

2 Framework and method

This chapter describes the key concepts and definitions for the current study, relates them to the key data sources and outlines the study method. This study is largely an update of analyses undertaken in previous AIHW unmet demand studies, using the most recent available data. The methodology, including details of how it was developed and agreed with national disability administrators, is discussed in more detail in the earlier reports (AIHW 1997, 2002).

2.1 Study concepts and definitions

Disability and the CSTDA target group

Disability is a multidimensional concept that relates to a person's health conditions, their body functions and structures, the activities they do, the life areas in which they participate, and the factors in their environment which affect these experiences (WHO 2001). As in previous AIHW reports, the International Classification of Functioning, Disability and Health (ICF) is used as an overarching framework for describing relevant concepts and data sources.

Disability is something that is likely to affect most people in the population, at different life stages and to varying degrees. Disability can be measured along a continuum and prevalence estimates vary according to the definition used (AIHW 2005a).

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

- generic services and assistance available to the whole population, including health, housing, transport, education and employment services
- income support, including the Disability Support Pension and Carer Allowance
- specialist disability services
- equipment or environmental modifications and
- informal support from family and friends.

Specialist disability support services provided under the CSTDA are thus situated in this mosaic of services and assistance, and levels of availability of and access to one component may affect demand for other components.

The CSTDA does not include strict eligibility criteria but rather specifies that CSTDA services should be directed towards 'people with disabilities' who require significant ongoing and/or long-term episodic support and who have a disability that manifests itself before the age of 65 years (see Chapter 1). This definition essentially means that the target group for CSTDA services is a group of people who would be regarded by most members of the community as having high levels of disability (AIHW 2002).

Carers

The vast majority of care and support for people with disabilities is provided informally by family and friends (AIHW 2005a:Table 5.21). Although the CSTDA considers people with disabilities as the clients of CSTDA services (rather than their carers), there has been increasing recognition of the crucial role of families and carers of people with disabilities. Indeed, a key policy priority of the 2002–07 CSTDA is to strengthen individuals, families and carers. This report considers the support needs of carers separately to those of the people with disabilities they provide care and assistance to.

Eligibility, need and demand

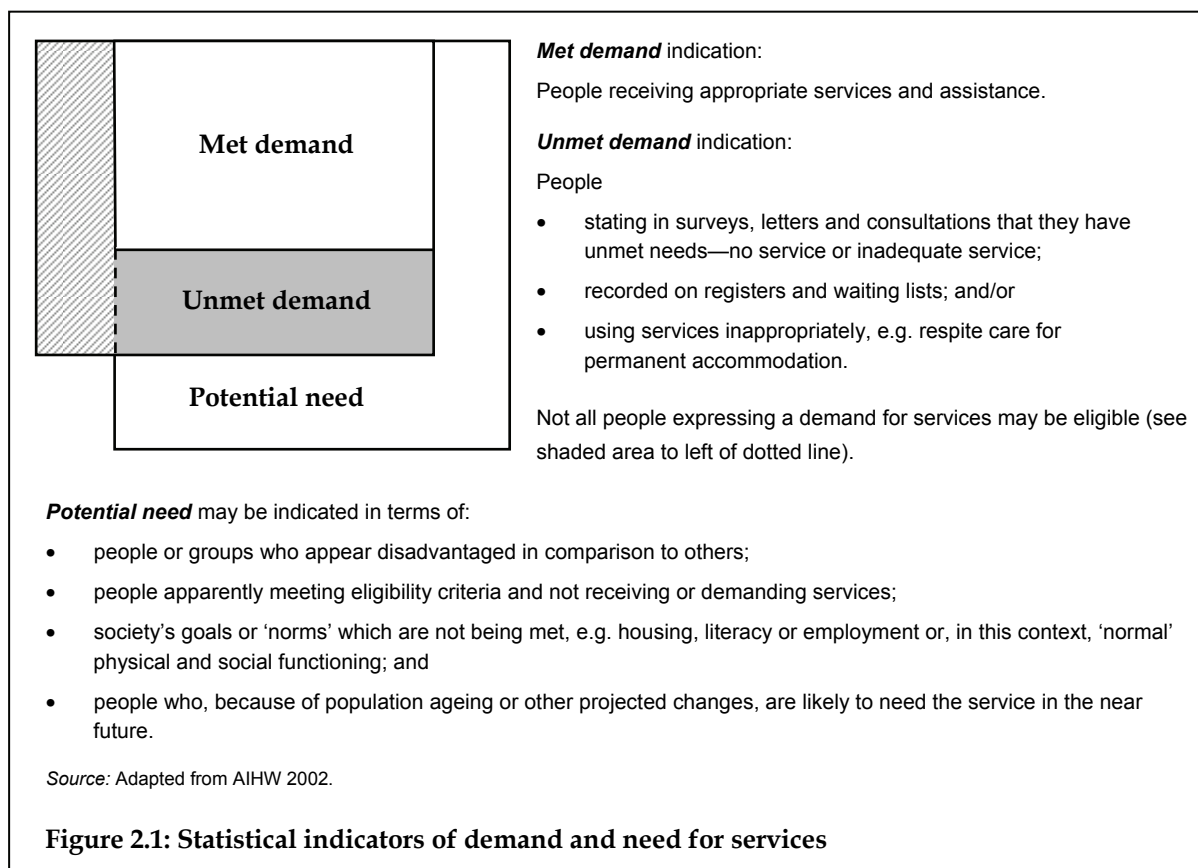
Needs and demands are complex, multidimensional concepts that may be experienced differently by people with a disability, carers, communities, service providers and program managers (AIHW 2002).

