

1 Introduction

1.1 Background and purpose of the study

The Commonwealth/State Disability Agreement (CSDA) 1991 sets out the responsibilities for the provision of disability support services by Australian Governments. Broadly, the Commonwealth takes responsibility for employment services, with the States and Territories assuming responsibility for accommodation and other support services. The first Agreement expired on 30 June 1997. Renegotiation of the Agreement has continued beyond this expiry date, with interim funding in place until February 1998.

An independent review of the Agreement was carried out before negotiation of a new Agreement began. The report of the review found that overall the CSDA had 'brought with it a number of important reforms and achievements' (Yeatman 1996:x). In reaching its conclusions, the review had used information from six supporting studies commissioned for the purpose. One of these studies, carried out by the Institute, examined the level of unmet demand for disability support services (Madden et al. 1996). One of the principal findings of the study was that there were an estimated 13,500 people in Australia in 1993 with unmet demand for formal support services of the kind provided as accommodation, accommodation support and respite care services under the CSDA. Population growth and ageing were expected to increase demand in the near future, especially in the age range 45–64 years. (A more detailed account of these findings is presented in Chapter 2.)

Purpose and outline of this study

After exploratory discussion in August 1997 the Disability Services Subcommittee (DSSC)¹ requested the Institute to conduct a study to:

- update and refine the previous estimates of unmet demand for disability support services;
- provide estimates of the cost of meeting this unmet demand; and
- update the previous estimates of growth in demand, and provide a more detailed picture of the relevant population.

¹ The Disability Services Subcommittee, of the Standing Committee of Community Services and Income Security Administrators, comprises senior government administrators from the disability field in each Australian jurisdiction.

More detail on the project brief is given in Box 1.1.

Box 1.1: Project brief for the study

The project brief given to the Institute required the study to address two main areas.

Area 1: What is the projected growth in the demand for specialist disability services arising from demographic changes over the next five years?

The following issues are to be addressed:

- *projected increase in the population with particular disabilities (e.g. intellectual, physical, sensory, neurological) over the next five years, by age cohorts;*
- *any major differences between the likely growth in different jurisdictions, based on such factors as age and sex structure and Aboriginality; and*
- *ageing of carers.*

Area 2: What is the best estimate which can be made of the current level of unmet demand for specialist disability services, with particular regard to accommodation and support, day programs and respite?

The following issues are to be addressed:

- *level of demand for accommodation and support, day programs and respite services funded under the CSDA; and*
- *costs of meeting such demand, based on existing cost structures in each jurisdiction.*

Process of the study

The study commenced in early September 1997, after previous discussion and finalisation of terms of reference. There were two main streams of work involved.

Further detailed analysis of the ABS Survey of Disability, Ageing and Carers was required, to arrive at estimates of unmet demand (in terms of people) as well as related demographic analysis to prepare growth estimates; this work proceeded steadily throughout the project.

The second main stream of work involved the analysis of a wide range of information on the costs of CSDA services in each jurisdiction. This analysis required a process of iteration, of seeking more information and reviewing estimates. Stages were:

- an early request to all jurisdictions to provide costs data;
- a workshop at the Institute in late September to discuss and compare information received so far; this resulted in a further detailed request; and
- analysis of data and compilation of first draft of national costs estimates for various service types.

A draft report was presented to a meeting of the Disability Services Committee in Melbourne on 27 October. Each jurisdiction was asked to provide comments on this report. All comments were considered and taken into account wherever possible in this final draft report.

The goal of the Institute has been to provide realistic estimates of unmet demand and the costs of meeting it. In doing so, the study team has had to make a number of assumptions, in particular to compile national cost estimates on the basis of sometimes incomplete or inconsistent information. Assumptions have at all times been explained, and there has been a conscious effort to ensure that these assumptions lead to cost estimates which tend to be conservative.

Outline of the report

The following chapters provide:

- estimates of current unmet demand for accommodation, support, respite and day programs (Chapter 2);
- estimates of the national costs of meeting this unmet demand (Chapter 3); and
- estimates in the growth of demand (in terms of the current population), and an indication of associated demographic factors (Chapter 4).

The remainder of this introductory chapter provides further context for the study. Section 1.2 describes in more detail the services provided under the CSDA, and the extent of interstate variation in the services offered. Section 1.3 outlines some of the conceptual underpinning of the following chapters, in terms of:

- concepts of demand and unmet demand;
- the definition and prevalence of disability;
- the consideration of broad human needs in relation to the need for services provided under the CSDA; and
- the role of carers.

1.2 The CSDA ‘on the ground’ in 1996–97

An overview of the service types that were agreed under the CSDA is provided in Box 1.2.

