receiving none, and assumptions made about how to take this into account. They also need to be split into a spectrum of needs that can be related to hours of support or places in residential settings. Estimates for community access places also need to be split into a spectrum of needs, for instance into ‘high/medium/low’ support needs, where that is the basis for funding places.

Step 4: Decide whether the policy and cost variations among the States and Territories are such that costing should be done for each jurisdiction separately, and combined into national totals, or whether national estimates should be attempted from the outset.

Note:

- In considering Steps 1 and 2 it is worth noting that this approach is consistent both with discussion during the CSDA MDS redevelopment and the data that will be available from the redeveloped collection. The input and output measures to be available from the new collection, such as hours of service, numbers of clients and duration of support, can be related to funding provided to agencies.
- Flexible packages can combine a number of different service types (for instance, accommodation support and community access). These are costed implicitly with this method, in terms of their components. Should it be desired to cost them explicitly, in terms of the numbers of packages, the estimates of unmet need would need to be modified to reflect this (for instance, to remove some accommodation and some community access numbers from the estimates and add a corresponding number of packages). Then suitable cost estimates for packages (as a cost unit) would need to be assembled, for example, jurisdictions may cost packages in terms of a high/medium/low categorisation.
- The estimation of cost will require (as indicated above) being able to estimate what proportion of the accommodation and respite clients may already receive some services. This figure cannot reliably be estimated from the 1998 ABS confidentialised unit record file but should be able to be estimated from the full file. This is not an issue with the community access estimates, as none of those estimated to need services are receiving them (that is, anyone receiving any level of service was excluded from the estimates).

Tables 8.1a, b and c provide possible templates for such an approach, depending on what is decided in Step 4.

This approach represents a similar approach to the 1997 costing approach, but with opportunities for updating and using possibly different components. For instance, the costing could split the estimates of people needing accommodation services into: residential (high, medium and low) and community (high, medium and low), and then use national cost estimates for each ‘unit’ based on Table 3.9 and some averaging. Data from the *Report on Government Services* (SCRCSSP 2002) could be used in combination with jurisdiction data or information on marginal costs of new services. Community access cost estimates could be undertaken using a less complex approach.

Alternatively, as outlined, costing could be undertaken using the suggested templates but varying the approach among jurisdictions.

Table 8.1a: Possible template for costing unmet need for accommodation support and respite services^(b)

	Support needs (described in survey terms)^(a)	What received now (from survey)	Possible policy approach (can be varied)		Cost
High-level needs for accommodation support	2 or more ADLs 3–5 times per day	Nothing	Group homes for X% of people	In-home accommodation support with high hours for (100 – X) % of people	Use cost per place in group home or cost per hour, together with client numbers, to show total cost for this row.
		Some assistance	–	In-home accommodation support (and/or respite) with lower hours (e.g. half the high hours)	Use cost per hour, together with client numbers, to show total cost for this row.
Middle-level needs for accommodation support and/or respite	1 ADL 3–5 times per day	Nothing		In-home accommodation support (and/or respite) with, for instance half the high hours	Use cost per hour, together with client numbers, to show total cost for this row.
		Some assistance		In-home accommodation support (and/or respite) with, for instance, 10–25% of the high hours	Use cost per hour, together with client numbers, to show total cost for this row.

(a) More detailed spectrums of needs can be calculated using other activities (and the related need for assistance) but the numbers would be small and the estimates less reliable.

(b) The need for respite services is not costed separately using this approach. Rather, it is considered as substitutable, or a complementary service to lower the need, for accommodation services. It is assumed that the hourly costs are similar to the hourly costs for accommodation.

Table 8.1b: Possible template for costing unmet need for community access services

	Support needs (described in survey terms)	Cost of place to support these needs	Total cost of these places
High-level support needs	No. of people who need (say) at least twice-daily assistance for all 3 ADLs	As estimated (nationally or for jurisdiction)	Calculated by multiplication
Middle-level support needs	No. of people who need (say) at least twice-daily assistance for 2 or more ADLs	As estimated (nationally or for jurisdiction)	Calculated by multiplication
‘Low’-level support needs	No. of people who need (say) at least once-daily assistance for 2 or more ADLs	As estimated (nationally or for jurisdiction)	Calculated by multiplication

Table 8.1c: Possible template for costing unmet need for employment services

	Support needs (described in survey terms)	Hours of support needed (policy decision) or no. of places	Cost per hour or place	Total cost
High-level support needs	No. of people who need (say) at least daily support with 2 or more ADLs plus guidance	Hours per person or no. of places for this level	Cost per hour or place for this level	Calculated by multiplication
Middle-level support needs	No. of people who need (say) at least daily support with 1 or more ADLs plus guidance	Hours per person or no. of places for this level	Cost per hour or place for this level	Calculated by multiplication
‘Low’-level support needs	No. of people who need (say) at least daily support with 1 ADL	Hours per person or no. of places for this level	Cost per hour or place for this level	Calculated by multiplication

Where appropriate, reference can also be made, in the course of costing, to the recommendations of the concurrent NDA-commissioned project 'Methods to Address Requirements for Changes in Funding Disability Services Brought About by External Change'.

8.3 Considering differing policy scenarios

Given the wider policy and service context in which the CSDA operates, it could be useful to undertake costing according to different scenarios.

For instance, varying policy assumptions could be made about:

The service spectrum, for example:

- respite models, for example, centre-based respite;
- assumptions about future supply of residential accommodation and de-institutionalisation;
- assumptions about younger people in nursing homes;
- other aged care/disability interface scenarios;
- various employment or day activity scenarios, varying by age;
- CSDA/HACC scenarios;
- equipment scenarios; and
- transport scenarios.

The population or eligibility criteria, for example:

- assumptions about 'every carer should have a two-week break every year'; and
- assumptions about older carers, for example, an assumption that, by a certain age, a very high proportion of carers prefer minimal responsibilities for caring.

The cost spectrum, for example, limits on the size of individual packages.

8.4 The possibility of adopting a population 'benchmark' approach

The previous sections relate to approaches to costing the unmet needs estimates provided in Chapter 7. This and the following section provide some further thought about planning, costing and data collection approaches.

A number of jurisdictions use population data for promoting equity in resource distribution (see Chapter 5). In the aged care field this is taken one step further, by using population data not only to promote equity (say, between regions) but also to establish benchmarks or planning ratios that allow resource provision over time to be monitored and targets to be set. These planning ratios (relating to residential care and care packages) make it explicit that only a proportion of the older population will require formal assistance from these government programs at any particular point in time; this point is particularly true of residential aged care provision.

Population change is one factor that suggests that there will be continuing growth in demand for disability support services, as new consumers move from the potential need category into the unmet demand category, until such time as entries balance exits. However,

the duration of this period of growth is not known. The HACC and aged care fields, also faced with growing demand, may suggest some options about alternative approaches to planning and resource allocation, when the total size of unmet demand is not known but is believed to be growing (for example, because of population growth and ageing).

The HACC and aged care sector use two different strategies to allocate resources to a growing number of clients:

- A geographic benchmark system was adopted for residential aged care and care packages in 1985. This system sets a target of 100 places per 1,000 people aged 70 and over (DHAC 2001). The benchmark was developed by considering both client needs and the number of places available in aged care. Currently, the balance of places is set at 40 high-care places to 50 low-care places to 10 community aged care places. This system therefore links resource allocation to growth in the target population, a broad categorisation of client need and desired shifts in service delivery options. Quality is considered via standards and accreditation.
- An incremental resourcing system was developed by the Home and Community Care (HACC) program in some States, in the form of its service provision targets system (Alt Statis & Associates 1994). This system was premised on an understanding that:
 - demand exceeded supply;
 - demand was expected to grow with the ageing of the Australian population and the growth in younger people with a disability living in the community; and
 - service may not reflect current and predicted distributions of the HACC target population, leading to inequities.

Under this system the current provision of HACC service types is compared to the target population of an area, according to three ratios:

- *a service provision ratio*: this is the number of units of each service type delivered in an area compared to each 1,000 of the area's HACC target population;
- *a service coverage ratio*: this is the number of clients supported by each service type in an area compared to each 1,000 of the area's HACC target population; and
- *a service intensity ratio*: this is the number of units of each service type provided in an area divided by the number of clients supported in that area.

Under this system, new resources are allocated to allow areas with lower than average service ratios to achieve average provision levels, and then for additional resources to be allocated incrementally and equitably thereafter. Thus new resource allocations are spread in a horizontally equitable way to move provision closer to meeting unmet demand. Matching resources to the needs of individuals is done at a local agency level.

The system was premised on additional work being done concurrently to determine optimum service provision ratios in relation to need and demand. While horizontal equity is assisted, the system does not consider quality or vertical equity factors, which need separate indicators.

Approaches such as the HACC approach could promote horizontal equity but adjustments would need to be made for particular population groups (for example, to adjust for the Aboriginal and Torres Strait Islander population as is done in the CSDA 'potential population' figures – see AIHW 1997b).

Such approaches are useful for broad-based resource allocation but may not be helpful in deciding exactly what to put on the ground. This requires regional information (such as that available to Aged Care Planning Committees in each aged care planning region) that is not the subject of this report.

8.5 Further developing the jurisdictional registers

This section discusses another possible approach that could make data on unmet need more routinely available.

