7 National population data on needs for assistance

The chapter uses the national population data on people with CP and CP-like disabilities to examine:

- profiles of support needs for assistance with various basic daily activities
- the extent to which need for assistance is met this population group.

The analyses are to assist in identifying the nature and quantifying the extent of met, partially met and unmet need for therapy and equipment services.

As discussed in earlier chapters, people with CP and like disabilities often have multiple disabilities and their needs therefore are often complex and multidimensional. The framework of Table 2.1 (Chapter 2) has been used to guide the analyses in this section, aiming to produce population indicators of need for therapy and equipment. The ICF broad domains for activity and participation have been used to guide the construction of the framework (see Chapter 2 for detailed discussions).

7.1 Profile of support needs for people with CP and like disabilities

Chapter 4 scopes and estimates the size of the population with CP and like disabilities, resulting in a population estimate of 33,800 people with CP and like disabilities who can be considered as 'candidates' for therapy and equipment services. The subgroup of people with CP-like disabilities consists of those who:

- had an ABI-related disability, and
- were aged under 45 years, and
- had acquired their main disabling conditions (not necessarily ABI) before age 30, and
- also had physical/diverse or hearing or speech disabilities, and
- needed personal assistance or supervision at least once per day with one or more of the core activities of self-care, mobility and communication.

People with CP-like disabilities have relatively high support needs with core activities, largely due to the criterion used to identify this group in the population data, restricting it to persons needing frequent personal assistance (at least daily) with one or more core activities of self-care, mobility and communication (see Section 4.5). People with CP-like disabilities and less frequent need for help were not included in the analysis of needs and unmet needs for therapy and equipment.

In the SDAC survey, people with a disability were asked questions about their need for assistance with various tasks associated with daily activities. The tasks were grouped into ten types of activities. Self-care, mobility and communication were designated in the survey as 'core activities' while the other seven activities (health care, housework, property maintenance, paperwork, meal preparation, transport and cognition and emotion) were 'non-core activities'.

Among the 33,800 people with CP and like disabilities, 2,000 (6%) were living in cared accommodation and 31,800 (94%) were living in households. In the survey, cared accommodation is defined to include hospitals, residential aged care facilities, cared components of retirement villages, and other 'homes' such as children's homes. The analysis presented here focuses on people living in households. People living in cared accommodation are assumed to require assistance with daily activities.

About 31,200 people (92%) needed assistance with either core or non-core activities; 29,300 (87%) needed help with at least one non-core activity; 26,500 (78%) needed help with at least one core activity; 24,500 (73%) needed help with both core and non-core activities (Table 7.1). In short, most people (98% or 33,200) in this population group needed assistance in daily activities (92% needed help with either core or non-core activity, plus 6% in cared accommodation). A majority of these people needed help with activities in multiple areas of life (see also Section 4.5 and Table 4.10).

Table 7.1: People with CP and CP-like disabilities: profile of need for assistance with daily activities, 2003

	Number ('000)	% of total
Lives in cared accommodation	2.0	5.9
Lives in households	31.8	94.1
Need help with either core or non-core activity	31.2	92.3
Need help with core activity	26.5	78.3
Need help with non-core activity	29.3	86.6
Need help with both core activity and non-core activity	24.5	72.6
Total	**33.8**	

Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers confidentialised unit record file.

Of the 31,800 people with CP and like disabilities living in households, need for assistance was most commonly reported in the areas of health care (23,100 people), cognition and emotion (22,300), self-care (22,100), mobility (21,800), and public and private transport (21,900) (Table 7.2).

Compared with all people with a severe or profound core activity limitation aged under 65 years, the proportion of people with CP and like disabilities needing help was substantially higher for many activities (Table 7.2). This was particularly so for self-care, communication, cognition or emotion, health care, and paperwork. Also, people with CP and like disabilities were more likely to need very frequent assistance with core activities—40% needed help 6 times a day or more, compared with just 8% of all people with a severe or profound core activity limitation aged under 65.

This pattern is broadly consistent with the CSTDA support needs data presented in Chapter 6—over half of all CP agency service users needed help in all three core activity areas,

compared with 26% of all other service users. This provides important support for an assumption employed in two of the methods of estimating the cost of unmet need for therapy among people with CP and like disabilities presented in Chapter 9, namely that need for help with core activities is an indicator of the need for therapy, and that unmet needs for such help indicate unmet needs for therapy (see further discussion in Section 9.3).

Table 7.2: Need for assistance: people with CP and CP-like disabilities, and all people aged under 65 with a severe or profound core activity limitation (people living in households), 2003

Activity with which help needed	CP and CP-like disabilities		Aged under 65 with a severe or profound core activity limitation	
	No. ('000)	% of total	No. ('000)	% of total
Self-care	22.1	69.6	318.6	48.2
Mobility	21.8	68.5	466.6	70.5
Communication	10.9	34.1	157.3	23.8
Cognition or emotion	22.3	70.0	316.8	47.9
Health care	23.1	72.5	305.4	46.2
Housework	13.4	42.1	259.6	39.3
Property maintenance	13.1	41.2	278.5	42.1
Paperwork	13.9	43.8	126.6	19.1
Meal preparation	10.9	34.3	116.2	17.6
Transport	14.0	44.0	268.3	40.6
Highest frequency of need for help with core activities				
6+/day	12.6	39.6	53.4	8.1
3–5/day	*6.3	*19.7	67.6	10.2
2/day	*3.9	*12.4	48.7	7.4
1/day	*2.7	*8.6	85.6	12.9
2–6/week	—	—	127.7	19.3
1/week	*0.6	*1.9	58.6	8.9
Less frequent or not needed	*5.7	*17.8	219.8	33.2
Total	**31.8**		**661.4**	

Note: Estimates marked with * has an associated relative standard error (RSE) of between 25% to 50% and should be interpreted accordingly.

Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers confidentialised unit record file.

An overview of difficulties and support needs for people with CP and like disabilities across eight of the nine ICF life areas (domains) is presented in Table 7.3, and the review of life areas relating to community, social and civic life is presented in Table 7.6.

In the areas of education and employment, a schooling or employment restriction is indicated by one or more of a range of difficulties or needs for assistance. These include, for instance, being unable to work or attend school; being restricted in the type of work or hours that can be worked; attending a special school or class; and needing special arrangements or support at work or school.

Of people with a severe or profound schooling restriction, about 77% (8,400 people) received some kind of support or special arrangement (Tables 7.3 and 7.4). About 7,900 people were either attending a special school or a special class at a mainstream school (Table 7.4).

Among people with a severe or profound employment restriction, only 27% (4,900 people) received some support or special arrangements (Table 7.3). Most people were not in the labour force. Only about 6,400 people were employed (Table 7.5).

Corresponding to the lower proportion of employment, most working age people in this group relied on a government pension or allowance as their main source of cash income (Table 7.5). A majority (73% or 23,200 people) of people with CP and like disabilities lived in major cities of Australia (Table 7.5), compared to 66% of the overall Australian population.

Table 7.3: People with CP and CP-like disabilities living in households: activities by whether has difficulty, assistance needed, assistance received and extent to which need for assistance met, 2003

ICF activities and participation domains[a]	ABS 2003 disability survey activity and participation areas	Total with difficulty or need help[b] No. ('000)	Need help[c] No. ('000)	Extent to which need for assistance met (% of total needing help)			Support and arrangements received
				Fully	Partly	Not at all	
Learning and applying knowledge	Learning and understanding	20.3	n.a.	n.a.	n.a.	n.a.	[d]
General tasks and demands	Paperwork	13.9	13.9	93.8	**1.5	**4.7	..
	Decision making or thinking through problems[e]	[e]	12.6	[e]	[e]	[e]	..
Communication	Communication	14.2	10.9	*82.1	**17.9	—	..
	Speech	14.7	n.a.	n.a.	n.a.	n.a.	..
Mobility	Mobility (including public transport)	22.3	21.8	67.6	**32.4	—	..
	Public and private transport	22.9	21.9	n.a.	n.a.	n.a.	..
	Private transport[f]	14.9	14.0	92.1	**6.4	**1.4	..
Self-care	Self-care	25.6	22.1	87.3	*9.8	**3.0	..
	Health care	24.7	23.1	81.9	*13.0	**5.1	..
Domestic life	Housework	14.9	13.4	*66.9	*25.5	**7.6	..
	Property maintenance	13.3	13.1	88.2	**11.8	—	..
	Meal preparation	12.3	10.9	74.7	*25.3	—	..
Interpersonal interactions and relationships	Cognition and emotion[e]	28.1	22.3	70.1	*26.0	**3.8	..
	Making or maintaining relationships[e]	[e]	14.1	[e]	[e]	[e]	..
	Coping with feelings or emotions[e]	[e]	13.7	[e]	[e]	[e]	..
Per cent of total with a restriction							
Major life areas	Schooling	10.9	*9.0	[d]	[d]	[d]	*76.8
	Employment	18.2	14.1	[g]	[g]	[g]	*27.0

(a)   The ICF domains also include 'Community, social and civic life' (see Table 7.6).

(b)   For schooling and employment, this category refers to total with a schooling restriction or an employment restriction.

(c)   For schooling and employment, this category refers to total with a severe or profound schooling restriction or employment restriction.

(d)   See support and special arrangements for people with a schooling restriction. These include special equipment (including computer), special tuition, special assessment procedure, a counsellor or disability support person, special access or transport arrangements and other support.

(e)   The 'Cognition and emotion' area of the survey includes making or maintaining relationships, coping with feelings or emotions and decision making or thinking through problems. In ICF terms, this grouping mixes 3 chapters across 2 dimensions (body function and activities).

(f)   Private transport refers to going to places away from the usual place of residence. Need for help or difficulty are defined for this activity as the need to be driven and difficulty going to places without help or supervision.

(g)   See support and special arrangements for people with an employment restriction. These include special leave arrangements, a special support person to assist/train on the job, help from someone at work, special equipment, modifying buildings/fittings, special/free transport or parking, training/retraining, allocating different duties and other support.

Notes

1.   Estimates marked with * have an associated relative standard error (RSE) of between 25% and 50% and should be interpreted accordingly.

2.   Estimates marked with ** have an associated relative standard error (RSE) of greater than 50% and should be interpreted accordingly.

Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers confidentialised unit record file.

Table 7.4: People with CP and CP-like disabilities in households: type of school attending, difficulty at school, support or special arrangements for attending school, 2003

Schooling characteristics	Number ('000)	%
Type of school and class		
Ordinary school class	*4.2	*13.3
Ordinary school (special class)	*2.6	*8.0
Special school	*5.3	*16.5
Total attending school	*12.1*	*37.9*
Experienced difficulty at school[(a)]	*8.9	*27.9
Received support or special arrangements[(b)]	*8.4	*26.4
Total	**31.8**[(c)]	

(a)   The difficulties experienced at school include difficulty sitting, hearing or sight problems, communication difficulties, learning difficulties, intellectual difficulties, fitting in socially, sports participation and other difficulties.

(b)   Support or special arrangements includes: special equipment (including computer), special tuition, special assessment procedure, counsellor or disability support person, special access or transport arrangements and other supports.

(c)   Excludes 2000 people with CP and CP-like disabilities in cared accommodation.

Note: Estimates marked with * have an associated relative standard error (RSE) of between 25% and 50% and should be interpreted accordingly.

Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers confidentialised unit record file.

Table 7.5: People with CP and CP-like disabilities in households: accessibility and remoteness, labour force status and main source of cash income, 2003

Social and economic characteristics	Number ('000)	%
Accessibility and remoteness index of Australia[a]		
Major cities of Australia	23.2	73.0
Inner regional Australia	*5.3	*16.5
Other areas[b]	*5.3	*16.7
Labour force status		
Employed working full-time	**1.5	**4.9
Employed working part-time	*4.9	*15.5
Not in the labour force	13.6	42.7
Not applicable[c]	13.7	43.2
Main source of cash income		
Wages or salary (including from own incorporated business)	*2.6	**8.1
Dividends or interest	**0.7	**2.2
Any government pension or allowance	14.7	46.1
Other main source, including workers' compensation or child support or maintenance	**0.9	**2.7
No source of income	**0.4	**1.2
Not known	**0.8	**2.5
Not applicable[c]	13.7	43.2
Total	**31.8**	

(a) The delimitation criteria for remoteness area are based on the Accessibility/Remoteness Index of Australia (ARIA). ARIA measures the remoteness of a point based on the physical road distance to the nearest Urban Centre in each of five size classes. For more information on how ARIA is defined see the Information Paper *ABS views on remoteness, 2001* (cat. no. 1244).

(b) This category combines outer regional Australia, remote Australia and remainder of very remote Australia.

(c) This includes mainly people aged under 15 years.

Notes

1. Estimates marked with * have an associated relative standard error (RSE) of between 25% and 50% and should be interpreted accordingly.

2. Estimates marked with ** have an associated relative standard error (RSE) of greater than 50% and should be interpreted accordingly.

Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers confidentialised unit record file.

'Community, social and civic life' is the ninth ICF domain for activities and participation. The available 2003 SDAC data relevant to this domain were collected differently from the data in Table 7.3 and are thus summarised in Table 7.6. A majority of people with CP and like disabilities had participated in social events or community activities in the three months preceding the 2003 survey. The most-common areas of activities were visits from and to family and friends, telephone calls with family and friends, and visits to restaurants and clubs. This pattern was similar to that for all people aged 5 to 44 years with a disability or with a severe or profound core activity limitation in households. However, the proportion participating in these types of activities was lower for people with CP and like disabilities than for the general people with a disability (Table 7.6).

Table 7.6: Comparisons of people with CP and CP-like disabilities with all people aged 5-44 years with a disability living in households: community participation, 2003

| | CP and CP-like disabilities | | All people with a disability | | |
| | | | Profound | Severe | All disability |
Community participation	No. ('000)	% of total	% of total	% of total	% of total
At home in the last 3 months					
Visits from family/friends	25.5	80.3	84.7	92.9	90.7
Telephone calls with family/friends	19.3	60.5	68.3	86.1	88.8
Craftwork for/with other people	*4.0	*12.5	15	19.3	19.2
Church/special community activities	**2.1	**6.7	*6.9	9.8	7.1
Voluntary work (including advocacy)	**0.6	**2.0	*2.2	8.1	6.3
None of the above	**2.0	**6.2	9.6	*2.9	2.6
Total number ('000)	**31.8**		**118.8**	**230.2**	**1239.2**
Away from home in the last three months					
Visited family/friends	24.8	78.1	79.4	91.4	89.6
Went to a restaurant or club	16.6	52.1	44.1	57.4	63.0
Attended church activities	*5.0	*15.9	18.0	20.0	18.9
Voluntary work (including advocacy)	*4.3	*13.6	9.1	14.8	16.8
Organised performing arts activities	*4.1	*12.9	*8.2	9.1	7.6
Organised art/craft group activities	*2.5	*7.8	*6.1	8.7	8.2
Other special interest group activities	*7.0	*22.0	18.1	16.3	17.1
None of the above	**1.4	**4.3	8.7	*4.1	4.2
Does not leave home	—	—	*4.0	—	*0.5
Total number ('000)	**31.8**		**118.8**	**230.2**	**1239.2**

Notes

1.   Estimates marked with * have an associated relative standard error (RSE) of between 25% and 50% and should be interpreted accordingly.

2.   Estimates marked with ** have an associated relative standard error (RSE) of greater than 50% and should be interpreted accordingly.

Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers confidentialised unit record file; AIHW 2005:Table 5.26.

7.2 Type of assistance provided and extent to which need for assistance met

Table 7.7 provides information about the main sources of assistance for people with CP and like disabilities. Informal care networks of family and friends provide most of the help received by this group of people living in households. Almost half (49% or 13,000) of them relied solely on informal care with core activities and another half (49% or 12,900) on a combination of both informal assistance and formal services. For non-core activities, about one-third (8,100) relied on informal assistance and about two-thirds (15,800) relied on both informal and formal assistance. Only about 2% or less of these people relied only on formal assistance with core or non-core activities.

Compared with all people aged under 65 with a disability who needed assistance with core activities, a higher proportion of people with CP and like disabilities received help from both informal and formal sources of assistance, while a lower proportion received informal assistance only. This was especially evident in the areas of mobility and self-care (Figures 7.1 and 7.2).

Table 7.7: People with CP and like disabilities living in households: type of assistance received and activity in which help is needed, 2003

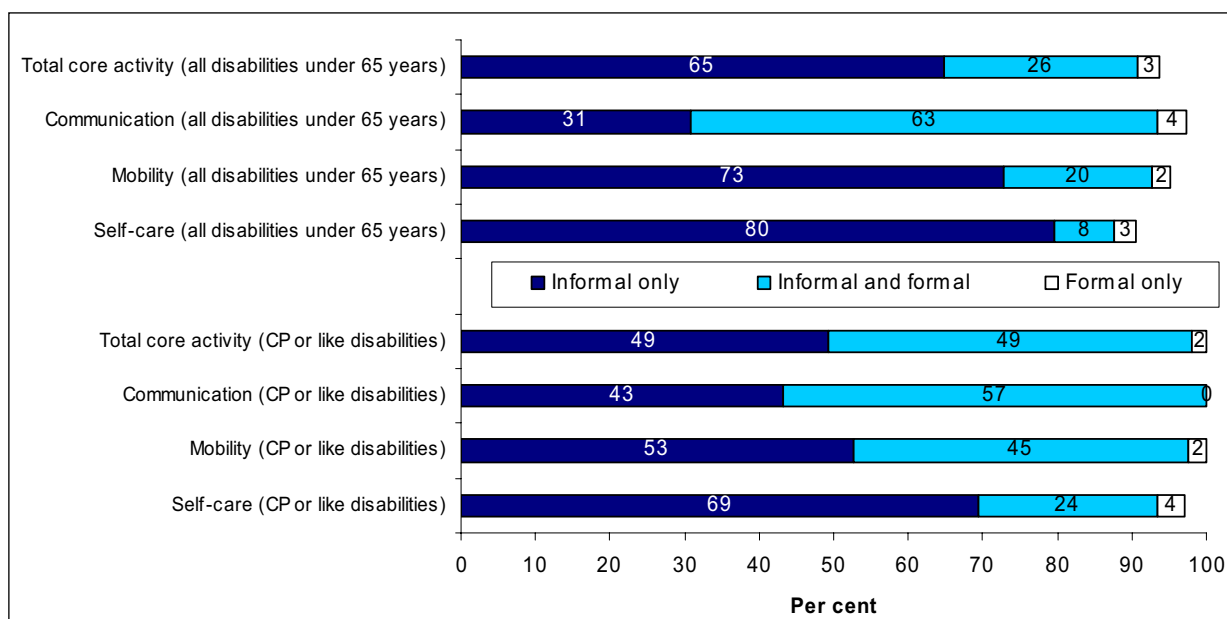| Activity with which help is needed | Type of provider | | | | |
	No provider	Informal only	Formal only	Informal and formal	Total
	Number ('000)				
Self-care	**0.7	15.4	**0.8	*5.3	22.1
Mobility	—	11.4	**0.5	*9.8	21.8
Communication	—	*4.7	—	*6.2	10.9
Total core activity[(a)]	**—**	**13.0**	****0.5**	**12.9**	**26.5**
Cognition or emotion	**0.9	12.4	**0.9	*8.2	22.3
Health care	**1.2	11.4	**1.4	*9.1	23.1
Housework	**1.0	11.7	—	**0.6	13.4
Property maintenance	—	*9.5	**2.1	**1.5	13.1
Paperwork	**0.7	11.6	**0.6	**1.1	13.9
Meal preparation	—	*9.7	**0.6	**0.7	10.9
Transport	**0.2	*8.9	—	*4.9	14.0
Total non-core activity[(b)]	****0.2**	***8.1**	****0.4**	**15.8**	**24.5**
	Per cent				
Self-care	**3.0	69.3	**3.7	*24.0	100.0
Mobility	—	52.6	**2.4	*45.0	100.0
Communication	—	*43.3	—	*56.7	100.0
Total core activity[(a)]	**—**	**49.3**	****2.0**	**48.8**	**100.0**
Cognition or emotion	**3.8	55.5	**4.0	*36.7	100.0
Health care	**5.1	49.4	**5.9	*39.6	100.0
Housework	**7.5	87.8	—	**4.7	100.0
Property maintenance	—	*72.6	*16.0	**11.4	100.0
Paperwork	**4.7	83.6	**4.0	**7.7	100.0
Meal preparation	—	*88.5	**5.1	*6.5	100.0
Transport	**1.4	*63.9	—	*34.7	100.0
Total non-core activity[(b)]	****0.8**	***33.2**	****1.5**	**64.5**	**100.0**

(a)   Includes people who need help with at least one core activity.

(b)   Includes people who need help with at least one core activity and one or more non-core activities.

Notes

1.   Estimates marked with * have an associated relative standard error (RSE) of between 25% and 50% and should be interpreted accordingly.

2.   Estimates marked with ** have an associated relative standard error (RSE) of greater than 50% and should be interpreted accordingly.

Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers confidentialised unit record file.

Figure 7.1: People receiving assistance from informal sources only, formal sources only, and both informal and formal sources, by activities in which help is needed, 2003

Source: Table 7.7; AIHW 2005: Table 5.21.

Having a source of assistance does not imply that a person's needs for help are fully met. Of the 31,200 people in households who needed help with either core or non-core activity, just over half (16,700 people or 54%) had their needs fully met and 14,500 (or 46%) had their needs only partly met (Table 7.8). Among the 26,500 people who needed help with core activities, 17,100 (65%) had their needs fully met and 9,400 (35%) had their needs partly met.

Among people who needed help with either core or non-core activities, 8,000 people aged 5–24 and 5,100 aged 25–44 had their needs only partly met (Table 7.9). Of people who needed help with core activities, 4,800 people aged 5-24 and 3,700 aged 25-44 had their needs only partly met.

It is noticeable that the overall proportion having needs fully met (Table 7.8) was substantially lower than the proportions for some specific activities (Table 7.3). For example, overall, 65% of those needing help with core activities had their needs fully met, compared to 87% with self-care, 82% with communication and 68% with mobility. The overall proportion having needs only partly met was higher than the proportions for some specific activities. For example, 35% of those needing help with core activities had their needs only partly met, compared to 10% with self-care, 20% for communication and 32% with mobility.

This overall pattern may be attributable to two main reasons. First, the extent to which need for assistance is met varies greatly across specific activities (Table 7.3), depending in part on the type of main source of assistance (Table 7.7) and other factors affecting the provision of assistance. Second, the nature and needs for assistance are complex and often related to multiple areas of life for this population group. The data item on the extent to which need for help is met summarises the survey responses relating to various areas of activity for the group. For example, people needing help with all the three core activities, are only counted as having their needs fully met if their needs are fully met for all the three activities.

Table 7.8: People with CP and like disabilities living in households: extent to which need for assistance met, 2003

Extent to which need for assistance met	Number ('000)	%	% of total
Need help with either core or non-core activities			
Fully met	16.7	53.6	52.6
Partly met	14.5	46.4	45.5
Total	*31.2*	*100.0*	*98.1*
Need help with core activities			
Fully met	17.1	64.7	53.8
Partly met	*9.4	*35.3	*29.4
Total	*26.5*	*100.0*	*83.3*
Need help with non-core activities			
Fully met	18.4	62.8	57.8
Partly met	10.7	36.5	33.6
Not at all	**0.2	**0.7	**0.6
Total	*29.3*	*100.0*	*92.1*
Need help with both core activity and non-core activities			
Fully met	14.8	60.5	46.7
Partly met	*9.5	38.7	29.9
Not at all	**0.2	**0.8	**0.6
Total	*24.5*	*100.0*	*77.2*
Total	**31.8**		

Notes

1. Estimates marked with * have an associated relative standard error (RSE) of between 25% and 50% and should be interpreted accordingly.

2. Estimates marked with ** have an associated relative standard error (RSE) of greater than 50% and should be interpreted accordingly.

Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers confidentialised unit record file.

Table 7.9: People with CP and like disabilities living in households: extent to which need for assistance met by age, 2003

	Extent to which need for assistance met							
	Fully	Partly	Not at all	Total	Fully	Partly	Not at all	Total
Age	Number ('000)				Per cent			
Need help with either core or non-core activities								
0–4	**1.5	**1.4	—	*2.9	**9.0	**9.4	—	*9.1
5–14	*5.8	*3.1	—	*8.9	*34.8	*21.3	—	*28.6
15–24	*5.3	*4.9	—	10.2	*31.7	*34.0	—	32.8
25–44	*4.1	*5.1	—	*9.2	*24.5	*35.3	—	*29.5
Total	16.7	14.5	—	31.2	100.0	100.0	—	100.0
Need help with core activities								
0–4	**1.9	**0.9	—	*2.9	**11.4	**9.7	—	*10.8
5–14	*5.4	*2.4	—	*7.8	*31.5	*25.6	—	*29.4
15–24	*5.1	*2.4	—	*7.4	*29.6	*25.3	—	*28.1
25–44	*4.7	*3.7	—	*8.4	*27.5	*39.4	—	*31.7
Total	17.1	9.4	—	26.5	100.0	100.0	—	100.0
Need help with non-core activities								
0–4	**1.1	**1.0	—	**2.1	**5.8	**9.6	—	**7.1
5–14	*5.6	*2.1	—	*7.7	*30.5	*20.0	—	*26.5
15–24	*7.0	*3.1	0.2	10.2	*37.9	*28.6	100.0	34.9
25–44	*4.7	*4.5	—	*9.2	*25.8	*41.8	—	*31.5
Total	18.4	10.7	0.2	29.3	100.0	100.0	100.0	100.0

Notes

1. Estimates marked with * have an associated relative standard error (RSE) of between 25% and 50% and should be interpreted accordingly.

2. Estimates marked with ** have an associated relative standard error (RSE) of greater than 50% and should be interpreted accordingly.

Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers confidentialised unit record file.

Table 7.10: People with CP and like disabilities living in households: type of assistance received and extent to which need for assistance met, 2003

	No provider	Informal only	Formal only	Informal and formal	Total	Total informal[a]	Total formal[b]
Total core activity			Number ('000)				
Fully met	—	*8.4	—	*8.7	**17.1**	17.1	*8.7
Partly met	—	*4.6	**0.5	*4.2	***9.4**	*8.8	*4.7
Total	—	13.0	**0.5	12.9	**26.5**	26.0	13.4
Total non-core activity							
Fully met	—	*7.2	**0.7	10.5	**18.4**	17.7	11.2
Partly met	—	**2.1	—	*8.6	**10.7**	10.7	*8.6
Not at all	**0.2	—	—	—	****0.2**	—	—
Total	**0.2	*9.2	**0.7	19.1	**29.3**	28.4	19.8
Total both core activity and non-core activity							
Fully met	—	*6.1	**0.4	*8.4	**14.8**	14.5	*8.8
Partly met	—	**2.1	—	*7.4	***9.5**	*9.5	*7.4
Not at all	**0.2	—	—	—	****0.2**	—	—
Total	**0.2	*8.1	**0.4	15.8	**24.5**	24.0	16.2
			Per cent				
Total core activity							
Fully met	—	*49.2	—	*50.8	**100.0**	100.0	*50.8
Partly met	—	*49.3	**5.6	*45.0	***100.0**	*94.4	*50.7
Total	—	49.3	**2.0	48.8	**100.0**	98.0	50.7
Total non-core activity							
Fully met	—	*39.0	**3.8	57.2	**100.0**	96.2	61.0
Partly met	—	**19.4	—	*80.6	**100.0**	100.0	*80.6
Not at all	**100.0	—	—	—	****100.0**	—	—
Total	**0.7	*31.6	**2.4	65.3	**100.0**	96.9	67.7
Total both core activity and non-core activity							
Fully met	—	*40.9	**2.5	*56.6	**100.0**	97.5	*59.1
Partly met	—	**21.8	—	*78.2	***100.0**	*100.0	*78.2
Not at all	**100.0	—	—	—	****100.0**	—	—
Total	**0.8	*33.2	**1.5	64.5	**100.0**	97.7	66.0

(a)   Includes informal only, both informal and formal.

(b)   Includes formal only, both informal and formal.

Notes

1.   Estimates marked with * have an associated relative standard error (RSE) of between 25% and 50% and should be interpreted accordingly.

2.   Estimates marked with ** have an associated relative standard error (RSE) of greater than 50% and should be interpreted accordingly.

Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers confidentialised unit record file.

7.3 Conclusion

In summary, of the 33,800 of people with CP and like disabilities, 2,000 people lived in cared accommodation. Of those living in households, 26,500 people needed assistance with core activities (Table 7.1). Compared with the broader population with disability, people with CP and like disabilities were more likely to need very frequent assistance with core activities (6 times a day or more), and had higher rates of need for assistance with self-care and communication (Table 7.2.)

Of the 26,500 people who needed assistance with core activities, 13,400 received formal services (including 12,900 who also received informal assistance), and 13,000 received informal assistance only (Table 7.10). About 9,400 people who needed help with core activities had their needs only partly met. Of these, around 4,600 received informal assistance only.

Of the 13,400 people who needed help with core activities and were clients of formal services, 4,700 had their needs only partly met (Table 7.10). Although the SDAC population data contain no information about specific types of formal service agencies, as discussed in earlier chapters, the profile of support needs of the population group with CP and like disabilities was similar to that of clients of CP Australia agencies, characterised by high rates of need for help with the core activities of self-care, mobility and communication. These 13,400 people with CP and like disabilities could reasonably be considered as similar to clients of CP Australia agencies.

Those 13,000 people who received informal help only for core activities are considered not to be clients of service agencies for the purposes of this study (although it is possible that some of these people were accessing formal services for other types of assistance). Of these, 4,600 people had their needs only partly met.

Of people with a severe or profound schooling restriction, about 77% (8,400) received some kind of support or special arrangement (Table 7.3). About 7,900 people were either attending a special school or a special class at a mainstream school (Table 7.4).

Among people with a severe or profound employment restriction, only 4,900 (27%) received some support or special arrangements. Most people were not in the labour force. Only about 6,400 people were employed.

Most working age people in this group relied on a government pension or allowance as their main source of cash income. A majority (73% or 23,200 people) of people with CP and like disabilities lived in major cities of Australia, compared to 66% of the overall Australian population.

8 Archetypal cases

8.1 Introduction

Estimation of the cost of meeting unmet need for therapy is an important aspect of the project. National data sources alone provide inadequate information relevant to this issue. An archetypal cases approach was developed to fill this data gap, by drawing on the wealth of knowledge held by experienced therapists who work with people with cerebral palsy and like disabilities (see Section 2.2).

