

# **7 Demand for specialist disability services—interfaces, influences and perspectives**

## **7.1 Introduction**

This chapter presents information on service interfaces and other issues that have the potential to influence demand for CSTDA disability services. This information is intended to provide a broader context within which the data presented in earlier chapters, including estimates of unmet demand, can be interpreted.

Section 7.2 discusses interfaces between disability services and other service systems where there are boundary issues that may affect levels of demand for CSTDA services.

Section 7.3 looks at how projected population change, trends in health conditions that have particularly strong associations with disability prevalence, and the future supply of informal care may affect levels of demand for CSTDA services.

Section 7.4 presents a summary of views from the disability field concerning unmet demand and associated issues. Main sources of information are a disability peaks discussion session held at the AIHW to inform the current demand study, and submissions made to the Senate Community Affairs Committee inquiry into the funding and operation of the CSTDA.

## **7.2 Interfaces between disability services and other service systems**

People with disabilities, like the broader population, use a range of government-funded and provided services to meet a range of needs. The primary role of disability services is to enable people with disabilities to participate in society by meeting their disability-related needs. It is widely agreed that disability services should not necessarily replace generic or other specialist services available to the wider community, or be expected to meet all the needs of people with disability. Nonetheless, which service program should most appropriately carry responsibility for meeting particular needs is rarely clear and, in many cases, cooperation and collaboration between CSTDA and other service programs may offer the best way to meet the needs of people with disability, both in terms of efficiency and quality of outcome for the person.

Levels of access to generic services, such as health, housing and aged care services, can affect levels of demand for CSTDA services, and vice versa. Barriers to accessing generic services can increase pressure on CSTDA services. One jurisdiction, in its response to the demand study questionnaire, commented that ‘increasingly, CSTDA funding is being directed to provide services which were once available to all members of the community’. In the 2002–2007 CSTDA, Australian, state and territory governments agreed on the incremental implementation of five strategic policy priorities, the first of which is to

‘strengthen access to generic services for people with disabilities’. CSTDA Annual Public Reports outline the many initiatives pursued by different governments to make progress on this strategic priority (see, for example, NDA 2006).

While the main focus of this section is on interfaces between CSTDA services and other service programs, interfaces between CSTDA service types are also important. In some cases, service users may substitute one service type for another, depending on relative availability and accessibility. For example, a Disability Advisory Council report on day options in South Australia identified that insufficient day options funding impacts on demand for services such as respite and full-time accommodation.

There are also interface issues associated with the split of responsibility for services relevant to people with disabilities between levels of government, both within the CSTDA and between CSTDA and other service programs. Concerns are frequently expressed about the difficulties faced by people who seek to access complementary services funded or provided by different levels of government (for example, community access services and employment services, or CSTDA accommodation support services and HACC services). Problems include the burden of having to go through multiple assessment and eligibility processes, and having access to one program restricted because of receiving support from another program (see Table A7.3).

Under the 2002–2007 CSTDA, bilateral agreements may be made between governments, to complement the main multilateral agreement. The aim of these bilateral agreements is to foster collaboration between the Australian Government and individual states/territories on strategic disability issues, help to break down barriers between programs and services funded by different levels of government, and improve service access and coordination. Nonetheless, the frequency with which inter-government interface issues are raised as concerns by service user and service provider peak organisations, and government departments and agencies, suggests more work is needed in this area.

Below, interfaces between CSTDA services and the program areas of aged care, employment and housing are considered in some detail; interface issues relating to other non-CSTDA or generic services are also raised briefly.

## **Interface with aged care services**

Traditionally, aged care services and disability services are funded through different government departments, and different levels of government. Although both sectors provide some similar services, there are also some services that do not overlap between sectors; for example, aged care services have a greater focus on the provision of health services such as nursing and allied health, which is not mirrored in CSTDA services. Thus, people may need complementary combinations of support from both sectors.

The interface between the disability and aged care sectors is of particular pertinence for people ageing with early onset disability. For these people the ageing process often begins at earlier ages than for the general population, and they are likely to have both ageing-related and disability-related needs. CSTDA data show that there is considerable variation between jurisdictions in the size of this group as a proportion of all CSTDA service users (Figure 3.3, Table A3.3). For example, in 2004–05 the proportion of CSTDA service users aged 45 years and over was 39% in South Australia and 33% in Western Australia, compared with 28% across all jurisdictions. This variation may reflect a combination of factors, including demographic differences, different service mixes (for example, large service agencies

offering services targeted at particular age groups), and also possibly variation in levels of access to other services that meet the needs of people ageing with a disability.

Anecdotally, disability service user and service provider peak organisations report that people with a disability often experience barriers at the point of assessment and in the allocation of places in both residential and community-based aged care services. There is also a perception that many aged care service providers lack the relevant skills to meet the needs of people ageing with an early onset disability (see Table A7.3).

There are also interface issues for younger people with disabilities, both in terms of their ability to appropriately access services funded under the aged care sector, and their possible inappropriate placement in residential aged care in the absence of more age-appropriate accommodation and support.

The Home and Community Care (HACC) program is jointly funded by the Australian Government and all the states and territories. Administration of the program at the Australian Government level is through the Department of Health and Ageing. HACC provides maintenance and support services to enhance the independence of frail older people and younger people with disabilities and to avoid their premature admission to long-term residential care (Commonwealth of Australia 2002). While the HACC national guidelines state that the HACC program generally does not provide services to recipients of disability accommodation support services, younger people with disabilities may seek to access complementary combinations of support from the CSTDA and HACC programs (for example, respite services from CSTDA and home modification and allied health care from HACC).

In practice, HACC eligibility requirements and prioritising practices on the ground vary between regions and, in some areas, the extent to which younger people with disabilities can access both HACC and CSTDA services is limited. This has been raised repeatedly as an issue of concern in discussions with consumer and industry peak organisations to inform successive demand studies, in the 2006 demand study questionnaire responses of some jurisdictions, and in many submissions to the current Senate inquiry.

In 2004–05 there were 182,408 HACC clients aged under 65 years, including 56,489 who were aged under 40 years (Table 7.1). Clients aged under 65 years increased as a proportion of all HACC clients between 2002–03 and 2004–05, from 23.3% to 24.5%. This was mainly due to an increase in the proportion of clients aged between 55 and 65 years. The number of clients aged under 40 years increased by more than 8,221 over this 2-year period, although as a proportion this group remained at just over 7% of all HACC clients. The average number of service hours received was higher for clients aged under 65 years than for those aged 65 years and over<sup>6</sup>. However, average hours decreased for clients aged under 65 years, from 63.6 in 2002–03 to 57.6 in 2004–05, while remaining stable at just over 45 hours for older clients; the decrease in average hours was particularly marked for clients aged under 40 years – from 74.8 to 62.8 hours.