In a market economy, demand, supply and price are interconnected, each factor affected by movements of or interventions on another. Typically, the demand for publicly provided resources tends to exceed supply. The availability of clear eligibility criteria and open and accountable administrative processes is therefore required to promote equitable allocation of resources among competing demands (Charles & Webb 1986).

As previously noted, the CSTDA does not contain strict eligibility criteria but rather a definition of its target group. In practice, eligibility for services is determined at the jurisdiction (state, territory or Australian government level) or service provider level, based on more detailed criteria for prioritising competing demands among people within the CSTDA target group (see Chapter 4).

The approach used to define and describe need and demand for services in the 1997 and 2002 AIHW studies is again used in this study.

Figure 2.1 illustrates the relationships between met demand, unmet demand and potential need along with ways in which these concepts may be indicated statistically.



'Met demand' is generally considered to be people receiving an appropriate service. While met demand may be indicated by data on the number of people receiving services, such information needs to be supplemented or qualified by other information that accounts for people receiving an insufficient quantity of service or people receiving inappropriate services because the most appropriate service was not available.

'Unmet demand' is generally considered to be people who have expressed a need for a service but are not receiving the service, receiving an inadequate amount of the service or receiving an inappropriate service. Need for services may be expressed through a population survey or through administrative means such as waiting lists, registers or application processes. Some people with an 'expressed need' for a service may not be eligible for that service (but may perhaps be eligible for another type of disability service or mainstream service) and these people are represented by the striped shaded area to the left in Figure 2.2.

The terms unmet need and unmet demand are often used interchangeably in the field, and the 2002 AIHW study (AIHW 2002) predominantly used the term 'unmet need' to reflect the study's focus on 'unmet need funding' provided under CSTDA bilateral agreements (see Section 1.3). This report uses the terminology represented in Figure 2.1, referring only to the concept of unmet demand, not unmet need. Unmet demand is indicated when an individual has expressed a need for a service or assistance but this need has not been met, or has not been fully met, because, for example, a relevant service was not available or was too costly.

The concept of 'potential need', although not expressed as demand, is also important to consider for equity reasons. The larger group of people with 'potential need' for disability services also includes people with inferred and predicted need for services. These people

have similar characteristics to people currently receiving services, or demanding services, but have not expressed need for services. While neither the person nor their carers may have expressed a need for formal services, it is possible that they may do so at some time in the future. As carers age, the likelihood that potential need will translate into demand (expressed need) increases.

The concepts and terminology used in the AIHW studies of unmet demand are generally consistent with relevant literature on this topic. For example, the four definitions of 'social need' proposed by Bradshaw (1972) ('felt need', 'expressed need', 'comparative need' and 'normative need') can all be located in the above framework (see AIHW 2002 and 1997 for further discussion).

2.2 Main data sources

Population data

The Australian Bureau of Statistics (ABS) has conducted surveys on the topic of disability, ageing and carers in 1981, 1988, 1993, 1998 and 2003. This study predominantly uses the 2003 Survey of Disability, Ageing and Carers to estimate demand and unmet demand for disability support services among the Australian population. The 1998 survey is also analysed to examine changes over time in the extent and nature of met and unmet demand.

The ABS disability surveys are designed to collect comprehensive information about disability in the Australian population, with the aim of:

- measuring the prevalence of disability in Australia
- measuring the need for support for people with disability and older people
- providing a demographic and socioeconomic profile of people with disabilities, older people and carers, that can be compared with the Australian population overall (ABS 2004a).