Box 1.2: Funded service types provided under the CSDA

1.00 ACCOMMODATION SUPPORT non-specified

- 1.01 Institution/large residential
- 1.02 Hostels
- 1.03 Group homes
- 1.04 Attendant care
- 1.05 Outreach support/other ‘in-home’ support/drop-in support
- 1.06 Alternative family placement
- 1.07 Other accommodation

2.00 COMMUNITY SUPPORT non-specified

- 2.01 Advocacy
- 2.02 Information/referral
- 2.03 Combined advocacy/information
- 2.04 Early childhood intervention
- 2.05 Recreation/holiday programs
- 2.06 Therapy (physiotherapy, occupational therapy, speech therapy)
- 2.07 Family/individual case practice/management
- 2.08 Behaviour intervention/specialist intervention
- 2.09 Counselling: individual/family/group
- 2.10 Brokerage/direct funding
- 2.11 Mutual support/self-help groups
- 2.12 Print disability
- 2.13 Resource teams/regional teams
- 2.14 Other community support

3.00 COMMUNITY ACCESS non-specified

- 3.01 Continuing education/independent living training/adult training centre
- 3.02 Post-school options/social and community support/community access
- 3.03 Other community access and day programs

4.00 RESPITE non-specified

- 4.01 Own home respite
- 4.02 Centre-based respite/respite homes
- 4.03 Host family respite/peer support respite
- 4.04 Other respite/flexible respite/combination

5.00 EMPLOYMENT non-specified

- 5.01 Competitive Employment Training and Placement
- 5.02 Individual Supported Job
- 5.03 Supported employment
- 5.04 Sheltered employment (business services)
- 5.05 Employment support—*State or Territory funded, no job placement component*
- 5.06 Other employment

6.00 OTHER SUPPORT non-specified

- 6.01 Service evaluation-training
- 6.02 Peak bodies
- 6.03 Research and development
- 6.04 Other

Note: Employment services, categories 5.01–5.04 and 5.06, are funded by the Commonwealth only.

This study addresses unmet demand for accommodation and accommodation support (categories 1.01 to 1.07), respite (categories 4.01 to 4.04) and community access (categories 3.01 to 3.03, which are generally referred to as day programs). It is important to remember, throughout this report, that the scope of Area 2 of Box 1.1 focuses Chapters 2 and 3 on unmet demand for accommodation and support, day programs and respite; unmet demand for other service types is not estimated or costed.

Data relating to CSDA services and users are collated annually in a nationally agreed format—the CSDA Minimum Data Set (MDS) (see Box 1.3).

Box 1.3: The 1996 CSDA Minimum Data Set (MDS) collection

The CSDA MDS collection results in data on the services listed in Box 1.2.

There is some variation among jurisdictions in what services are considered to fall under the CSDA. For instance, psychiatric disability services and early childhood intervention services are particularly ‘grey’ areas and are not included as CSDA services in all jurisdictions. The provision of community-based support services under other programs may also vary, and affect interstate comparisons.

The collection is still developing. In 1996, features to be aware of were:

- *Western Australia collects data in an annual census of client and service use conducted at the end of June each year for the preceding 12 months; in some tables, therefore, Western Australian MDS data are counted on a different basis from other jurisdictions.*
- *The Commonwealth did not collect client data from business services (supported employment services); client data for open employment services were extracted from an ongoing database managed by the Institute.*
- *The Australian Capital Territory did not participate in the 1996 CSDA MDS collection.*
- *Response rates improved in 1996; in 1995 only four jurisdictions had response rates over 90%, whereas in 1996 all did—most over 95%; Victoria’s response rate in 1995, for instance, was only 80%, whereas in 1996 it was over 95%.*

Most jurisdictions collect the data on forms on an agreed ‘snapshot day’—a form for each service type at each outlet, and one for each person receiving that service type at that outlet. Client forms may double count clients, in so far as one person may receive more than one service on the snapshot day.

Note: The data set and its ongoing development are described in more detail in: Black & Madden (1995); AIHW (1995); Black & Eckerman (1997); Black et al. (forthcoming).

Table 1.1 provides data from the CSDA MDS collection showing the State and Territory distribution of service recipients, on a ‘snapshot day’ in 1996, by broad service type.

Table 1.1: Recipients of CSDA funded services, service type by State and Territory, Commonwealth, States and Territories, snapshot day, 1996

Service type	NSW	Vic.	Qld	WA	SA	Tas.	ACT	NT	Total
Institutions/large residential/hostels	2,701	1,584	687	920	1,042	283	n.a.	0	7,217
Group homes	2,286	2,204	1,453	727	523	267	n.a.	101	7,561
In-home and other accommodation	880	1,452	887	684	383	70	n.a.	42	4,398
<i>Total accommodation support</i>	<i>5,867</i>	<i>5,240</i>	<i>3,027</i>	<i>2,181</i>	<i>1,948</i>	<i>620</i>	<i>n.a.</i>	<i>143</i>	19,026
Total community support	3,320	3,237	1,831	12,112	1,343	232	n.a.	32	22,107
Total community access	2,889	5,077	1,205	3,230	358	518	n.a.	50	13,327
Total respite	519	408	411	1,634	70	74	n.a.	38	3,154
Total employment	4,176	5,098	3,565	1,901	658	270	49	88	15,805
Other/not stated	0	62	0	159	0	0	n.a.	0	221
Total	16,771	19,122	10,039	16,065	4,377	1,714	49	351	68,488