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<sup>6</sup> Amounts of HACC services received by a client are measured in two different ways. Hours of service received is recorded for some service types, such as domestic assistance and personal care. A unit-based measure is used for recording service types such as the number of meals, number of transport trips, numbers of aids and equipment items provided. While clients aged under 65 years received a higher average number of service hours than clients aged 65 years and over, this does not capture the full service profile of clients. Compared with clients aged under 65 years, a greater proportion of those aged 65 years and over received services for which a unit-based measure is used.

**Table 7.1: HACC clients: clients and average hours received, by age,<sup>(a)</sup> 2001–05**

Age group (years)	2001–2002 <sup>(b)</sup>	2002–2003	2003–2004	2004–2005
<b>Number of clients</b>				
0–39	43,161	48,268	52,823	56,489
40–49	24,667	28,165	32,051	34,489
50–54	17,034	19,407	21,775	22,177
55–59	20,218	24,279	27,324	30,594
60–65	28,391	33,101	36,101	38,659
<i>Total under 65</i>	<i>133,471</i>	<i>153,220</i>	<i>170,074</i>	<i>182,408</i>
65+	449,711	504,046	537,133	561,789
<b>All clients</b>	<b>583,182</b>	<b>657,266</b>	<b>707,207</b>	<b>744,197</b>
<b>Percentage of clients (%)<sup>(c)</sup></b>				
0–39	7.4	7.3	7.5	7.6
40–49	4.2	4.3	4.5	4.6
50–54	2.9	3.0	3.1	3.0
55–59	3.5	3.7	3.9	4.1
60–64	4.9	5.0	5.1	5.2
<i>Total under 65</i>	<i>22.9</i>	<i>23.3</i>	<i>24.0</i>	<i>24.5</i>
65+ <sup>(a)</sup>	77.1	76.7	76.0	75.5
<b>All clients<sup>(a)</sup></b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>
<b>Average hours received<sup>(d)</sup></b>				
0–39	75.2	74.8	70.5	62.8
40–49	71.9	72.3	68.9	63.7
50–54	61.5	59.0	61.1	58.6
55–59	55.6	55.3	55.3	54.4
60–64	47.7	47.7	48.1	46.4
<i>Total under 65</i>	<i>64.2</i>	<i>63.6</i>	<i>61.9</i>	<i>57.6</i>
65+	45.0	45.2	45.7	45.3
<b>All clients</b>	<b>49.6</b>	<b>49.6</b>	<b>49.8</b>	<b>48.6</b>

(a) Clients with missing age are included in 65+ totals, and 'all clients'. Only clients with recorded assistance are included in this table.

(b) The Home and Community Care (HACC) program National Minimum Data Set (NMDS) collection commenced in January 2001. The 2001–02 data were the first data extraction and should therefore be interpreted with caution.

(c) Client numbers include all clients who received assistance, although around 10–13% of clients (2001–02=73,600; 2002–03=73,900; 2003–04=79,200; 2004–05=80,000) only received assistance which is not measured in hours of service (that is, home modification, receipt of goods and equipment, meals, transport and linen deliveries).

(d) Amount of service measured in hours is averaged only over HACC clients receiving services measured in hours.

Source: AIHW analysis of the HACC NMDS.

HACC clients aged under 65 years, and particularly those aged under 40 years, are likely to be candidates for CSTDA services, and may indeed be accessing both CSTDA and HACC services. Data on patterns of concurrent CSTDA and HACC service use would be helpful in understanding this service interface better. The common linkage key in the HACC and CSTDA national data collections could be used to conduct such analysis.

Residential aged care services are generally viewed as inappropriate for younger people with disabilities, mostly on the basis that they are unlikely to be able to provide age-appropriate supports. However, there continue to be some younger people with disabilities accommodated in residential aged care facilities, both for permanent and for respite care. This situation may reflect unmet need for CSTDA accommodation support and respite services, as well as other service gaps (see below). Between 2001 and 2005 the number of people aged under 65 years living in residential aged care increased from 5,946 to 6,474, although the number aged under 40 years decreased from 303 to 242 (Table 7.2).

There have been recent efforts to address this issue through the COAG Helping Younger People with Disability in Residential Aged Care Program. Under this program, Australian and all state/territory governments are entering into bilateral agreements designed to support innovative strategies to move people out of this type of accommodation, divert future potential clients to more suitable accommodation, or provide additional, age-appropriate supports to people who remain in residential aged care.

The Aged Care Innovative Pool Disability Aged Care Interface Pilot, an initiative of the Australian Government Department of Health and Ageing that commenced in November 2003, trialled a new approach to providing aged care for people in the CSTDA target group. The initiative targeted people living in disability supported accommodation facilities at risk of entering residential aged care. It made available a limited pool of service places which delivered individually tailored aged care services to people in their current residential setting. An evaluation of the Pilot (AIHW: Hales et al. 2006) found that the benefits of this approach include assisting people to age in place and avoid or delay entry into residential aged care, improving the quality of life of participants as a result of receiving community-based aged care, and helping to identify factors that contribute to premature entry into residential aged care.

The evaluation found that unmet need identified among pilot clients tended to fall into two main areas: the need for specialist disability services, such as community access services, to be adapted following retirement from work, and increased need for personal care and therapy services due to the impact of ageing processes. The evaluation pointed to two further issues contributing to early admission to residential aged care: service gaps (such as lack of access to 24-hour care in supported accommodation, additional personal assistance, and equipment and aids such as continence aids), and the difficulty experienced by disability sector staff in understanding and meeting the needs of people with disabilities who are ageing.

Although clients of the pilot phase of this initiative will continue to receive support, there are no signs that new clients will be accepted or that the pilot will be developed into an ongoing program. There has been strong support from peak bodies and some states for the continuation of this initiative.

Thus, at the interface between the disability and aged care service systems, there continue to be a number of important issues concerning both demand for services and outcomes for individuals. Ageing of the general population, and of the population with a disability, is likely to increase demand for services to support both disability and ageing needs in future.

**Table 7.2: Permanent residents in aged care homes, by age, 2001–05**

Age group (years)	2001	2002	2003	2004	2005
<b>Number</b>					
<b>Persons</b>					
Under 40	303	286	273	239	242
40–44	281	297	276	268	265
45–49	508	494	456	487	511
50–54	997	950	976	974	989
55–59	1,433	1,551	1,585	1,680	1,751
60–64	2,424	2,411	2,511	2,596	2,716
<i>Total under 65</i>	<i>5,946</i>	<i>5,989</i>	<i>6,077</i>	<i>6,244</i>	<i>6,474</i>
65+	128,045	130,505	134,213	138,743	142,595
<b>Total persons</b>	<b>133,991</b>	<b>136,494</b>	<b>140,290</b>	<b>144,987</b>	<b>149,069</b>
<b>Per cent</b>					
Under 40	0.2	0.2	0.2	0.2	0.2
40–44	0.2	0.2	0.2	0.2	0.2
45–49	0.4	0.4	0.3	0.3	0.3
50–54	0.7	0.7	0.7	0.7	0.7
55–59	1.1	1.1	1.1	1.2	1.2
60–64	1.8	1.8	1.8	1.8	1.8
<i>Total persons under 65</i>	<i>4.4</i>	<i>4.4</i>	<i>4.3</i>	<i>4.3</i>	<i>4.3</i>
65+	95.6	95.6	95.7	95.7	95.7
<b>Total persons</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>

Source: AIHW extracts from the latest refresh of Aged and Community Care Management Information System (ACCMIS) provided to the AIHW by the Department of Health and Ageing in September 2006. Figures may vary slightly from reports using earlier refreshes of ACCMIS.