The 2003 survey included people in both urban and rural areas of all states and territories, except for people living in remote and sparsely settled areas of the country. It included people in private and non-private dwellings, including those in cared accommodation establishments, but excluded people living in jails and correctional institutions. More detailed information on the survey is included in other AIHW publications (e.g. AIHW 2006e:Appendix 3)).

In the survey, a person has a disability if he/she has at least one of 17 limitations, restrictions or impairments, which has lasted or is likely to last for at least 6 months. People with a disability, so defined, were asked further questions about core activity limitations and schooling/employment restrictions. Those reporting core activity limitation or schooling/employment restriction are the population with a disability and a specific limitation or restriction. The population of interest for this study falls within this broad group, but is further restricted to those people requiring substantial levels of assistance (see Chapter 5).

This study also uses ABS data on the 2005 estimated resident population to update the estimates of unmet demand for population growth (Chapter 5), and ABS population

projections (Series 8) to estimate the projected growth in the population with severe or profound core activity limitation between 2006 and 2010 (ABS 2003).

Service data

Commonwealth State/Territory Disability Agreement National Minimum Data Set (CSTDA NMDS)

The Commonwealth State/Territory Disability Agreement National Minimum Data Set (CSTDA NMDS) is the primary source of disability services data for this project and is described in detail in Chapter 1. CSTDA NMDS data are used in Chapter 3 to profile 'met demand' for CSTDA services in 2004–05 and in Chapter 5 to update estimates of unmet demand (based on 2003 population data) for increases in the supply of CSTDA services between 2003–04 and 2004–05.

'Waiting list' data

Jurisdictions were asked, via a questionnaire, to provide information about their methods for managing demand for CSTDA services and to provide data from associated waiting lists or registration or application processes. This material is described in Chapter 4 and discussed in Chapter 5 in terms of validating or cross-checking the baseline estimates of unmet demand.

Other service data

A number of other service data sources are drawn on in Chapter 7 (for example, Home and Community Care National Minimum Data Set (HACC NMDS), Supported Accommodation Assistance Program National Data Collection (SAAP NDC)) in the discussion of interfaces between CSTDA services and closely related community-based aged care and other related services.

2.3 Relating study concepts to data sources

Study methodology

In brief, the study method involved:

- describing 'met demand' for (or supply of) services under the CSTDA from the CSTDA NMDS (Chapter 3)
- estimating the extent of unmet demand for disability support services using detailed analysis of the 2003 ABS Survey of Disability, Ageing and Carers
- projecting these 2003 population estimates of unmet demand forward to 2005 using ABS data on population growth
- adjusting the 2005 estimates of unmet demand to account for increases in service supply between 2003–04 and 2004–05 using CSTDA NMDS data (Chapter 5)
- comparing the resulting estimates, to check orders of magnitude, with information provided by some states on numbers of people waiting for services (Chapters 4 and 5).

To complement the data analysis, information on relevant service interfaces and other issues that have the potential to influence demand for CSTDA services is presented and discussed (Chapter 7). Main sources of this information are published reports and data, a disability peaks discussion session held at the AIHW to inform the study, and submissions made to the Senate Community Affairs Committee inquiry into the funding and operation of the CSTDA. These broad components have formed the basis of each of the AIHW unmet demand studies (AIHW: Madden et al. 1996; AIHW 1997, 2002). Further detail about each of them is contained below and in the following chapters.

Disability and the CSTDA target group

The CSTDA target group corresponds very closely to the ABS definition of people with 'severe and profound core activity limitation'. According to the ABS, people have a 'profound core activity limitation' if they report always needing assistance from another person to perform a core activity (self-care, mobility or communication) and a 'severe core activity limitation' if they report sometimes needing assistance from another person with a core activity or having difficulty in specified communication areas. Estimates of the number of people with severe and profound core activity limitation have been used for service planning purposes since 1999 (SCRCSSP 1999). This group is often referred to as the 'potential population' who may at some time require services. These potential population estimates correspond to the concept of 'potential need' for services (see Appendix B).

Carers

This study uses the ABS definition of carer, namely, a person of any age who provides any informal assistance, in terms of help or supervision, to people with disabilities or long-term conditions, where the assistance has to be ongoing or likely to be ongoing for at least six months (ABS 2004a). Analysis in this study focuses on primary carers, the person specified as providing the most informal assistance, in terms of help or supervision, to a person with one or more disabilities. The support needs of primary carers is analysed separately from the support needs of people with disabilities and is presented in Chapter 7.