The current data framework in which the CSDA operates

At the 'front end' of the CSDA system there now exists a number of registers or holistic application processes to describe need and unmet need of applicants.

At the centre of the system (service provision) there will soon exist the redeveloped CSDA MDS, containing the data items articulated by jurisdictions in 18 months of consultation, as meeting the majority of their information needs (in relation to nationally comparable data items). The expenditure data contained in the *Report on Government Services* are similarly negotiated multilaterally among jurisdictions, the Productivity Commission and the AIHW and where appropriate accord with the CSDA MDS definitions, so as to enable the two data sources to be combined.

At the 'back end' of the system are developments in relation to performance indicators for the CSDA program as a whole.

There are benefits in building on existing data frameworks and relying on nationally agreed data standards for community services. As part of the CSDA MDS redevelopment project considerable effort has been put into developing appropriate input and output counts for CSDA services. A number of 'indicators' workshops were conducted (with State, Territory, Commonwealth, and service provider and consumer representation) in addition to the lengthy consultation processes employed as part of the project design (such as jurisdiction field testing with service providers, AIHW field testing with service providers and jurisdictions). The final MDS, agreed by the NDA in December 2001, provides the following measures, depending on service type:

- *number of clients, duration of support, hours received (reference week, typical week)* – for attendant care/personal care; in-home accommodation support; alternative family placement; case management/local coordination and development; learning and life skills development (day activities); other community access; respite services;
- *number of clients; duration of support* – for residential/institutions; hostels; group homes; other accommodation support; therapy services; early childhood intervention; behaviour/specialist intervention; counselling; regional resource and support teams; other community support; employment services;
- *number of clients* – recreation/holiday programs; advocacy, information and print disability services.

The CSDA MDS redevelopment has also invested considerable effort into the collection and collation of improved, comparable funding data – specifically, funding data that are able to be more directly related to service types and client profiles, and can be obtained from jurisdictional information systems. When the agreed approach for the CSDA MDS is fully implemented it will provide jurisdictions and Administrators with more detailed cost data

than is currently available through the Productivity Commission process, meaning cost data that can be related at agency level and to specific groups of clients.

The possibility of further developing registers and holistic application approaches to facilitate future costing approaches

A range of registers and holistic application approaches was discussed in Chapter 5. The CSDA program seems suited to further development of such mechanisms to plan for long-term services for a relatively stable, life-long population.

Signatories to the CSDA could consider agreeing on the use of CSDA MDS items, as Queensland has done, and some basic pooling of data for this purpose. One way to improve the data currently available would be to increase the consistency with which applicants are asked to describe the services they are seeking (for example, using CSDA MDS service types). At some stage in the process, information on support needs would be helpful in indicating possible service levels needed. Additional multilaterally agreed definitions could be developed for additional data items if needed.

This approach is taken in other areas, for instance, in relation to hospital waiting lists, where the population is much more fluid. Some benchmarks and indicators have been nationally agreed. This type of approach may be well suited to the CSDA program.

The relationship of costs to the assessment processes in place in the CSDA sector should also be considered. For example, the CSDA MDS support needs question provides an information grid, based on national and international standard classifications, to which a range of current assessment tools can be mapped, and which also incorporates basic ABS survey concepts¹. This enables the service data to be related to the population data and to other service data.

If registers were to be used as part of a cost estimation process, consideration may need to be given to further definition and national consistency of eligibility criteria.

Information on these registers may also be useful in terms of addressing the 'life cycle planning' issues raised at peak discussions. That is, with appropriate data collection rules, registers could enable people to express future needs for support (for example, people may want to register their need well in advance to plan for a life transition). Such use of registers would thus facilitate a system that might support and encourage people to plan their own lives. While register data, in combination with population data, may also relate to long-term policy and funding strategies, further discussion of these uses is considered beyond the scope of this study.

The balance of measurement

The use of both types of estimates of people needing services – population based (for equity reasons) and application based (essentially for equity reasons of a different kind, related to empowerment) appears to be an accepted part of the administration and planning of the CSDA program. This study therefore relies on both methods. As discussed in this chapter there would appear to be the possibility of improving data on both fronts, to support future planning and costing initiatives.

¹ The information available from the HACC sector would be able to be related much more closely to the CSDA sector if the HACC MDS included data items compatible with the CSDA 'disability group' and 'support needs' questions.

The use of registers relates to expressed need and 'demand'. This process makes publicly transparent the outcomes of the application and waiting process. These are intrinsic characteristics of services where receipt is voluntary – there has to be an application process at some stage that provides people with the opportunity to ask for services they need. However, there are also disadvantages in relying solely on data emanating from such processes for estimating unmet need. The disadvantages of submission-based funding models are well documented, and, as indicated by the peak discussions, can be a particular problem for some population groups including Indigenous people.

A crucial aspect of data improvement is to build onto the investments already made, most notably the CSDA MDS.

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Appendixes

Appendix tables

Table A4.1: Percentage of CSDA-funded service recipients needing continual support, and frequent and 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

	Continual					Frequent and continual				
	1997	1998	1999	2000	2001	1997	1998	1999	2000	2001
Accommodation										
Activities of daily living	43.3	46.4	47.2	47.3	46.1	68.1	69.6	70.2	70.2	70.6
Home and social living	56.5	58.7	59.2	60.3	58.2	85.1	87.6	86.3	86.5	86.8
Education, work and leisure	58.0	60.1	63.6	64.1	64.7	80.8	83.3	84.1	84.0	86.0
Community support										
Activities of daily living	37.8	38.8	38.2	39.4	39.9	63.9	65.8	64.1	65.5	65.1
Home and social living	38.1	39.5	39.7	40.5	35.7	66.3	66.8	67.0	68.1	59.7
Education, work and leisure	39.8	41.6	41.4	44.8	42.3	67.6	67.2	66.5	69.1	64.0
Community access										
Activities of daily living	36.3	37.4	38.4	41.5	39.9	62.3	61.6	63.3	63.9	64.9
Home and social living	49.1	50.3	52.0	54.7	53.3	81.3	81.7	81.3	82.7	82.8
Education, work and leisure	59.0	58.9	64.7	67.9	66.3	83.2	83.6	84.5	87.1	86.6
Respite										
Activities of daily living	43.1	47.5	45.4	47.3	46.4	69.8	75.3	71.6	72.4	73.3
Home and social living	47.0	53.0	50.6	56.2	51.4	75.4	80.6	77.1	81.0	78.8
Education, work and leisure	48.0	54.6	53.8	60.1	61.1	75.1	79.6	76.9	81.7	81.3
Employment^(a)										
Activities of daily living	14.8	13.1	13.2	12.5	13.0	35.7	32.7	33.7	34.1	36.6
Home and social living	24.5	21.5	21.1	20.1	21.4	58.0	57.5	55.2	54.1	57.0
Education, work and leisure	41.6	22.1	23.9	22.3	24.0	73.4	60.5	59.1	56.8	59.7

(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. Results in this table suggest that the varied question format in 1997 affected the responses provided by agencies.

Table A6.1: People aged under 65 with a severe or profound core activity restriction living in households: the highest frequency of need for help with core activities, by severity of restriction and by core activities in which assistance is needed, 1998 ('000)^(a)

Core activities in which help is needed	The highest frequency of need for help with core activities ^(b)								Does not need	Total
	6+/day	3–5/day	2/day	1/day	2–6/week	1/week	1–3/month	<1/month		
Profound										
Self care only	**2.1	*5.0	*4.2	*8.0	**1.8	**0.3	0.0	0.0	0.0	21.4
Mobility only	**1.3	**1.2	*6.6	*8.0	*7.6	*3.4	**1.2	**1.7	0.0	30.9
Communication only	*2.7	*2.9	**0.6	**0.1	**0.3	**1.4	0.0	**0.2	0.0	*8.1
Self care and mobility only	24.4	13.2	*7.9	12.6	*8.0	**0.9	0.0	**1.5	0.0	68.5
Self care and communication only	*4.4	*3.5	**2.4	**1.6	**0.4	0.0	0.0	0.0	0.0	12.2
Mobility and communication only	**1.1	**1.3	**0.6	*3.2	**1.4	**0.6	0.0	0.0	0.0	*8.2
All three activities	30.5	12.8	*2.9	*3.2	**1.0	0.0	**0.1	0.0	0.0	50.4
Does not need	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	**2.4	**2.4
Total with one activity only	*6.0	9.0	11.3	16.1	9.8	*5.1	**1.2	**1.8	0.0	60.4
Total with two activities only	29.9	18.0	10.9	17.4	9.8	**1.5	0.0	**1.5	0.0	89.0
Total with two or three activities	60.5	30.8	13.7	20.6	10.7	**1.5	**0.1	**1.5	0.0	139.4
Severe										
Self care only	**0.5	*3.5	*3.1	10.4	12.7	13.3	12.6	34.3	0.0	90.4
Mobility only	**1.7	*5.1	*5.5	*7.7	29.5	22.0	35.5	66.5	0.0	173.5
Communication only	*4.5	*5.5	*2.7	**2.1	*8.3	*4.0	9.9	*4.7	0.0	41.7
Self care and mobility only	*3.8	*8.3	*8.7	10.7	22.0	14.6	15.7	23.3	0.0	107.2
Self care and communication only	**0.6	0.0	**1.0	**1.6	**1.5	0.0	0.0	**0.7	0.0	*5.5
Mobility and communication only	**0.5	**0.8	0.0	0.0	**1.0	*2.6	**0.7	**1.0	0.0	*6.6
All three activities	**1.2	**0.8	**1.1	**0.9	0.0	0.0	**0.3	**1.2	0.0	*5.5
Does not need	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	*3.3	*3.3
Total with one activity only	*6.7	14.0	11.3	20.2	50.6	39.4	58.1	105.4	0.0	305.6
Total with two activities only	*5.0	9.1	9.7	12.3	24.5	17.2	16.4	25.0	0.0	119.3
Total with two or three activities	*6.2	9.9	10.9	13.2	24.5	17.2	16.7	26.3	0.0	124.9