## Interface with employment services

With regard to demand for CSTDA services, it is important to consider both interfaces between CSTDA-funded employment services, generic employment services, and other non-CSTDA service programs such as education and health, and interfaces between CSTDA-funded employment services and other CSTDA service types.

Where there is unmet demand for employment services, pressure may be placed on other service types. For instance, if people with a disability cannot access sufficient support to find or keep work they may leave the labour force, potentially increasing demand for community access services (as an alternative source of day-time activity) and respite and accommodation support services (where people require informal or formal assistance to remain at home during the day). Timely access to employment support is particularly important for school leavers, and for people with psychiatric disability exiting crisis care delivered through the health sector.

Likewise, inadequate access to other CSTDA and generic services may increase demand for employment services. For people ageing with a disability who want to retire from employment services, the retirement process may be hampered by lack of access to, for instance, appropriate day activities and attendant care.

As described in Chapter 4, CSTDA employment services are administered by the Australian Government under several different programs. Supported employment 'business services', tailored generally to a client group with high support needs, are administered by the Department of Families, Community Services and Indigenous Affairs (FaCSIA), while the Department of Employment and Workplace Relations (DEWR) administers open employment services for people able, with some support, to participate in the open labour market. DEWR also provides a range of non-disability-specific programs aimed at helping people find and keep work; people with disabilities may be referred to these programs where the services they provide are judged to meet their needs.

Some aspects of the programs under which CSTDA-funded employment services are now delivered are relatively new. There have also been other recent employment-related policy changes, such as changes to Disability Support Pension eligibility rules (see Box 7.1). It is too early to assess the impact of these program and policy changes. However, it is relevant to outline some issues and concerns regarding unmet demand and service interfaces relating to CSTDA-funded employment services, as raised by jurisdictions (in response to the questionnaire circulated to inform this project) and disability peak organisations (during the discussion session held at the AIHW, and in submissions to the Senate Community Affairs Committee inquiry into the funding and operation of the CSTDA).

As outlined in Chapter 4, the Australian Government believes that the programs introduced in July 2006 substantially increase the capacity of disability employment services (although data on unmet demand are not collected). These new programs may therefore be expected to take some pressure off other CSTDA service types.

Nonetheless, there remains a view among states, territories, and disability peak organisations that there is currently unmet demand for employment services. For instance:

- It is claimed that many disability employment services are operating at near-full capacity and cannot accommodate new referrals. Thus, for some school-leavers, the transition into employment services is delayed; young people, especially those with intellectual disabilities, can rapidly lose skills and confidence without timely post-school support.
- There are concerns that, for people with high support needs, access to employment services has been reduced as a result of reforms initiated in the late 1990s. These reforms required organisations operating Business Services to be certified against the Disability Employment Standards, which includes offering workers competitive employment conditions. There is a view that this locks some people out of Business Services because their productivity is insufficient to contribute to commercial outcomes; this, in turn, increases demand for day activities.

On the other side of the interface, the Australian Government claims that supported employment services are sometimes used inappropriately to cover shortfalls in day programs for clients who express a preference for non-vocational activities.

### **Box 7.1: Changes to Disability Support Pension eligibility**

*In July 2006, changes to Australian Government welfare policy were introduced with the aim of encouraging income support recipients, including people with disability, to enter the workforce. The changes included creating additional new places for people with disability in employment placement programs, and tightening eligibility criteria for the Disability Support Pension.*

*New Disability Support Pension (DSP) applicants who need to demonstrate a 'continuing inability to work' for eligibility purposes must have their capacity to work determined by a Job Capacity Assessor. Current DSP recipients whose cases are under review, and applicants for Newstart Allowance or other forms of income support who may face barriers to employment, also receive Job Capacity Assessments. Job Capacity Assessors advise Centrelink about a client's work capacity and can refer clients to a variety of service providers for interventions designed to enhance the client's work capacity.*

#### **Hours**

*Previously, clients who needed to demonstrate a 'continuing inability to work' for DSP eligibility purposes were eligible for DSP if their future work capacity within the next 2 years was less than 30 hours per week. From 1 July 2006, clients who are assessed as being unable, with assistance and training, to work at least 15 hours per week without support, within 2 years, may be eligible to receive DSP. Existing DSP clients whose cases are reviewed will be assessed against the 30 hours per week benchmark if they began receiving the pension before 11 May 2005, while clients who claimed DSP payments between 11 May 2005 and 1 July 2006 will be assessed against the 15 hours per week benchmark.*

#### **Training activities**

*From 1 July 2006, there were legislative changes to the definition of training activities that may be undertaken to enhance an individual's assessed work capacity – in addition to mainstream educational, vocational and on-the-job training, activities specially tailored to people with disabilities are now included.*

#### **Newstart Allowance (partial capacity to work) or Youth Allowance (partial capacity to work)**

*Clients who do not meet DSP eligibility criteria may instead qualify for another form of income support. The person may qualify for Newstart Allowance (partial capacity to work) or Youth Allowance (partial capacity to work) if he or she has a physical, intellectual or psychiatric impairment and is assessed by a Job Capacity Assessor as being unable to work or to be trained for work of at least 30 hours per week independently of support within the next 2 years. Recipients of Newstart Allowance (partial capacity to work) or Youth Allowance (partial capacity to work) are eligible for a Pensioner Concession Card, Pharmaceutical Allowance and Telephone Allowance. A client in receipt of Newstart Allowance (partial capacity to work) or Youth Allowance (partial capacity to work) will have their activity test requirements modified to take into account their assessed capacity.*

There are also concerns regarding barriers to people moving between community access services and employment services, or accessing a combination of employment and community access ('mixed options'). Individuals who choose to enter the labour force may not be guaranteed a return to community access support if they lose or are unable to find work; this may discourage people from seeking to enter the workforce. Many community access programs are only available to people with no work capacity, making development of mixed options packages difficult.

