

8 Study conclusions

8.1 Accommodation and respite services

The estimates presented in Chapter 5 suggest that there is substantial unmet demand for accommodation support and respite services. The estimate of 23,800 people with unmet demand for accommodation and respite services in 2005 is 11,300 more than the 2001 estimate of 12,500.

Factors that may have contributed to the apparent increase in unmet demand since the previous study include:

- an increase in the size of the population with a severe or profound core activity limitation
- increased levels of need for assistance, due to ageing of the CSTDA service-user population and ageing of their carers
- reduced access to some mainstream housing options of particular relevance to people with disabilities, particularly public housing and boarding houses
- the ongoing trend towards community-based living arrangements for people with disabilities – the continued shift to community-based living (both people moving out of cared accommodation and people not entering cared accommodation who previously would have) may be expected to increase estimated unmet demand due to an increase in demand for community-based accommodation support and respite, and inclusion of a level of unmet demand previously ‘hidden’ due to the fact that survey-based estimates of unmet demand assume that people living in cared accommodation have no unmet demand.

The estimate of unmet demand for accommodation support and respite services includes people with under-met demand – that is, people who are receiving some formal help with core activities, but who still have unmet need (see Figure 5.1). There are various indications that under-met demand may constitute a substantial part of the estimated unmet demand:

- Western Australian jurisdiction data indicate that applicants with ‘partially met need’ substantially outnumber those with ‘unmet need’.
- In the 2003 survey, more than half of the primary carers with unmet demand for respite reported that they had received respite but needed more.
- HACC data suggest that, while numbers of younger people accessing HACC services over recent years has increased, the amount of service they receive (average hours) has fallen.

It is important to note that many of the estimated 23,800 people with unmet demand for accommodation support and respite services may require both these service types. Neither the population survey data nor the jurisdiction-level waiting list data currently available can support the separate quantification of unmet demand for these two service types.

It is likely that demand for accommodation and respite services will continue to increase over coming years. In particular, the broad CSTDA target population is projected to grow substantially – the number of people aged 0–64 years with severe or profound core activity

limitations is projected to increase by 34,600 people (4.8%) between 2006 and 2010. In addition, increases over the 1990s in the prevalence of some long-term health conditions particularly related to disability may result in further increases in the size of the target population for CSTDA services. Also, the ratio of informal carers to people with a disability is projected to fall over coming years.

Anecdotally, there are suggestions that barriers to accessing services funded under the aged care sector for people ageing with early onset disability increase pressure on CSTDA services and make it difficult for people with a disability to access complementary combinations of services to support them as they age. Ageing of the general population and of the population with a disability will place increasing pressure on services at the disability-aged care interface in future years. There is clearly a need for ongoing development of innovative approaches to service delivery and funding arrangements at this interface, and for the development of better data on patterns of service use across the two sectors.

Projections show that a decline in the willingness of people to take on informal caring roles could have a substantial negative effect on the future supply of informal care, resulting in increased demand for formal services. Accommodation and respite services are crucial in providing support for carers and enabling them to continue in the caring role.

8.2 Community access services

The estimate of 3,700 people with unmet demand for community access services in 2005 is a decrease of around 4,500 compared with the 2001 estimate of 8,200 people. As explained in section 5.5, this estimate focuses on unmet demand for regular services that meet people's ongoing need for meaningful day activities, rather than more irregular recreation/holiday activities.

This apparent reduction in unmet demand is despite an increase between 1998 and 2003 of 25,300 people aged 15–64 years with severe or profound core activity limitations who were not in the labour force. The decrease in unmet demand may be partly explained by increased supply of community access services. Although CSTDA NMDS data cannot be used to look at changes in numbers of service users over the full period, disability survey data suggest an increase in supply between the 1998 and 2003 surveys (that is, an increase of 9,100 people who reported attending day activities among those who could not work or who had other reasons for not being in the labour force).

This unmet demand estimate may be regarded as conservative because:

- in adjusting the estimate for changes in service supply between 2003–04 and 2004–05, recreation/holiday programs were excluded (their inclusion would have resulted in an estimate of 9,400, rather than 3,700); and
- unlike the estimate of unmet demand for accommodation support and respite services, this estimate does not include under-met demand – only people who reported that they did not currently attend a day activity were included (see Figure 5.2).

In coming years, demand for community access services may be expected to increase, due to growth of the CSTDA target population. However, levels of demand for these services are also likely to be affected by recent changes in policy and programs relating to disability employment services. If the effect of these changes is that more people with disabilities move into the labour force, and that more disability employment service places are available

to assist them in finding and keeping work, then demand for community access services may be reduced.