(continued)

Table A6.1 (continued): People aged under 65 with a severe or profound core activity restriction living in households: the highest frequency of need for help with core activities, by severity of restriction and by core activities in which assistance is needed, 1998 ('000)^(a)

Core activities in which help is needed	The highest frequency of need for help with core activities ^(b)								Does not need	Total
	Total severe or profound									
Self care only	*2.6	*8.4	*7.3	18.4	14.6	13.6	12.6	34.3	0.0	111.8
Mobility only	*3.0	*6.3	12.1	15.6	37.1	25.4	36.8	68.1	0.0	204.3
Communication only	*7.2	*8.3	*3.3	**2.2	*8.6	*5.4	9.9	*4.8	0.0	49.9
Self care and mobility only	28.2	21.6	16.7	23.3	30.0	15.5	15.7	24.8	0.0	175.8
Self care and communication only	*5.0	*3.5	*3.4	*3.1	**1.9	0.0	0.0	**0.7	0.0	17.6
Mobility and communication only	**1.7	**2.1	**0.6	*3.2	**2.4	*3.3	**0.7	**1.0	0.0	14.9
All three activities	31.7	13.5	*4.0	*4.1	**1.0	0.0	**0.4	**1.2	0.0	56.0
Does not need	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	*5.7	*5.7
Total	79.4	63.7	47.3	70.0	95.6	63.2	76.2	135.0	*5.7	636.0
Total with one activity only	12.8	23.0	22.7	36.2	60.4	44.4	59.3	107.2	0.0	366.0
Total with two activities only	34.9	27.1	20.6	29.7	34.3	18.7	16.4	26.5	0.0	208.3
Total with two or three activities	66.6	40.6	24.6	33.8	35.3	18.7	16.8	27.8	0.0	264.3

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

(b) For people who needed help with more than one core activity, the highest frequency of need for help is recorded.

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

Table A6.2: People with a severe or profound core activity restriction in households: the highest frequency of need for help with core activities, by age and by severity of restriction defined by the 1998 disability survey ('000)^(a)

The highest frequency of need for help ^(b)	0–4 years		5–64 years		65 years or more		All ages	
	Profound	Severe	Profound	Severe	Profound	Severe	Profound	Severe
6+/day	9.3	*2.9	57.2	10.0	26.5	**1.3	92.9	14.2
3–5/day	*3.9	**1.2	35.9	22.7	26.2	*6.3	66.0	30.2
2/day	0.0	**1.4	25.1	20.8	14.7	*3.4	39.8	25.6
1/day	**0.8	**0.8	35.8	32.6	24.4	15.8	61.0	49.2
2–6/week	**0.3	*3.9	20.2	71.2	34.6	26.9	55.1	102.0
1/week	0.0	0.0	*6.6	56.6	23.8	32.8	30.3	89.4
1–3/month	0.0	**2.5	**1.4	72.3	18.8	29.6	20.2	104.3
<1/month	0.0	**0.5	*3.3	131.1	9.2	23.8	12.5	155.4
Does not need	0.0	0.0	**2.4	*3.3	*4.2	*3.6	*6.5	*6.9
Total	14.3	13.2	187.8	420.6	182.2	143.4	384.3	577.3

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

(b) For people who needed help with more than one core activity, the highest frequency of need for help is recorded.

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

Table A6.3: Projected population^(a) of persons with a profound or severe core activity restriction living in households, by age and sex, Australia, 1998 and 2001 ('000)

Age	1998 survey data			2001 estimates ^(b)		
	Males	Females	Persons	Males	Females	Persons
0–4	20.3	7.2	27.5	20.0	7.1	27.0
5–9	43.9	24.9	68.8	44.2	25.0	69.2
10–14	32.7	14.7	47.3	33.6	14.9	48.5
15–19	17.3	13.4	30.7	17.8	13.9	31.8
20–24	11.0	9.3	20.4	11.1	9.5	20.6
25–29	13.7	15.3	29.0	13.8	15.0	28.8
30–34	20.0	18.4	38.4	20.9	19.0	39.9
35–39	17.9	28.7	46.7	17.9	28.4	46.3
40–44	24.1	27.0	51.1	25.6	28.4	54.0
45–49	31.7	42.2	73.9	33.0	44.7	77.6
50–54	33.3	36.7	70.0	37.1	41.4	78.5
55–59	37.5	32.9	70.5	43.1	37.9	81.0
60–64	28.6	33.1	61.7	31.6	35.9	67.4
65–69	22.9	27.7	50.6	22.8	27.4	50.2
70–74	27.4	41.1	68.6	28.8	41.5	70.3
75–79	29.5	53.4	83.0	33.2	58.3	91.5
80–84	15.7	39.1	54.7	18.2	42.7	60.9
85+	21.6	47.1	68.7	25.9	54.5	80.3
Total	449.4	512.2	961.6	478.4	545.6	1,024.0
Total 5–64	311.9	296.5	608.5	329.5	314.1	643.6
Total 15–64	235.3	257.0	492.3	251.8	274.1	525.9
Total 0–64	332.2	303.7	636.0	349.5	321.2	670.7
Total 18–64	224.9	249.0	473.9	241.0	265.8	506.8
Total 65+	117.2	208.4	325.6	128.9	224.4	353.3

(a) ABS estimated resident population as at 30 June 2001.

(b) Estimated numbers were calculated using age- and sex-specific prevalence rates derived from the ABS 1998 Survey of Disability, Ageing and Carers confidentialised unit record file.

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

Table A6.4: People aged under 65 with a severe or profound core activity restriction living in households, who reported as having an unmet need for formal services with core activities, by number of activities in which assistance needed, by frequency of need for assistance, 1998^(a)

Frequency of need for assistance	Age group		
	0–4	5–64	Total
	Number ('000)		
(A) One ADL at least 3–5/day	*2.6	10.9	13.6
(B) Two ADLs at least one ≥ 2 /day	**1.2	22.9	24.1
(C) Three ADLs at least one ≥ 1 /day	*4.7	25.1	29.8
Other lower frequencies	**1.3	88.6	89.9
Total	9.8	147.5	157.3
Total (A) (B) (C) (accommodation & respite)	*8.5	58.9	67.4
	Per cent		
(A) One ADL at least 3–5/day	26.9	7.4	8.6
(B) Two ADLs at least one ≥ 2 /day	12.0	15.5	15.3
(C) Three ADLs at least one ≥ 1 /day	47.4	17.0	18.9
Other lower frequencies	13.7	60.0	57.1
Total	100.0	100.0	100.0
Total (A) (B) (C) (accommodation & respite) ^(b)	86.3	40.0	42.9

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

(b) The % distributions are to be applied to the estimated number of people who reported as having unmet need because no services is available, unable to arrange a service, service costs too much or service does not provide sufficient hours.

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

Table A6.5: Accommodation and respite services

	Number of core activities	Defining 'in', i.e. bottom line (frequency of need for help)	Other criteria
Defining 'in', i.e. bottom line	1	$\geq 3-5$ /day	Number of core activities and frequency of assistance ('severity') help grade the range of estimates when 'in'
	2	At least one activity ≥ 2 /day	
	3	At least one activity ≥ 1 /day	

Table A6.6: People aged 15–64 with a severe or profound core activity restriction living in households, who were not in the labour force, requirements to enable workforce participation, by how often attended supervised activity programs for disability, 1998^(a)

Requirements to enable workforce participation	How often attended supervised activity program for disability						Total
	Not applicable	Does not attend	3–5 days per week	1–2 days per week	1/fortnight or occasionally	attended	
Not applicable	**1.8	277.7	*6.6	12.2	10.0	28.7	308.3
Could work with special arrangements ^(b)	0.0	12.9	0.0	**0.6	0.0	**0.6	13.4
Not applicable	**0.7	88.5	**2.2	*3.8	*4.2	10.2	99.4
Could not work at all	**1.1	202.1	*4.4	*8.9	*5.8	19.1	222.3
Total	**1.8	290.6	*6.6	12.7	10.0	29.3	321.7

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

(b) Including equipment, training or other assistance.

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

Appendix 1: Summary of AIHW 1997 demand study

Objectives of the study

This study was commissioned by the Disability Services Subcommittee to provide information on unmet demand and growth factors for services funded under the Commonwealth/State Disability Agreement (CSDA) and in particular to provide estimates of:

- the level of current unmet demand for accommodation and support, respite and day programs;
- the national costs to governments of meeting this unmet demand;
- the projected growth in demand for specialist disability services arising from demographic changes over the next five years, and related factors.

