

## 2 Framework and method

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

### 2.1 Concepts and definitions for the study

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

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

#### Disability and the CSDA target group

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

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

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

- self care/management
- mobility
- communication

requiring ongoing or episodic support.

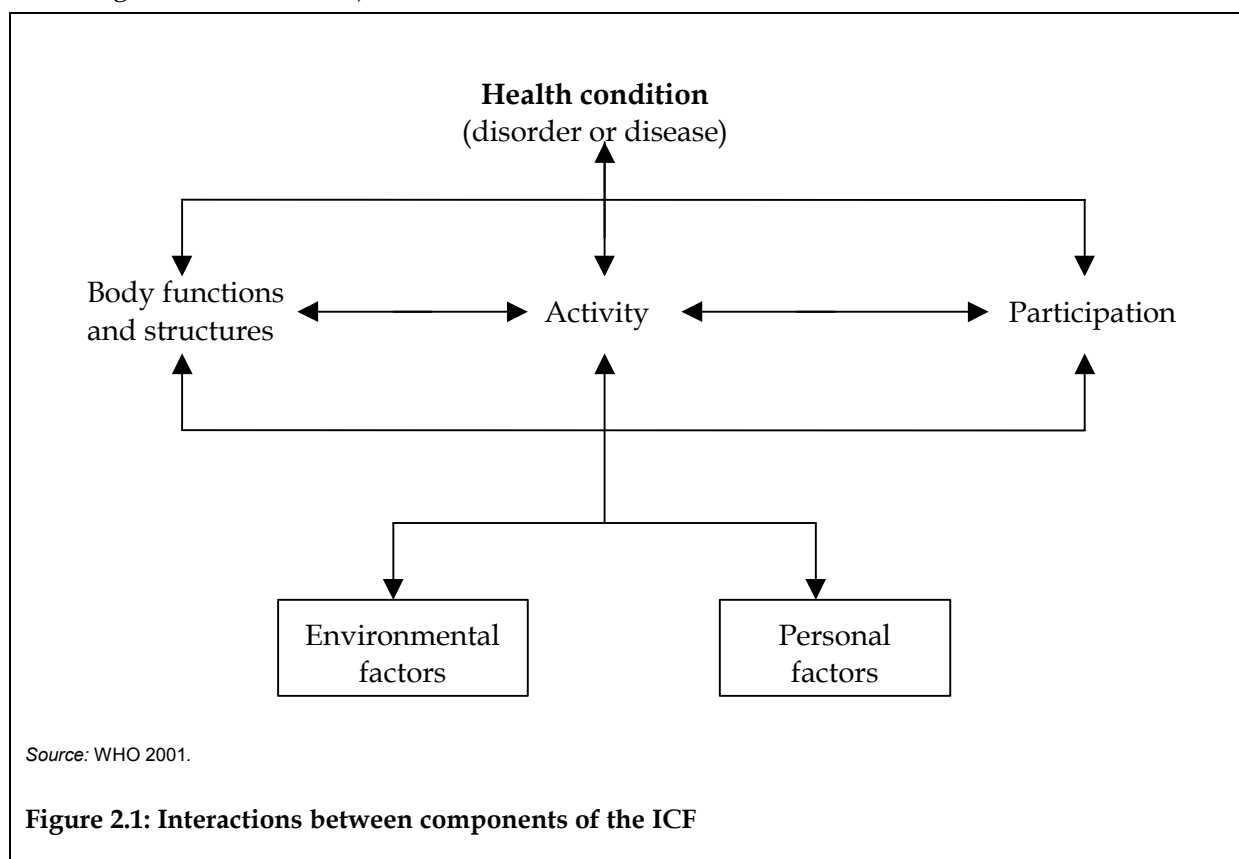
This means that CSDA services are specifically targeted to a group of people who would be regarded as having high levels of disability by most members of the community. Further detail about the CSDA is provided in Chapter 1, but this description of the target group is repeated here, as it underpins much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

#### Disability and relevant services

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

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

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



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

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

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

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

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

## **Effectiveness and CSDA service goals**

The project brief defined 'effectiveness' as:

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

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

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

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

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

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

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

## **Eligibility, needs and demand**

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

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

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

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

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

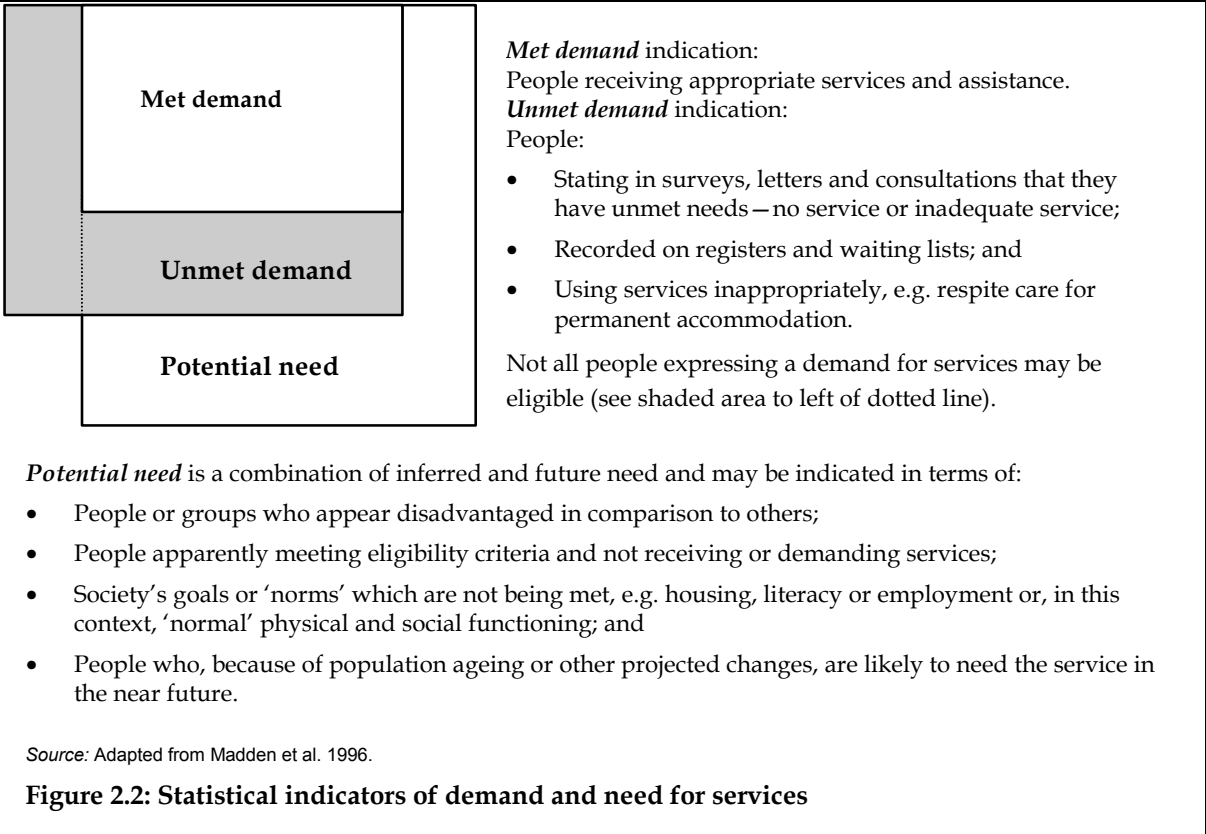
In the strict economic sense, the term 'demand' may not apply to the CSDA program, as the price mechanisms are not 'pure', although there are prices at work. However the term

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

**The 1997 AIHW 'demand study': relating to data**

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

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



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

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

On equity grounds, it is nevertheless important to consider needs for formal services other than those actually expressed. The term 'potential need', as used in the previous AIHW studies, embraced two notions. First, a level of need may be *inferred* by comparing the characteristics of people receiving services, or demanding services, with those in apparently similar circumstances but not expressing the need for services. This approach is often used in service planning. Second, the term 'potential need' also embraces an element of *prediction*. For instance, consider the situation of an adult person with a disability living with ageing carers. Neither the person nor the carers express a need for formal assistance, and they are not on any waiting lists. They are not included as 'unmet demand', but they could be included in data on potential need, as they *may*, in the not too distant future, begin to express the need for assistance. The older the carer, the more likely it is that this need will indeed be expressed as demand in the near future<sup>1</sup>.

### **Estimating 'unmet need' or shortfalls in 2002**

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

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

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

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

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

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

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

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

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

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

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

### **Concepts of need and the available data**

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

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

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

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

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

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

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

## **Expressed need for CSDA services specifically**

Recipients of CSDA-funded services are, by definition, receiving assistance from formal services. While data are not systematically collected on those who request a service but do not receive it<sup>2</sup>, some such data are increasingly available.

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

## **The balance of measurement**

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

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

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

## **Carers**

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

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

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

## 2.2 Relating key data sources to the key concepts

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

### Needs and CSDA service types

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

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

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

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

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

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

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

service types and, in some circumstances, they may be in effect somewhat substitutable<sup>3</sup>. A national data analysis cannot meaningfully distinguish between needs for similar types of services when people may move from one type to another on the basis of availability. When analysing data on the need for assistance, the identification of specific service types required is difficult, not just because of the mix of available services, but also due to the non-exclusiveness of many models of service delivery.

