

# **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**

**July 2002**

Australian Institute of Health and Welfare  
Canberra

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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<sup>(a)</sup> of effects of unmet need funding**

	People in 2000–01: Estimates based on CSDA MDS snapshot data adjusted for full-year ratios <sup>(b)</sup>	People in 2000–01: As reported in jurisdictional survey, equivalent to 35% of recurrent funding <sup>(c)</sup>	People in a full year of ongoing funding: Estimates based on jurisdictional forward estimates equivalent to 38% of recurrent funding <sup>(c)</sup>
<b>Accommodation &amp; respite</b>	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
<b>Community support services (including indiv. packages)</b>	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
<b>Community access</b>	2,425	1,315	2,536
<b>Other</b>	(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**

	<b>Estimate of unmet need</b>	<b>Description of group</b>
<b>Accommodation and respite</b>	12,500 people	<p>People needing assistance at least 3–5 times per day with one ADL<sup>(a)</sup> 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.</p> <p><i>Confirmed by:</i> Numbers of people on State registers in three jurisdictions</p>
<b>Community access<sup>(b)</sup></b>	8,200 places	<p>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.</p> <p><i>Confirmed by:</i> Numbers of people on State registers in three jurisdictions</p>
<b>Employment support<sup>(b,c)</sup></b>	5,400 people	<p>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</p> <p>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.</p>

(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.