The ageing of the CSTDA target population may tend to increase demand for day activity programs that meet the needs of older people who 'retire' from disability employment services. Comparison of 1998 and 2003 disability survey data showed substantial decreases in numbers of people aged over 50 years with severe or profound core activity limitations who were employed (Table 5.7).

8.3 Employment services

The 2005 estimate suggests a low level of unmet demand for disability employment services, and a substantial decrease from the estimate of 5,400 people with unmet demand in 2001.

This decrease may be partly due to the decrease between 1998 and 2003 in numbers of people with a severe or profound core activity limitation who were in the labour force (Table 5.6). A possible increase in the supply of day activity services over the period, as suggested by the survey data, may also have contributed. No data are available to show changes in the supply of disability employment services over the period, so it is not possible to say whether this may also have been a factor.

This unmet demand estimate may be regarded as conservative because:

- people who report being unemployed but who attend a day activity are excluded; and
- some proportion of the 134,300 people with severe or profound core activity limitations who were employed may have unmet demand for assistance from a disability employment service to help them maintain their employment.

Recent disability employment policy and program changes are not reflected in the available data used as a basis for the 2005 estimate. The recent increase in service places reported by the Australian Government (see Section 4.2) could potentially further decrease unmet demand in future. However, as some of the policy changes are aimed at encouraging people with disabilities to move into the labour market, demand for disability employment services is likely to increase.

The lack of administrative data on unmet demand for employment services means that there is no way to check the disability survey-based estimate of unmet demand in 2005; this lack of data will also be an impediment to assessing the future effects of the new disability employment programs.

8.4 Broader data issues

The estimates of unmet demand presented in this report are based mainly on the national disability survey. While this is a rich data source, it does not directly provide information on unmet demand for specific CSTDA service types; unmet demand must be implied, based on a mosaic of relevant information supplied by survey respondents. It should also be remembered that estimates of unmet demand based on the survey data do not include several important population groups – in particular, people living in cared accommodation, people living in remote and sparsely populated areas, people who are homeless, and people who are in prison.

The CSTDA NMDS is a valuable source of detailed and nationally consistent data concerning the supply of disability services. It provides no information on demand or

unmet demand, and currently there is no nationally consistent source of such data. Available jurisdiction data on numbers of people waiting for services do not provide a solid basis for validating or confirming the estimates of unmet demand based on survey data. As discussed in Chapters 4 and 5, jurisdiction data are incomplete, inconsistent and subject to various data issues and limitations.

Ideally, jurisdiction administrative data on unmet demand should:

- identify unmet demand in a way that can be related to CSTDA service types
- where appropriate and possible, also include some indication of the quantity of service needed
- distinguish between unmet and under-met demand, by separately identifying those applicants not currently receiving any disability service of the type needed
- include measures of turnover and/or waiting times for specific services
- include relevant information about applicants (for example, demographic data, presence of a carer, factors relevant to assessing priority)
- be comparable across jurisdictions.

The final chapter of the 2002 unmet needs study included a section on 'further developing the jurisdictional registers', which provided some suggestions on ways to improve data on unmet demand. To achieve comparable jurisdictional data on unmet demand of a quality that could be used to inform a national picture of unmet demand for CSTDA-funded services would be a major undertaking. It would involve jurisdictions agreeing on key data items and their definitions, and may require some jurisdictions to make modifications to their methods of managing demand. While the nationally agreed data items that constitute the CSTDA NMDS would provide a strong starting point for developing a minimum data set on unmet demand, some additional data items would probably be required.

Inclusion of the linkage key in any agreed unmet need minimum data set would be of great value. Not only could it be used to reduce double counting of applicants, it could also be used to help distinguish unmet from partially met demand, by separately identifying applicants who are and are not receiving CSTDA services.

In addition to informing national studies such as this one, other benefits of improving the data available from jurisdiction registers (as noted in the 2002 report) could include:

- making the outcomes of application processes more publicly transparent
- informing longer term policy and funding strategies (if registers included information on individuals' expected future needs for support, as well as their current needs)
- providing a better information base for jurisdiction-level service planning.

There is also a need for better information about service interfaces, including interfaces between CSTDA services types, especially between disability employment services and state and territory managed services. As discussed in Chapter 7 of this report, influences operating at the interfaces between service sectors and service programs have the potential to substantially affect levels of demand for CSTDA services.