While there is enormous variation in the needs and situations of people with cerebral palsy and like disabilities, to estimate costs it is necessary to generalise across some of this variation. The archetypal cases approach was developed as a way of doing this, while capturing the main dimensions of variation in the overall cost of therapy.

Archetypal cases are hypothetical client profiles, intended to represent key groups in the client population. A set of archetypal cases was used as a vehicle for gathering information from therapists about the therapy and equipment needs of different client groups and the extent to which these needs are met. This information is used as a basis for estimating the costs of providing services to meet the therapy needs of these different groups.

In Chapter 9 of this report, the costed archetypal cases are brought together with other available data to estimate the cost of meeting unmet need. They are a key input into the data triangulation approach used to produce overall estimates of the cost of unmet need.

In addition to their role in costing, analysis of the archetypal cases provides insights into how therapy and equipment needs vary (in quantity and nature) with age and disability severity, and how the mix of therapy and equipment interventions provided to clients is affected by resource constraints.

This chapter outlines the archetypal cases method and presents analyses of the resulting data on hours of therapy required, cost, and estimates of unmet need.

8.2 Method

A summary of the archetypal cases method is illustrated in Figure 8.1. The main steps are described below. This innovative methodology was developed with advice from a panel of people with expertise in a range of relevant areas. Members included actuaries, economists, clinicians and service managers.

Definitions of key terms are given in Box 8.1.

Developing the archetypal cases

Define archetypal case categories and subcategories

age x disability severity

| 'median' | 'additional needs' |

Develop case stories for each subcategory

'Trial run': develop therapy regimes for sample case stories. Refine stories and recording method.

Input from clinicians

Develop 'ideal' therapy and equipment regimes for each case story. Record:

- details of individual interventions
- client-attributable hours
- travel time

Alter 'ideal' regimes assuming resources available are 75%, 50% and 25% of 'ideal'.

Analysis of therapy and equipment regimes

Total 'ideal' hours per case story
(replicates from two states per story)

Quantitative analysis:

- % travel
- clinicians vs. therapy aides
- impact of age, severity and needs on total hours
- national estimate for total hours in each case story

Qualitative analysis:

- what is an 'ideal regime'?
- how do regimes change with fewer resources?
- what do therapists consider as priorities?

Figure 8.1: Archetypal cases method: developing the archetypal cases and analysing the therapy and equipment regimes

> **Box 8.1: Key terms relating to archetypal cases**
>
> *Archetypal case categories*: the nine age-by-severity categories used to divide up the population of people with CP and like disabilities; there are two case stories within each category – a typical 'average' client, and a typical 'additional needs' client.
>
> *Additional needs*: elevated need for therapy for a limited period of time, due to transition points associated with different life stages (such as initial diagnosis, moving into primary or high school, moving out of home), recovery from surgery or acute personal factors.
>
> *Clients*: people with CP or like disabilities who are in contact with CP agencies or other similar specialist services, whether or not currently receiving therapy services.

Archetypal case categories

The archetypal cases are a set of case stories, each of which fits within an archetypal case category. The categories were used as a means of dividing the population of people with CP and like disabilities into mutually exclusive groups. The creation of the categories was guided by two principles: (i) capturing as much as possible of the variation in therapy and equipment costs, and (ii) characterising each category in terms of a small number of parameters, which are reflected in key national data.

As a first step, factors important in predicting need for therapy and equipment were identified using information gathered during the focus groups, and from relevant literature. Factors identified are summarised in Table A8.1, which also indicates which of the factors correspond to data items in national data collections.

Age and severity were chosen for defining the categories because these are two key factors in predicting need for therapy that can also be represented using data items in national data collections. This is crucial, as the archetypal cases alone cannot be used to estimate the cost of unmet need. Rather, age group and severity act as data 'hooks' in the archetypal cases that enable them to be used in conjunction with data from other key sources to provide national cost estimates. While there is not a data item called 'severity' in either the CSTDA or the ABS disability survey, both sources contain data on frequency of need for support with core activities (self-care, mobility and communication), which can be used to construct a severity variable (see Section 9.3).

The archetypal case categories are:

1. Age 0–4, mild/moderate disability
2. Age 0–4, severe disability
3. Age 5–14, mild/moderate disability
4. Age 5–14, severe disability
5. Age 15–24, mild/moderate disability
6. Age 15–24, severe disability
7. Age 25–44, mild/moderate disability
8. Age 25–44, severe disability
9. Age 45 and over, mild/moderate disability

Only one severity level (mild/moderate) was used for the '45 and over' age group. This was primarily because the methodology used to develop each case story could not be strictly adhered to, that is, there were not insufficient actual files in the 'severe' category of this age group to consult in order to develop an average archetypal case. Additionally, members of the project team advised that, compared with the younger age groups, therapists' experience concerning the needs of older people with CP or like disabilities was likely to be relatively limited.

Case stories

Within each archetypal case category two case stories were developed:

- a typical 'average' client—someone in the middle of the spectrum of clients in the category in terms of therapy/equipment resources needed.
- a typical client with 'additional needs'—someone who requires extra equipment and/or therapy input for a period of time, and is near the top of the category in terms of therapy/equipment resources needed.

Additional needs may be due to transition points associated with different life stages (such as initial diagnosis, moving into primary or high school, moving out of home), recovery from surgery, or acute personal factors. This split within categories was made because there was strong evidence from the literature and focus groups suggesting that people at such transition points tend to need more and/or receive more therapy. This factor was not used in the definition of the archetypal case categories themselves because few of these transition points can be identified using data items in national data sources.

The 18 case stories were developed by extracting common themes and goals after examining a selection of client files. Thus the stories reflect the needs and circumstances of real clients, but are not identifiable as any individual client. A pilot exercise with a group of experienced therapy professionals was used to refine the case stories and the instructions on developing the therapy and equipment regimes. Example case stories are presented in Appendix C. A table summarising the key features of each of the 18 case stories is presented in Table A8.2.

Developing the therapy and equipment regimes

Therapy and equipment regimes for the case stories were developed by four groups of experienced therapy professionals in four different jurisdictions. For each case story, the groups undertook the following exercise:

- Specified an ideal therapy and equipment regime relating to the stated goals for the person described, detailing interventions and quantifying them in hours, in terms of clinician and therapy aide time, including travel time (set to 1 hour per return trip[12]).

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12 The four groups of therapy professionals estimated average return trip travel times ranging from 1 to 2 hours. Data available suggested that a figure closer to the bottom of this range would be most realistic; also, excessive use of clinician time in travel should not be considered best practice. It would be difficult to account in a detailed way for real differences in average travel time around Australia. Choosing to use 1 hour as the return trip travel time for all regimes is consistent with a conservative approach to estimating need for therapy.

- Detailed how this ideal regime would be modified if only 75%, 50% and 25% of the therapy resources were available.

- Estimated the proportion of clients (with the age, disability severity, and additional needs status represented by that case story) who were receiving a therapy and equipment regime equivalent to:
    - the 75% regime or more
    - between the 25% regime and 75% regime
    - the 25% regime or less.

Three groups worked on the case stories in category 9 (age 45 and over), and two groups worked on each of the other case stories. This produced three jurisdictional replicates for the case stories in category 9, and two for all other case stories.

In developing the therapy and equipment regimes, the groups were asked to consider what therapy/equipment should be provided within a 6-month period to address the goals given in the case story.

As a way of benchmarking the ideal regime, the groups were instructed to include only therapy and equipment that could reasonably be hoped for in a 'real world' context—the test of this was that one or more of the participants must have known of instances where someone in similar circumstances to the case story received a comparable regime. Instructions also specified that the regime should embrace best practice principles, reflecting both the ICF and family centred/client centred practice. That is, it should relate to the specified client and family goals, and comprise a program of interventions designed to be delivered in the least restrictive environment. Disciplines 'in scope' for the regimes were physiotherapy, occupational therapy, speech pathology, psychology and social work.

A spreadsheet was developed to record the therapy/equipment regimes and estimated levels of unmet need for each case story. The work of each group in filling out these templates was led by the project team member in that jurisdiction, using standard materials developed by AIHW and CP Australia. Before the exercise was carried out, group leaders had a briefing session with AIHW and CP Australia project leaders to ensure that all groups were following the same approach in developing the regimes and estimates.

Example sets of therapy and equipment regimes are presented, together with their corresponding case stories, in Appendix C.

Analysing the therapy and equipment regimes

For each case story, the therapist groups developed a set of regimes: 'ideal', '75%', '50%' and '25%' regimes. Qualitative and quantitative analyses of these regimes were undertaken by the AIHW.

Qualitative analysis involved looking at how the content of regimes varies by age group and severity, and how content changes when resources are limited, in terms of the relative quantity of different types of intervention and associated activities (e.g. travel). Details are given in Section 8.3, below.

Quantitative analysis involved investigating the relationship between total client-attributable hours (in the ideal regime) and:

- age group
- severity
- additional needs status
- jurisdiction (that is, which state the therapist groups were from).

The results of this quantitative analysis informed the method for arriving at an overall number of therapy hours for each category, to be used as a basis for costing. Results are presented in Section 8.4, and unit cost figures applied in Section 8.5.

8.3 Qualitative analysis of archetypal cases

What does an ideal regime look like?

Client-attributable hours, including associated travel time, were calculated for each type of intervention within each regime. Then interventions were categorised into the intervention groups outlined in Box 8.2.

Using the intervention groups, the makeup of ideal regimes can be compared between archetypal case categories. Direct and indirect therapy accounted for a substantial proportion of client attributable hours in all categories, particularly for children aged under 15 and people with severe disability (Figures 8.2 and 8.3). More time was spent on equipment-related interventions for case stories with severe compared to mild/moderate disability. Interventions providing social support to clients and families were also significant contributors to total hours in a number of archetypal case categories, especially in the 0–4 years age group.

Among individual case story replicates, indirect and direct therapy were the intervention groups most likely to be included. In contrast, interventions classified as information and education, interagency liaison and general administration were included in less than half of all ideal regimes (Table 8.1). Total hours for administration was affected by the differing level of detail provided by groups when regimes were developed. One group recorded administration generally, while others specified, for example 'physiotherapy report writing'. The latter was properly classified as indirect therapy.

Box 8.2: Intervention groups

Indirect equipment interventions

- *Researching items*

- *Funding applications*

- *Providing information about options*

Direct equipment interventions

- *Initial assessment of equipment needs*

- *Trialing items*

- *Training in the use of items*

Indirect physiotherapy, occupational therapy and speech pathology

- *Program development*

- *Report writing*

- *Team meetings that do not involve the client*

Direct physiotherapy, occupational therapy and speech pathology

- *Hands-on therapy*

- *Hydrotherapy*

- *Includes school visits where therapy interventions take place*

- *Transport training*

Assessment/review

- *Discipline-specific assessments or reviews, except social work/psychology*

- *Equipment reviews (existing items only)*

- *Environmental assessment*

Social work/psychology

- *Direct social work and psychology sessions with the client*

- *Social work/psychology assessment*

- *Researching and providing information to support the client's participation (for example, links to community services, exploring daytime activities)*

(continued)

Box 8.2 (continued): Intervention groups

Family support

- *Family playgroups*

- *Parental education workshops*

- *Sibling activities*

- *Respite*

- *Social work for family members other than the client*

- *Provision of information to families*

Education and training

- *Training aides or carers*

- *Educating and training school staff*

- *Preparing/distributing school information packages*

Interagency liaison

- *Communication between public and private therapists, including alternative therapists*

- *Communication between therapists and medical professionals*

Client/family meetings

- *All meetings with the client/family*

Administration

- *General documentation*

- *Statistics*

For some analyses it was desirable to reduce the number of groups. Therefore, the groups described above were combined into:

- *'Therapy' (direct and indirect together)*

- *'Equipment' (direct and indirect together)*

- *'Assessment' (assessment/review)*

- *'Support' (family support, social work/psychology, and client/family meetings)*

- *'Information' (education and training, and interagency liaison)*

- *'Administration'*
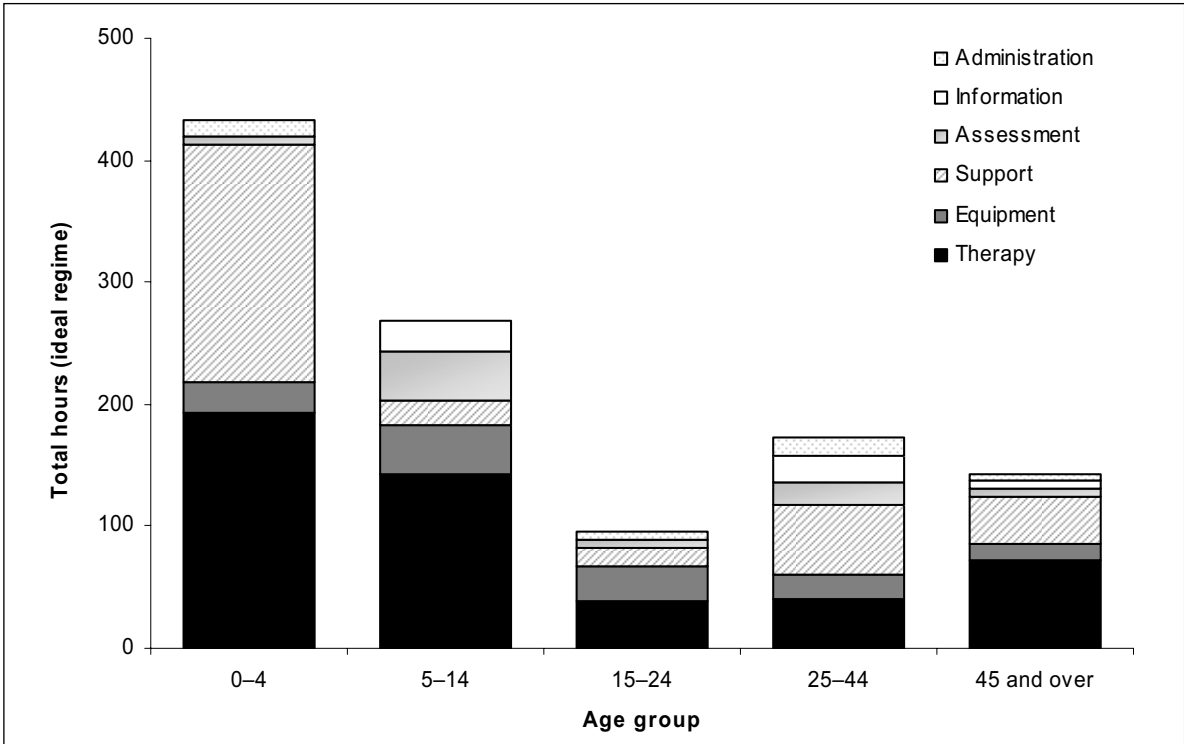
Note: See Box 8.2 for explanation of the intervention categories used in this figure