Many peak bodies and disability advocacy organisations have expressed concerns about the potential impacts of recent employment-related program and policy changes on people with disabilities (see Table A7.3). For example:

- There are concerns that people who are referred to generic employment services may not have their employment support needs adequately met, because these services are not properly equipped to meet the specific needs of people with disabilities. This could result in a level of hidden unmet need.<sup>7</sup>
- There is a view in the disability sector that greater pressure may be placed on carers and personal care services to assist people with disabilities undertaking work in the open market, or meeting job seeking obligations while on income support.
- A person may be judged ineligible for the DSP because they are assessed to be able to work at least 15 hours per week with assistance/training, even where relevant assistance/training is not available to the person in practice.
- There is a concern that people who would previously have received the DSP, but do not meet the new eligibility criteria, may face greater financial hardship while they look for work, due to lower payment rates, stricter income and assets tests, and higher effective marginal tax rates applied to Newstart Allowance. Financial stress may place more pressure on people with disabilities and their carers, and impact on their ability to privately purchase equipment and services. This may, in turn, increase demand for CSTDA services.

Data that would enable assessment or exploration of these claims and concerns are not currently available.

## **Interface with housing services**

Interfaces between CSTDA and housing services exist because of the need for people with disabilities to access appropriate, community-based housing options. Many people with disabilities depend on being able to access relevant support services, such as those provided under the CSTDA, in order to achieve housing stability in community-based housing options.

Broad-scale deinstitutionalisation through the 1980s and 1990s and, more recently, criticism of disability group homes as an appropriate accommodation model, has meant increased demand for appropriate community-based accommodation and associated support services. Barriers to access to mainstream housing options such as private rental accommodation, public housing, and boarding houses will tend to increase demand pressure on CSTDA accommodation support and respite services.

Public housing is of particular relevance to people with disabilities, as a source of affordable, stable accommodation. The availability of public housing has decreased over recent years, with the number of public housing dwellings falling from around 359,000 in 2001 to around 341,500 in 2006 (AIHW 2005a, AIHW 2006b). People with disabilities face particular barriers to accessing public housing. For instance, public housing stock is sometimes inappropriate for people with disabilities, and generally there is no reduction of public housing rents paid by people with disabilities in recognition of the extra disability-related expenses they face (AIHW 2006c; SCRGSP 2006; Saunders 2006). Nonetheless, although people with disabilities are not specifically recognised as a priority group for quicker access to public housing,

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<sup>7</sup> The government's view is that the operation of the Job Capacity Assessment will ensure job seekers' needs are appropriately assessed and job seekers referred to the most appropriate employment streams.

households for which disability is identified as a special need are increasing as a proportion of all new households allocated public rental housing (Table 7.3).

**Table 7.3: New households allocated public rental housing: special needs status and whether disability identified as a special need, 2001–06**

	2001–2002	2002–2003	2003–2004	2004–2005	2005–2006
Disability identified as a special need	8,129	6,837	8,923	9,130	10,252
Total 'special needs'	15,466	15,518	16,131	15,527	16,482
Total households where special needs status is known	35,237	32,291	30,148	26,693	26,600
Total households allocated public housing	36,894	33,365	30,962	27,776	27,544
% of households allocated public housing with disability	22.0	20.5	28.8	32.8	37.2

*Notes*

1. Disability refers to the disability status of a household. A household is said to have a disability if one or more members has a disability.
2. 'Special needs' is Commonwealth State Housing Agreement (CSHA) performance indicator P5 Special needs in the CSHA public rental housing national data report. A household is said to have a special need if it satisfies certain criteria, one of the criteria is disability. Households may satisfy more than one criteria but are only counted once, ie. the sum of the households in each criterion may not total to the number of households with a special need.
3. See the respective year's CSHA national data reports, *Public rental housing*, for more information on data definitions, quality and exclusions.

Source: AIHW analysis of National Housing Data Agreement NMDS.

Boarding houses are often used by people with disabilities as an affordable housing option; some boarding houses also provide services such as meals. However, concerns about their quality, the introduction of the GST, and the retirement of older proprietors have placed pressure on the sector, and numbers of boarding houses are decreasing (Greenhalgh et al. 2004; Anderson et al. 2003). Various strategies have been used by governments to slow the decline in boarding house numbers, including building public accommodation based on boarding house models.

The Supported Accommodation and Assistance Program (SAAP) provides services to people who are homeless or at risk of homelessness. While national data on people who use SAAP services do not specifically identify people with a disability, between 2000 and 2005 people reporting disability-related income sources consistently accounted for just over one-fifth of SAAP support periods. The majority of these support periods were provided to people receiving a Disability Support Pension (19.6% in 2004–05) (Table 7.4). In 2005, 706,782 people received a Disability Support Pension from the estimated resident adult population of 16,350,400 (DEWR 2005; ABS 2005a). Therefore, the proportion of people in the general adult population receiving a DSP was 4.3%.

Although people with a disability tend to be over-represented among SAAP service users, many SAAP services are not tailored to meet the needs of people with disabilities. For example, there is a lack of appropriately modified SAAP dwellings, and some services cannot accommodate clients with behavioural issues (NSW Ombudsman 2004). Compared with other SAAP clients, SAAP clients with a disability are more likely to live alone rather than with family and friends when they leave SAAP accommodation (AIHW 2005c).

**Table 7.4: SAAP support periods, by main income source, 2000–01 to 2004–05 (per cent)**

	2000–2001	2001–2002	2002–2003	2003–2004	2004–2005
Disability Support Pension	17.9	18.9	18.7	20.7	19.6
Department of Veterans' Affairs disability pension	0.8	0.7	0.5	0.6	0.4
Sickness Allowance	1.7	1.4	1.1	0.9	0.6
Workcover/compensation	0.2	0.1	0.2	0.2	0.2
<i>Total disability related income sources</i>	20.6	21.1	20.4	22.5	20.8
All other income sources	79.4	78.9	79.6	77.5	79.2
<b>Total number</b>	<b>170,200</b>	<b>176,200</b>	<b>175,600</b>	<b>186,500</b>	<b>172,500</b>

Source: SAAP National Data Collection.

The combined influences of the ongoing trend away from institutional and group home models of accommodation for people with disabilities, reductions in public housing stock and boarding house beds, and increasing costs of private rental accommodation (ABS 2006a) are likely to increase demand for CSTDA community-based accommodation support services in the future. Also, as people who are homeless are not included in the ABS disability survey, there is likely to be a level of masked unmet need for CSTDA accommodation support services.

## Other non-CSTDA or generic services

While this report does not attempt to present a comprehensive discussion of the full range of service interfaces that are likely to affect demand for CSTDA services, some examples of other important service interfaces are mentioned briefly below. Except where otherwise indicated, this material is sourced mainly from the disability peaks discussion session held at the AIHW to inform the current demand study, submissions made to the Senate Community Affairs Committee inquiry into the funding and operation of the CSTDA, and jurisdiction responses to the demand study questionnaire.

