

## **Appendix 1: Summary of AIHW 1997 demand study**

### **Objectives of the study**

This study was commissioned by the Disability Services Subcommittee to provide information on unmet demand and growth factors for services funded under the Commonwealth/State Disability Agreement (CSDA) and in particular to provide estimates of:

- the level of current unmet demand for accommodation and support, respite and day programs;
- the national costs to governments of meeting this unmet demand;
- the projected growth in demand for specialist disability services arising from demographic changes over the next five years, and related factors.

### **Assumptions and data sources**

#### **Assumptions**

It was necessary to clarify a number of assumptions about how and what new services are being provided, before proceeding to the estimation of unmet demand. The assumptions used are detailed in Chapters 2 and 3 but were, chiefly:

- New clients for accommodation services are generally not being assigned to large institutions.
- People with high support needs are being accommodated in group homes or with high-level support in their own homes.
- Day programs will be expected to support clients with higher dependencies than did community access services in the past.
- A trend to service provision via non-government services is expected to continue, but governments may not be able to rely on significant non-government contributions towards the cost of establishing new services.
- While informal care by families is likely to remain the most important source of care for people with ongoing support needs, Australian society does not expect carers to provide lifelong, 24-hour care for people with high support needs. Targeted day services represent an important means of ensuring the participation of people with disabilities and their carers in the wider community.

#### **Data sources**

The study drew chiefly on the following data sources:

- the 1993 Australian Bureau of Statistics (ABS) Survey of Disability, Ageing and Carers;
- financial data for 1996–97 provided by all jurisdictions to the Industry Commission in the course of joint work for the Review of Commonwealth/State Service Provision;
- supplementary data requested by the Institute and provided by jurisdictions; and

- the 1996 CSDA Minimum Data Set collection, providing data on users of CSDA services.

### **The level of unmet demand for accommodation and support, respite and day programs (Chapter 2)**

The target group for CSDA services is people with disabilities that result in:

- (a) a substantially reduced capacity ... for communication, learning or mobility; and
- (b) the need for ongoing support services.

It is estimated that in 1996, of the 368,300 people aged 5–64 years needing ongoing assistance with self care, mobility or verbal communication (a ‘severe or profound handicap’ in ABS survey terms), there were 13,400 who:

- were living in households; and
- reported unmet need for formal assistance with self care, mobility or verbal communication; and
- had attempted to obtain the assistance needed but could not do so because the service was not available or could not be arranged for other reasons.

These 13,400 people comprise the estimate for unmet demand for accommodation, support and respite services in 1996.

There were also in 1996 an estimated 12,000 people aged 18–64 years with ongoing support needs who:

- *always* needed assistance with at least one of the self care, mobility or verbal communication activities (in the terms of the ABS survey they have a ‘profound handicap’);
- were not in the labour force and were reported to be ‘permanently unable to work’;
- were not studying;
- would have liked to go out more but were prevented from doing so by their illness or condition; and
- were *not* currently receiving day programs under the CSDA.

These 12,000 people (or full-time-equivalent places) comprise the estimate for unmet demand for day programs in 1996.

### **Conservative nature of the estimates**

The estimates for accommodation and support and respite are considered to be conservative because:

- At each step of the estimation process, groups were excluded if there was any doubt about the demand in a subgroup. For instance, some people said that the reason they had not obtained a formal service was that they did not know the services existed; some of these people could well be considered to represent unmet demand, but they were not included in the estimates.
- The estimates are of the same order of magnitude as the (incomplete) waiting list data available from some States, relating to people whose needs are already known to the States.
- The estimates exclude people in 'health establishments' (some 19,000 in 1993) including hospitals, nursing homes and other institutions, some of whom may be waiting for community accommodation.
- The estimates exclude children aged under 5 years, because their severity of handicap is not indicated in the ABS survey data.
- There are growth factors, discussed in Chapter 4, which indicate the ongoing pressures on services, chiefly the ageing of clients and their carers.

The day program estimates are considered to be conservative for several reasons, including that:

- They exclude people with a 'severe' handicap, who need assistance sometimes rather than always, on the assumption that these people will be eligible for employment programs.
- They exclude people who are employed part-time, thereby excluding people who are able to attend supported employment programs part-time but may require a day program for the other times of the working week.
- They assume no growth in total demand since 1993, even to allow for population growth.
- They offer no additional service to current users of the programs.

### **A spectrum of support needs**

Both groups indicating unmet demand were further subdivided, according to the number of activities with which people needed help, and whether or not they were already receiving some formal assistance. This was done to estimate a spectrum of their support needs. Hours of support were estimated for those requiring in-home and respite packages. This was required to make realistic estimates of the costs to government of meeting unmet demand for accommodation and support, respite and day programs. The results are incorporated in Summary Tables 1 and 2.