Figure 8.2: Mild/moderate disability: breakdown of total hours (ideal regime) by intervention categories, averaged across median and additional needs regimes and state replicates
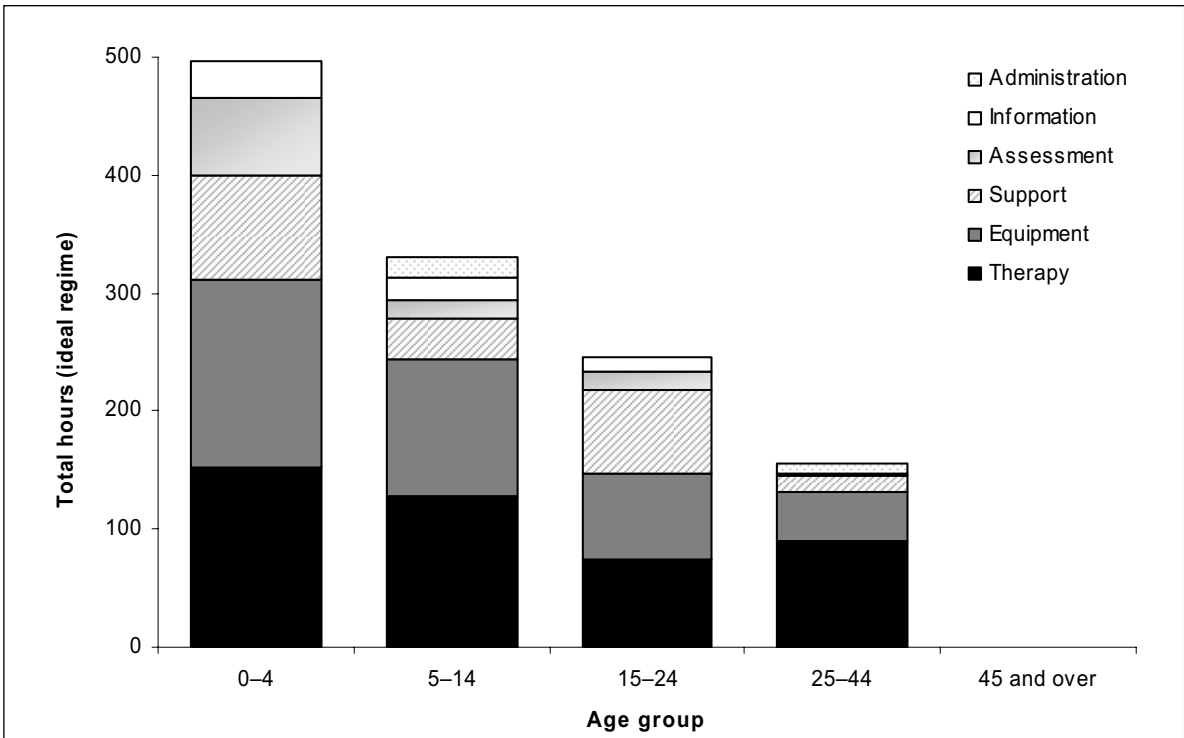
Note: See Box 8.2 for explanation of the intervention categories used in this figure

Figure 8.3: Severe disability: breakdown of total hours (ideal regime) by intervention categories, averaged across median and additional needs regimes and state replicates

Table 8.1: Frequency of occurrence of intervention groups across all ideal regimes

	Regimes including this group	
Intervention group	**No.**	**%**
Therapy (indirect)	36	94.7
Therapy (direct)	31	81.6
Equipment (indirect)	27	71.1
Equipment (direct)	26	68.4
Client/family meetings	25	65.8
Assessment/review	24	63.2
Social work/psychology	23	60.5
Family support	21	55.3
Administration	15	39.5
Interagency liaison	14	36.8
Information and education	10	26.3

Reduced resource regimes

Therapist groups altered the ideal regimes for each case story to produce 'cut down' regimes, with total hours of 75%, 50% and 25% of the ideal. Hours were cut by reducing the frequency and/or duration of interventions, or the number of staff involved, or by eliminating interventions altogether, according to therapists' assessment of priorities for the case story in question.

Social work/psychology and family support interventions were the intervention groups most likely to be removed from therapy regimes when resources were reduced—these interventions were dropped from almost 40% of regimes when resources were restricted to 25% of the ideal (Table 8.2). Hydrotherapy was the single intervention that most commonly dropped out as resources were reduced. Other individual interventions that tended to be removed were resource-intensive training (such as Hanen training), support groups, training or discussion of equipment options, and interventions related to community participation (such as transport training, leisure activities, and links to community groups).

The contribution of different intervention groups to total client-attributable hours varied between the ideal and reduced resources regimes. While the actual hours associated with each intervention group invariably decreased between the ideal and 25% regimes, some groups comprised a greater percentage of total hours in the 25% regimes compared to the ideal (Table 8.3). This reflects the decisions made by therapists about which interventions take priority when resources are limited. The average percentage of time spent on direct therapy decreased with each reduction in resources while indirect therapy increased.

Table 8.2: Deletion of intervention groups in 25% regimes

Intervention group	% deleted
Social work/psychology	39.1
Family support	38.1
Interagency liaison	21.4
Administration	20.0
Equipment (direct)	19.2
Equipment (indirect)	14.8
Therapy (indirect)	13.9
Information and education	10.0
Therapy (direct)	9.7
Assessment/review	8.3
Client/family meetings	4.0

Note: The data in this table represent the percentage of 25% regimes that have no entries for an intervention group, out of all case story replicates that included the group in the ideal regime.

Table 8.3: Contribution of different intervention groups to ideal and 25% regimes

Intervention group	No. ideal regimes including this intervention	% of total hours accounted for by intervention groups		Change between ideal and 25% regime
		ideal	25%	
Therapy (indirect)	36	15.3	21.6	↑
Therapy (direct)	31	33.5	18.8	↓
Equipment (indirect)	27	16.8	20.4	↑
Equipment (direct)	26	12.8	14.8	↑
Client/family meetings	25	5.0	8.5	↑
Assessment/review	24	10.6	16.7	↑
Social work/psychology	23	17.9	14.3	↓
Family support	21	14.1	12.3	↓
Administration	15	8.2	10.3	↑
Interagency liaison	14	5.6	4.2	↓
Information and education	10	11.1	8.1	↓

Notes

1. The figures presented in the table are the percentage of total hours made up by different intervention groups, averaged over all regimes that included the group. As not all regimes include all eleven intervention groups, the columns do not sum to 100%.

2. Intervention groups that contribute a greater percentage to total hours in 25% regimes compared to ideal regimes are marked with an arrow pointing up. Intervention groups that contributed a smaller percentage to total hours in 25% regimes than ideal regimes are marked with an arrow pointing down.

Qualitative differences in individual interventions between the ideal and reduced resources regimes were also apparent across case stories. The key patterns were:

- Centre-based appointments replaced home visits.

- Meetings between professionals (such as between therapists and hospital staff) were replaced by phone discussions.

- The number of therapists involved in complex interventions decreased.

- Family meetings often involved a single therapist acting in a transdisciplinary role (or else only the discipline relating to the client's area of highest need was represented).

- Interventions were limited to a single goal (for example, speech therapy for mealtime management only, not also for communication).

- Team meetings became discussions between only two therapists.

- Team meetings became as short as 15 minutes.

- In some cases, when the frequency of sessions of a particular type of intervention was reduced, the length of the sessions were increased to partially compensate.

- Giving out information replaced interactive workshops.

- Occasionally aides were used to replace therapists, but as aide training is often required, this was not widely used as a means of reducing resource input.

8.4 Quantitative analysis of archetypal cases

Relationship between age, severity and additional needs on total hours

Total client attributable hours over a 6-month period were calculated for each ideal regime and for each state replicate (Figures 8.4 and 8.5).

Generalised linear modelling methods were employed to study the relationship between the age group, severity and additional needs variables and total hours. Age group and severity were found to be statistical predictors of total hours in an interactive model (p=0.032). Case stories in older age groups tended to receive fewer intervention hours than those in younger age groups, while increased severity was associated with higher total hours in all age groups below 25 years. Severe disability case stories in the 25–44 years age group had slightly fewer hours for the six month period than mild/moderate case stories in the same age group.

These patterns may reflect therapists' perceptions of greater need for therapy input in younger age groups, which is consistent with the principle of early intervention, that is, that access to therapy and equipment early in life can have an important role in preventing problems later in life. However, it is also possible that, in developing the regimes, the groups may have been influenced by current funding realities that result in less therapy being available for adults than children.

The impact of severity may also reflect a clinical reality. That is, younger clients with more severe disabilities may tend to receive more therapy than those with mild/moderate disability, particularly interventions addressing impairment and activity goals. For adult clients, those with less severe disabilities may have more apparent potential for improvement, and higher levels of participation (in community life, workforce, etc.), and this may be associated with a tendency to receive more therapy.

Note: Both/all state replicates are represented for each case story

Figure 8.4: Total client attributable hours over 6 months per ideal regime, mild/moderate disability case stories

Note: Both/all state replicates are represented for each case story

Figure 8.5: Total client attributable hours over 6 months per ideal regime, severe disability case stories
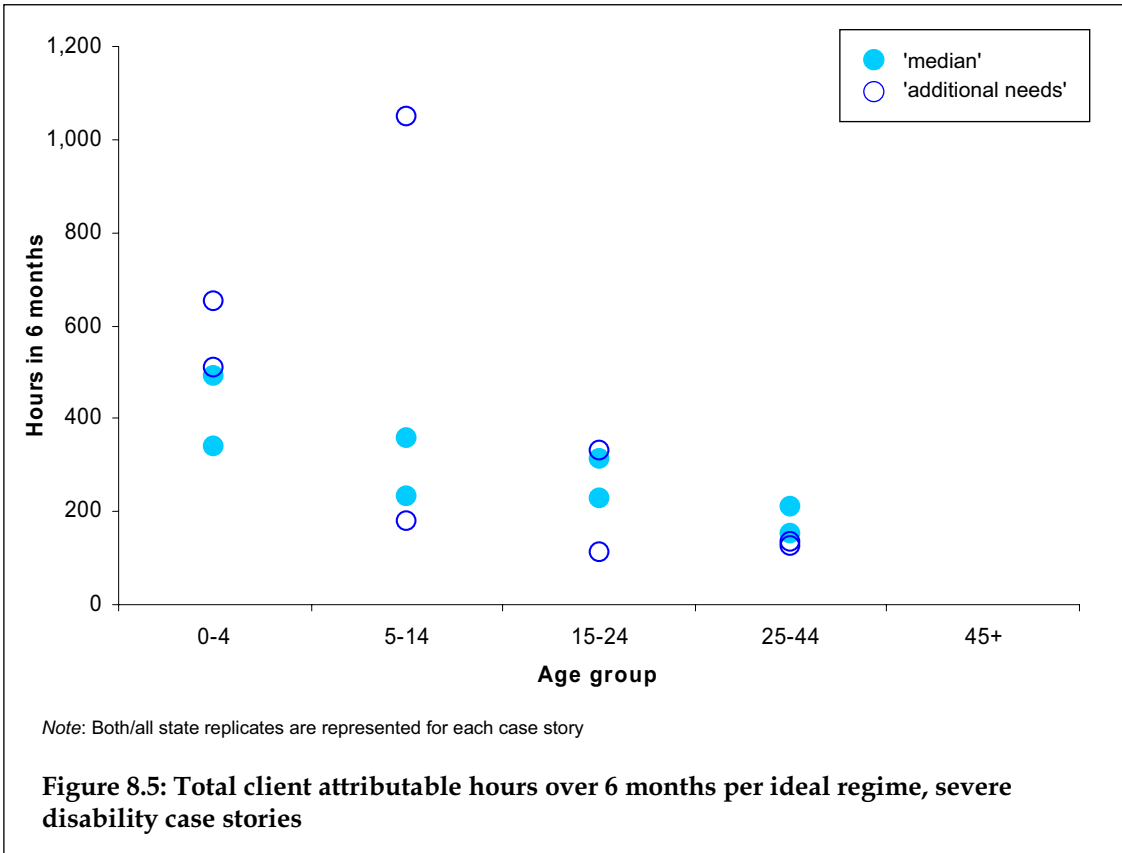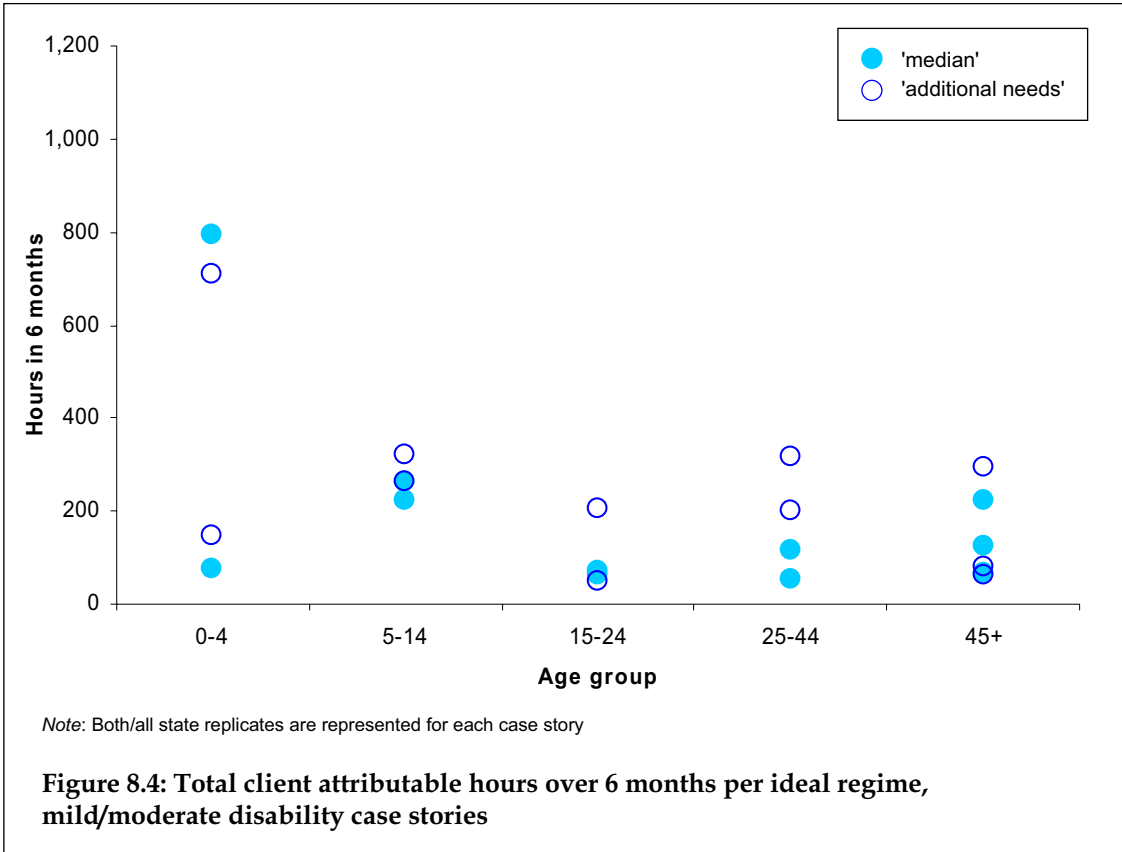
'Additional needs' status did not emerge as a predictor of total hours from the modeling exercise. That is, there was no significant difference between total hours for 'average' and 'additional needs' case stories. Possible reasons for this include:

- A person's additional needs may take priority over and displace ordinary ongoing needs for a period of time, so that different interventions are provided but total therapy time is not greater.

- People with additional needs may be more likely to receive some therapy; that is, they may receive priority over others, rather than receiving more hours. However, this is not reflected in the therapists' estimates of unmet need for 'average' and 'additional needs' clients — see Section 8.6, below.

- Additional needs may be managed by prioritising needs and having targeted episodes of intervention, rather than by adding extra hours — perhaps due in part to staffing realities.

- There may be a temporal 'smoothing' effect in service provision — that is, peaks and troughs are smoothed to avoid overloading clients during a period of additional needs.