### Health services

Where timely access to essential health services is limited through the public health system (for example, neuropsychological assessments for people with acquired brain injury), CSTDA funding may be used to provide these services. Lack of accommodation and support for people with disability can put pressure on health services, for example, people may remain in hospital for extended periods because no appropriate accommodation is available. Inadequate links between health and disability services can mean people exiting health services are not referred to appropriate community-based support services; this is a particular issue for people with psychiatric disability.

### Education services

In some cases, mainstream education policies do not accommodate the needs of children with disabilities and their families. For example, expulsion or suspension of children with behavioural issues related to their disability can make it difficult for parents to maintain employment; this can translate into unmet need for CSTDA services such as respite.

Similarly, insufficient funding for teachers' aides may mean that children with disabilities are not able to attend school for the full school week, affecting their educational and social outcomes, as well as the potential for their parents to participate in the labour force.

## **Equipment**

Access to appropriate equipment is crucial in enabling many people with disabilities to maintain levels of independence and participation. Unmet need for equipment can result in increased demand for CSTDA support services. The fragmentation and complexity of existing equipment schemes, and temporal fluctuation in equipment funding, has long been identified as a problem, and has led to calls from the disability field for a unified national equipment scheme (see, for example, AIHW 2006e).

## **Criminal justice**

People with disabilities tend to be over-represented in the prison population and, as a group, are particularly vulnerable to abuse while in prison. This over-representation can be seen both as indicating a level of hidden demand for disability support services (that is, many people with disabilities in prisons would be more appropriately accommodated in the community with necessary supports) and the result of unmet demand for appropriate services (that is, where contact with the criminal justice system could have been avoided).

## **Transport services**

The interface between transport services and CSTDA services was an issue raised particularly strongly during disability peak organisation consultations for the previous AIHW unmet need study – 'transport is essential in being able to access employment and day activities, yet transport support appears to be shrinking' (AIHW 2002). Restricted access for people with disabilities to mainstream public transport, and transport funded under other programs such as HACC, places pressure on the CSTDA and/or on people with disabilities themselves to locate and pay for appropriate transport services. There have been anecdotal reports of CSTDA flexible respite funding being used to pay for transport assistance.

## 7.3 Other influences on demand for CSTDA services

### Population change

This section focuses on the possible effects of population growth on demand for disability services.

#### Projected growth in population and severe or profound core activity limitations

As discussed in Chapter 6, in addition to the growth of the overall size of the population, three particular aspects of the population trends are likely to impact on disability prevalence and demand for services:

- the increase in life expectancy of the population
- the rapid pace of ageing of the working-age population (15–64 years)
- the ageing of the aged population.

Life expectancy of Australians has increased markedly over the last century. Gains in life expectancy were accompanied by an increase in expected years of life both with and without disability or a severe or profound core activity limitation (AIHW 2006d). In 2003, males could expect, on average, to experience 18.6 years of life with disability (5.4 of which are expected years of life lived with a severe or profound core activity limitation). Females could expect, on average, to experience 20.7 years of life lived with disability (8.3 years with a severe or profound core activity limitation).

Recent trends (1998–2003) showed that, for older males, 67% of gains in life expectancy at age 65 years (1.5 years over that period) were years with disability (1 year) and 27% were years with a severe or profound core activity limitation (0.4 year). For older females, over 90% of their gains in life expectancy at age 65 years (1.2 years) were years with disability (1.1 years), and about 58% were years with a severe or profound core activity limitation (0.7 year) (AIHW 2006d).

Projected changes in the number of people with a severe or profound core activity limitation provide a broad indicator of future demand for disability services. Between 2006 and 2010, the broad CSTDA target population of people aged 0–64 years with severe or profound core activity limitations is projected to increase to 752,100 people (an increase of 34,600 people, or 4.8%) (Table 6.1). The projected growth in the working-age population (15–64 years) with a severe or profound core activity limitation is 6.9%, or 37,500 people.

Overall, the total number of Australians of all ages with a severe or profound core activity limitation is projected to increase by 8.7% (116,200 people). This overall projected growth is mainly attributable to rapid growth in the age groups of 65+ (13%, or 81,600 people) and 45–64 years (10%, or 32,800 people). The number of children aged 0–14 years with a severe or profound core activity limitation is projected to decrease by 1.7%, or 2,800 people.

## **Influence on the level and pattern of demand for services**

The growth of the Australian population, especially the ageing of the population and the greater longevity of individuals, is likely to account for a substantial proportion of the future increase in the level of demand for services. There will be increasing needs for flexible services that span broad program areas or cross traditional divides to accommodate changing individual needs.

As a result of population ageing, people with a disability are also ageing (AIHW 2000). The baby-boom generation is now moving into older age groups, and the high projected growth rate in the number of people aged 45 years or over with a severe or profound core activity limitation suggests that the ageing trend of people with a disability is likely to continue. Also, survival into older age is now a reality for many people with an early onset disability, including some with more severe disability (AIHW 2000). This has resulted in the ageing of people with an early onset disability – an increased number and proportion of older people among those with an early onset disability. These trends may potentially lead to ageing of the CSTDA service users.

Analyses of time series data from the CSTDA NMDS collections suggest that, in line with overall population ageing, the age distribution of service users is changing, with people in late adulthood making up an increasingly large proportion of service users. On the basis of 'snapshot' day collections, the median age of clients of CSTDA-funded services gradually rose over the three years 1999–2002, from 33.1 years to 34.0 years (AIHW 2003c). Based on two full-year collections, the median age of service users rose from 30.4 years to 30.9 years between 2003–04 and 2004–05 (over a 12-month period) (AIHW 2006b).

As people with a disability age their service needs are likely to change. People with an early onset disability may age more rapidly and thus have higher support needs at an earlier age than older people generally. Thus, in response to the ageing of the CSTDA service user population, either disability services will need to provide services to increasingly older clients with changing needs, or transitional arrangements between disability services and suitable aged care services or other non-CSTDA services will need to be put in place. For instance, the 'retirement' of people currently in CSTDA-funded disability employment services may create needs for other services to replace employment services, putting pressure on other CSTDA service types, such as day activity services. Similarly, 'retirement' of people using accommodation services may result in a need for greater service flexibility, either to enable 'ageing in place' or to facilitate a smooth transition to appropriate residential aged care.

As discussed in Chapter 6, growth rates of numbers of people aged 0–64 years with severe or profound core activity limitation vary by disability group, reflecting the different age and sex profiles of those groups. Projected growth is highest for physical/diverse disability (6.0%) and acquired brain injury (5.1%), and lowest for intellectual disability (1.8%). These differential growth rates for different disability groups may have implications for the mix of support services required in the future.

## **Trends in particular health conditions**

The prevalence of disability is determined by the combined effect of various factors, including past and recent incidence, remission rates for diseases, rehabilitation rates, age at

onset of disability, and survival rates of people with disability and of the general population.