Assumptions and data sources

Assumptions

It was necessary to clarify a number of assumptions about how and what new services are being provided, before proceeding to the estimation of unmet demand. The assumptions used are detailed in Chapters 2 and 3 but were, chiefly:

- New clients for accommodation services are generally not being assigned to large institutions.
- People with high support needs are being accommodated in group homes or with high-level support in their own homes.
- Day programs will be expected to support clients with higher dependencies than did community access services in the past.
- A trend to service provision via non-government services is expected to continue, but governments may not be able to rely on significant non-government contributions towards the cost of establishing new services.
- While informal care by families is likely to remain the most important source of care for people with ongoing support needs, Australian society does not expect carers to provide lifelong, 24-hour care for people with high support needs. Targeted day services represent an important means of ensuring the participation of people with disabilities and their carers in the wider community.

Data sources

The study drew chiefly on the following data sources:

- the 1993 Australian Bureau of Statistics (ABS) Survey of Disability, Ageing and Carers;
- financial data for 1996–97 provided by all jurisdictions to the Industry Commission in the course of joint work for the Review of Commonwealth/State Service Provision;
- supplementary data requested by the Institute and provided by jurisdictions; and

- the 1996 CSDA Minimum Data Set collection, providing data on users of CSDA services.

The level of unmet demand for accommodation and support, respite and day programs (*Chapter 2*)

The target group for CSDA services is people with disabilities that result in:

- (a) a substantially reduced capacity ... for communication, learning or mobility; and
- (b) the need for ongoing support services.

It is estimated that in 1996, of the 368,300 people aged 5–64 years needing ongoing assistance with self care, mobility or verbal communication (a ‘severe or profound handicap’ in ABS survey terms), there were 13,400 who:

- were living in households; and
- reported unmet need for formal assistance with self care, mobility or verbal communication; and
- had attempted to obtain the assistance needed but could not do so because the service was not available or could not be arranged for other reasons.

These 13,400 people comprise the estimate for unmet demand for accommodation, support and respite services in 1996.

There were also in 1996 an estimated 12,000 people aged 18–64 years with ongoing support needs who:

- *always* needed assistance with at least one of the self care, mobility or verbal communication activities (in the terms of the ABS survey they have a ‘profound handicap’);
- were not in the labour force and were reported to be ‘permanently unable to work’;
- were not studying;
- would have liked to go out more but were prevented from doing so by their illness or condition; and
- were *not* currently receiving day programs under the CSDA.

These 12,000 people (or full-time-equivalent places) comprise the estimate for unmet demand for day programs in 1996.

Conservative nature of the estimates

The estimates for accommodation and support and respite are considered to be conservative because:

- At each step of the estimation process, groups were excluded if there was any doubt about the demand in a subgroup. For instance, some people said that the reason they had not obtained a formal service was that they did not know the services existed; some of these people could well be considered to represent unmet demand, but they were not included in the estimates.
- The estimates are of the same order of magnitude as the (incomplete) waiting list data available from some States, relating to people whose needs are already known to the States.
- The estimates exclude people in 'health establishments' (some 19,000 in 1993) including hospitals, nursing homes and other institutions, some of whom may be waiting for community accommodation.
- The estimates exclude children aged under 5 years, because their severity of handicap is not indicated in the ABS survey data.
- There are growth factors, discussed in Chapter 4, which indicate the ongoing pressures on services, chiefly the ageing of clients and their carers.

The day program estimates are considered to be conservative for several reasons, including that:

- They exclude people with a 'severe' handicap, who need assistance sometimes rather than always, on the assumption that these people will be eligible for employment programs.
- They exclude people who are employed part-time, thereby excluding people who are able to attend supported employment programs part-time but may require a day program for the other times of the working week.
- They assume no growth in total demand since 1993, even to allow for population growth.
- They offer no additional service to current users of the programs.

A spectrum of support needs

Both groups indicating unmet demand were further subdivided, according to the number of activities with which people needed help, and whether or not they were already receiving some formal assistance. This was done to estimate a spectrum of their support needs. Hours of support were estimated for those requiring in-home and respite packages. This was required to make realistic estimates of the costs to government of meeting unmet demand for accommodation and support, respite and day programs. The results are incorporated in Summary Tables 1 and 2.

Costs to governments of meeting current unmet demand for these services (Chapter 3)

The task of the study team was to develop national estimates of the costs to Australian Governments of meeting the estimated unmet demand. The cost estimates were based on data provided by jurisdictions relating to the costs of existing and new services for:

- group homes per place;
- in-home accommodation support and respite per client; and
- day programs per client.

In preparing national cost estimates the study team took into consideration:

- the range of national variation (high and low figures) for each service type;
- the population of each jurisdiction;
- the difference between new service cost estimates and current costs, and the strength of the explanation of these differences; and
- the detail of the supporting data provided.

It was not possible, on the basis of available data, simply to prepare weighted averages of new service cost estimates. Data provided by jurisdictions, and explanation of the reasoning behind the national cost estimates, are included in Chapter 3 and the related appendix tables. It was not the purpose of this study to attempt to explain the inter-jurisdictional and other variations in detail, but rather to combine the various estimates judiciously, with explanation, to arrive at national cost estimates.

The main cost estimates used are:

- \$50,000 per group home place per year (net cost to government);
- \$25 per hour per client for in-home accommodation support or respite;
- for day programs, costs will vary according to the support needs of clients; low, medium and high costs per client per year were estimated to be \$6,000, \$12,000 and \$18,000 respectively.

These cost estimates were then applied to the numbers of people with estimated unmet demand for each of the two main groups of services, and the hours allocated to them for in-home and respite needs.

Total costs to government

The total estimated cost to government of meeting unmet demand for accommodation and support, respite and day programs is \$293.8 million, comprising \$178.3 million for accommodation, accommodation support and respite services and \$115.5 million for day programs.

The study does not estimate or cost unmet demand for other CSDA service types.

The main results are presented in Summary Tables 1 and 2.

Summary Table 1: Estimated net cost to government^(a) of meeting unmet demand for group homes, in home support and respite, 1996–97

Level of assistance	Number of clients	Assumed service response	Number of hours per week	Cost per hour	Cost per client	Total cost
People needing help with 2 or 3 activities and always with at least 1						
	Subtotal: 3,900					
No formal assistance now	1,500	750 Group home			\$50,000	\$37,500,000
		750 Respite/in-home support package	30	\$25	\$39,000	\$29,250,000
Some formal assistance now	2,400	Respite/in-home support package	15	\$25	\$19,500	\$46,800,000
People always needing help with 1 activity						
	Subtotal: 3,000					
No formal assistance now	2,300	Respite/in-home support package	10	\$25	\$13,000	\$29,900,000
Some formal assistance now	700	Respite/in-home support package	5	\$25	\$6,500	\$4,550,000
People needing help with 2 activities sometimes						
	1,900	Respite/in-home support package	5	\$25	\$6,500	\$12,350,000
People sometimes needing help with 1 activity						
	4,600	Respite/in-home support package	3	\$25	\$3,900	\$17,940,000
Total	13,400					\$178,290,000

(a) Excluding the cost of any major capital works for group homes.

Source: Table 2.5; discussion of Tables 3.1, 3.2, 3.3.

Summary Table 2: Estimated net cost to government of meeting unmet demand for day programs

Level of assistance needed	Nature of service	Estimated number of people with unmet demand	Cost per person	Total cost
People needing help with 3 activities and always with at least 1	Day program support—High	1,600	\$18,000	\$28,800,000
People needing help with 2 activities and always with at least 1	Day program support—Medium	4,050	\$12,000	\$48,600,000
People always needing help with 1 activity	Day program support—Low	6,350	\$6,000	\$38,100,000
Total—people <i>always</i> needing help with at least 1 activity		12,000		\$115,500,000

Source: Tables 2.7, 3.4, 3.6 and related discussion.

Growth estimates and trends (Chapter 4)

Demographic changes, along with changes in other factors, will have considerable impact on the growth in demand for disability support services in the next six years.

Demographic projections

The projected demographic trends, particularly population ageing, result in a substantial projected increase in the number of people in the CSDA target group – people with a profound or severe handicap – over the next six years (1997–2003):

- The increase in the age group of 5–64 years is 9.9% (39,100 people).
- The growth in the working age population (age 15–64) with severe or profound handicap is 11.3% (37,200 people).
- Overall, the total number of Australians with a severe or profound handicap is projected to increase by 13.7% (109,200 people). The overall growth is mainly attributable to the rapid increase in the age groups of 45–64 years (19.5% or 32,600 people) and 65 years and over (17.3% or 70,200 people).

Projected growth in disability groups

Corresponding to the projected population growth, the estimated overall growth in different disability groups is mainly due to the rapid increases in the population age groups of 45–64 years and 65 years and over. Nevertheless, the sizes of the increase vary among different disability groups aged 5–64 years. The projected growth rates in the numbers of people in hearing (12.0%), circulatory (15.2%) and arthritis (16.0%) disability groups are higher than the overall growth rate (9.9%) of people with a profound or severe handicap in this age group. The higher growth rates of these disability groups are probably related to the higher growth rates in the older age groups, 45–64 years. In contrast, the growth rates of intellectual (5.0%), speech (4.9%) and learning disability (3.4%) disability groups are lower than the overall growth rate of people with a severe or profound handicap.