### **Relating need for assistance with activities to need for CSDA services**

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

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

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

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

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

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

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

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

It is important to note at this stage:

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

### **The importance of triangulation of estimates**

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

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

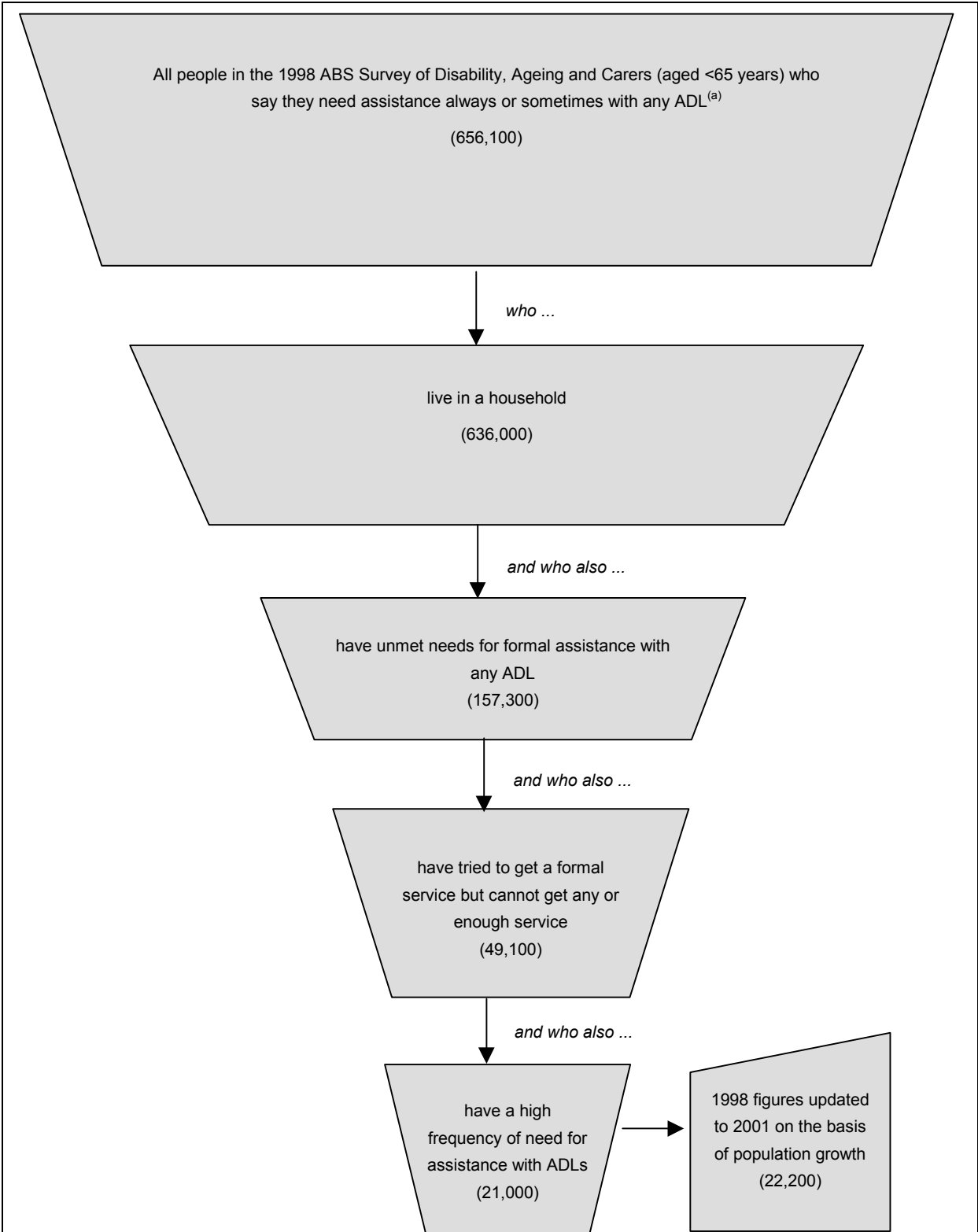
In Chapter 7, these two primary sources, together with other data, are compared and combined to arrive at consolidated estimates of unmet need. This process of cross-checking and corroboration using multiple data sources, for estimation purposes, is frequently referred to as 'triangulation' in the social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

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

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

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

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



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

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

Source: Figure 6.1.

## 2.3 Study method

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

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

Tasks for this project component included the following.

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

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

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

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

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

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

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

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

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

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

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

#### *Macro data analysis*

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

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

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

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

#### *Analysis of data concerning related services*

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

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

#### *Other information*

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

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

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

### *Population data analysis*

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

### *Analysis of data from individual jurisdictions*

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

### *Qualitative analysis: the nature of unmet need.*

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

### *Discussions with peak organisations*

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

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

The purpose was to:

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

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

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

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

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