- Therapy provided is influenced not only by the person's apparent needs, but also by the family's readiness for therapy.

Differences between states

While there was reasonable consistency between ideal regimes for case story replicates in terms of total intervention hours, one state provided estimates that were substantially lower than the other three states. The extent of the difference is particularly apparent in the 0–4 age group in Figure 8.4 (mild/moderate disability) and the 5–14 age group in Figure 8.5 (severe disability).

A generalised linear modeling exercise was conducted to explore this state effect. Across all regimes, total hours were significantly lower for the outlier state than for the other three states (p=0.017). The difference was even more pronounced when age group was included as an effect in the model (p=0.001). Compared with total hours for regimes developed by the group of therapists in the outlier state, average total hours for regimes developed by groups in the other states were 5 times greater in the 0–4 age group, double in the 5–14 age group, and nearly 4 times greater in the 15–24 years age group (Table 8.4).

Table 8.4: Average hours per regime by age group, outlier state versus other states

Age group	Average total hours of ideal regimes from outlier state	Average total hours of ideal regimes from other states
0–4	111.9	582.6
5–14	206.4	413.0
15–24	58.3	208.1
25–44	143.2	170.7
45 years and over	104.1	161.4

In developing the ideal regimes, therapists may have been influenced by their experience of resource constraints in their state, and this may in part explain the variation. Indeed, this link to reality was built into the method, in that groups were instructed that at least one participant must have known of a client in similar circumstances to the case story who had received therapy/equipment comparable to the ideal regime.

The effect of the outlier state was a concern particularly because it affects only half of the case stories (that is, those assigned to the group from that state). However, it was decided that no adjustment should be made for state differences. Instead, simple averages were taken of the replicates for each case story. The reasons for this were:

- all replicates provide valid information reflecting the professional opinions of experienced therapists, in response to the instructions provided to the groups
- only four states participated in the exercise; if other states had participated they may have provided total hours estimates closer to those of the outlier state than those of the three higher states.

Use of therapy aides

Therapy aides were used in 45% of ideal regimes. Client attributable hours delivered by aides accounted for 5.8% of total hours in ideal regimes, averaged across all regimes (including those that did not use aides at all). States did vary in their tendency to use aides, but there were no consistent patterns in the distribution of aide hours between age or severity groups, or between ideal and reduced resource regimes.

Travel time

The contribution of travel time (clinician and aides combined) to total therapy hours, and how this changes with each successive 25% restriction in resources, was analysed. The results indicate that travel time reduces as a proportion of total hours as resources are restricted (Table 8.5). This is largely due to therapists substituting centre-based interventions for home-based interventions as they rationalise resources.

Table 8.5: Travel as a percentage of total client-attributable hours, average of all case story regimes

Regime	Ideal	75%	50%	25%
% travel	26.3	25.6	24.0	21.9

Agency data provided by CPAWA (Chapter 6, Table 6.12) indicate that travel accounted for 16.6% of all client-attributable time in 2005, averaged across all clients. The higher proportion of travel in the archetypal cases may reflect a focus on the best practice model of service delivery, where assessments and interventions preferentially take place in a client's normal living environment—home, school and/or workplace.

Average annual ideal hours for each age-by-severity category

In order to use the archetypal cases as a basis for estimating the cost of unmet need, it was necessary to produce a single figure representing annual ideal hours for each age-by-severity category. This involved:

- averaging total hours for regimes in each category, and
- converting total hours for a 6-month period into total hours for 12 months.

Calculating average total hours for a 6-month period

As discussed above, it was decided to use state replicates for each case story without any adjustments. As a result, total hours for categories including regimes developed by the outlier state can be expected to be lower than they might otherwise have been. The decision not to adjust the hours upwards to account for this effect is consistent with a conservative approach to estimating cost.

As 'additional needs' status was not a predictor of total hours, the case stories for 'average' and 'additional needs' clients within each age-by-severity category were treated as replicates. Thus, for all but one age-by-severity category, state replicates for 'average' and 'additional needs' case stories were averaged.

A different procedure was used for Category 4 (severe disability, age 5–14). The two replicates for the 'additional needs' case story in this category had very different total hours—(see Figure 8.5). The high figure was due to a regime that involved intensive equipment-related interventions associated with a high-technology communication device. It was considered that, although total hours were very high for this replicate, it is likely to reflect real best practice in a state in which a specialist high-technology service operates. Therefore, it was decided to use a weighted averaging approach for Category 4, as follows:

- Based on advice from expert panel members and CP Australia client data available from two states, it was estimated that approximately 20% of clients in this category would require similar high-technology equipment, and that episodes of high-intensity therapy input to set up the equipment and provide relevant training could be expected to be needed every 5 years (that is, twice within this age range—at entry to primary school and at transition to high school). Thus, in any year, approximately 4% of clients in this category would need an episode of high-intensity intervention.

- On this basis, rather than averaging the two 'average' and two 'additional needs' replicates in this category, a weighted average was used. The total hours figure for the 'high' additional needs replicate was multiplied by 4%, and the average total hours for the two replicates of the 'average' case story was multiplied by 96%. The 'low' additional needs replicate was excluded from the calculation of an overall average for the category.

Resulting from all the above calculations, average ideal hours figures for each age-by-severity category are given in Table 8.6.

Table 8.6: Average hours of therapy and related time per ideal regime in a 6-month period

Age group	Mild/moderate disability	Severe disability
0–4	432.6	497.3
5–14	268.0	454.7
15–24	95.3	246.0
25–44	172.4	155.2
45 years and over	142.3	n.a.

Converting 6-monthly figures to total annual hours

The archetypal case regimes were developed for a 6-month period to reflect the typically episodic nature of therapy delivery. However, as government funding is usually allocated on an annual basis it was desirable to translate the 6-monthly figures presented in Table 8.4 into annual estimates of ideal therapy time.

On the advice of the expert panel advising this aspect of the project the following approach was developed for converting 6-monthly to annual hours:

- For the 0–4 year age group, a high level of input is likely to be required throughout an entire year, as intensive, ongoing input is common for the first year or two after initial diagnosis. However equipment-related interventions, such as prescribing and training in the use of new aids, would only be expected to be needed once in 12 months. Therefore, the average hours for an ideal regime in each severity category, minus the hours associated with equipment-related interventions, were added to the 6-month estimate to arrive at an annual total.

- For all other age groups a doubling of the 6-monthly figures could not be justified, as ongoing therapy over a 12-month period would not generally be expected or considered desirable. Instead, an allowance for assessment and review throughout the remainder of the year was added to the 6-month average for each age-by-severity category. This was set at 6.7%, which was the proportion of intervention hours spent on assessment and review in the ideal regimes, averaged across all case stories and replicates.

Once annual figures for each age-by-severity category were calculated, total hours were split into clinician and aide hours by applying the average percentage of aide hours for the category (Table 8.7). These figures were used to cost the ideal regime for each category.

For each category, average hours per week over the original 6-month period are also presented in Table 8.7. These were calculated before adjustments were made to convert the 6-monthly figures to total hours annually. When interpreting the hours per week figures, it is important to remember that they include both direct and indirect service hours, and reflect time spent by all clinicians and aides involved in delivering services to the client over the 6 months.

Table 8.7: Total annual hours (ideal regime) for each archetypal case age-by-severity category

		Mild/moderate					Severe			
		Clinician	Aide	Total	*Hrs/wk*		Clinician	Aide	Total	*Hrs/wk*
0–4	Category 1	792.0	47.1	839.1	*16.6*	Category 2	768.7	66.8	835.5	*19.1*
5–14	Category 3	281.9	4.0	286.0	*10.3*	Category 4	308.8	39.6	348.4	*12.6*
15–24	Category 5	94.0	7.7	101.7	*3.7*	Category 6	256.6	5.9	262.5	*9.5*
25–44	Category 7	169.8	14.1	183.9	*6.6*	Category 8	155.6	10.0	165.6	*6.0*
45+	Category 9	143.5	8.3	151.8	*5.5*					

Note: Hours per week is the average hours per week for the 6 month period for which the regimes were originally developed.

8.5 Costing the therapy regimes

The ideal regime for each archetypal case category was costed by applying separate cost-per-hour figures to total hours for clinicians and therapy aides. The unit cost figures used were:

- $70 per hour for clinician time
- $44 per hour for therapy aide time.

These figures are intended to represent the actual cost (not just cost to government) of providing therapy services to people with CP and like disabilities, for CP Australia and similar specialist agencies receiving public funding. Both client attributable or direct costs and program support or indirect costs are included. An allowance for depreciation is also included, recognising that vehicles, equipment and buildings are essential for delivering therapy services. The unit cost figures were arrived at after reviewing available cost studies, service provider cost information, salary rates and unit price rates (see Appendix D).

Although hours delivered by aides accounted for, on average, less than 6% of total hours, it was considered important to cost aide time using a lower unit cost, because:

- This approach is in keeping with the objective of providing conservative cost estimates.
- It can be assumed that all use of aides specified in the ideal regimes (on which the costing of cut-down regimes is based) is consistent with a best practice approach, so to cost these hours at clinician rates would artificially inflate the cost of the ideal regime.
- The regimes can be assumed to take into account the need for supervision of aides, and the longer time that aides may take to do a task (so this would be reflected in the hours specified).

For the purpose of considering unmet need, clients within each category receiving therapy equivalent to the 75% regime, or more, are regarded as having their needs fairly well met. Therefore, 75% of the cost of providing the ideal regime is taken as the cost of meeting the therapy needs of each client in a given archetypal case category. The decision to regard clients receiving 75% of the ideal as having their needs met helps to ensure that estimates of the cost of unmet need based on data from the archetypal cases are defensible and not over-estimates; this is reflective of the overall conservative approach taken in this study.

The annual cost of the 75% regime for each archetypal case category was obtained by applying the unit cost figures to the ideal regime total hours figures in Table 8.7, above, and taking 75% of the resulting dollar amount (Table 8.8).

Table 8.8: Annual cost of the 75% regime for each archetypal case age-by-severity category

Age group	Mild/moderate		Severe	
0–4	Category 1	$43,138	Category 2	$42,561
5–14	Category 3	$14,932	Category 4	$17,519
15–24	Category 5	$5,189	Category 6	$13,666
25–44	Category 7	$9,380	Category 8	$8,499
45+	Category 9	$7,808		

Taking the cost of the relevant 75% regime as the cost of meeting the therapy needs of a given client, the cost figures in Table 8.8 can be used to calculate the cost of meeting unmet need for clients receiving less than the 75% regime. This is done as follows:

- It is assumed that clients receiving equivalent to between the 25% regime and 75% regime receive, on average, equivalent to 50% of the ideal regime; that is, two-thirds of the 75% regime. Therefore, an additional one-third of the cost of the relevant 75% regime would be required to meet their needs (Table 8.9).

- It is assumed that all clients receiving equivalent to the 25% regime or less receive equivalent to 25% of the ideal regime; that is, one-third of the 75% regime (this assumption is conservative, as some clients in this group are likely to be receiving less). Therefore, an additional two-thirds of the cost of the relevant 75% regime would be required to meet their needs (Table 8.10).

Table 8.9: Annual cost of meeting unmet need for clients receiving therapy equivalent to between 25% and 75% of the ideal regime, for each archetypal case age-by-severity category

Age group	Mild/moderate		Severe	
0–4	Category 1	$14,379	Category 2	$14,187
5–14	Category 3	$4,977	Category 4	$5,840
15–24	Category 5	$1,730	Category 6	$4,555
25–44	Category 7	$3,127	Category 8	$2,833
45+	Category 9	$2,603		

Table 8.10: Annual cost of meeting unmet need for clients receiving therapy equivalent to the 25% regime or less, for each archetypal case age-by-severity category

Age group	Mild / moderate		Severe	
0–4	Category 1	$28,758	Category 2	$28,374
5–14	Category 3	$9,955	Category 4	$11,679
15–24	Category 5	$3,459	Category 6	$9,111
25–44	Category 7	$6,253	Category 8	$5,666
45+	Category 9	$5,205		

Use of the archetypal case in data triangulation to estimate the cost of meeting unmet need for therapy among clients

In Chapter 9, three methods of estimating the cost of meeting unmet need for therapy are presented. The three methods use the population data, CSTDA data and archetypal cases data in the three possible pair-wise combinations.

The figures in Tables 8.9 and 8.10, together with therapists' estimates of unmet need (Table 8.11), are applied to counts of CP agency clients corresponding to each archetypal cases category, obtained from analysis of CSTDA data (Table A8.3).

In addition, the figures in Tables 8.9 and 8.10 can be used to calculate the cost of therapy regimes averaged across all nine categories. Rather than obtaining a straight average, a weighted average can be calculated to more accurately reflect the differences in regime costs and population numbers between categories:

- Population data analysis showed that slightly more than half of all people with CP and like disabilities had severe disability, which in the context of the archetypal cases was defined as always needing help in at least one core activity, as well as needing help or using aids in at least two core activities (Table A8.4). For the purposes of calculating a weighted average cost per therapy regime, the split between mild/moderate and severe disability was regarded as being equal in all age groups. The average of the annual costs associated with mild/ moderate and severe disability case stories (Table 8.8) was then averaged within each age group.

- The age distribution of people with CP and like disabilities was shown in Chapter 4 (Table 4.1). Multiplying the annual cost per age group by the percentage of people with CP and like disabilities in each age group, and summing the total, provides a weighted average annual cost of a 75% therapy regime. This equals approximately $13,900 per client (Table 8.11).

- The average annual cost per client of meeting unmet need for clients receiving therapy equivalent to between 25% and 75% of the ideal regime is 1/3 of $13,900, or $4,630.

- The average annual cost per client of meeting unmet need for clients receiving therapy equivalent to the 25% regime or less is 2/3 of $13,900, or $9,270.

These figures are used to estimate the cost of unmet need among clients, bringing together archetypal cases data and population data on people with partially met needs for assistance who are in contact with formal services.

Table 8.11: Calculation of the average cost of 75% therapy regimes, weighted for age and disability severity distribution in the population of people with CP and like disabilities

Age group	Average annual cost per client[a]	% of population with CP and like disabilities[b]	Contribution to weighted average
0–4	$42,850	8.6	$3,685
5–14	$16,226	26.5	$4,300
15–24	$9,428	31.9	$3,007
25–44	$8,940	29.6	$2,646
45 and over	$7,808	3.4	$265
Total		**100.0**	**$13,903**

(a)   Cost per client was calculated as the arithmetic average of the annual cost of the 75% regime for mild/moderate disability and severe disability case stories in each age group (Table 8.8). Figures are reported to the nearest dollar.

(b)   See Table 4.1 for more detailed breakdown of age distribution among people with CP and like disabilities.

8.6 Therapists' estimates of unmet need among clients

The four groups of experienced therapy professionals who developed the therapy and equipment regimes for the case stories also estimated the proportion of clients (with the age-by-severity category) who were receiving a therapy and equipment regime equivalent to:

- the 75% regime or more
- between the 25% regime and 75% regime
- the 25% regime or less.

This set of estimates was given separately for the 'average' and the 'additional needs' case story in each category. Further, for each case story this set of estimates was given separately for metropolitan and non-metropolitan areas. That is, within each archetypal cases category, each group produced four sets of estimates.