The number of females aged 5–64 years with severe or profound handicap is projected to remain higher than the number of males. Among people under the age of 65 years, the numbers for males are higher than those for females in the disability groups of intellectual, acquired brain injury, visual, hearing, speech, and ‘other musculoskeletal’.

Growth, ageing, de-institutionalisation and carers

The projected demographic trends, and other trends in families and carers outlined in Chapter 4, have a number of implications for the future of CSDA services:

- The high projected rates of increase in the number of people with a severe or profound handicap aged 45 years and over is likely to result in the ageing of the client population of disability support services. The high growth in ages 45–64 years will bring particular pressure on CSDA services, either to provide services to an increasingly older clientele, or to make transitional arrangements between CSDA services and suitable aged care services.
- The increase in the number of people with a profound or severe handicap among both the working age population (and people aged 65 years and over) will further increase the need for carers.

- The ageing of carers is likely to continue to be an important issue. The number of parents aged 65 years and over who are the principal carers for people with a profound or severe handicap is projected to increase from 7,700 in 1993 to 9,000 in the year 2003.
- There will be pressure on related services such as Home and Community Care.
- There will be pressure on both families and community-based services from ongoing trends in de-institutionalisation. Between 1981 and 1993 the number of people aged 5–64 years with ‘severe handicap’ (ongoing support needs) living in households rose from 244,100 to 349,100 while the number living in establishments fell from 27,000 to 19,200. The trend is even more marked for people aged under 30 years – in 1981 there were, on average, 15.9 people aged under 30 years with a ‘severe handicap’ living in establishments for every 100 living in households, whereas by 1993 this ratio had dropped to 3.1 for every 100 living in households. There has been a related rise, since 1981, in the numbers of people in the CSDA target group living with their families.
- While the structure of families may be changing, there is strong evidence of continuing mutual support among family members, in various patterns and relationships. When family support is likely to be intense and long-term, formal assistance from support services can ensure its stability and continuation.

Projected population distributions among the States and Territories

The main estimates in Summary Tables 1 and 2 are based on the premise that the presence of severe or profound handicap is an important population indicator of the need for CSDA services. The presence in a population of a large proportion of Aboriginal or Torres Strait Islander people is considered to be a further indication of higher need, in that population, of such services. While there is not extensive data on disability among Indigenous people, what evidence there is points to higher rates of disability.

It has been previously accepted that, for this reason and based on service usage, the Indigenous population in each jurisdiction should be weighted by 2, in order to give an adjusted ‘potential population’ for CSDA services.

Results for 1996 and projections to 2003 are summarised in Summary Table 3, showing total population, population with severe or profound handicap, and the adjustment to the latter figure, from weighting the Indigenous population by a factor of 2.

Summary Table 3: Distribution of the population aged under 65 years, among the States and Territories: total population, people with severe or profound handicap, adjusted 'potential population', 1996, 2003

People under 65 years	NSW	Vic.	Qld	WA	SA	Tas.	ACT	NT	Australia
Percentage									
All people, 1996	33.66	24.78	18.42	9.83	7.87	2.57	1.77	1.09	100.0
People with severe or profound handicap, 1996	33.80	24.88	18.26	9.75	8.01	2.59	1.72	0.99	100.0
People with severe or profound handicap, 1996 (adjusted)	33.69	24.47	18.45	9.85	7.96	2.62	1.70	1.24	100.0
All people, 2003	33.40	24.02	19.53	10.13	7.60	2.43	1.79	1.09	100.0
People with severe or profound handicap, 2003	33.47	24.11	19.41	10.05	7.75	2.48	1.72	1.02	100.0
People with severe or profound handicap, 2003 (adjusted)	33.36	23.71	19.61	10.15	7.70	2.51	1.70	1.27	100.0

Source: Tables 4.11, 4.12; ABS 1994; ABS 1997; AIHW analysis of the ABS 1993 Survey of Disability, Ageing and Carers.

Adjustment from weighting the Indigenous population by 2 leads to upward adjustments to the figures for Queensland, Western Australia and the Northern Territory, and downward adjustments for New South Wales, Victoria and South Australia. The adjustment to the Northern Territory numbers is quite significant. The projected population growth for Queensland and Western Australia is of greater significance in their growing share of the target population for CSDA services than is the adjustment for Indigenous population.

Appendix 2a: Questionnaire to inform the CSDA 'Needs Study' (States and Territories)

You have been nominated by your department to provide information in relation to a study recently commissioned by the National Disability Administrators: The effectiveness of existing funding to reduce unmet need for disability services and identification of any remaining shortfalls.

The Australian Institute of Health and Welfare (AIHW) is leading the project study team, which also includes members of Alt Beatty Consulting (Sydney and Armidale). The final report is due to the National Disability Administrators in April 2002.

Shortly after you receive this questionnaire, a member of the study team will contact you. One purpose of this initial conversation is to clarify any questions or problems that you may have in relation to the questionnaire and give you the opportunity to specify what further information you may need to assist you in providing the requested information on schedule.

Louise York (AIHW) and Merilyn Alt (Alt Beatty Consulting) will contact New South Wales, Victoria and Tasmania. Chrysanthé Psychogios (AIHW) and Dianne Beatty (Alt Beatty Consulting) will contact Queensland, South Australia, Western Australia, the Northern Territory and the Australian Capital Territory. AIHW staff will focus on general questions about the effectiveness of the unmet need funding while Alt Beatty Consulting will focus on specific questions relating to the provision of financial data.

We will be contacting you in three waves:

- Merilyn or Dianne will contact you before 21 December 2001 to confirm receipt of the questionnaire, respond to any preliminary questions you have, and set up a telephone meeting with you in the week starting 14 January 2002 to discuss the financial data questions (sections 1, 2 and 5 of the questionnaire);
- Louise or Chrysanthé will contact you in the week 7–11 January 2002 to discuss sections 3 and 4 of the questionnaire and respond to any further queries you may have;
- Merilyn or Dianne will meet with you (by phone) in the week 14–18 January 2002 to discuss sections 1, 2 and 5 in detail and respond to any remaining queries that will assist you to finalise your jurisdiction's input to this study.

Should you need to contact a member of the study team, contact details are included below.

As the study team is required to prepare a draft report in February 2002 and the final report by April 2002, it is essential that responses to this questionnaire are received by the project team no later than **18 January 2002**. Please send your response by e-mail to louise.york@aihw.gov.au or by mail to Louise York, AIHW, GPO Box 570, Canberra, ACT, 2601.

We look forward to working with you to gather and analyse this important information.

Ros Madden
Head, Disability Services Unit

18 December 2001

‘Needs study’ contacts for jurisdiction questionnaire

Name	Phone	E-mail	Jurisdictions and area of focus
Louise York	02 6244 1187	louise.york@aihw.gov.au	NSW, Victoria and Tasmania – sections 3 and 4 of the questionnaire
Merilyn Alt	02 9953 3464	malt@bigpond.net.au	NSW, Victoria and Tasmania – sections 1, 2 and 5 of the questionnaire
Chrysanthe Psychogios	02 6244 1068	chrysanthe.psychogios@aihw.gov.au	Queensland, SA, WA, the NT and the ACT – sections 3 and 4 of the questionnaire
Dianne Beatty	02 6775 2257	diannebt@ozemail.com.au	Queensland, SA, WA, the NT and the ACT – sections 1, 2 and 5 of the questionnaire
Ros Madden	02 6244 1189	ros.madden@aihw.gov.au	Project manager

Questionnaire to the States and Territories to inform the CSDA 'Needs Study'

This study has been commissioned by the National Disability Administrators, to be completed in April 2002.

The objectives of the project are to:

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

The outcomes of the project will inform discussion and negotiations regarding the third Commonwealth/State Disability Agreement (CSDA).

The full title of the study is: *The effectiveness of existing funding to reduce unmet need for disability services and identification of any remaining shortfalls.*

The study team will use a range of methods to gather information to meet the project objectives, including data analysis, literature reviews and discussions with peak bodies.

This questionnaire seeks information from all States and Territories that will be of key importance to the study. Information is being sought separately from the Commonwealth Department of Family and Community Services (FaCS).

PART I—CONTACT DETAILS

A. Who is the key contact person within your jurisdiction in relation to this request for information?

Name	
Position/title	
Phone number	
Fax number	
E-mail address	

B. Please also provide the contact details for the officer handling the financial components of this request. If this is the contact person above, simply indicate 'as above'.

Name	
Position/title	
Phone number	
Fax number	
E-mail address	

PART II—QUESTIONS

The questionnaire begins with general questions about the new unmet needs funding, its objectives and effectiveness and moves to more detailed questions about policies and expenditure in your jurisdiction.

- Section 1 asks you to attach some general information about the way your jurisdiction has gone about identifying the types of services to which your share of the unmet need funding is directed. It also tries to identify what readily available sources of information may exist that will help in measuring and describing changes in services.
- Section 2 seeks information to assist in evaluating the effectiveness of the new funding provided under the unmet needs funding arrangements. Again much of the information requested in Section 2 will require the attachment of descriptive material.
- Section 3 asks you to provide information about areas of unmet need that have not yet been fully addressed and any plans that are in train to address those needs in the future.
- Section 4 allows you to provide any other information that may assist the project team.
- Section 5 seeks detailed information about the way unmet need funding is being distributed among CSDA service types and clients in your jurisdiction.