This section focuses on available published information on health conditions particularly associated with disability among people aged under 65 years, including trends in prevalence of those conditions that may in turn influence trends in prevalence of disability and future demand for disability services.

In 2003, autism and paralysis headed the list of health conditions most likely to be associated with severe or profound core activity limitation for people aged under 65 years (Table 7.5). For each of these conditions, around 80% of people reported sometimes or always needing assistance with a core activity. However, some conditions further down the list accounted for much larger numbers of people with severe or profound core activity limitations, in particular back problems, arthritis, speech problems, asthma and hearing disorders.

A 2004 AIHW report that examined the relationship between disability and health conditions described different groupings of health conditions in terms of their associations with prevalence and severity of disability (measured as level of need for assistance with core activities):

- high disability prevalence but low level of severity (for example, arthritis, back problems, hearing, hypertension and asthma).
- low disability prevalence but high level of severity (for example, autism, dementia, Down syndrome, cerebral palsy and Parkinson's disease).
- high disability prevalence and high level of severity (for example, speech problems, which were most likely to be associated with intellectual and learning conditions for children, and stroke and dementia for older people) (AIHW 2004b).

Arguably, increases in the prevalence of conditions in any of these three groups would be expected to lead to increased numbers of people with severe or profound core activity limitations, and thus result in increased demand for disability services.

Data from successive ABS National Health Surveys can be used to look at trends in the prevalence of self-reported health conditions over time. The proportion of the population reporting one or more long-term conditions increased from 66% in 1989-90 to 78% in 2001, and remained at around this level (77%) in 2004-05 (ABS 1991, 2002, 2006b). Although changes in the questionnaire between surveys mean that comparisons between years for particular conditions should be made with caution, trend data suggest that, for many of the conditions that have important associations with disability, prevalence appears to have increased during the 1990s. Two condition groups for which there appear to have been particularly strong increases in self-reported prevalence are mental and behavioural problems (10.7% in 2004-05, compared with 5.9% in 1995) and back pain/problems (15.1% in 2004-05, compared with 6.4% in 1995) (ABS 2006).

**Table 7.5: Proportion of severe or profound core activity limitations among people aged under 65 years with a specific condition (based on all conditions), 2003**

Condition	% severe or profound <sup>(a)</sup>	Number ('000)	Prevalence rate (%) <sup>(a)</sup>
Autism	81.6	24.7	0.1
Paralysis	*79.1	*3.8	*0.0
Speech problems	66.7	129.3	0.8
Cerebral palsy	63.5	10.4	0.1
Dementia	**55.1	**1.4	—
Multiple sclerosis	*48.4	*6.0	*0.0
Epilepsy	41.8	33.5	0.2
Schizophrenia	41.1	18.4	0.1
ADHD	35.5	33.4	0.2
Stroke	33.4	31.3	0.2
Vision disorders (total)	32.1	50.0	0.3
Depression	22.6	83.8	0.5
Osteoporosis	21.3	24.7	0.1
Parkinson's disease	**19.5	**1.3	—
Cancer	17.9	17.2	0.1
Heart diseases	17.4	36.1	0.2
Hearing disorders (total)	16.1	106.8	0.6
Arthritis	16.1	148.6	0.9
Back problems	15.3	207.4	1.2
Diabetes	14.5	48.1	0.3
Migraine	10.8	53.4	0.3
Hearing (noise-induced)	10.7	28.1	0.2
Hypertension	10.4	94.7	0.5
Asthma	8.9	115.2	0.7
Glaucoma	**2.8	**0.4	—

(a) Percentage of the Australian population aged under 65.

\* These estimates have an associated relative standard error of between 25% and 50% and should be used with caution.

\*\* These estimates have an associated relative standard error of greater than 50% and are considered too unreliable for general use.

Source: AIHW 2005a:tables A5.7 and A5.8.

A recent report on asthma in Australia reports prevalence rates of 14–16% in children and 10–12% in adults, rates that are high by international standards. While prevalence increased through the 1980s and 1990s, rates appear to have stabilised since. Also, asthma deaths, and general practitioner visits and hospitalisations for asthma, have declined over the past 5 to 10 years; over the same period there have been changes in the nature of drug treatment for asthma, and increases in expenditure on asthma (AIHW Australian Centre for Asthma Monitoring 2005).

Data from various sources indicate that the prevalence of overweight and obesity has increased substantially over the past two decades. Excess body weight is a risk factor for various health conditions, including type 2 diabetes, cardiovascular disease and

osteoarthritis. Incidence data from the national diabetes register suggest that the incidence of type 1 diabetes among children is increasing (AIHW 2006a).

Successive ABS disability surveys provide another source of data on trends in prevalence of health conditions associated with disability. Between 1981 and 1998 there were increases in the prevalence rates of disabling conditions grouped into the broad categories of psychiatric, intellectual, diseases of the ear, circulatory diseases, respiratory diseases, and musculoskeletal disorders (AIHW 2003b). In some of these condition categories there was a steady trend across the four surveys, while for others the increase appeared to occur over a shorter period between two or three of the surveys. Only diseases of the eye and diseases of the nervous system showed little change in prevalence over the period.

The increase in prevalence of intellectual disabling conditions was particularly marked for children aged 0–14 years between the 1993 and 1998 surveys (from 1.7% to 3.6%). This may in part be due to a change in the wording of a key screening question from ‘slow at learning or understanding’ (1993 survey) to ‘difficulty learning or understanding’ (1998 survey), which may have increased reporting of intellectual disability, particularly among males. Attention deficit hyperactivity disorder (ADHD) was separately classified for the first time in the 1998 disability survey – there were about 42,700 children aged 0–14 years with ADHD in 1998. It is likely that increased levels of diagnosis and heightened awareness among parents, educators and health professionals may have contributed to increased reporting of ADHD (AIHW 2001).

While it is hard to draw conclusions from the patchy data available, it appears there were increases in the prevalence of some conditions and risk factors over the 1990s which may be expected to result in increased demand for CSTDA services in the future. A more detailed analysis of individual conditions, including consideration of the population age groups particularly affected, would be needed to reach conclusions about the extent to which these changes could translate into increased demand, the time frame over which this might occur, and the types of services most likely to be affected.

## **The role and future supply of informal (unpaid) care**

Data from the ABS disability survey highlight the enormous contribution made by informal carers to meeting the needs of people with disability. The data also show that many carers seek, and receive, relatively little assistance in carrying out their caring role (AIHW 2005a).

In 2003, of the 641,500 people with a severe or profound core activity limitation aged under 65 years and living in households who needed help with at least one core activity, 415,900 (65%) received assistance with core activities (self-care, mobility and communication) only from informal sources, and an additional 166,600 (26%) received assistance from a mix of informal and formal sources. Only 18,100 (3%) relied solely on formal sources of assistance (AIHW 2005a:Table 5.21).