CSTDA service types

The services offered under the CSTDA provide support in a broad range of activities, with the goal of enhancing participation in society by people with disabilities. CSTDA services are by no means the only services that can enable this participation.

The terms of reference for this study required the Institute to examine the extent of unmet demand for accommodation and respite services, community access services and employment services. Estimates of unmet demand for community support services (for example, early childhood intervention, therapy, case management, counselling) were not requested as part of this study.

Separate estimates of unmet demand are presented for community access and employment services. However, as in past Institute studies on this topic, this study presents a combined estimate of unmet demand for accommodation support and respite services. While in some senses, many of the CSTDA service types are potentially substitutable with others (for example, employment services with day activity services), it is particularly difficult to

disentangle needs for accommodation support and respite services, using population data. In considering the most appropriate services for an individual, they may be identified as potentially in need of in-home support, supported accommodation and/or respite. If any one of these services is provided, the need for the others may be reduced or disappear altogether. It is therefore often assumed that people may move between these service types and that they are, in some respects, substitutable. It is not possible to use national population data to establish which of the possible alternatives is the most appropriate – this type of assessment can only be made at an individual level, taking into account the needs of the person and their family and carers. The service response may also be heavily influenced by the greater availability of one service type than another. For these reasons, it is not possible in this study to make sharp distinctions between accommodation support and respite care.

Demand for CSTDA services

In this study, CSTDA NMDS data on supply of CSTDA services are used to indicate met demand (Chapter 3), although it is acknowledged that some people using CSTDA services may not be receiving adequate or appropriate services (that is, may have their demand only partially met). These quantitative data are complemented by the use of qualitative information about the extent to which this 'met demand' is both adequate and appropriate (Chapter 7).

Unmet demand for CSTDA services is estimated through detailed analysis of the Australian Bureau of Statistics' Survey of Disability, Ageing and Carers (2003 and 1998).

The CSTDA itself does not specify eligibility criteria for services, other than via the broad target group. However, to use the ABS data to infer demand (expressed need) and unmet demand among the population it is necessary to relate the survey data to the desired or reasonably expected operation of the CSTDA in practice. That is, it is necessary to identify the population who, on the basis of their survey responses, would be expected to express a need for specified CSTDA service types. Critically, to infer demand for CSTDA service types, a threshold in each ABS question on frequency of need for assistance must be applied. The framework in Table 2.1 was developed, in conjunction with disability administrators, for this purpose (AIHW 2002).

This framework allows CSTDA NMDS data, ABS data and information about the CSTDA target group to be related, and thus underlies the baseline estimates of unmet demand presented in Chapter 5. The ICF broad domains for activities and participation were used to guide the construction of the relationship framework because both the ABS Survey of Disability, Ageing and Carers and the CSTDA NMDS were designed to be consistent with the international classification.

The ABS disability surveys asked respondents defined as having a disability about their frequency of need for assistance in 10 life areas: self-care, mobility, communication, health care, housework, meal preparation, property maintenance, transport, cognition and emotion, and paperwork. The frequency of assistance options are: does not need, <1/month, 1-3/month, 1/week, 2-6/week, 1/day, 2/day, 3-5/day and 6+/day (see more discussion in Chapter 5).

While needs for assistance in all of these areas are potentially relevant in determining the types of assistance an individual may require, need for CSTDA services is indicated by higher frequency needs for assistance with only some of these specified activities – self-care, mobility and communication. The need for accommodation and respite services is indicated

by higher frequency of need for assistance (at least 3–5 times a day) with the core activities (self care, mobility and communication). The need for day activity services is indicated by the need (at least daily) for assistance with two or more core activities and the need for employment services is indicated by the need for assistance (at least daily) in any core activity.

It is important to note that this framework does not represent a full picture of the approach to the ABS survey analysis undertaken in Chapter 5, as questions other than need for support with activities are also used to ‘drill’ through the population data and identify the group with unmet needs for specified CSTDA service types. The process for drilling down through the ABS data to develop baseline estimates of the number of people with disabilities who have unmet demand for CSTDA services in 2005 is illustrated in Figure 2.2, using the example of accommodation and respite services. Different criteria are used for employment and community access services, but the logic is similar. For example, in estimating unmet demand for employment and community access services, additional relevant information includes information about whether the individual currently attends a day activity and their reasons for not currently participating in the labour force.