Notes

1. An individual may be counted more than once in the 'snapshot' numbers if more than one service type was accessed on the 'snapshot' day.
2. Data for recipients of CSDA services funded by Western Australia cover a 12-month period and have been adjusted for identified multiple service use, therefore service type totals and subtotals will vary from the sum of components. Because of this possible variation, these data may also differ slightly from data published elsewhere, for instance in the Western Australia DSC Annual Report.
3. Data for recipients of some CSDA directly provided 'Intellectual Disability Service' services funded by Queensland cover a fortnightly period.
4. Data for recipients of CSDA services funded by the Australian Capital Territory are not available for 1996.
5. Data for recipients of CSDA-funded services with service types: Advocacy; Info./referral; Combined advocacy/info.; Print disability/alt. formats of communication; Service evaluation/training; Peak bodies; Research/development; and Other were not collected.
6. Data for recipients of CSDA services funded by the Commonwealth were not collected, except for those receiving open employment services. There were a small number of recipients recorded in the National Information Management System open employment collection whose service provider was coded as either a supported or sheltered service. Data on supported or sheltered employment services are otherwise unavailable.

Source: Black et al. (forthcoming).

Table 1.2 provides data on the number of service recipients by broad service type and auspice. The data are recorded in three ways: the number on the snapshot day; the services' estimate of the numbers on a 'typical operating day'; and the estimate of the number of individuals over the financial year. The annual figures are generally higher than the other two figures, particularly those for community support services, illustrating the different nature, intensity and turnover of these services.

Table 1.2: Recipients of CSDA-funded services, service type by auspicing organisation and time period, Commonwealth, States and Territories, 1996

Service type	Government provided			Non-government provided			Total		
	Snapshot day	Estimate for a typical day	Estimate for 1995–96	Snapshot day	Estimate for a typical day	Estimate for 1995–96	Snapshot day	Estimate for a typical day	Estimate for 1995–96
Institutions/large residential/hostels	4,304	4,418	4,883	2,874	2,952	10,160	9,178	7,370	15,043
Group homes	3,759	3,775	5,747	3,718	3,875	5,754	7,477	7,650	11,501
In-home and other accommodation support	384	412	1,452	3,649	3,986	12,690	4,033	4,398	14,142
Total accommodation support	8,447	8,605	12,082	10,241	10,813	28,604	18,688	19,418	40,686
Total community support	5,898	6,830	58,502	5,526	7,760	76,334	11,424	14,590	134,836
Total community access	2,816	2,942	6,643	8,639	9,846	58,351	11,455	12,788	64,994
Residential respite	457	473	8,163	405	564	5,865	862	1,037	14,028
Other respite	209	217	963	745	1,223	10,984	954	1,440	11,947
Total respite	666	690	9,126	1,150	1,787	16,849	1,816	2,477	25,975
Employment	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.

Notes

1. An individual may be counted more than once in the 'snapshot' numbers if more than one service type was accessed on the 'snapshot' day.
2. Data for recipients of CSDA services funded by the Australian Capital Territory were not available for 1996.
3. Data for recipients of CSDA-funded services with service types: Advocacy; Info./referral; Combined advocacy/info.; Print disability/alt. formats of communication; Service evaluation/training; Peak bodies; Research/development; and Other were not collected.
4. Data for recipients of CSDA services funded by the Commonwealth were not collected. Hence data for employment services are not available.
5. Recipient numbers are those provided on the MDS Service Form, and hence do not equate exactly to those in Table 1.1 based on Consumer Form returns from services. In particular, the consumer data in Table 1.1 contain annual data for Western Australia and snapshot day data for all other jurisdictions.

Source: Black et al. (forthcoming). More details on the CSDA MDS collection are provided in Box 1.3, in particular special characteristics of the 1996 collection of which data users need to be aware.

Overview of State and Territory services

While the service types provided under the CSDA are generally as outlined in Box 1.2, there are some variations among the States and Territories as to what is actually 'on the ground' and considered to fall under the Agreement.

CSDA services are generally agreed to consist of:

- those services for people with a disability that were transferred between the Commonwealth, States and Territories under the CSDA at its inception in 1991;
- those services for people with a disability that were funded or provided by the 'disability program area' of each State and Territory before the CSDA, and which were considered to be of a type to be included in the base;
- services provided or funded with CSDA dollars since the signing of the CSDA.

'Grey areas' are considered by States and Territories to be mainly:

- services for people with psychiatric disability; to differing degrees these services may be under either health or community services authorities;
- early intervention services, which may be under education, health or community services authorities; and

- therapy services, which are not generally under the CSDA but which may be included as a component of another service type (generally one of the accommodation categories).