Table 1 summarises unmet needs funding. **Funding figures provided by your jurisdiction in this questionnaire should add to the total unmet needs funding figures for your jurisdiction in table 1.**

Table 1: Unmet need funding offer: Commonwealth and State contributions

State	Commonwealth funding offer			State offer		
	2000–01 \$m	2001–02 \$m	Total over 2 years \$m	2000–01 \$m	2001–02 \$m	Total over 2 years \$m
New South Wales	16.84	34.45	51.29	93.41	119.308	212.718
Victoria	12.29	25.14	37.43	38.4	38.4	76.8
Queensland	9.155	18.73	27.885	9.0	18.0	27.0
South Australia*	4.045	8.28	12.325	6.0	6.0	12.0
Western Australia	4.905	10.04	14.945	9.5	15.97	25.47
Tasmania	1.315	2.69	4.005	1.5	6.132	7.632
Northern Territory	0.605	1.24	1.845	0.652	1.23	1.882
Australian Capital Territory	0.845	1.73	2.575	1.5	1.5	3.0
Total	50	102.3	152.3	159.962	206.54	366.502

*In addition, South Australia announced \$2 million in new funding for unmet need in 1999–00.

Notes

- Commonwealth approach to presenting new funds is used, i.e. second year is cumulative new money, from first and second years. Some States will express funding amounts differently in their own material.
- Updated November 2001.

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

1. 'New money': objectives and use of the 2000–01 unmet needs funding

The Commonwealth has provided copies of the 2000 bilateral agreements (which incorporate its funding objectives) as well as the most recent reports it has received from States and Territories about the use of Commonwealth funds.

- 1.1 In 2000–01, the Commonwealth provided \$50 million to meet unmet needs for disability services (focused on support of people with a disability with ageing carers) and the States and Territories provided a total of \$160 million to meet unmet needs, within their own priorities. In relation to your jurisdiction, can you distinguish the State's/Territory's own contribution to the unmet needs funding from its other disability funding (as identified in Table 1)?
- ☐ YES: *If yes, please answer the remaining questions in the questionnaire in relation to this figure.*
- ☐ NO: *If no, please provide estimates as to how these funds have been and will be used, and answer the remaining questions in relation to these estimates.*
- 1.2 What are your jurisdiction's objectives in relation to its contribution to the 2000–01 unmet need funding? Please provide:
- (a) details of your funding objectives (including the source of statements); and
 - (b) your 2000–01 annual reports with passages on your objectives flagged and/or any other materials on those objectives.
- 1.3 What were the policy processes used for selecting service types in need and allocating both the Commonwealth and State/Territory unmet need funding?
- 1.4 Please describe your strategy for service provision for ageing carers.
- 1.5 For the use of new funding within your jurisdiction, please explain your:
- (a) contract arrangements;
 - (b) costing models; and
 - (c) accountability arrangements.
- 1.6 Please provide copies of any reports and/or financial statements (preferably audited) that indicate the purpose and extent of expenditure of new State/Territory money for unmet need.
- 1.7 Please provide copies of recent annual financial statements or other reports that identify expenditure levels in recent years, preferably by service type.

2. Effectiveness of ‘new money’ and costs of services

- 2.1 Please describe any specific innovative projects undertaken as a result of the unmet need funding (e.g., new services hoped to be particularly effective based on literature or policy directions).
- 2.2 Please provide copies of, or references to, any evaluations conducted of these – or similar – services. Such studies may include evaluations of new service types or services similar to those receiving new funding. Please include, or provide references to, any information about the impact on individuals of receiving support funded with the unmet need funds.
- 2.3 Do you have specific data on costs incurred in providing these services to:
1. rural and remote communities?
 2. Indigenous Australians?
 3. people of diverse cultural or language backgrounds?

If yes, please provide details.

- 2.4 Are there any special features of your jurisdiction that should be considered in understanding cost differentials between jurisdictions, for instance:
- Higher costs (e.g., price of real estate);
 - Lower current provision levels;
 - Varying service types characteristics (e.g., staffing levels)
 - The balance between the use of Government versus non-Government service providers;
 - Demographic issues (e.g., age structure, geographic distribution and ethnic make-up of the population);
 - Changes in multiple service usage by clients;
 - Other factors that might influence the cost of delivering services.

Please describe and provide any supporting material.

3. Possible remaining shortfalls and methods of managing 'need'

- 3.1 Are you developing any other/new service delivery/funding models/contractual models, on which you expect to expend unmet need funding, but on which no unmet need funding has yet been allocated?

☐ YES

☐ NO

If yes, please describe the reasons for their development, their nature, purpose, target group, and the anticipated funding model (including minimum, average and maximum cost/funding structures).

- 3.2 Please provide a description of any coordinated registers of unmet need used in your jurisdiction, including:

- (a) criteria for inclusion in the registers;
- (b) criteria for prioritising in the registers;
- (c) explanation of the items included in the registers;
- (d) analysis of the data in the registers.

Please provide as much detail as possible.

- 3.3 Please provide a description of processes you have in place, or require funded organisations to follow, for assessing and accepting new clients into different service types.

Please attach relevant supporting material if appropriate.

- 3.4 Please provide any other qualitative or quantitative information or data held by your jurisdiction about unmet needs for disability services. This information may include information from:

- (a) peak bodies;
- (b) complaints;
- (c) submissions to ministers;
- (d) records of Hansard questions in Parliament, Parliamentary Committee discussions, etc.

In particular, please attach any analysis or any program thinking you may have done, which discusses or estimates the amount and type of remaining unmet need and how you would propose to meet these needs, should resources be available.

- 3.5 Please provide any information you hold about consultations with consumers addressing the issue of unmet need.

- 3.6 Please provide copies of, or references to, any projects related to unmet needs for disability services, carried out in, or by, your jurisdiction, of which you are aware. Such studies may include assessments of unmet need.

4. Other issues

- 4.1 The relationship between disability services and other support programs (for example, residential aged care, community care – including Home and Community Care (HACC), housing programs, etc.) impacts on the level of unmet need for disability support. Please comment on this relationship, including:
- (a) how disability services in your State/Territory relate to other support programs;
 - (b) what, if any, impact does the support of other programs have on the level of unmet need for disability services in your State/Territory; and
 - (c) processes, if any, in place to ensure that people with a disability and/or their carers get equitable access to the support of other programs.

Please provide any available supporting qualitative or quantitative material.

- 4.2.1 As per question 4.1, please comment on the relationship between CSDA-funded employment programs and the level of unmet need for disability support funded by your jurisdiction.
- 4.2.2 Please provide any other comments, which could assist the project team in costing unmet need and/or developing models for future funding. This question relates to the NDA requirement for the project team to formulate recommendations regarding appropriate costing models/approaches to assist in determining the costs of any remaining unmet need for disability services.

5. Detailed information about ‘unmet needs’ funding

Section 5 is asking you to provide detailed information about the way unmet need funding is being distributed among CSDA service types and clients in your jurisdiction.

- Section 5.1 asks you to identify **each** of the service types or program areas to which unmet need funding was directed and answer a series of detailed questions about the objectives of the funding, the way funding was allocated and the clients assisted.
 - Section 5.2 asks you to summarise the distribution of unmet need funding according to each of the service types or program areas specified in section 5.1.
- 5.1 Please complete a separate response for **each** service type (or service type sub-category or service type aggregation/program) included in the answer to question 5.2. That is, please make copies of section 5.1 for every service type (or service type sub-category or service type aggregation/program) to which unmet need funding has or will be directed.

5.1(a) Service identification information

*The reference number below links service information provided for each service type/sub-category or program in question 5.1 to the financial data provided in question 5.2. It is assigned by you and should be used consistently in answering questions 5.1 and 5.2.

State/Territory	
Reference number (i.e., 1, 2, 3 ... use the same number in table 5.2)*	
Service type, sub-category or aggregation/program name	
CSDA MDS service type(s) (e.g., 4.01 – own-home respite) Please use national CSDA MDS codes as per the 2001 CSDA MDS Data Guide.	
CSDA MDS service outlet IDs (as per CSDA MDS data returns to AIHW)	

5.1(b) Did this service type, sub-category or program exist prior to the 2000–01 unmet need funding? ☐ YES ☐ NO, / /
(Tick one box only) started:

Please provide a brief description of what this sub-category or program aims to achieve:	
Please provide a brief description of what this sub-category or program offers clients:	

5.1(c) Estimate the proportions of funding that went to new clients and existing clients with unmet needs

New clients: % Existing clients: %

5.1(d) Is this service type, sub-category or program targeting *(tick all categories that are appropriate)*:

Indigenous Australians	<input type="checkbox"/> Yes, please describe:
Australians from other culturally or linguistically diverse groups	<input type="checkbox"/> Yes, please describe:
People living in rural or remote areas	<input type="checkbox"/> Yes, please describe:
Other client group	<input type="checkbox"/> Yes, please describe:
A particular level of disability	<input type="checkbox"/> Yes, please describe:
Particular geographic area(s)	<input type="checkbox"/> Yes, please describe:
Some other characteristic	<input type="checkbox"/> Yes, please describe:

5.1(e) If this service type/sub-category/program is not specifically targeted, what proportion of your clients do you estimate are:

• Indigenous?	%
• From another culturally or linguistically diverse group?	%
• Living in rural or remote areas?	%

5.1(f) Please specify the number of clients assisted using the unmet need funding

As at	30 June 2001	30 June 2002 (estimate)
Number of clients^(a)		

^(a) If estimated please provide details of estimating method.