While the framework is broad, covering the full range of activities and participation areas in which a person may have limitations and needs, in developing the estimates of unmet demand the AIHW maintained its conservative approach. For example, while it is possible that people with lower level needs than those indicated by the framework might access CSTDA services, it is intended that the support needs are fairly typical of the intended client group (AIHW 2002). Similarly, while it is possible that people with disabilities with high levels of need for assistance in non-core activities such as cognition and emotion, housework or health care, might access CSTDA services even in the absence of significant core activity limitations, these people are not included in the estimates of unmet demand. A profile of the support needs of service users accessing CSTDA services in 2004–05 is presented in Chapter 3, including a profile of their support needs across the broad range of life areas indicated in Table 2.1.

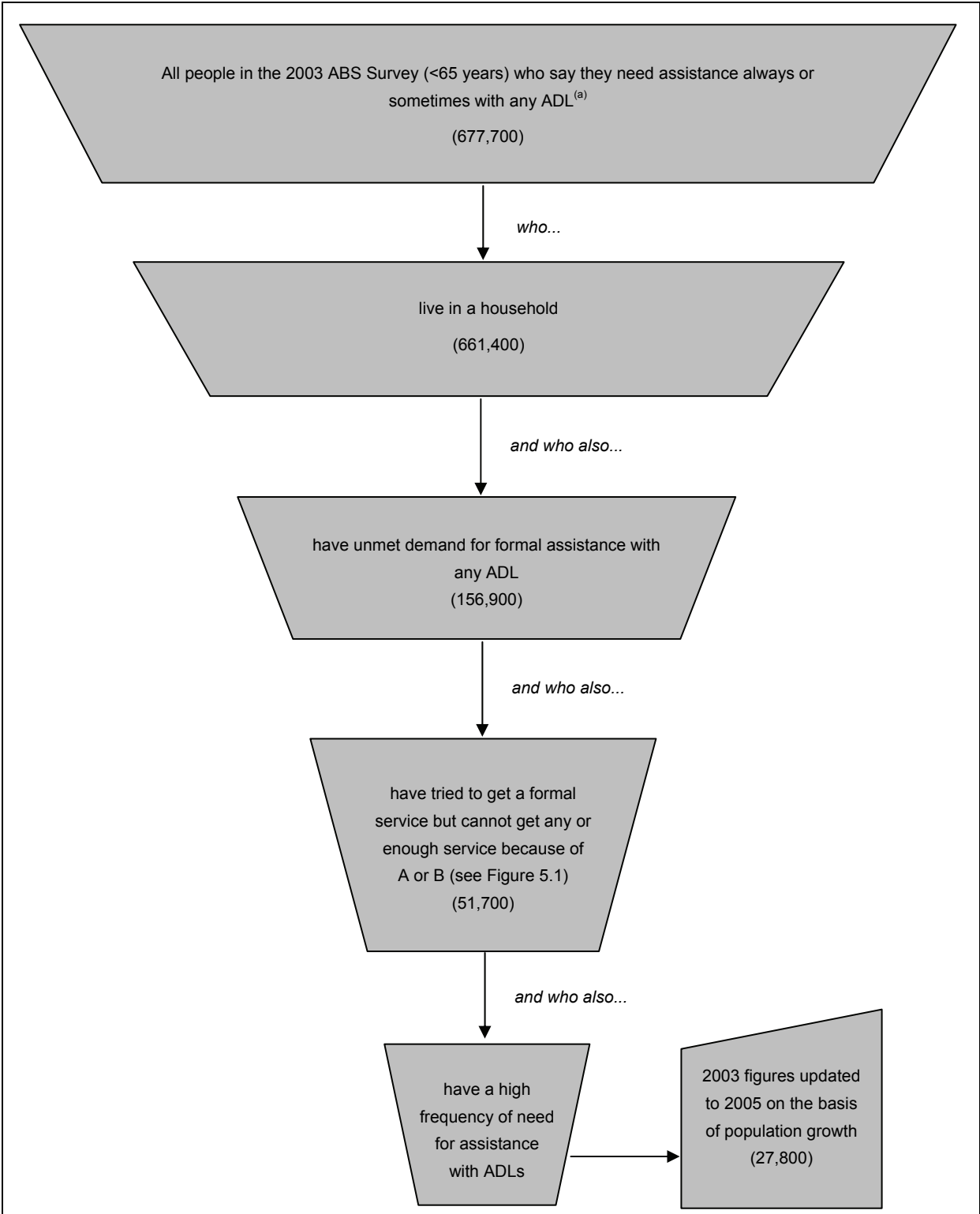
Table 2.1: Relating ABS data to the need for CSTDA services