Eligibility for services and priority of access

A range of eligibility criteria apply across jurisdictions, with some States having implemented more specific criteria since the completion of the Institute's 1995 demand study. For example, in Western Australia the Disability Services Commission operates a three-level eligibility system:

- Level one is based on self-identification as having a disability within the coverage of the Western Australia *Disability Services Act 1993*, and access being to information, advocacy and/or referral services.
- Level two covers the broad service categories of accommodation or individual and family support programs (excluding psychiatric disability) with services such as Post School Options and Local Area Coordination having criteria based on a combination of diagnostic and relative need criteria.
- Level three covers those services that have been historically, and are currently, provided to people with intellectual disabilities through the Commission's predecessor, the Authority for Intellectually Handicapped Persons. Access is determined through a needs assessment and IQ and adaptive behaviour assessment.

It was further stated that:

- people with specific conditions (attention deficit disorder and psychiatric disabilities) are not eligible for level two and three services;
- in Western Australia the need for accommodation continues to be given higher priority than the need for day activities; and
- people receiving a service are in practice not automatically excluded upon reaching the age of 65. There is a growing demand for services and level of unmet need as this cohort increases in size in line with the general ageing of the population.

Services and eligibility criteria generally reflect the historic growth of the sector. Direct government services are largely directed to people aged under 65 years with an identified intellectual disability. In practice, access to new services is restricted to those persons meeting these criteria and who are further identified as being in crisis. Not all States have a fixed definition of crisis; some use broad descriptions; other States have developed specific criteria. 'Crisis' is generally defined in terms of imminence of family breakdown, homelessness, death of the primary carer or danger to the person.

Data systems

Historically most State and Territory record keeping systems were established to meet basic financial reporting requirements. No State or Territory has a comprehensive data retrieval system covering financial, service user and demand data. Some States and Territories are moving toward a needs-based planning approach by decentralising control of service provision to regions and introducing regional case managers or teams.

The CSDA MDS data collection is the only nationally reliable collection on services and service users, and required considerable State and Territory effort and resources to implement.

Waiting lists and unmet demand

At the time of the 1995–96 study, waiting lists were not consistently kept or maintained, however a number of other sources of information are now available; in some States accommodation funding rounds provide an indication of the level of ‘critical’ unmet need for accommodation services. A register of people with unmet accommodation needs is likely to be implemented in Western Australia in the near future; a recent review of day services and employment options identified significant areas of unmet need for day placement and areas of inappropriate service provision; and a review of applications received during the 1995–96 funding round for the Individual, Family and Carer Support Grants program provides an indication of the level of unmet need for a range of services.

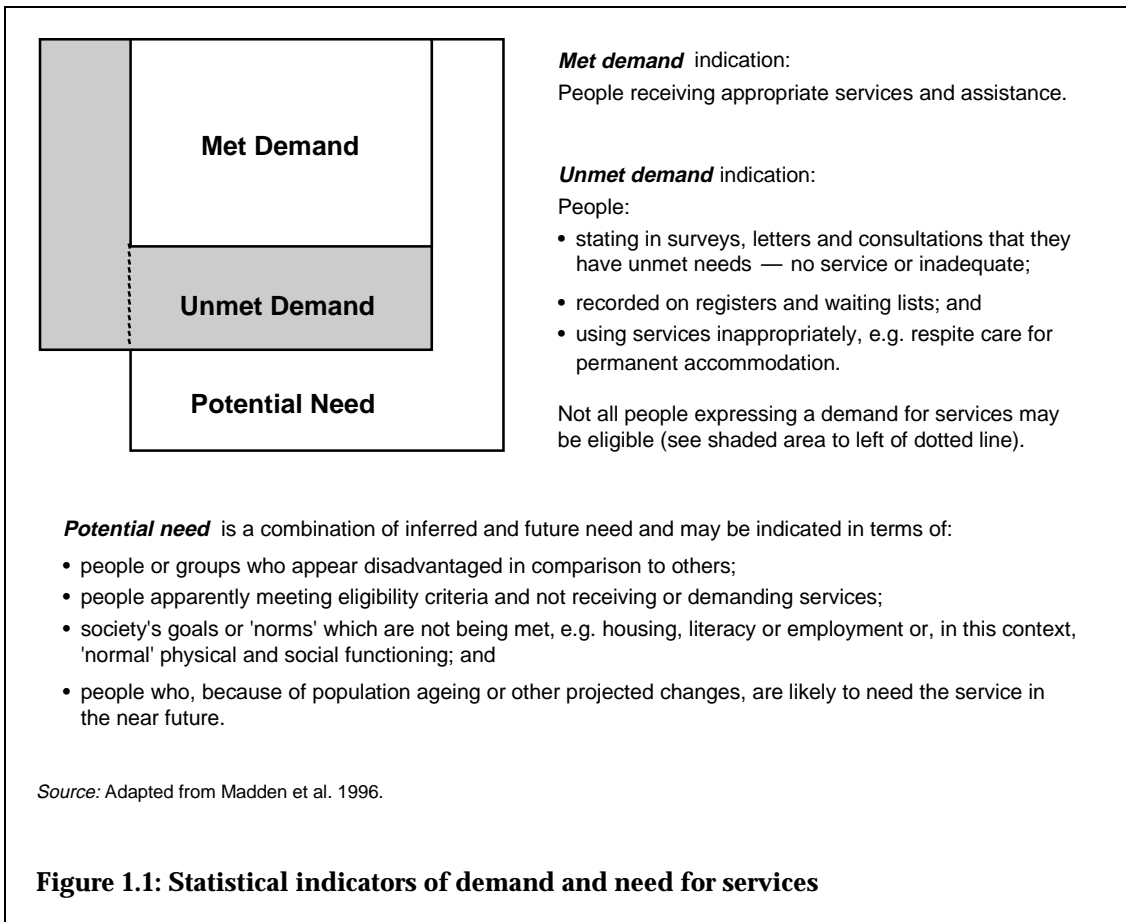
Since the time of the previous study, Victoria has implemented a Service Needs Register which is a consolidated database which holds details of client eligibility, expressed need for service and assessment of need and priority (the data currently relate to people with an intellectual disability who are registered in relation to facility based or non-facility based accommodation services).