5.1 (g) The aim of this question is to measure the total quantity of service provided for this service type/sub-category/program. Indicate the measure of service quantity and the quantity for each year (e.g., number of hours, days, places, beds, programs etc.). *Please provide all the measures you use for this service type/sub-category/program. For instance, a sub-category/program may incorporate one or two service types and so will have one or two measures.*

Type of measure	1998-99	1999-2000	2000-01	2001-02

5.1(h) How is this service type, sub-category or program funded? *(tick one box only)*

According to prescribed funding levels per service	<input type="checkbox"/> Yes, please describe:
According to prescribed funding levels per client	<input type="checkbox"/> Yes, please describe:
By individual funding packages (i.e., by independent assessment of the individual needs and associated costs of each priority applicant)	<input type="checkbox"/> Yes, please describe:
Other	<input type="checkbox"/> Yes, please describe:

5.1(i) If you provide funding by level of need, please complete the following table: *(if there is insufficient space, please attach a list)*

Level of need	Unit for which this funding is paid (e.g., per client, per service, per place)	Amount of funding per unit (\$ p.a.)	Average hours of support anticipated to be provided with this funding (if unit is not per hour)	% of clients expected to receive this funding level

Please briefly describe how you determined these funding levels:

5.1(j) Do you expect to try to continue to offer this sub-category/program in the same way to new clients if additional funds become available? *(tick one box only)*

☐ Yes. ☐ No *(please explain why not, or why variation from this model is expected)*

5.1(k) Please attach any expenditure and/or client data you may have compiled by geographic area, for this service type/sub-category/program, or for the unmet needs funding overall.

5.2 Summary of financial information on the use of unmet need funding
(see notes for completion below)

Reference number and name of service type/sub-category/program (from 5.1a) (e.g., 1/in-home respite for people with ageing carers)	Type of funding	Total existing funding for 1999–2000	Unmet need funding				Estimated full year recurrent costs (2001–02 prices) \$
			2000–01 actual expenditure		2001–02 projected expenditure		
			Common-wealth (\$)	State (\$)	Common-wealth (\$)	State (\$)	
	Capital funding						
	Other set-up costs						
	Recurrent funding						
	Capital funding						
	Other set-up costs						
	Recurrent funding						
	Capital funding						
	Other set-up costs						
	Recurrent funding						
Total unmet need funding ^(a)							

(a) This total should be consistent with the total figure for your State or Territory (including Commonwealth funds) provided in Table 1.

Notes for completing table 5.2:

1. Please complete this table, which summarises your jurisdiction's current and projected application of the unmet needs funding. It also seeks expenditure on each service type/sub-category/program in 1999-2000 (prior to unmet need funding) to demonstrate whether the new unmet needs funding was used to complement an existing funding base or for a new direction.
2. Please report at the most detailed level possible.
3. Please use the reference numbers from this page for the individual service information sheets (see question 5.1). Please copy this page and extra copies of the questions in 5.1 if you have more than 8 sub-programs.
4. Where possible provide and/or estimate actual and projected expenditure under the Commonwealth/State unmet need funding arrangements for 2000–01 and 2001–02 and its estimated full-year recurrent cost. If you are unable to provide these figures by service type, please provide by service type sub-category or by service type aggregation or funding program. If you have only aggregated data on some service types, please note the service types that are included in the aggregation and attach estimates of their percentage composition within the aggregation.

(Note: For the purposes of this questionnaire, capital is defined as non-current assets with a value of more than \$10,000.)

Thank you for providing this information

Appendix 2b: Questionnaire to inform the CSDA 'Needs Study' (Commonwealth)

Cathy Ellis
Office of Disability
Department of Family and Community Services
GPO Box 7788
CANBERRA MAIL CENTRE ACT 2610

Dear Cathy

Questionnaire to inform the CSDA 'Needs Study'

We are seeking information in relation to a study recently commissioned by the National Disability Administrators: *The effectiveness of existing funding to reduce unmet need for disability services and identification of any remaining shortfalls.*

The Australian Institute of Health and Welfare is leading the project study team, which also includes members of Alt Beatty Consulting (Sydney and Armidale). The final report is due to the National Disability Administrators in April 2002.

The attached questionnaire contains a range of questions about the Commonwealth contribution toward Commonwealth/State Disability Agreement funding in recent years, including 'unmet needs' funding, as well as questions about Commonwealth initiatives designed to effectively manage demand for services. The questionnaire contains similar questions to those asked of all States and Territories (the notable exception being the detailed financial questions asked of States and Territories).

*As the study team is required to prepare a progress report in February 2002 and the final report by April 2002, it is essential that responses to this questionnaire are received by the project team no later than **7 February 2002**. Please send your response by e-mail to louise.york@aihw.gov.au or by mail to Louise York, AIHW, GPO Box 570, Canberra, ACT, 2601.*

Please contact Louise York on 6244 1187 or me on 6244 1189 if you have any queries or expect to have any difficulty meeting the deadline.

We look forward to working with you to gather and analyse this important information.

Ros Madden
Head, Disability Services Unit

24 January 2001

Questionnaire to the Commonwealth to inform the CSDA ‘Needs Study’

This study has been commissioned by the National Disability Administrators, to be completed in April 2002.

The objectives of the project are to:

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

The outcomes of the project will inform discussion and negotiations regarding the third Commonwealth/State Disability Agreement (CSDA).

The full title of the study is: *The effectiveness of existing funding to reduce unmet need for disability services and identification of any remaining shortfalls.*

The study team will use a range of methods to gather information to meet the project objectives, including data analysis, literature reviews and discussions with peak bodies.

A similar questionnaire seeks information from all States and Territories. The information received from all jurisdictions will be of key importance to the study.

CONTACT DETAILS

Who is the key contact person within your jurisdiction in relation to this request for information?

Name

Position/title

Phone number

Fax number

E-mail address

QUESTIONS

- Section 1 asks you to attach some general information about the way your jurisdiction has approached the unmet need funding and related policies.
- Section 2 asks about trends in Commonwealth funding, contractual arrangements and cost factors.
- Section 3 seeks information to assist in evaluating the effectiveness of the new funding provided under the unmet needs funding arrangements.
- Section 4 asks you to provide information about areas of unmet need that have not yet been fully addressed and any plans that are in train to address those needs in the future.
- Section 5 allows you to provide any other information that may assist the project team.

1. 'New money': objectives and use of the 2000–01 unmet needs funding

The Commonwealth has already provided the AIHW with copies of the bilateral agreements signed with each State/Territory. In this question, we are seeking any additional information that may be relevant to the project.

- 1.1 *In 2000–01, the Commonwealth provided \$50 million to meet unmet needs for disability services (focussed on support of people with a disability with ageing carers) and the States and Territories provided a total of \$160 million to meet unmet needs, within their own priorities. State/Territory departments have been asked to explain their strategy for allocating unmet needs funding to certain service types or client groups.*

What were the policy processes used for selecting service provision for people with disability with ageing carers as a Commonwealth priority for funding? Please provide:

- (a) details of your funding objectives (including the source of statements); and
- (b) your 2000–01 annual reports with passages on your objectives flagged and/or any other materials on those objectives.

- 1.2 How does this funding relate to other Commonwealth programs for carers?

2. Other Commonwealth funding

Information about the levels of funding for all service types in recent years is being requested from jurisdictions to provide context about the environment within which the new 'unmet needs' funding has been used. Remaining questions are seeking information about the way funding has recently been spent on CSDA service types for which the Commonwealth is responsible.

- 2.1 Please provide copies of recent annual financial statements or other reports that identify expenditure levels in recent years, preferably by
- service type (e.g., open employment, supported employment, open/supported employment, other services);
 - State and Territory of location of the service;
 - numbers of clients (full-years totals and snapshot totals).

2.2 For this funding, please explain your:

- (a) contract arrangements;
- (b) costing models; and
- (c) accountability arrangements.

This is particularly relevant if new funding has been distributed.

2.3 Are there any special features of your jurisdiction that should be considered in understanding cost differentials between Commonwealth and State/Territory jurisdictions, for instance:

- higher costs;
- lower current provision levels;
- varying service types characteristics (e.g., staffing levels)
- the balance between the use of Government versus non-Government service providers;
- demographic issues (e.g., age structure, geographic distribution and ethnic make-up of the population);
- changes in multiple service usage by clients;
- other factors that might influence the cost of delivering services.

Please describe and provide any supporting material.

3. 'New money': Effectiveness and costs of services

The Commonwealth has provided copies of the 2000 bilateral agreements signed with each State/Territory as well as the most recent reports it has received from States and Territories about the use of Commonwealth funds.

In this question, we are seeking any additional information that may be relevant to the project. These questions have also been asked of the States and Territories.