Individual's life areas^(a)	Disability support services (CSTDA)	Relevant 'activities' questions in ABS survey	Relationship between frequency of need for assistance in ADLs^(b) and CSTDA services
Learning and applying knowledge	Community support, Community access, Employment	Guidance, communication	Community support possible.
General tasks and demands	Community support, Accommodation, Respite	Guidance, property maintenance, mobility , paperwork, communication	Accommodation & respite if at least 3–5 times per day, or less frequent if other ADL needs present.
Communication	Community support, Accommodation, Respite	Communication	Accommodation & respite if at least 3–5 times per day, or less frequent if other ADL needs present.
Mobility	Community support, Accommodation, Respite	Mobility , transport	Accommodation & respite if at least 3–5 times per day, or less frequent if other ADL needs present.
Self-care	Accommodation, Respite	Self-care , health care	Accommodation & respite if at least 3–5 times per day, or less frequent if other ADL needs present.
Domestic life	Accommodation, Respite	Housework, meal preparation	Accommodation & respite if at least 3–5 times per day, and other ADL needs present.
Interpersonal interactions and relationships	Community support, Community access, Respite	Guidance, communication	
Major life areas (education, work, economic life)	Employment, Community access	Communication, self-care, mobility , guidance, paperwork	Employment if needs at least daily support in any ADL. Community access if once daily or more for two or more ADLs.
Community, social and civic life	Community access, Community support	Communication, self care, mobility , guidance, paperwork	Community access if twice daily or more.

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

(b) Activities of Daily Living (ADLs), as mentioned in CSTDA target group definition, are highlighted in bold.

Source: Adapted from AIHW 2002.



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

Sources: AIHW 2002 and Figure 5.1.

Figure 2.2: The process of drilling down through population data to develop baseline estimates of unmet need for accommodation and respite services in 2005

The ABS survey data are not the sole foundation of the final estimates of unmet demand. The ABS survey data are used to estimate the baseline estimates of unmet demand for accommodation and respite services, community access services and employment services, presented in Sections 5.2–5.4. These baseline estimates are updated to 2005 to account for population growth (using the 2005 ABS estimated resident population data) and also updated to account for increased supply of CSTDA services between the survey year (2003) and 2005 (using CSTDA NMDS data for 2003–04 and 2004–05). These estimates of unmet demand are then compared with other available data sources, most notably jurisdictional waiting list information, to present consolidated estimates of unmet demand in Section 5.5.

The concept of potential need has, in recent years, often been operationalised as the ‘potential population for CSTDA services’ (for example, SCRCSSP 1999). This ‘potential population’ is broadly defined as people with a severe or profound core activity limitation and some information on this group is presented in Appendix B. The ‘potential population’ for CSTDA services is generally assumed to be larger than the group of people who are likely to demand CSTDA services at any one time.

2.4 Data limitations

CSTDA NMDS

CSTDA NMDS data for 2004–05 had some limitations, relating principally to service type outlet response rates and ‘not stated’ or ‘not known’ rates for individual data items.

Overall, 94% of service type outlets provided data according to the CSTDA NMDS, varying between 70% and 100% of all outlets across jurisdictions (Table 2.2). In particular, the numbers of CSTDA service users is underestimated in the Northern Territory (where 70% of service type outlets provided data), New South Wales (85%) and, to a lesser extent, Victoria (92%).

Table 2.2: Response rates for service type outlets reported by jurisdictions, 2002–03 to 2004–05

	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Aus Gov	Total
2002–03 (%)	70	79	93	100	100	100	98	97	100	82
2003–04 (%)	80	94	97	100	100	100	93	95	100	93
2004–05 (%)	85	92	99	100	100	96	98	70	100	94

Notes

1. Response rates are based on figures provided by jurisdictions.
2. The ‘total’ response rate is based on the number of outlets in the data set, divided by the number of total outlets that would have been in the data set if all jurisdictions had a 100% response rate.
3. The response rate for Australian Capital Territory in 2003–04 is based on agency response rates rather than service type outlets.
4. During 2003–04, Queensland reported 38 service users as not providing consent for their data to be transmitted, and the Australian Capital Territory reported 35 service users.
5. During 2004–05, Queensland reported 133 service users as not providing consent for their data to be transmitted, and the Australian Capital Territory reported 36 service users.

Source: AIHW 2006b: Table 7.1.