1.3 Conceptual framework for the study

The methods used in addressing the three main aspects of this study will be described in each of the three following chapters. They share, however, some basic conceptual underpinning which is now outlined.

The need and demand for services

Needs and demands for services or assistance may be indicated by statistical data in a number of different ways. Figure 1.1 illustrates the relationships between met demand, unmet demand and potential need and suggests approaches to the statistical indication of each.



In Chapter 2 'demand' is indicated by needs expressed in some way; no inferences are drawn about demand from 'unexpressed need'.

'Met demand' is considered, generally, to be people receiving a 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. Indicators of these situations were sought, in order to temper the uncritical use of data on service users as directly indicating met demand.

'Unmet demand' is indicated by numbers of people expressing the need or desire for a service, but not receiving the service, or receiving inadequate service or an inappropriate service. 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 1.1 by the shaded area to the left.

On equity grounds, it is nevertheless important to consider needs other than those expressed as 'demand'. The term 'potential need' embraces 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 'demanding' services. The presence of severe levels of disability will be used to infer a level of need for support services; rather than assuming these people necessarily need services, we will describe them as 'potentially needing' services. 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 will not be included as 'unmet demand', but they may be included in the 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.

Disability definition and prevalence

Disability is usually conceptualised as being multidimensional for the person involved. There may be effects on organs or body parts, for instance impairments in the mobility of joints or bones. There may be effects on certain activities, for instance lifting or gripping objects with the hand. There may be effects on a person's participation in a full community life; for instance, environmental modification or equipment may be needed so that the person is enabled to work in their usual employment.

Three dimensions of disability are recognised in the International Classification of Impairments, Disabilities and Handicaps (ICIDH); the 1980 definitions are set out in Box 1.4.

Box 1.4: Definitions of the ICIDH 1980

The ICIDH provides a conceptual framework for disability which is described in three dimensions—impairment, disability and handicap:

Impairment: In the context of health experience an impairment is any loss or abnormality of psychological, physiological or anatomical structure or function.

Disability: In the context of health experience a disability is any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being.

Handicap: In the context of health experience a handicap is a disadvantage for a given individual, resulting from an impairment or a disability, that limits or prevents the fulfilment of a role that is normal (depending on age, sex, and social and cultural factors) for that individual. (WHO 1980)

Impairment is considered to occur at the level of organ or system function. Disability is concerned with functional performance or activity, affecting the whole person.

The third dimension—'handicap'—focuses on the person as a social being and reflects the interaction with and adaptation to the person's surroundings. The classification system for handicap is not hierarchical, but is constructed of a group of dimensions, with each dimension having an associated scaling factor to indicate impact on the individual's life.

Source: WHO 1980.

A new version of the ICIDH is now being drafted, to embrace developments in the field since 1980, and comments on the first ICIDH.

The most recent national Australian population survey on disability was the 1993 Survey of Disability, Ageing and Carers; the next is scheduled for 1998. The ABS survey was the main data source used in the previous demand study (Madden et al. 1996), decided on after a comprehensive review of available data. Data from the survey were used to make estimates, and other sources used to confirm orders of magnitude. A similar approach is used in the present study for the estimates of unmet demand in Chapter 2 and the growth estimates in Chapter 4.

The 1993 ABS survey defined 'disability' as the presence of one or more of fifteen 'restrictions, limitations or impairments' identified by survey respondents (see Box 1.5).

Box 1.5: Areas of limitation, restriction or impairment identified by the ABS

Affirmative responses to any of the following categories 'screen' the person into the ABS survey, where the limitation, restriction or impairment has lasted or was likely to last for six months or more:

- *loss of sight, not corrected by glasses or contact lenses*
- *loss of hearing*
- *speech difficulties in native languages*
- *blackouts, fits or loss of consciousness*
- *slowness at learning or understanding*
- *incomplete use of arms or fingers*
- *difficulty gripping or holding small objects*
- *incomplete use of feet or legs*
- *treatment for nerves or an emotional condition*
- *restriction in physical activities or in doing physical work*
- *disfigurement or deformity*
- *long-term effects of head injury, stroke or any other brain damage*
- *a mental illness requiring help or supervision*
- *treatment or medication for a long-term condition or ailment, person still restricted*
- *any other long-term condition resulting in a restriction.*

This list thus creates the implicit definition of disability for the survey. In ICIDH 1980 terms the ABS notion of disability ranges over impairment, disability and even handicap and health condition.