## **Costs to governments of meeting current unmet demand for these services** (Chapter 3)

The task of the study team was to develop national estimates of the costs to Australian Governments of meeting the estimated unmet demand. The cost estimates were based on data provided by jurisdictions relating to the costs of existing and new services for:

- group homes per place;
- in-home accommodation support and respite per client; and
- day programs per client.

In preparing national cost estimates the study team took into consideration:

- the range of national variation (high and low figures) for each service type;
- the population of each jurisdiction;
- the difference between new service cost estimates and current costs, and the strength of the explanation of these differences; and
- the detail of the supporting data provided.

It was not possible, on the basis of available data, simply to prepare weighted averages of new service cost estimates. Data provided by jurisdictions, and explanation of the reasoning behind the national cost estimates, are included in Chapter 3 and the related appendix tables. It was not the purpose of this study to attempt to explain the inter-jurisdictional and other variations in detail, but rather to combine the various estimates judiciously, with explanation, to arrive at national cost estimates.

The main cost estimates used are:

- \$50,000 per group home place per year (net cost to government);
- \$25 per hour per client for in-home accommodation support or respite;
- for day programs, costs will vary according to the support needs of clients; low, medium and high costs per client per year were estimated to be \$6,000, \$12,000 and \$18,000 respectively.

These cost estimates were then applied to the numbers of people with estimated unmet demand for each of the two main groups of services, and the hours allocated to them for in-home and respite needs.

### **Total costs to government**

The total estimated cost to government of meeting unmet demand for accommodation and support, respite and day programs is \$293.8 million, comprising \$178.3 million for accommodation, accommodation support and respite services and \$115.5 million for day programs.

The study does not estimate or cost unmet demand for other CSDA service types.

The main results are presented in Summary Tables 1 and 2.

**Summary Table 1: Estimated net cost to government<sup>(a)</sup> of meeting unmet demand for group homes, in home support and respite, 1996–97**

Level of assistance	Number of clients	Assumed service response	Number of hours per week	Cost per hour	Cost per client	Total cost
<b>People needing help with 2 or 3 activities and always with at least 1</b>						
	Subtotal:	<b>3,900</b>				
No formal assistance now	1,500	750 Group home			\$50,000	\$37,500,000
		750 Respite/in-home support package	30	\$25	\$39,000	\$29,250,000
Some formal assistance now	2,400	Respite/in-home support package	15	\$25	\$19,500	\$46,800,000
<b>People always needing help with 1 activity</b>						
	Subtotal:	<b>3,000</b>				
No formal assistance now	2,300	Respite/in-home support package	10	\$25	\$13,000	\$29,900,000
Some formal assistance now	700	Respite/in-home support package	5	\$25	\$6,500	\$4,550,000
<b>People needing help with 2 activities sometimes</b>						
	<b>1,900</b>	Respite/in-home support package	5	\$25	\$6,500	\$12,350,000
<b>People sometimes needing help with 1 activity</b>						
	<b>4,600</b>	Respite/in-home support package	3	\$25	\$3,900	\$17,940,000
<b>Total</b>	<b>13,400</b>					<b>\$178,290,000</b>

(a) Excluding the cost of any major capital works for group homes.

Source: Table 2.5; discussion of Tables 3.1, 3.2, 3.3.

**Summary Table 2: Estimated net cost to government of meeting unmet demand for day programs**

Level of assistance needed	Nature of service	Estimated number of people with unmet demand	Cost per person	Total cost
People needing help with 3 activities and always with at least 1	Day program support—High	1,600	\$18,000	\$28,800,000
People needing help with 2 activities and always with at least 1	Day program support—Medium	4,050	\$12,000	\$48,600,000
People always needing help with 1 activity	Day program support—Low	6,350	\$6,000	\$38,100,000
<b>Total—people <i>always</i> needing help with at least 1 activity</b>		<b>12,000</b>		<b>\$115,500,000</b>

Source: Tables 2.7, 3.4, 3.6 and related discussion.

## **Growth estimates and trends (Chapter 4)**

Demographic changes, along with changes in other factors, will have considerable impact on the growth in demand for disability support services in the next six years.

### **Demographic projections**

The projected demographic trends, particularly population ageing, result in a substantial projected increase in the number of people in the CSDA target group – people with a profound or severe handicap – over the next six years (1997–2003):

- The increase in the age group of 5–64 years is 9.9% (39,100 people).
- The growth in the working age population (age 15–64) with severe or profound handicap is 11.3% (37,200 people).
- Overall, the total number of Australians with a severe or profound handicap is projected to increase by 13.7% (109,200 people). The overall growth is mainly attributable to the rapid increase in the age groups of 45–64 years (19.5% or 32,600 people) and 65 years and over (17.3% or 70,200 people).