The number of 'not stated' responses for service user data items was generally higher in the 2004–05 CSTDA NMDS collection than in previous years, varying widely across jurisdictions for most data items (Table 2.3). Of particular concern is the high level of 'not stated' rates for basic demographic and disability items such as Indigenous status (21%) and primary disability group (16%). The increase in the level of 'not stated' rates is generally assumed to be the result of jurisdictions bringing agencies into the collection that have previously supplied no data. While this practice has a positive impact on the service type outlet response rate, it has a negative impact on the accuracy with which the service user population can be profiled.

Finally, the CSTDA NMDS uses a statistical linkage key to eliminate double counting of clients who use CSTDA services provided by more than one service type outlet over the financial year. High numbers of invalid or incomplete statistical linkage keys mean that it is not possible to eliminate double counting of clients and leads to an overestimate of service user numbers. The process for collecting the statistical linkage key data items in Victoria (where clients are required to 'opt in' to the collection rather than 'opt out' as in other jurisdictions) contributes to a relatively high number of invalid statistical linkage keys and an associated relatively high estimated number of service users (see AIHW 2006b for more detail on CSTDA NMDS collection methods).

In summary, estimating the number of service users accessing CSTDA services is currently affected by low outlet response rates in some jurisdictions (leading to underestimates of client numbers in those jurisdictions) and high rates of invalid statistical linkage keys in others (leading to overestimates of service user numbers in those jurisdictions). CSTDA NMDS service user numbers are used in Chapter 5 to update the population estimates of unmet demand for CSTDA services for increases in supply of services between 2003–04 and 2004–05. There was little change in the national outlet response rate over this period (93% in 2003–04 and 94% in 2004–05) and, with the exception of the Northern Territory, there was little change in the outlet response rates for each jurisdiction over this period (Table 2.2). Similarly, there was little change over this period in the number of invalid statistical linkage keys, including those from Victoria. Thus, while it is possible that these data issues have implications for the estimates of unmet demand for CSTDA services (presented in Chapter 5), it is highly unlikely that these issues are significant since the CSTDA data used are the increases in service user numbers between 2003–04 and 2004–05, rather than the total numbers of service users. In any case, in the absence of detailed information from jurisdictions about the numbers of service users missing from CSTDA NMDS data returns (including the service types they accessed) in both 2003–04 and 2004–05, there is no methodology available to accurately eliminate these limitations statistically. High levels of 'not stated' and 'not known' responses for specific service user data items limit the accuracy with which the current CSTDA service user population can be described (Chapter 3).

Table 2.3: 'Not stated' and 'not known' response rates for service user data items, 2004–05

Data item	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Aus Gov	Australia
Not stated										
Age	—	0.2	—	0.1	0.9	—	0.1	—	—	0.1
Date of birth	—	9.5	—	0.1	0.8	—	0.1	—	—	2.9
Sex	0.2	9.4	0.0	0.0	0.0	0.1	0.4	—	—	2.9
Indigenous status	3.6	54.8	0.0	23.3	2.2	0.4	1.2	1.9	4.1	20.8
Country of birth	7.4	19.9	1.0	29.4	3.7	0.2	2.5	0.6	3.5	11.4
Need for interpreter services	7.2	30.6	1.4	25.1	3.8	1.5	1.6	1.0	—	13.1
Method of communication	16.5	17.4	1.7	24.6	5.0	2.0	8.7	4.1	0.8	10.9
Living arrangement	9.8	24.6	1.2	24.9	2.4	1.4	1.9	2.3	2.7	12.4
Postcode of usual residence	1.7	12.2	0.2	7.2	0.9	0.3	0.3	0.8	—	4.7
Residential setting	8.0	32.4	1.1	24.4	2.2	0.7	4.0	11.5	0.0	13.7
Primary disability group	8.0	41.7	0.9	10.6	3.1	0.1	60.3	27.1	—	16.2
Frequency of support or assistance needed										
Self-care	34.3	35.5	3.5	26.7	5.9	1.1	69.3	29.8	4.7	21.6
Mobility	34.1	34.7	1.7	26.7	5.9	1.0	69.3	29.8	3.7	20.9
Communication	33.9	34.2	1.8	25.8	5.9	1.5	69.3	30.9	3.3	20.5
Interpersonal interactions and relationships	34.2	36.2	1.9	27.1	6.1	2.1	69.5	29.9	4.6	21.8
Learning, applying knowledge & general tasks & demands										
Education	31.6	31.3	5.4	29.5	7.4	5.1	46.3	35.3	7.1	21.1
Community (civic) & economic life	35.0	30.6	3.4	27.4	7.3	2.3	47.3	31.8	9.4	21.6
Domestic life	39.2	38.4	3.5	26.3	6.9	2.8	3.5	29.8	9.5	23.9
Working	43.5	40.0	7.3	29.6	7.8	6.3	4.2	33.8	4.4	24.1
Carer—existence of										
Carer—primary status	4.8	10.5	8.3	6.3	8.8	5.5	4.8	54.9	n.a.	8.6
Carer—residency status	4.8	13.4	8.7	3.5	15.8	4.5	16.0	41.0	n.a.	9.9
Carer—relationship to service user	2.7	3.7	6.0	6.6	8.3	1.1	6.0	25.2	2.4	4.6
Carer—age group	9.7	16.7	12.3	10.5	20.1	7.4	30.0	53.7	n.a.	14.6
Main income source (adult)										
Receipt of carer allowance (child)	8.6	52.3	7.6	9.7	55.5	5.9	91.3	3.3	—	31.1
Labour force status										
Individual funding status	11.9	9.7	2.2	0.4	65.6	14.7	70.1	7.2	—	11.1
Not known										
Main income source (adult)	3.2	0.1	2.5	2.3	21.7	3.5	21.7	4.3	4.8	4.6
Receipt of carer allowance (child)	39.8	0.9	24.5	34.1	14.9	42.6	5.0	18.9	30.0	20.4
Individual funding status	17.9	—	8.7	2.8	16.5	4.3	10.8	11.1	—	5.0