In 2003, 472,500 people, or 2.4% of the population, were primary carers.<sup>8</sup> Of the 202,000 primary carers who were caring for someone with a severe or profound core activity limitation aged under 65 years, 7% were aged 15–24, 40% were aged 25–44 years, 45% were aged 45–64 years, and 8% were aged 65 or over (AIHW 2005a:Table 5.22). Many carers spent

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<sup>8</sup> A ‘primary carer’ is defined as the person who provides the most informal assistance to a person with one or more disabilities.

long hours caring – 37% spent on average 40 hours a week or more, and 18% spent between 20 and 39 hours a week. About 70% of primary carers were women. Negative health, wellbeing and financial impacts of the caring role are reported by substantial numbers of primary carers (AIHW 2000:Table 16.10; AIHW 2004a:Table 2.6).

Nationally, the opportunity cost of time devoted to informal care (that is, income foregone due to caring rather than undertaking paid work) has been estimated at \$4.9 billion in 2005; the replacement valuation of informal care (that is, the cost of providing equivalent amounts of care through the formal economy) has been estimated at \$30.5 billion annually (Access Economics 2005).

### **Estimates of support needs of ageing primary carers**

In the 2002 unmet need study (AIHW 2002), analyses were carried out to estimate the support needs of ageing carers, reflecting policy priority in this area. In particular, attention was focused on two groups of ageing carers identified in the 2000 Commonwealth/State Disability Agreement Bilateral Agreements (AIHW 2002: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.

The 2002 estimates relating to support needs of ageing carers are updated here, based on available data items from the ABS 2003 Survey of Disability, Ageing and Carers. Two groups of ageing primary carers are defined, as follows:

- Group A – primary carers aged 65 years or more with a co-resident main recipient aged under 65 (15,300 people); and
- Group B – primary carers aged under 65 with a co-resident main recipient aged under 65 years, who either had been caring for 30 years or more or were aged 60–64 years and living in a non-capital city (13,100 people).

Combining these groups, there were 29,100 ageing primary carers of a co-resident aged under 65 years (Table A7.1). They were most likely to be caring for a spouse or partner (57%, or 16,100 people), or a son or daughter (29%, or 8,100 people).

In 2003, 14,800 ageing carers had a disability themselves, and 3,900 of these had a severe or profound core activity limitation; 3,500 ageing carers had been diagnosed with a stress-related illness.

About 11,200 (38%) carers did not have a fall back informal carer. Some 5,900 carers reported either that they needed assistance in their caring role, but did not receive any, or received some assistance but needed more. The majority of ageing primary carers (84%) had never received respite, and most of these said they did not need or want respite services. However, 2,300 carers expressed unmet need for respite, including 1,900 people who had received the service in the past.

About 19,600 carers reported that their main recipient of care could not manage at home alone for a few days, 6,900 stated that their main recipient could not manage at home alone for a few hours, and 3,100 said their main recipient could not manage at home alone for less than one hour.

A high proportion of ageing carers had been in their caring role for decades. About 12,500 people (44%) had been caring for 30 years or more. Many carers spent 40 hours or more per week actively caring for or supervising their main recipient of care (12,300 carers).

More detail on the situations and support needs of ageing primary carers is given in Table A7.1. When 2003 survey data on ageing carers are updated to 2005 to allow for population growth (Table A7.2), the data indicate there were 30,300 ageing primary carers in the target groups of the Bilateral Agreements (that is, Group A and Group B). Of these

- 15,800 had a disability themselves
- 12,000 did not have a fallback informal carer
- 6,300 needed help in their caring role but had never received it, or received it at some stage but needed more
- 2,500 had unmet demand for respite
- 13,100 spent, on average, 40 hours or more per week providing care
- 13,300 had been in a caring role for 30 years or more.

### **The projected supply of informal care**

Factors that may interact to affect the supply of informal care over coming years include:

- population ageing
- changes in patterns of labour force participation
- changes in attitudes to caring
- changes in family and living arrangements (for example, rates of family break-up).

While population ageing will increase the supply of carers in older age groups, greater life expectancy of people with early-onset disability and the general population will increase demand. Increasing numbers of carers are likely to find themselves in the position of having to care for an ageing parent as well as a child or spouse with a disability.

The AIHW has produced projections of the number of primary carers to the year 2013, based on 1998 ABS disability survey data (AIHW: Jenkins et al. 2003). Baseline projections reflected the effects of projected changes in population age and sex distribution, part-time and full-time labour force participation rates (including increases in female labour force participation) and living arrangements; carer availability rates were held constant at 1998 levels within age, sex, living arrangement and employment categories. The projections relate to carers of people of all ages with a severe or profound core activity limitation.

The baseline projections suggested that the number of primary carers would increase by 27% between 1998 and 2013 as a result of projected demographic changes alone, from 450,900 to 573,900. Numbers of carers aged between 25 and 59 years (who made up the majority of carers in 1998) would grow by 20%; the rate of increase would be greatest in the 60-plus years age group, where carer numbers would grow by 47%. However, the ratio of carers to people with a disability would decline slightly, from 43 to 40 primary carers per 100 people with severe or profound core activity limitation between 1998 and 2013.

The effect of possible changes in various factors likely to impact on the availability of family carers was also explored. It was found that neither a moderate decline in the willingness of employed women to reduce or give up paid work, nor an increase in co-resident spouses and partners among people aged 60 years or more, would have much effect on the ratio of

carers to people with a disability. However, a decline in the willingness of people to care could have a negative effect – an overall 20% reduction in caring rates would result in a ratio of 0.32 in 2013 (that is, 32 primary carers per 100 people with severe or profound core activity limitation, compared with 43 in 1998). The plausibility of this scenario is difficult to assess, as rates of willingness to care are affected by a large number of interacting factors.

The 15-year projection period used by the AIHW – from 1998 to 2013 – will be characterised by the transition of the large population group of baby boomers into age groups that have traditionally been the source of most primary carers, and the age groups most involved in the care of older parents, that is, 40–59 years.

The National Centre for Social and Economic Modelling (NATSEM) has produced projections of need for and supply of informal care for older people with disability over the period 2001 to 2031. While projections over such a long time period relating to something so sensitive to social and attitudinal changes should be treated with caution, results showed a substantial decline in carer ratios – the number of principal carers for every 100 older persons needing informal care was projected to fall from 57 in 2001 to 35 in 2031 (NATSEM 2004).

In the modelling, population ageing was the main driver in the increase in the number of older persons needing care and the lesser increase in the number of persons likely to be their carer. In interpreting the NATSEM projections, it should be noted that in the first part of the projection period the supply of informal care is likely to increase due to the transition of the baby boom generation into traditional primary carer age groups, while in the latter part of the period surviving baby boomers will be moving into the very old age groups when many will themselves need care.