These sets of estimates varied greatly between replicates. Some of this variation no doubt reflects real differences in the level to which needs are met, and some probably results from the fact that it is difficult to accurately estimate levels of unmet need for specific client groups. Figures 8.6 and 8.7 show that there appears to be a tendency for the older age groups to have larger proportions of clients receiving equivalent to the 25% regime or less, and smaller proportions receiving equivalent to the 75% regime or more. This is consistent with information gathered from focus groups—therapy is more readily available for children than adults. There is no clear relationship between levels of unmet needs and severity of disability.
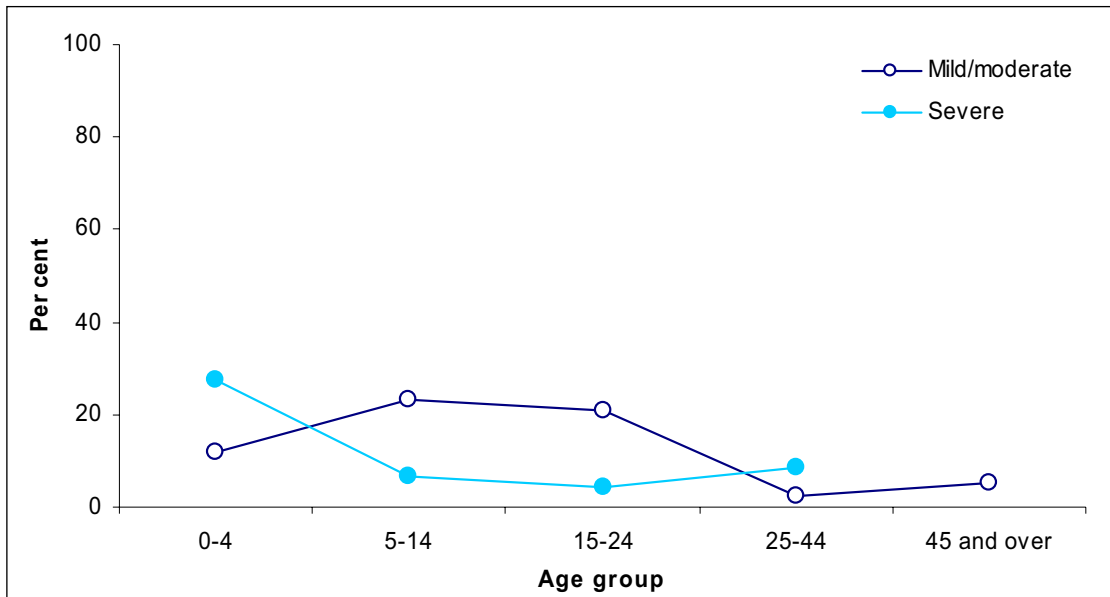
Figure 8.6: Clients receiving equivalent to the 75% regime, or more
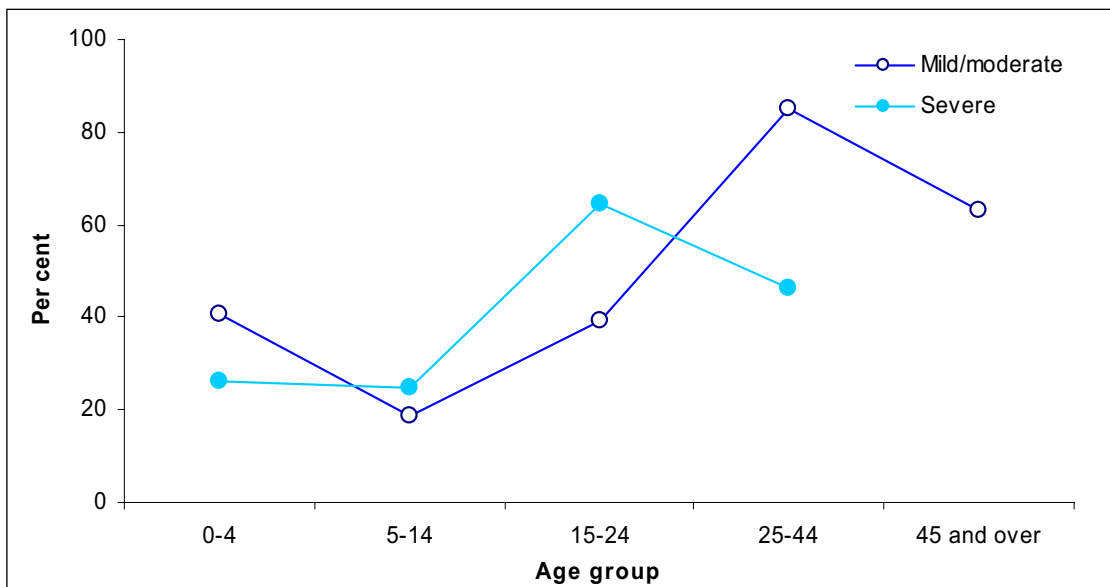
Figure 8.7: Clients receiving equivalent to the 25% regime, or less

In order to provide a national estimate of the percentage of clients in each category with these different levels of unmet need, estimates were averaged across state replicates, and also across the 'average' and 'additional needs' case stories within each category. The resulting figures, set out in Table 8.12, are applied to estimated numbers of people within each category who are in contact with specialist disability services (clients), based on CSTDA data (see section 9.2).

Averaging across all categories, and across estimates for metropolitan and non-metropolitan areas gives the following estimates:

- 13% of clients receive equivalent to the 75% regime or more
- 43% of clients receive equivalent to between the 25% regime and 75% regime
- 44% of clients receive equivalent to the 25% regime or less.

These figures are applied to the estimated overall number of people who are in contact with formal services and have partially met needs for assistance, based on population data (see section 9.2).

As explained above, because there was no statistical effect of additional needs status on total hours, regimes for the 'average' and 'additional needs' case stories were averaged to give a total hours figure for each category. 'Additional needs' clients had slightly higher estimates of unmet needs than 'average' clients. Therapists estimated that, on average, 48% of 'additional needs' clients receive equivalent to the 25% regime, or less, compared to 38% of 'average' clients. However, this pattern did not emerge as statistically significant in modelling analysis.

State was the only factor that was found to significantly influence the unmet needs estimates.

Table 8.12: Clients in each category receiving therapy and equipment equivalent to the 75% regime or more, between the 25% regime and 75% regime, and the 25% regime or less, by metropolitan or non-metropolitan area (average percentage)

		Archetypal cases category								
		1	2	3	4	5	6	7	8	9
Total	75% or more	12	28	23	7	21	4	3	9	5
	25–75%	48	46	58	69	40	31	13	46	32
	25% or less	41	26	19	24	39	64	85	45	63
Metropolitan	75% or more	18	38	29	8	21	8	4	10	5
	25–75%	38	34	49	74	40	30	19	60	43
	25% or less	45	29	23	18	39	63	78	30	52
Non-metropolitan	75% or more	6	18	18	6	21	0	0	8	5
	25–75%	58	59	68	63	43	33	0	30	15
	25% or less	36	24	15	31	40	67	100	62	80

8.7 Equipment issues

Equipment-related therapy interventions

In the focus groups, one of the factors raised by therapists as contributing to unmet need for equipment was the therapy time that needs to be spent prescribing, trialling and applying for equipment, and training in its use. Therapists commented that this time is generally not considered when large grants are periodically provided by governments to cut down equipment waiting lists. Analysis of regimes devised for the archetypal cases illustrates how therapy is associated with equipment.

Ninety-five per cent of the archetypal case regimes had equipment-related therapy interventions. These were divided into direct interventions (such as assessment of equipment needs, trialling and training in the use of items) and indirect interventions (sourcing items, providing information about options and completing funding applications). Fifty-three percent of these regimes involved both direct and indirect equipment-related interventions, 22% involved direct interventions only, and 25% had only indirect interventions. The relative contribution of equipment-related interventions to total therapy hours varied widely between case stories, from 1% to 66% of total hours in the ideal regime.

Averaging across all archetypal cases, equipment-related interventions accounted for just over 20% of total hours (Table 8.13). In the majority of regimes, equipment-related intervention time increased as a percentage of total hours with reduced resources. The relative contribution of equipment-related intervention time increased between the ideal and 25% regimes in almost two-thirds of case stories that included equipment-related interventions. For eight case stories (22%) the proportion decreased, and for one case story (3%) the proportion remained the same. For four case stories (11%), equipment-related interventions were removed altogether—in each case at 50% of ideal regime hours (Figure 8.8).

Table 8.13: Equipment-related therapy hours as a percentage of total therapy hours: average across all archetypal case 6-month regimes

	Ideal regime	75% regime	50% regime	25% regime
Direct	9.2	10.4	10.5	10.5
Indirect	12.2	12.6	13.5	14.0
Total	**21.4**	**22.9**	**24.0**	**24.5**

Figure 8.8: Change in the relative contribution of equipment-related interventions to total therapy hours from ideal to 25% regimes
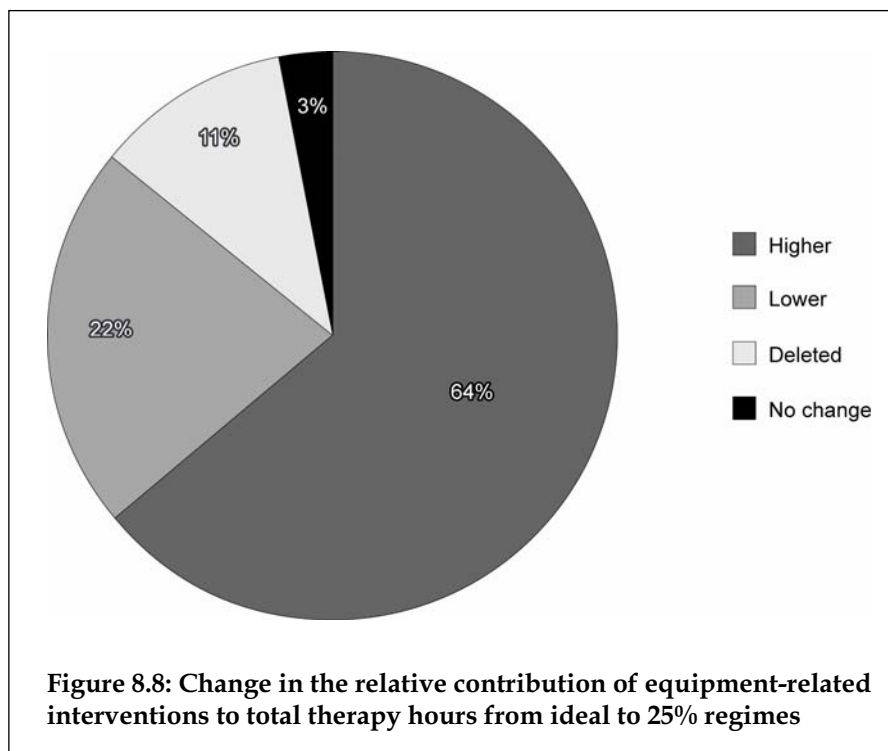
Costing issues

While the equipment identified in the archetypal case regimes is an important source of information about need for equipment, there are a number of issues that make it difficult to use this information as a basis for estimating the cost of meeting unmet need for equipment.

- An individual's need for equipment in a given 6-month period is not necessarily predictive of their need for equipment over a longer time frame. Often a large investment in equipment is needed at particular times, such as around transition points, then little else may be required for several years other than maintenance and repairs. Home modifications and the purchase/modification of vans are particularly high costs that seldom recur.

- Assumptions about replacement of items in ideal regimes differed between groups. While therapists were instructed to list only those new items that would need to be purchased, some groups included replacement of some equipment items already owned by the client, to account for growth or in anticipation of adulthood, when funding eligibility changes.

- The equipment lists were not modified in line with the reduced resources regimes, therefore it is not valid to apply therapists' estimates of unmet need (that is, the percentage of clients in each age by severity category who receive less than 25% of the ideal regime, and so on) to the purchase of equipment. Clients who receive less than 25% of the ideal regime do not necessarily receive equipment worth less than 25% of the cost of all equipment prescribed.

Equipment items prescribed for archetypal cases

Therapist groups provided lists of equipment to accompany each archetypal case regime, along with approximate costs of each item. Where therapists were unable to provide estimates, costs were obtained from various specialist sources, primarily the Independent Living Centre Equipment database and equipment waiting list data provided by CP agencies in New South Wales and Western Australia.

The equipment items listed by therapist groups varied greatly in price and complexity, from modified cutlery to adjustable beds, wheelchairs and augmentative communication devices. While most items were one-off purchases, continence products and food/food thickener for a gastrostomy tube were also listed.

While the cost of equipment prescribed for each case story varied considerably between state replicates, cases with severe disability were consistently prescribed more expensive equipment than mild/moderate disability cases. On average, therapists listed equipment costing $3,274 for mild/moderate disability case stories, compared to $26,905 for severe disability case stories. Age and 'additional needs' status did not appear to affect the cost of equipment prescribed. Expensive items contributing to the high cost of equipment in severe case stories included customised wheelchairs, modified vans, and sophisticated communication devices. While these items require regular servicing, updating and eventual replacement, the purchase cost would not be considered to recur annually. Therefore the average yearly expenditure on equipment for clients with severe disability is expected to be somewhat less than $26,905.

8.8 Discussion

The archetypal cases component of the project provides information on the nature and extent of unmet need for therapy, based on the knowledge of experienced therapists who work with people with CP and like disabilities. In Chapter 9, estimates of hours of therapy required and levels of unmet need for the 9 archetypal cases categories are brought together with population and disability services data to estimate the cost of meeting unmet need for therapy (Section 9.3).

The archetypal cases methodology relies on the advice provided by groups of allied health professionals who, it may be argued, are not necessarily impartial in their opinions about the amount and type of therapy needed by people with CP and like disabilities. However, the application of the method used here can be considered to be valid for a number of reasons:

- Therapists were provided with detailed instructions about what constitutes an ideal regime (see Section 8.2), including the stipulation that at least one member of the group must have known a client who received a level of service equivalent to the ideal regime. This ensured that the ideal regimes are deliverable in practice.

- The 75% regimes were used as the basis for calculating the cost of fully meeting need (Sections 8.5 and 9.3). Using these 'practical ideal' regimes as the benchmarks of met need is typical of the conservative approach used throughout the methodology.

- Ideal and reduced resources regimes were developed by at least two independent groups in different states for each case story. Despite different experiences of therapy funding and service delivery between states, the total hours associated with ideal regimes are of similar magnitude.

- The use of consensus opinions of a group of experts in the health sciences is not a novel approach. A review of two such methods—the Delphi process and the expert panel—is provided in Jones and Hunter (1995). These methods have wide application, including a number that may be considered to parallel the archetypal cases exercise here. For example, expert opinion is used to develop quality indicators in health care (Campbell et al., 2002).

The method used to devise the case stories for the archetypal cases was careful and thorough, based on an evaluation of typical case files for each archetypal case category. Likewise, the work of therapist groups in developing the therapy regimes was supported by a detailed set of instructions and a briefing session, to ensure as far as possible that all groups approached the exercise in the same way. Each of the groups included experienced professionals from a range of clinical backgrounds (Appendix E). Nonetheless, some caveats must be acknowledged:

- Comparison of the case stories with data on CSTDA clients confirms that they can be considered representative of clients in each of the age-by-severity categories in terms of their support needs; however, there is no practical way of testing whether the case stories represent the median in terms of therapy needs within each archetypal case category.

- There is no single best practice approach to addressing the therapy needs of any given client; different professionals will inevitably make different decisions about the ideal set of interventions for a particular case story, resulting in a level of unavoidable variation in the total hours used as a basis for costing the archetypal cases.