Notes

1. Figures are the percentage of total data item responses for each data source.
2. Service users accessing service type 3.02 were required to report only on data items relating to age and sex. Service users who accessed only this service type over the 12-month period are therefore excluded from calculations of 'not stated' rates for all other data items.
3. Service types 6.01–6.05 and 7.01–7.04 did not collect service user data and are therefore excluded from this table.
4. Service types 5.01–5.03 were not required to collect data on carer—primary status, carer—residency status, and carer—age group. 'Not stated' rate calculations therefore exclude 5.01–5.03 service types for these data items.
5. 'Not stated' rates for carer—primary status, carer—residency status, carer—relationship to service user, and carer—age group are based only on those service users who answered 'yes' to the item carer—existence of.
6. The high level of data missing on some data items for the Australian Capital Territory is due to the inclusion of clients of therapy services in the collection process for the first time, for which minimal client information was submitted.
7. Data from a new electronic database which is under development have contributed to a number of 'not stated' data items in Western Australia.

Source: AIHW 2006b: Table 7.2.

Jurisdiction waiting list and registration data

A questionnaire was used to gather information from jurisdictions on methods of managing demand and numbers and characteristics of people waiting for CSTDA services. Five of the nine jurisdictions were able to provide data from waiting lists, registers or application processes on numbers of people with unmet demand. However, the data provided were not comparable between jurisdictions, and were subject to various data issues and limitations (discussed in Section 4.3); also, there was substantial and unexplained variation in the national equivalent estimates of unmet demand for different service types based on jurisdiction data (Section 5.5). In the context of the current study, therefore, only very limited use can be made of these jurisdiction data.

ABS Survey of Disability, Ageing and Carers

As with any population survey, there are some data limitations to the ABS Survey of Disability, Ageing and Carers (2003). In terms of coverage, the survey sample included people in private and non-private dwellings, including those in cared accommodation establishments, but excluded people living in jails and correctional institutions. People in remote or sparsely settled areas of Australia were not sampled. Estimates produced from sample surveys are based on information obtained from occupants of a sample of dwellings (the 2003 disability survey included 36,241 people for the household component and 5,145 people for the cared accommodation component). Sampling error – the difference between the published estimates, derived from a sample of persons, and the value that would have been produced if all persons in the scope of the survey had been included – is indicated in ABS publications, and in this report, as a relative standard error (RSE). Estimates with an RSE of 25% to 50% could be used with caution and estimates with an RSE of greater than 50% are considered too unreliable for general use (ABS 2004a). Finally, it has been noted that the ABS disability survey questions about core activity limitations mainly focus on physical abilities, and may emphasise the presence of limitations arising from physical impairment (Madden et al. 1995). It is therefore possible that the number of people with a severe or profound core activity limitation may mismatch, to some extent, the number of people for whom CSTDA-funded services would be appropriate. This has particular implications in estimating the number of people with intellectual or psychiatric disability, where this disability is present in the absence of core activity limitations (see Chapter 5 for more detail).