## **Implications for disability services**

The interplay between formal and informal support is highlighted by the fact that over half of all CSTDA service users report that they have an informal carer (Figure 3.6), and a quarter of people with a severe or profound core activity limitation aged under 65 years received assistance with core activities from a mix of informal and formal sources (AIHW 2005a:Table 5.21). Overall, the quantity of care provided by informal sources far outweighs that provided through the formal services system. Thus, any reduction in the supply of informal carers relative to demand could result in substantially increased demand for CSTDA services, particularly accommodation support and community access services.

The importance of the care provided by informal carers is increasingly being recognised by governments across Australia. Family, community, and government support and recognition provides an important positive signal to carers, and may potentially influence the willingness of people to continue in or take on the caring role (AIWH 2004a).

Over recent years, governments have allocated considerable funds to programs and services designed to support carers. As the supply of carers relative to demand is predicted to fall over coming years, there will increasingly be a need for measures to support carers in order to maximise the supply and sustainability of informal care. Older carers, who are currently the focus of many carer support initiatives, account for only 8% of all primary carers of people aged under 65 years (AIHW 2005a:Table 5.22); there will clearly be an ongoing need for support programs that meet the needs of carers in a range of different situations, including women who are working and/or who would like to increase their workforce participation (working women made up one-third of primary carers in 1998). The need for

more, and more appropriate services to support carers is a view still strongly expressed by disability and carer peak organisations (Table A7.3).

## 7.4 Perspectives from the field

An important component to the project has been to canvas views from the field concerning the level and nature of unmet demand for CSTDA services. This was done by gathering information from a disability peaks discussion session held at the AIHW in October 2006 to inform this project, and reviewing submissions made to the Senate Community Affairs Committee inquiry into the funding and operation of the CSTDA. Below, a selection of key issues and themes raised are briefly outlined. Based on a comparison with material reported in the 2001 unmet need study (AIHW 2002), many of these are clearly ongoing concerns. A more comprehensive list of issues raised is given in Table A7.3.

There remains a strong view from the field that there is substantial unmet need for disability services. While lack of access to appropriate services clearly has negative impacts for individuals with disabilities and their carers, there are also broader implications – unmet need has a cumulative effect. Problems that result from unmet needs tend to snowball and become whole-of-government and whole-of-community problems.

It is a common perception that CSTDA services operate on a crisis-management basis and, because of rationing, generally meet only basic, minimum needs, rather than supporting people to achieve life goals. This is not an efficient model, as crisis services are generally more costly to provide than early intervention services, and there are emotional and social costs associated with addressing needs only when crisis hits. Also, in operating in this manner, CSTDA services do not succeed in meeting the more holistic, participation-oriented goals set out in the CSTDA itself. Views from peak discussions reported in the 2001 study included the related concern that spreading resources thinly (that is, providing small amounts of service to large numbers of clients) can make unmet need less visible.

Other suggested reasons for the perceived high levels of hidden unmet need include:

- lack of awareness of or accessible/relevant information about services available
- perceptions that services are not available, are of an inadequate standard, or are full (i.e. that there is no hope of gaining a place)
- available services do not meet the needs of the person with a disability or their family (including particular cultural and religious needs).

These may all be reasons for people not seeking services. In addition, some potential service users may not be aware that they have needs that could be met by support services. For instance, some parents have low expectations for their child with a disability and focus only on meeting the child's basic needs. Likewise, some carers from different cultural backgrounds may not understand the concept of respite – the idea of taking a break may be a foreign one, or they might not feel comfortable asking for help.

As for the 2001 study, many concerns were expressed relating to services that provide support for informal carers. There is a perceived lack of respite services that meet people's needs – for instance, available respite services may not be age-appropriate, culturally appropriate, flexible enough, or tailored to meet the needs of people with particular disability types (for example, psychiatric disabilities). This may partly explain why respite services tend to be underutilised by carers, especially ageing carers.

Other commonly expressed views relate to the need for:

- provisions allowing carers to retire
- support services to assist ageing carers with long term planning
- a broader range of respite options
- other types of services that provide practical support for carers, e.g. training in injury prevention.

The point was also made that the caring role impacts heavily on younger carers; much of the current policy and service program focus is on meeting the needs of ageing carers, and this is resulting in higher levels of unmet need among younger carers.

Other issues that continue to be raised strongly include the difficulty of accessing equipment and the need for a uniform national equipment scheme, and the view that the range of accommodation support options available for younger people with disabilities should be equivalent to those available to the older population, and should include appropriate larger scale cared accommodation.

Two matters around which concern seems to have grown since the 2001 study are disability employment services and the interface between the disability and aged care sectors.

In relation to employment services, there is widespread concern in the field about potential negative implications of recent policy and program changes. For example, there are concerns that under 'Welfare to work' there will be additional demands placed on carers and on other specialist disability services to support people finding and keeping a job, and that some people with disabilities will be referred to generic employment services where case managers do not have the time, skills or experience to provide the extra or specialised help needed.<sup>9</sup>

There is a perception of substantial unmet demand for employment services. Lack of access to employment services makes it difficult for many people with disabilities to make the transition into the labour force; young people with disabilities can quickly lose skills and confidence, and may not attempt to enter the labour force if services are not available to help them make the transition.

There are also concerns about interfaces between supported and open employment services, and between employment services and other CSTDA-funded services. With business services and open employment services now administered by different departments, people may be reluctant to make the move to open employment for fear of not being able to return to their business service place if things do not work out (previously, their place was kept open until they had achieved a stable placement in a job). The transition from employment to day programs can also be difficult, and is hampered by the fact that it is often viewed as cost shifting between levels of government. This is particularly an issue for older people wanting to retire. A commonly expressed view is that links between day programs and employment programs need to be improved.

There is a perception that there are barriers to people with disabilities accessing aged care services where this is appropriate, that is, where people ageing with a disability have age-related needs as well as disability needs, or where younger people with disabilities seek to

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<sup>9</sup> The government's view is that the operation of the Job Capacity Assessment will ensure job seekers' needs are appropriately assessed and job seekers referred to the most appropriate employment streams.

access HACC services to complement CSTDA services. Also, in many cases, aged care service providers do not have the expertise to adequately support people with disabilities – training for staff in both disability and aged care sectors is needed to increase understanding of mutually relevant issues. The innovative pool model is recognised as a good model that should be more widely implemented.

A more comprehensive list of issues raised is given in Table A7.3. This material is presented to complement the more concrete and quantitative, data-based information presented in other sections of this report. While many of the views expressed may be open to debate, the fact that available data are limited in terms of the light they can shed on questions of unmet demand for disability services means that anecdotal material plays an important role in informing an overall picture of unmet demand, and providing a basis for further investigation of particular issues.