- Total hours for the 75% regimes were high, compared with data available from two states on actual hours of therapy received (Table 6.12 and Table 6.13). On this basis, it may be argued that the ideal regimes are unrealistic. However, analysis of services received by individual clients of CPAWA in 2005 shows that some clients did in fact receive equivalent to the 75% regimes, or more (Table 8.14). Comparing these data to the therapists' estimates that, on average, only 13% of clients receive therapy equivalent to the 75% regime, or more (Table 8.12), supports the validity of the archetypal cases methodology.

Table 8.14: Percentage of CPAWA clients receiving intervention hours equivalent to different therapy regimes, 2005

	0–4	5–14	15–24	25–44	45 and over
No. clients	107	289	155	138	102
≥75% regime	—	2.4	5.2	—	1.0
25–75% regimes	5.6	28.4	22.5	22.5	25.5
≤25% regime	94.4	69.2	77.5	77.5	73.5

Note: CPAWA data on hours received by individual clients are compared with archetypal cases annual hours for mild/moderate case stories only.

Source: CPAWA ; archetypal cases data, Table 8.7.

While the archetypal cases are a rich and unique source of information on need and unmet need for therapy and equipment, they only provide a partial picture. In particular, they do not provide specific information on the extent to which people with CP and like disabilities access therapy and equipment from sources other than specialist, publicly supported organisations such as CP Australia agencies, although this may be partly reflected in the

groups' estimates of levels of unmet need (that is, clients who access private therapy and also receive services from CP agencies may be included in therapists' estimates of the proportion of clients in the 75% and over group within each category).

While every attempt has been made to produce reliable but conservative estimates with this method, the archetypal cases do not claim to reflect the full breadth and diversity of experience concerning need for therapy, and levels of unmet need, across Australia. In particular, the needs and situations of Indigenous people from remote communities are different in many ways from those of people living in less remote parts of Australia, as is acknowledged in the literature review (see sub-section on 'Use of services' within Section 3.3).

9 Answering the main questions

This chapter sets out the key results of the study and draws these together to answer the questions posed by the three study objectives. The first and third study objectives are discussed in section 9.1. Findings on the second study objective are detailed in sections 9.2 to 9.4. Conclusions of these findings are summarised in section 9.5.

9.1 Do therapy and equipment make a difference?

The first study objective was to:

> Review and summarise the key findings of national and international literature about the definitions, costs and benefits of therapy, and whether therapy 'makes a difference' for people with disabilities related to, or similar to those related to, cerebral palsy—that is, its relationship to improvements in and maintenance of levels of functioning.

What are the benefits of therapy?

While there is an emerging literature concerning the efficacy of therapy for people with disabilities, there are as yet few published studies that provide a scientific evaluation of the benefits of individual types of therapy. Most research to date has focused on therapy interventions aimed at the impairment level. The impact of therapy on functioning and participation is a newer area of research.

Overall, examination of the literature found no strong evidence to either support or reject the benefit of therapy (see Section 3.7). In part, this is because of methodological issues associated with measuring the effects of therapy. Heterogeneity in the population group under consideration, including diverse and changing goals set by clients and families in a best practice model, make designing standardised outcomes measures difficult. Additionally, a strong belief in the effectiveness of therapy held by many clients and therapists prevents the construction of control groups for assessment of any potentially beneficial intervention; that is, clients do not willingly opt for a no therapy regime. Improved research techniques (including more sensitive outcome measures and greater consideration of effects on activity and participation, and the role of environmental factors) may see more definitive results produced in the future. In the meantime, the research neither proves nor disproves the efficacy of therapy.

Anecdotal evidence gathered during focus groups (Chapter 5) indicates that people with disabilities and their families generally attribute improved levels of functioning and participation to therapy.

- 'Therapy is the thing that keeps me sitting in my chair for 12 hours a day. Without it I'd be lying in bed unable to move.'
- 'Without it I might as well be dead. I can't move without it, I can't sit up without it.'
- 'It relieves pain associated with shoulder and neck and allows me to keep functioning.'
- 'I see results from therapy. If I don't see results there is no point in doing it.'

- 'She does horse riding and I find that really helpful in holding her head up. It gives her mobility and strength…and helps to improve her hip and body function.'

Some clients additionally described physical deterioration in the absence of therapy.

- 'When [my son] has physio, OT and speech [therapy] he thrives and when he doesn't he drops back. Now he's limping a lot and only speaks to me…He doesn't like speaking to other people because they don't understand him.'

- 'When she's had intensive speech or physiotherapy she's skyrocketed. When it stopped, it's dropped away just as quickly.'

- 'I do notice my muscles are looser and without physiotherapy I notice the stiffening of my muscles.'

Therapy was also believed to benefit people with disabilities emotionally and socially.

- 'Therapy is helping her become better integrated into society.'

- '[My daughter] is becoming more social and more with her peers in terms of being able to climb on playground equipment and things like that. And it means a dramatic improvement in her overall quality of life.'

One group of therapists listed interventions they considered to be most effective at sustaining and improving functioning. These included strengthening programs to delay surgery and prevent deformity, communication interventions, independence training and social skills training. However, it was noted that interventions are 'only effective in the context of a functioning family, supportive education systems and understanding community.'

Thus, while the research evidence is inconclusive, the message from the focus groups was unequivocal. The focus group participants, who had extensive experience with therapy, consistently described the connection between therapy and maintained or improved functioning, and expressed the view that therapy makes a difference and is a real need for many people with cerebral palsy and similar disabilities.

What are the benefits of equipment?

While the use of equipment by people with disabilities is not a topic generally covered by evidence-based research, throughout the course of this project clients, their families and carers, and allied health professionals were emphatic in their description of the benefits that specialised equipment can bring. Focus group participants gave many examples of often dramatic improvements in individual functioning and participation attributed to equipment provision. For example:

- One family added a modified bathroom to their house, allowing their teenage daughter privacy in bathing and toileting. This has given her 'a new lease on life'.

- Another family's home modifications enable their daughter to get herself to bed and use the kitchen.

- An adult with cerebral palsy gave a series of lectures at a university using a sophisticated speaking device.

- Several parents commented on the relief provided by hoists, slings and adjustable beds, without which they had experienced substantial back pain.

- 'From the computer I can access reading material because right now I have trouble turning pages. Also when I was driving I didn't have power steering, then when I deteriorated I benefited from power steering.'

- 'Equipment allows me to do the everyday things I want to do. I participate in the community—it increases the number of options, for example, a power wheelchair requires less energy than walking.'

- 'My gopher [scooter] opened up a new world…I go shopping and for coffee in my gopher.'

- 'Without these [powerchair, hoist and sling, incontinence aids, computer]…I wouldn't have a quality of life.'

The impact of equipment breakdown on clients' social participation was discussed. For example, clients whose wheelchairs broke down and who had no other seating equipment had spent days in bed while waiting for repairs. At least two clients who use communication devices had been unable to communicate for days or even weeks when the devices needed repairing and no replacement was provided.

The effects of provision of therapy and equipment

The third study objective was to:

> Estimate the effects of the provision of therapy and equipment in terms of improved or maintained individual functioning and participation, at different ages, and in terms of reduced social costs of disability.

There is as yet little in the way of published studies on the effects of therapy and equipment provision, making it difficult to quantify the effects of therapy. Again, we must rely on evidence from focus group discussions.

The potential for therapy and equipment provision to reduce the social cost of disability was widely supported by focus group participants.

> Equipment and therapy can have a flow-on effect to the family and the community…It has the potential to reduce medical complications and facilitate more time in the community…[There will be] less cost to the community because there will be fewer hospital admissions.

> [Therapy] has a flow-on effect to the family and to the community.

> [Therapy can result in] less burden on the hospital system, [clients] can learn to write, read and be employed.

The benefits of therapy and equipment to clients' families was mentioned, and several parents also commented on therapists as a source of information and ideas.

> [Therapy] makes a big difference to our life because I've got two other children, and having somebody else helping and taking the pressure off us…has untold benefits.

During the course of the project, the view was frequently expressed by therapists and families that when appropriate therapy and equipment are not provided to a person in a timely manner, this often leads to increased problems later. For example:

- One child required a wheelchair with appropriate seating to help cope with aspiration and swallowing problems. Medical complications developed while on the waiting list. '[The child] ended up with a gastrostomy [tube] instead of a wheelchair.'

- Another child needed a few hundred dollars of modifications made to their wheelchair. The modifications did not occur and within 18 months the child had developed deformities requiring surgery and a new wheelchair.

- A child went without AFOs (ankle foot orthoses) for a year while on a surgery waiting list, having outgrown her old AFOs. She could not stand or put weight on her legs during this time, exacerbating her osteoporosis. She subsequently broke her leg.

However, it is not possible to quantitatively evaluate the effects of therapy and equipment provision, either in terms of individual participation or reduced social costs. There are few published research studies that address these questions, and no data sources found that contain relevant information.

Increased research effort in this area is needed, particularly research focusing on the efficacy of therapy and equipment in relation to facilitating increased participation. This would improve the evidence base available to support therapists in the decisions they make about how best to meet the needs of clients, as well as informing service development and resource allocation decisions made by service provider organisations, policy makers and funding bodies.

9.2 The nature of met and unmet needs for therapy and equipment

The second study objective was to:

> Identify the nature and quantify the extent of met, partially met and unmet need for therapies and equipment among people, of different ages, with cerebral palsy and similar disabilities.

Quantification of the extent of unmet need for therapy and equipment is addressed in Sections 9.3 and 9.4, respectively. This section focuses on the nature of met and unmet need, drawing on several different sources of information—the archetypal cases (Chapter 8), the focus groups (Chapter 5), population survey data (Chapter 7), and waiting list data (Chapter 6).

Archetypal cases

The archetypal cases provide qualitative data that shed some light on the nature of unmet need that may arise in an environment of restricted therapy resources. Therapist groups altered the ideal regimes for each case story to produce regimes with total hours of 75%, 50% and 25% of the ideal. The content of the resulting 'cut down' regimes reflects the decisions made by therapists about which interventions take priority when resources are limited.

Analysis of these 'cut down' regimes showed that, when resources were restricted, the proportion of time spent on direct, hands-on therapy tended to decrease, while the proportion of time spent on indirect therapy (such as program development and report writing) increased. Social work, psychology and family support interventions were most

likely to be dropped from therapy regimes, and interventions related to community participation also tended to be sacrificed.

Information-sharing between professionals often decreased (for example, shorter and less frequent team meetings involving fewer therapists), and communication with and information provision to clients was also reduced (for example, fewer therapists participating in meetings with the client/family, and loss of interventions focused on training or discussion of equipment options).

The number of client goals addressed reduced to focus on what were considered the highest priorities, and there was a tendency for home visits to be replaced by centre-based interventions.

The resulting 'cut down' regimes did not, on the whole, appear consistent with best practice approaches to delivering therapy services. They tended to be heavily impairment-focused, with less emphasis on participation or the broader wellbeing of the client—at 25% of ideal resources, social work and psychology interventions remained a substantial component of regimes only in case stories where significant stress was part of the case story (such as new diagnosis, surgery or medical complications, or family stress). With fewer therapists involved in any given intervention, therapy provision necessarily becomes less transdisciplinary and team-based. With more centre-based interventions there is little scope for the ecological approach (that is, providing services in the context of the client's usual environment), which is advocated as part of best practice.

These patterns reflect how experienced therapists believed regimes ought to be modified to accommodate resource constraints. In reality, patterns of modification in response to resource restrictions may also be affected by a range of other factors, including staffing structures, incentives operating on organisations and individual therapists, and the views and priorities of clients when faced with limited resources.

Focus groups

Information from the focus groups supported the general patterns that emerged from the archetypal cases. In particular, participants in client groups commented that they would like more assistance accessing information and coordinating services—functions carried out by case managers or social workers. Some clients had received social work support, but this was generally for limited periods of time, and only in crisis situations. Information on staff numbers provided by agencies in three states indicate that CP agencies do employ social workers and psychologists,[13] but high case loads often make it necessary to ration these services based on perceived greatest need.

Therapists believed that the unmet need for social support is especially high in regional and rural areas.

- 'It is hard to do therapy [in rural areas] because no family support is available.'

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13 In June 2006, The Spastic Centre, NSW, employed five social workers and five psychologists among 150 allied health staff. CPAWA employed 3.5 FTE (full-time equivalent) social workers and one psychologist, among 51.5 FTE allied health staff. Novita Children's Services employed 10 FTE family support workers and 10 FTE psychologists among approximately 98 FTE allied health staff.

- 'There is a lack of social work in rural areas. Things won't work unless the family is functioning.'

Other aspects of actual services received, as described by focus group participants, correspond to qualitative findings that emerged from the archetypal cases. Many clients said they did not receive as much 'hands-on' therapy as they felt they needed. Therapists agreed that direct therapy is lacking.

- '[There is a] need for direct and indirect forms of therapy…The unmet need is in the direct form of therapy, which is affected by the number of therapists and learning skills.'

- '[There is] almost no room for hands-on therapy for adults…as they age, they probably need more hands-on therapy.'

Almost every adult who participated in the focus groups wanted more physiotherapy. In particular, hydrotherapy was singled out as a beneficial intervention many clients desired, but did not have access to.

Therapists remarked on spending a great deal of time on activities such as applications for funding, rather than working with clients directly. Two comments encapsulated this attitude well:

- 'We'd like to provide therapy rather than chase up money'.

- 'Therapy is way down the list of priorities as a therapist.'

The issue of transport was also raised in a number of focus groups. Adult clients in particular had to travel to therapy sessions (therapy for children was more often delivered in schools or at home). As well as the financial burden, this places a significant time cost on clients. Many clients described waiting—sometimes up to 2 hours—for taxis to take them to appointments, and problems with inaccessible public transport. The effort required to obtain therapy has forced some people to limit sessions or even give it up. Difficulties associated with travelling to therapy appointments places restrictions on clients' ability to participate fully in the workforce and community life.

- 'Getting a ride can take half a day for 30–40 minutes of therapy.'

- 'It takes a long time to get to therapy and back—that takes up two days a week and I can't do anything else. It has an impact on my family.'

Population data on participation and need for assistance

The population survey data presented in Chapter 7 provide information on the need for assistance in various life areas of the 31,800 people with CP and like disabilities living in the community. Of these people, 26,500 needed assistance with the core activities of mobility, communication and/or self-care (Table 7.1). In particular, people with CP and like disabilities had higher rates of needing assistance with communication and self-care than the broader population with a disability, and additionally were more likely to need very frequent assistance with core activities (Table 7.2). In this study, need for assistance with core activities is treated as an indicator of need for therapy. This will be discussed in detail in Section 9.3.

The 26,500 people who needed assistance with core activities received help from a combination of formal and informal sources. Twelve thousand and nine hundred received both formal and informal assistance and 13,000 received informal assistance only (Table

7.10). While most people who needed help with core activities reported having their needs fully met, 9,400 had unmet need. Almost half of these (4,600) received assistance from informal sources only, while 4,700 people were in contact with formal services but still had unmet need for assistance with core activities (Table 7.10).

A majority of people with CP and like disabilities had participated in social events or community activities in the 3 months preceding the 2003 survey. The most common activities were visits from and to family and friends, telephone calls with family and friends, and visits to restaurants and clubs. While this pattern was similar to that for people with a disability generally, in terms of the types of activities participated in, the proportion of people participating was lower for people with CP and like disabilities (Table 7.6).