Source: ABS 1993; AIHW 1995.

In designing the survey the ABS attempted as far as possible to use the definitions of the 1980 ICIDH, and collected data on 'handicap' as well as on 'disability'. 'Handicap' was identified where a person, because of their disability, had a limitation or restriction in performing certain tasks associated with self-care, mobility, verbal communication, schooling or employment (more details in Box 1.6).

Box 1.6: Levels of need for service or assistance—ABS data

The ABS surveys collected data on limitations in performing certain tasks associated with daily living. The limitation must be due to a disability and in relation to one or more of the areas listed below.

- *Self-care: difficulties in showering, bathing, dressing, eating, toileting, bladder or bowel control;*
- *Mobility:
–profound/severe/moderate—difficulties going places away from home or establishment, moving about the house/establishment, transferring to or from a bed or chair;
–mild—limitation in walking 200 metres, walking up or down stairs or using public transport;*
- *Verbal communication: difficulties understanding or being understood by strangers/family/friends/staff in person's native language;*
- *Schooling: limited in the ability to attend school, or needing to attend a special school or special classes;*
- *Employment: limited in the ability to work, the type of work performed and other work problems such as the amount of time off required and special arrangements which need to be made.*

Severity of 'handicap', as defined by the ABS, was determined on the basis of the person's ability to perform tasks in the first three areas—self-care, mobility and verbal communication—and on the amount and type of help needed.

- *Profound handicap: personal help or supervision always required;*
- *Severe handicap: personal help or supervision sometimes required;*
- *Moderate handicap: no personal help or supervision required, but the person has difficulty in performing one or more of the tasks;*
- *Mild handicap: no personal help or supervision required and no difficulty in performing any of the tasks, but the person uses an aid, or has a mild mobility handicap or cannot easily pick up an object from the floor.*

Source: ABS 1993.

According to these definitions there were 3,176,700 people in Australia reporting disability in 1993.² Of these, 2,031,900 were aged under 65, of whom 925,700 (45.6%) were female, and 1,106,200 (54.4%) male (Table 1.3).

There were 1,519,000 people aged under 65 years who reported handicap (9.7% of the population in that age group). A total of 368,300 (or 2.6% of the population aged 5 to 64) reported 'severe or profound handicap' meaning that they always or sometimes needed personal assistance or supervision with activities of daily living (self-care, mobility or verbal communication) (Table 1.3 and AIHW 1995:245).

Table 1.3: People with a disability aged 0–64 years ('000): disability status, severity of handicap,^(a) by sex as a percentage of the Australian population of that sex and age group, Australia, 1993

Disability status	Males		Females		Persons	
	Number	%	Number	%	Number	%
Profound	82.5	1.0	74.8	1.0	157.3	1.0
Severe	99.8	1.3	111.2	1.4	211.0	1.4
Total profound and severe	182.3	2.3	186.0	2.4	368.3	2.4
Moderate	136.0	1.7	121.4	1.6	257.3	1.7
Mild	291.9	3.7	262.6	3.4	554.5	3.6
Not determined ^(b)	199.8	2.5	139.2	1.8	338.9	2.2
Total with handicap	809.9	10.3	709.1	9.2	1,519.0	9.7
Disability, no handicap	296.3	3.8	216.6	2.8	512.9	3.3
Total with disability	1,106.2	14.0	925.7	12.0	2,031.9	13.0

(a) Severity of handicap was not determined for children with a disability aged 0–4 years. Some totals include people aged 5–64 only.

(b) This group comprises all children with a disability aged 0–4 years and people who had a schooling or employment limitation only.

Source: AIHW 1995: 246, 395, 396; AIHW 1997:295.

Disability groupings

A common form of terminology in Australia refers to disability groupings, such as 'intellectual disability', when what is usually meant is disability related to intellectual impairment. 'Physical disability' may similarly be related to physical impairment but also to more complex impairments such as quadriplegia (which is generally categorised as physical disability because the effects on the body are primarily physical and the relevant organisations use this term). The CSDA MDS used these broad groupings, and included the term 'disability group' rather than 'disability type' in the 1997 collection.

² Strictly people did not 'report' disability and handicap in the ABS survey. They reported activity limitations, restrictions or impairments from which they were classified as having a disability or handicap. The term 'report' is used, nevertheless, both for brevity and to emphasise the self-reported nature of the data. Prevalence estimation from population surveys depends on the reliability of self-reported data. There is little evidence that any one data source is intrinsically more 'reliable' than another, but rather that definitions, survey questions, assessment instruments, personal perspectives and collection methods can all affect estimates, and care must be taken that the data are suitable to the purpose of their application. Comparability of self-reported results in non-homogeneous communities is considered to be promoted by the use of instruments focusing on activities of daily living (ADLs), with precise specification of severity categories (Mathers 1996).