- 3.1 Please describe any specific innovative projects undertaken as a result of the Commonwealth contribution of \$50 million (e.g., new services hoped to be particularly effective based on literature or policy directions).
- 3.2 Please provide copies of, or references to, any evaluations conducted of these – or similar – services. Such studies may include evaluations of new service types or services similar to those receiving new funding. Please include, or provide references to, any information about the impact on individuals of receiving support funded with the unmet need funds.
- 3.3 Do you have specific data on costs incurred in providing these services to:
 - rural and remote communities?
 - Indigenous Australians?

- people of diverse cultural or language backgrounds?

If yes, please provide details.

4. Possible remaining shortfalls and methods of managing 'need'

- 4.1 Please describe your strategies for managing 'need' in Commonwealth-funded service types.

e.g. What were the policy processes used for selecting service types in need?

e.g. Up-to-date information about the progress of, for example, the Case Based Funding Trial, Assessment and Contestability Trial.

e.g. Data about the interface between mainstream and other CSDA services with Commonwealth-funded CSDA employment services. (Note: The AIHW has not been able to access a copy of the 'Employment Interface' report or the data provided by the Commonwealth for that report. Any assistance you could provide (e.g., statistics about clients being referred back to Centrelink) would be appreciated.

- 4.2 Please provide a description of any coordinated registers of unmet need used in your jurisdiction, including:

- (a) criteria for inclusion in the registers;
- (b) criteria for prioritising in the registers
- (c) explanation of the items included in the registers;
- (d) analysis of the data in the registers.

Please provide as much detail as possible.

- 4.3 Please provide a description of processes you have in place, or require funded organisations to follow, for assessing and accepting new clients into different service types.

Please attach relevant supporting material if appropriate.

- 4.4 Please provide any other qualitative or quantitative information or data held by your jurisdiction about unmet needs for Commonwealth-funded disability services. This information may include information from:

- (a) peak bodies;
- (b) complaints;
- (c) submissions to ministers;
- (d) records of Hansard questions in Parliament, Parliamentary Committee discussions, etc.

In particular, please attach any analysis or any program thinking you may have done, which discusses or estimates the amount and type of remaining unmet need and how you would propose to meet these needs, should resources be available.

- 4.5 Please provide any information you hold about consultations with consumers addressing the issue of unmet need for Commonwealth-funded disability services.

- 4.6 Please provide copies of, or references to, any projects related to unmet needs for disability services, carried out in, or by, your jurisdiction, of which you are aware. Such studies may include assessments of unmet need.

5. Other issues

- 5.1 The relationship between Commonwealth-funded disability services and other support programs (for example, residential aged care, community care—including Home and Community Care (HACC), housing programs, etc) and the availability of informal care, impacts on the level of unmet need for disability support. Please comment on this relationship, including:
- (a) the interface between Commonwealth-funded disability services and other State/Territory-funded support programs;
 - (b) the interface between Commonwealth-funded disability services and the provision of suitable mainstream/generic services;
 - (c) the interface between Commonwealth-funded disability services and the availability of informal carers;
 - (d) what, if any, impact does the support of other programs have on the level of unmet need for Commonwealth-funded disability services; and
 - (e) processes, if any, in place to ensure that people with a disability and/or their carers get equitable access to the support of other programs.

Please provide any available supporting qualitative or quantitative material.

- 5.2 Please provide any other comments, which could assist the project team in costing unmet need and/or developing models for future funding.
This question relates to the NDA requirement for the project team to formulate recommendations regarding appropriate costing models/approaches to assist in determining the costs of any remaining unmet need for disability services.

Thank you for providing this information.

Appendix 2c: Jurisdiction staff

Jurisdiction	Project contacts
New South Wales	
Department of Ageing and Disability	Simon Watts Susan Krimmer
Victoria	
Department of Human Services	Chris Allen Glenn Foard
Queensland	
Disability Services Queensland	Clare O'Connor Alison Crisp Jodie Osborne
Western Australia	
Disability Services Commission	Charlie Rook Geoff Holloway Jenni Perkins Dana Bensky
South Australia	
Department of Human Services	David Caudrey Mike Griffiths Jo Perkins Segaran Murugeson
Tasmania	
Department of Health and Human Services	John Nehrmann
Australian Capital Territory	
Department of Health and Community Care	Ian Ross Tania Shaw
Northern Territory	
Aged and Disability Care Services	Damien Conley Eilish Kelly Helen O'Connell Leonie Warburton
Commonwealth	
Department of Family and Community Services	Cathy Ellis Rosemary Woldhuis Alan Landford Carl Princehorn

Appendix 3: Agenda and program for discussions on the need for CSDA disability services

Discussions organised through peaks were held in Canberra (26 February), Brisbane (5 March) and Melbourne (7 March). Background papers were provided.

The agenda focused on the two main objectives – effectiveness and unmet need. Participants were encouraged to raise any issues they wished, but also to consider both positive and negative aspects of both topics. Participants were offered a feedback sheet enabling them to send more detailed explanation or further examples to the study team, for a short time after the discussions. Notes were made of the discussions and sent back to participants for comment. These notes, once amended in line with comments received, were then used extensively in the report.

Agenda/program

Arrival and tea/coffee (9.45 a.m. to 10.00 a.m.)

1. Aims and overview of day, and introductions (10.00 a.m. to 10.20 a.m.)

Each participant introduces themselves briefly.

2. Overview of the study (10.20 a.m. to 10.35 a.m.)

Terms of reference, timing and the method being used (AIHW). The ‘new money’.

3. Questions and clarifications (10.35 a.m. to 10.50 a.m.)

4. Where has the new CSDA funding gone? What good has it done?

(10.50 a.m. to 12.30 p.m.)

Questions/issues for discussion:

- Service types, why chosen and their efficacy. ‘Good’, i.e., effective new service types.
- People receiving new services or funding: who and why chosen
- Processes: how was it done, who did it involve, etc.?
- Have the new initiatives for ageing carers been effective? In what way?
- Benefit/positive impacts for people who received services for the first time in 2000–01, or who had increases in service levels.
- Concerns about the use of money or ‘wrong’ priorities in who received new funding. Other impacts.

LUNCH 12.30 to 1.15 PM

5. Are there needs still not met and what is the evidence?

(1.15 p.m. to 2.30 p.m.)

Questions/issues for discussion:

- What types of needs may still be unmet?
- What people, if any, are missing out (includes current clients as well as people not currently receiving services)?
- What service types, if any, should be increased? What should be decreased? That is, should the service mix be changed?
- What is the evidence about any of this unmet need?
- What is the effect of any shortfalls?

6. Close

(2.30 p.m. to 3.00 p.m.)

Wrap-up and what next?

Participants

Canberra discussion session – 26 February 2002

Participants			
Fay Rice	Caucus/Head Injury Council of Australia	Kim Adams	Caucus/People First ACT
Dorothy Fox	Caucus	Kasy Chambers	ACOSS/YWCA
Alice Anne Macnaught	Carers Australia	Brian Corley	ACROD ACT
Ken Baker	ACROD National	Peter Bray	ACROD ACT
Margaret Spalding	ACROD/Koomarri Association ACT Inc.		
Study team members			
Ros Madden	AIHW	Phil Anderson	AIHW
Louise York	AIHW	Tim Beard	AIHW
Chrysanthe Psychogios	AIHW	Dianne Beatty	Alt Beatty Consulting
Xing-yan Wen	AIHW	Merilyn Alt	Alt Beatty Consulting

Brisbane discussion session – 5 March 2002

Participants			
Judy Young	Caucus/Parent to Parent Qld	Kellie Caught	Queensland Council of Carers
Lorella Piazzetta	Multicultural Development Association	Chris Allison	Queensland Council of Carers/Parent/Carer
Helen Palmer	Queensland Council of Carers (QCC)/Parent	John Skelton	Qld Alliance of Mental Illness & Psychiatric Disability Groups Inc./Association of Relatives and Families with Mental Illness Qld Inc.
Sue Waite	ACROD Qld division	Matt Carrodus	ACROD/Lifeline Community Care
Anne-Maree Maguire	ACROD/Work Venture Queensland	Garry Davison	Job Match Association Inc.
Peter Mewett	Queensland Unmet Needs Campaign/Paraplegic & Quadriplegic Association of Queensland	Penny Beeston	Parent–carer/Paraplegic & Quadriplegic Association of Queensland
Felicity Maddison	Parent–carer, QCC		
Study team members			
Ros Madden	AIHW	Dianne Beatty	Alt Beatty Consulting
Chrysanthe Psychogios	AIHW		

Melbourne discussion session – 7 March 2002

Participants

Christine Scott	Caucus/VALID	Bill Skinner	South Gippsland Carers Group
Laurell Hall	Carers Australia	Rachael Kenward	Carers Australia
Julie Nankervis	Carers Australia/Carers Victoria	Jill Cameron	Carers Australia/Carer Links West
Mel Warner	ACROD	Diana Heggie	ACROD
Marsha Sheridan	ACROD	Mark Feigan	ACOSS
Ian Spicer	NDAC/NIDN	Jean Tops	Gippsland Carers Association
Margaret Ryan	One Voice	Michael Gourlay	Association for Children with a Disability

Study team members

Ros Madden	AIHW	Merilyn Alt	Alt Beatty Consulting
Louise York	AIHW		