### **Projected growth in disability groups**

Corresponding to the projected population growth, the estimated overall growth in different disability groups is mainly due to the rapid increases in the population age groups of 45–64 years and 65 years and over. Nevertheless, the sizes of the increase vary among different disability groups aged 5–64 years. The projected growth rates in the numbers of people in hearing (12.0%), circulatory (15.2%) and arthritis (16.0%) disability groups are higher than the overall growth rate (9.9%) of people with a profound or severe handicap in this age group. The higher growth rates of these disability groups are probably related to the higher growth rates in the older age groups, 45–64 years. In contrast, the growth rates of intellectual (5.0%), speech (4.9%) and learning disability (3.4%) disability groups are lower than the overall growth rate of people with a severe or profound handicap.

The number of females aged 5–64 years with severe or profound handicap is projected to remain higher than the number of males. Among people under the age of 65 years, the numbers for males are higher than those for females in the disability groups of intellectual, acquired brain injury, visual, hearing, speech, and ‘other musculoskeletal’.

### **Growth, ageing, de-institutionalisation and carers**

The projected demographic trends, and other trends in families and carers outlined in Chapter 4, have a number of implications for the future of CSDA services:

- The high projected rates of increase in the number of people with a severe or profound handicap aged 45 years and over is likely to result in the ageing of the client population of disability support services. The high growth in ages 45–64 years will bring particular pressure on CSDA services, either to provide services to an increasingly older clientele, or to make transitional arrangements between CSDA services and suitable aged care services.
- The increase in the number of people with a profound or severe handicap among both the working age population (and people aged 65 years and over) will further increase the need for carers.

- The ageing of carers is likely to continue to be an important issue. The number of parents aged 65 years and over who are the principal carers for people with a profound or severe handicap is projected to increase from 7,700 in 1993 to 9,000 in the year 2003.
- There will be pressure on related services such as Home and Community Care.
- There will be pressure on both families and community-based services from ongoing trends in de-institutionalisation. Between 1981 and 1993 the number of people aged 5–64 years with ‘severe handicap’ (ongoing support needs) living in households rose from 244,100 to 349,100 while the number living in establishments fell from 27,000 to 19,200. The trend is even more marked for people aged under 30 years – in 1981 there were, on average, 15.9 people aged under 30 years with a ‘severe handicap’ living in establishments for every 100 living in households, whereas by 1993 this ratio had dropped to 3.1 for every 100 living in households. There has been a related rise, since 1981, in the numbers of people in the CSDA target group living with their families.
- While the structure of families may be changing, there is strong evidence of continuing mutual support among family members, in various patterns and relationships. When family support is likely to be intense and long-term, formal assistance from support services can ensure its stability and continuation.

### **Projected population distributions among the States and Territories**

The main estimates in Summary Tables 1 and 2 are based on the premise that the presence of severe or profound handicap is an important population indicator of the need for CSDA services. The presence in a population of a large proportion of Aboriginal or Torres Strait Islander people is considered to be a further indication of higher need, in that population, of such services. While there is not extensive data on disability among Indigenous people, what evidence there is points to higher rates of disability.

It has been previously accepted that, for this reason and based on service usage, the Indigenous population in each jurisdiction should be weighted by 2, in order to give an adjusted ‘potential population’ for CSDA services.

Results for 1996 and projections to 2003 are summarised in Summary Table 3, showing total population, population with severe or profound handicap, and the adjustment to the latter figure, from weighting the Indigenous population by a factor of 2.

**Summary Table 3: Distribution of the population aged under 65 years, among the States and Territories: total population, people with severe or profound handicap, adjusted 'potential population', 1996, 2003**

<b>People under 65 years</b>	<b>NSW</b>	<b>Vic.</b>	<b>Qld</b>	<b>WA</b>	<b>SA</b>	<b>Tas.</b>	<b>ACT</b>	<b>NT</b>	<b>Australia</b>
	<b>Percentage</b>								
All people, 1996	33.66	24.78	18.42	9.83	7.87	2.57	1.77	1.09	<b>100.0</b>
People with severe or profound handicap, 1996	33.80	24.88	18.26	9.75	8.01	2.59	1.72	0.99	<b>100.0</b>
People with severe or profound handicap, 1996 (adjusted)	33.69	24.47	18.45	9.85	7.96	2.62	1.70	1.24	<b>100.0</b>
All people, 2003	33.40	24.02	19.53	10.13	7.60	2.43	1.79	1.09	<b>100.0</b>
People with severe or profound handicap, 2003	33.47	24.11	19.41	10.05	7.75	2.48	1.72	1.02	<b>100.0</b>
People with severe or profound handicap, 2003 (adjusted)	33.36	23.71	19.61	10.15	7.70	2.51	1.70	1.27	<b>100.0</b>

Source: Tables 4.11, 4.12; ABS 1994; ABS 1997; AIHW analysis of the ABS 1993 Survey of Disability, Ageing and Carers.

Adjustment from weighting the Indigenous population by 2 leads to upward adjustments to the figures for Queensland, Western Australia and the Northern Territory, and downward adjustments for New South Wales, Victoria and South Australia. The adjustment to the Northern Territory numbers is quite significant. The projected population growth for Queensland and Western Australia is of greater significance in their growing share of the target population for CSDA services than is the adjustment for Indigenous population.