This common terminology, while not clearly defined, and not based on a one-dimensional classification, is generally understood and is adopted by the major disability groups in Australia. Table 1.4 attempts to relate available population data to the major disability groupings, as follows.

The groupings used in output from the ABS Survey of Disability, Ageing and Carers are generally based on either the survey screening questions, or conditions categorised according to the International Classification of Disease 9th revision (ICD-9). The ABS category of 'primary disabling condition' is based solely on the ICD classification; this provides the only category which counts individuals (rather than conditions), and was used to derive Table 1.4.

In an attempt to align the ABS and CSDA MDS disability categories more closely for interpretation of unmet demand data, the AIHW 1995–96 demand study used the detailed ICD-9 codes within the ABS Unit Record File to derive groups based on the CSDA MDS disability groupings. In particular, people with Down syndrome recorded as the primary condition were moved from the ABS category of 'all other diseases' to 'intellectual' and people with autism recorded as the primary condition were moved from 'other psychoses' to 'intellectual'.

In the current study this approach has been retained, with two further refinements to enable more detailed examination of unmet demand to be carried out. Firstly, the largest group in the ABS data—people with a physical disability in ABS terms—have been split into the ABS subgroups of 'neurological', 'circulatory disease', respiratory disease', 'arthritis' and 'other physical'. Secondly, the CSDA MDS collection has recently, at the request of service funders and service recipient representative groups, split the largest category of service recipients — 'intellectual/learning'—into 'intellectual', 'specific learning' and 'autism'. In order to reflect this change the ABS code relating to 'developmental dyslexia', 'reading disorder' and 'specific delays in development' has, for this study, been separated from intellectual to a new category of 'learning' (autism has been retained in 'intellectual'). (A full listing of the disability groupings is contained in Table A1.2.)

Most people with profound or severe handicap had main disabling conditions that were likely to be related to physical disabilities. The next most common disability group for these people was intellectual, followed by the psychiatric disability group (Table 1.4).

Table 1.4: People aged 5–64 years with a profound or severe handicap ('000): main disabling conditions by severity of handicap, Australia, 1993^(a)

Main disabling conditions	No.			%		
	Profound	Severe	Total	Profound	Severe	Total
Intellectual	28.7	9.1	37.8	18.2	4.3	10.3
Learning	3.7	2.8	6.5	2.3	1.3	1.8
Psychiatric	14.2	16.3	30.5	9.0	7.7	8.3
Acquired brain injury	7.3	5.1	12.5	4.7	2.4	3.4
Vision	4.0	7.2	11.2	2.5	3.4	3.1
Hearing	5.5	5.0	10.5	3.5	2.4	2.8
Speech	3.0	1.9	4.9	1.9	0.9	1.3
<i>Physical</i>	<i>72.4</i>	<i>138.5</i>	<i>211.0</i>	<i>46.1</i>	<i>65.7</i>	<i>57.3</i>
Circulatory	4.3	10.6	14.9	2.7	5.0	4.1
Respiratory	8.8	18.0	26.8	5.6	8.5	7.3
Arthritis	7.9	38.4	46.3	5.0	18.2	12.6
Other musculoskeletal disorder	11.4	44.9	56.4	7.3	21.3	15.3
Other physical	40.1	26.5	66.6	25.5	12.6	18.1
Neurological	12.7	11.5	24.2	8.1	5.4	6.6
Other	5.7	13.5	19.2	3.7	6.4	5.2
Total	157.3	211.0	368.3	100.0	100.0	100.0

(a) Estimates of 1,900 or less have a relative standard error (RSE) of 50% or more. Estimates of 8,000 or less have an RSE of 25% or more. These estimates should be interpreted accordingly.

Source: Table A1.1; AIHW analysis of ABS 1993 Survey of Disability, Ageing and Carers data.

Human needs, disability services and data

In order to proceed with the study, it was also necessary to relate the needs for assistance with certain activities, reported in the ABS population survey, to the need for the specific services provided under the CSDA. The reasoning in the 1995 study still applies (Madden et al. 1996:11):

It was strongly urged by the Project Advisory Group that the report, in looking at needs, should 'start with the individual' ... The growing number of 'case management' or 'direct funding' services in the field also reflects this evolution.

A second consideration affecting the approach to analysis was the suggestion, from the Project Advisory Group and the public consultations, that people, in order to meet their needs, will 'flow' between categories of similar services, depending on the availability of services. For instance, 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 instance, accept a place in a nursing home.

As an outcome of both these factors—the need to ‘start with the individual’ and the flow of people between similar services—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 services, including respite care.

The approach to data analysis in this report therefore starts with the needs of the individual by addressing broad categories of human need. These categories of need are related to abilities and activities, then to groups of services providing assistance in these categories. A framework relating needs, activities and services is outlined in Table 1.5.

Table 1.5: Individual needs, services and data—a framework for data analysis and planning

Need	Activities, abilities	Services (non-CSDA)	Disability support services (CSDA)
Shelter, living environment	Management skills	Housing, income support, home modification and maintenance, respite	Accommodation, respite
Food & clothing	Mobility, meal preparation	Income support, home help, meals services	—
Daily maintenance	Self-care, mobility, communication	Accommodation support, respite, aids & appliances, community nursing, personal affairs, specific income support, personal care, transport	Accommodation support, respite, attendant care
Health	Self-care, ability to access services	Health (GPs, pathology, pharmacy, hospital, rehabilitation & therapy, community nursing), personal care, specific income support	Early intervention, school therapy
Income	Education, employment, self-management	Education, employment, income support	Employment services
Employment, education	Employment, education, mobility	Employment, education, transport	Employment services
Other meaningful day activity	Mobility, communication, personal affairs, social contact, community activity, information, training	Transport, mobility, training, interpreting services, specific income support	Day activities, independent living training & community access, day services, pre-employment, early intervention, print disability, post-school options
Community participation & leisure	Mobility, communication, personal affairs, social contact, community activity, information, training, recreation	Transport, mobility, specific income support, respite	Recreation
Personal relationships and responsibilities	—	Respite	Respite, advocacy, information
Rights, autonomy, personal development, safety	—	Law, education	Advocacy, information, care coordination

Source: Adapted from Madden et al. 1996.

The framework starts by considering ten broad categories of human need; the categories have been adapted to dovetail with the study’s focus on people with a disability. The second column suggests activities or abilities that enable individual people to fulfil these needs. The services that may assist people to carry out these activities, or enhance the necessary abilities, are listed in the next two columns of the table, distinguishing between generic services and specialist support services available under the CSDA. Table 1.5 underpins the analyses in this report, especially in Chapter 2.

These human needs are felt 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 the need for daytime activity of the person being cared for. The conflict may be resolved by the provision of a day program to the person with a disability.

Meaningful day activities for people with a disability who are not likely to join the labour force are, thus, not only an important acknowledgement of their right to stimulation, development and social activity after they leave school, but also a recognition that society does not expect one family or carer (frequently a woman) to provide a 24-hour care and development program to a person with high support needs for the duration of her life.

The role of carers

The presence of close personal relationships and responsibilities appears to be a pivotal feature of the disability field. These relationships create strong, caring environments which, nevertheless, often require external support to be maintained.

Most of the assistance given to people with a disability is provided not through the formal service system, but through informal networks of family (mainly) and friends. Of people living in a household, reporting handicap and receiving assistance in 1993, 91.9% received assistance from family and friends, 38.9% received formal services, and 31.7% received both informal assistance and formal services. For people with profound or severe handicap, living in households in 1993, the main provider of assistance with self-care activities was an informal carer usually resident in the same household (AIHW 1995:289-91).

The monetary value of the contribution of informal care has been estimated at some \$16.6 billion in 1995-96 and far exceeds the value of all sectors providing formal welfare services (AIHW 1997:11):

The *household* sector is by far the dominant sector in the welfare services area. In 1995-96, the bulk of services, estimated at about \$16.6 billion, were provided by members of households for the consumption of others in the household or people in other households, without any form of monetary payment. These services included work done at home caring for people who are sick or with a disability, caring for other people's children, caring for one's own sick children and other welfare services. Households also provided child care services worth \$213 million to other households in 1995-96, for which a monetary payment was received.

In total, welfare services provided by households, non-government community service organisations and governments in 1995-96 were estimated to have a value of \$27.5 billion, of which \$16.8 billion worth was provided by the household sector, \$7.2 billion worth by non-government community service organisations and \$3.5 billion worth by governments.

The relative contributions of these sectors in the *provision* of welfare services is not, however, mirrored in their relative contributions in the *funding* of these services. The Commonwealth Government contributed some 35% to the total, and was the major funder of welfare services (AIHW 1997:16). State and Territory Governments contributed 29%, client contributions made up 25% of the total, and non-government organisations contributed some 10% from fundraising and other sources of income.

The caring role affects the lives of those who undertake it. Documented effects of caring for people with a disability include experiencing frequent sleep interruptions, losing touch with friends, strain on family relationships, giving up work to take on the caring role, and diminished social activity. These effects fall mainly on women aged 30 and over (Madden et al. 1996).

What distinguishes the role of the carer of a person with a disability is the duration of care. Parent carers of people with severe or profound handicap in 1993 had, on average, been caring for considerably longer periods of time than other family, including spouses. It is estimated that, of the 7,700 parents aged 65 years and over who were principal carers in 1993, almost half had been caring for a person with a severe or profound handicap for over 30 years (Madden et al. 1996:67).

The goal of disability support services has been stated to be:

Governments 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. (SCRCSSP 1997:389)

In order to achieve this goal, it is reasonable to assume that:

- the role of carers must be sustained, because of its huge value; and
- carers' rights to participate in society must also be recognised.

The 1995–96 demand study noted 'the significance of informal care and the sensitivity of all (the unmet demand) estimates to factors that might change the availability of informal care' (Madden et al. 1996:102).

There will be further discussion of the role of carers and families in Chapter 4.