CP agency data on waiting lists

Data collected by CP agencies also provide an indication of unmet need for therapy and equipment (Chapter 6). Information from two states (New South Wales and Western Australia) show that a gap of 3 months between referral and acceptance into several programs is common, with many clients waiting for longer periods. Access to therapy appears to be particularly difficult in rural and remote areas, as over 300 clients were on a 16-month waiting list for services in rural and remote New South Wales, while therapy is unavailable for adult clients in non-metropolitan areas of Western Australia.

During focus group discussions in a third state, therapists explained that early intervention services can take on new clients only when other children leave the services upon starting school. In one region receiving two to three new referrals per week, the waiting list has stretched out to 2 years. Families who move to lower socio-economic regions to access affordable housing were believed to be particularly vulnerable to missing out on therapy. Therapists explained that waiting lists are also a major barrier for clients with complex needs, as the fragmented nature of many services means that issues are dealt with one at a time, with long waits in between.

CP agency data further revealed almost 800 applications waiting for equipment funding in Western Australia, New South Wales and South Australia in mid-2006[14] (Tables 6.16, 6.17 and 6.21). An analysis of all items submitted to the Spastic Centre Equipment Register in NSW between June 2004 and May 2006 indicated that application approval rate and waiting time vary according to client age (Table 6.18). In part, this may be due to eligibility criteria, which apply a means test to adult applicants. Clients aged 0–4 had the highest rate of funding approval in the analysis period and the shortest median waiting time. Still, 20% of all clients in this age group waited 6 months or more between submitting an application and securing funding. Almost half of the clients aged 0–4 whose applications were yet to be approved had been waiting 6 months or more. Only 17% of applications made by adults aged 25–44 years were approved within the analysis period. Of those clients who were still waiting for funding, three-quarters had waited 6 months or more. In one focus group, therapists remarked that a 6 month wait often follows an urgent request for a wheelchair. Anecdotal evidence from other focus groups suggests that equipment waiting periods of up to 2 years are not unusual.

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14   Each of these waiting lists count numbers of applications for equipment, not numbers of applicants.

Overall picture of the nature of unmet need

Together, these four sources of information highlight a number of issues. Unmet need appears to be high for types of therapy that support participation, especially in employment and social activities, for direct, hands-on therapy (especially physiotherapy), and for social work, psychology, and family support interventions. Long waiting times for therapy and equipment are a major concern, particularly in light of focus group evidence that lack of timely access to appropriate therapy and equipment can exacerbate problems and result in greater future need for services. There are suggestions that unmet need may be more of an issue in non-metropolitan areas, lower socioeconomic areas and for adults.

When resources are limited, services are rationed such that only people's most urgent needs are met; therapy becomes heavily impairment-focused and less geared towards enhancing participation. Information-sharing between professionals, service coordination and information provision to clients is reduced. Service provision becomes less transdisciplinary or team-based, and more centre-based. In short, best practice ideals are compromised under the kind of resource constraints that appear to affect many organisations that provide therapy and equipment for people with CP and like disabilities in Australia today.

9.3 The extent of met and unmet needs for therapy

The estimation of the extent of met and unmet need for therapy is based on the use of two national data sets—relating to disability in the population and disability services—and data constructed via the use of archetypal cases—typical but artificial cases, designed to create a 'hook' between reality and the existing data sets, and thus to help fill gaps in them. Data from these three sources are presented in Chapters 4, 6, 7 and 8. Key data to be used in this section are summarised in Table 9.1. The data are drawn together, in a process of triangulation, to present several different estimates of the cost of meeting unmet need, using the three sources in the three possible pairings and employing differing assumptions. These assumptions are outlined in Table 9.2 and described in the text as they are applied.

Both the population data (Chapters 4 and 7) and disability services data (Chapter 6) contain information about need for assistance in three core activities of daily living (mobility, communication and self-care). By using these support needs indicators to define different levels of disability severity, it is possible to relate data from all three sources (see Section 2.2).

The estimates presented below relate to unmet need for therapy experienced by clients, that is, people with CP or like disabilities who are in contact with CP agencies or other similar specialist services, whether or not they are currently receiving therapy services (see Box 8.1). There is no doubt additional unmet need among non-clients, that is, people with CP and like disabilities who are not in contact with CP agencies or other similar specialist services. However, it is much more difficult to estimate the size of this population, their level of need and their extent of unmet need, as discussed towards the end of this section. This population has therefore been excluded from calculations of unmet need.

Three methods for estimating the cost of meeting unmet need for therapy among clients

Method 1: Using population data together with CSTDA NMDS data for CP Australia agencies

Based on an analysis of the population data, of the 26,500 people with CP and like disabilities needing help with core activities in 2003, 9,400 had these needs partly met and the rest had them fully met (Table 7.8). Of those with needs partly met:

- 4,600 received informal assistance only (Table 7.10); these are non-clients. Their needs are difficult to quantify and therefore are not included in the estimation here, but are considered in the discussion below.

- 4,700 received a mix of formal and informal assistance (Table 7.10); these are clients, although the population data do not tell us of what agencies.

It is assumed, for this client group, that needing help with self-care, mobility and/or communication is a reliable indicator of the need for therapy, and that unmet needs for such help indicate unmet needs for therapy. The link between these two concepts is the severity of the disability. Because this is a key assumption for both this method and method 2 (below) it deserves close examination. It is helpful to split the assumption into two components, as follows:

(a) *Need for help with core activities indicates need for therapy*

There are three main pieces of evidence to support this:

- Compared with other CSTDA service users, CP agency clients have relatively high support needs (Table 6.4), and a much higher percentage of them use community support services, particularly therapy (Table 6.6). This suggests a relationship between need for help with core activities and need for therapy.

- Data provided by CPAWA indicate a strong relationship between support needs and FIM scores, which are used by some CP agencies to indicate need for therapy—this suggests that therapy professionals consider support needs a reliable indicator of need for therapy.

- In the archetypal cases, therapist groups developed more intensive therapy and equipment regimes for case stories of clients with more severe disability (characterised by higher support needs in self-care, mobility and communication)—this suggests that, in general, professionals regard people with higher support needs as likely to need more therapy. A study of therapy delivered to children with disabilities in Australia reported a similar broad finding (Dyson, 2000).

There is a conservative element to this component of the assumption, in that some people with CP and like disabilities who need therapy may not need help with ADLs—7.5% of CP agency service users did not require personal assistance with self-care, mobility or communication (including 2.3% who used aids) (Table A6.4). That is, the assumption could under-estimate needs for therapy.

However, conversely, some people who have regular, ongoing need for help with core activities may have only episodic need for therapy (perhaps every few years, for instance associated with equipment upgrades). To the extent that this is true, the assumption could over-estimate needs for therapy.

(b)   Unmet need for help with core activities indicates unmet need for therapy.

There is less direct evidence to support this component of the assumption.

It may be argued that if someone cannot get help with their basic core activity needs, they are not likely to be accessing what may be seen as less essential services, such as therapy—thus unmet need for help with core activities could be expected to be a reasonable indicator of unmet therapy need. However, without more information on patterns of service provision and availability it is difficult to know whether this is true. Meeting a person's core activity needs may involve intensive and costly service input (such as daily house visits), and the resources may not be available.

However, there is a conservative element to this component of the assumption in that it is likely that some people whose core activity support needs are fully met may have some level of unmet need for therapy. The population data show that there were 8,700 clients whose core activity support needs were fully met (or two-thirds of those who needed support with core activities—Table 7.10). All of these people also received informal support, and it is possible that for many people informal sources provided the bulk of core activity support. While informal carers may be well able to meet core activity support needs, it is less likely that they would be able to provide more specialised therapy input. Thus, a substantial proportion of the 8,700 people with fully met core activity support needs could be expected to have some level of unmet need for therapy.

Taken together, these arguments support the use of the figure of 4,700 as a reasonable, probably conservative, estimate of the number of clients with unmet need for therapy.

This 4,700 is roughly two-thirds of the 7,300 clients of CP agencies who received community support services funded by CSTDA (Table 6.6); thus the implication is that we are treating two-thirds of this client group as having some level of unmet or undermet need for therapy.

The quantum of unmet need among these 4,700 clients with partially met need could range from small to large. Some Australian literature provides support for the assumption that, on average, clients receive about half the amount of therapy that could be considered optimal. In a survey of therapists providing services to school age children, a comparison of the actual time spent on service delivery to therapists' stated ideal service time found that, on average, therapists believed 180% of current service time was needed to achieve the ideal service for their clients (Dyson, 2000). Further, a survey of actual and ideal case loads carried by therapists working with school age children found that, while the mean optimal case list reported by respondents was 25 clients, in actuality the therapists had a mean case list of 50 clients. Most therapists believed that a larger than optimal case lists resulted in less than optimal service provision (Dyson & Moore, 1997).

If we assume that, on average, the 4,700 clients with partially met therapy need have their needs half met, then with an average annual expenditure on CSTDA community support services per client of $4,400 in 2003–04 (see Table 9.1), the costs of covering these unmet needs would be 4,700 × $4,400, or $20.7m per annum.

Because this estimation method uses 2003–04 CSTDA funding data, while the following two methods use the archetypal cases unit cost figures that reflect 2005–06 prices, indexation is applied to this figure of $20.7m to give an equivalent 2005–06 figure of **$22.5m per annum.**[15]

Summary of assumptions

Unmet need for help with core activities indicates unmet need for therapy as discussed above.

Receipt of some assistance with core activities from formal sources indicates that these people are in contact with specialist disability services, including CP agencies, and can be regarded as clients for the purpose of this study.

People with CP and like disabilities identified in the population data are candidates for therapy services similar to those provided by CP agencies. While a substantial proportion of this group are people with ABI, and available CP agency data on diagnosis show that only a small percentage of clients have ABI (Table 6.8), it is appropriate to consider the whole CP and CP-like group as people with legitimate needs for therapy services similar to those provided by CP agencies. The method used to identify the CP-like group in the population data applied a series of filters to ensure maximum similarity with the CP group, in terms of indicators of therapy need. Further support for this assumption is provided by the fact that 4,700 is roughly two-thirds of the 7,300 CP agency service users who received community support services in 2003–04, which seems broadly consistent with levels of unmet need suggested by focus groups.

On average, these clients with partially met needs have their therapy needs half met (that is, they would need twice as much therapy to have their needs fully met). Three pieces of Australian research provide support for taking 50% as a reasonable estimate of average levels of unmet need (see above).

The average annual per client expenditure for therapy services for this group of clients with CP and like disabilities whose needs are partially met is the same as the average annual per client expenditure for CSTDA services overall—$4,400. This is likely to be a conservative assumption, as CP agency clients tend to have higher support needs than CSTDA service users overall; also, average annual expenditure estimates based on CP agency data are greater than $4,400 per client.

Method 2: Using population data together with archetypal cases data

Again, we start by considering the population estimate of 4,700 clients with CP and like disabilities who have partly met needs for assistance with core activities (Table 7.10). As discussed above, it is assumed that their unmet need for assistance with self-care, mobility and/or communication is an indicator of unmet need for therapy.

Archetypal cases data on the extent of unmet need and the cost of meeting unmet need can be applied to this figure of 4,700 clients.

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15   The index used is the General Government Final Consumption Expenditure—Implicit Price Deflator. The increase between 2003–04 and 2005–06 was 8.9% (ABS 2006).

Averaging across all archetypal case categories, and across estimates for metropolitan and non-metropolitan areas gives the following estimates of unmet need (Section 8.6):

- 13% of clients receive equivalent to the 75% regime or more

- 43% of clients receive equivalent to between the 25% regime and 75% regime

- 44% of clients receive equivalent to the 25% regime or less.

Thus, of clients with some level of unmet need for therapy, roughly half (2,350) receive between the 25% regime and 75% regime, and half (2,350) receive the 25% regime or less.

On average, the annual cost of meeting unmet need for the first group (receiving between 25% and 75%) would be $4,630, and for the second group (receiving ≤25%) would be $9,270 (see Section 8.5). So the total annual cost of meeting unmet need can be calculated as below.

> 2,350 x $4,630 = $10,880,500
>
> 2,350 x $9,270 = $21,784,500

This gives a total cost of meeting unmet need for clients of **$32.7m per annum.**

Summary of assumptions

Unmet need for help with core activities indicates unmet need for therapy (discussed under method 1, above).

Receipt of some assistance with core activities from formal sources indicates that these people are in contact with CP agencies or similar specialist services (clients), and it is thus valid to apply therapists' estimates of unmet need for therapy to this group (that is, estimates provided by therapist groups in the course of the archetypal cases exercise).

People with CP and like disabilities identified in the population data are candidates for therapy services similar to those provided by CP agencies as for method 1, above).

Clients receiving therapy equivalent to the 75% regime, or more, have their needs fairly well met. It is difficult to say whether this is conservative or not; on the one hand, it is 25% below the real world ideal (that is, therapists involved know at least one person who received equivalent to the ideal); on the other hand, the 75% regimes, in general, involved many more hours of therapy than most clients appear to get in reality (Tables 6.14 and 6.15, compared to Table 8.7, which shows hours for the ideal regimes).

Clients receiving between the 25% regime and 75% regime receive, on average, equivalent to 50% of the ideal (without knowing the distribution within this group it is not possible to say if this is conservative or not); clients receiving the 25% regime or less receive, on average, equivalent to the 25% regime (conservative, as it is likely that some receive less than 25%).

Method 3: Using CSTDA data on CP agency clients together with archetypal cases data

This method uses the archetypal cases data at a more detailed level, applied to numbers of clients of CP agencies from the CSTDA data. The method is as follows:

- CSTDA data were used to produce a count of clients of CP agencies broken down into the nine archetypal cases age-by-severity categories and, within each category, by metropolitan or non-metropolitan place of residence (Table A8.4).

In CSTDA terms, archetypal cases 'severe' case stories can be identified as:

– always needs help in at least one core area, and

– needs help or uses aids in at least two core activity areas.

Service users who did not meet these criteria were regarded as having 'mild/moderate' disability.

- Therapists' estimates of levels of unmet need (for each category, by metropolitan / non-metropolitan—see Table 8.12) were applied to these CSTDA numbers, to estimate the number of people in each category receiving therapy equivalent to:

    – between the 25% regime and 75% regime

    – the 25% regime or less

- These estimates were multiplied by the appropriate cost figure for that category (that is, the cost of meeting unmet needs for a person receiving equivalent to between the 25% regime and 75% regime, and equivalent to the 25% regime or less, respectively—Tables 8.10 and 8.11)

- The resulting dollar amounts were summed across all nine categories.

This gives a total cost of meeting unmet need for clients of CP agencies (and one similar agency) of **$54.8m per annum.** See Table 9.1 for detailed calculations.

Summary of assumptions

CSTDA data on CP agency service users capture all clients of specialist disability services who have CP and like disabilities. This is a conservative assumption—some people with CP and like disabilities receive disability services, including therapy, from other agencies, particularly in those jurisdictions where CP organisations do not provide services.

Clients receiving between the 25% regime and 75% regime receive, on average, equivalent to 50% of the ideal; clients receiving the 25% regime or less receive, on average, equivalent to the 25% regime, as for method 2, above.

Clients receiving therapy equivalent to the 75% regime, or more, have their needs fairly well met, as for method 2, above.

All clients of CP agencies need therapy. About 22% of this group did not use community support services in 2003–04 (Table 6.6); some of these people would have unmet needs for therapy, while some may not need therapy.

Table 9.1: Key data used for triangulation of unmet needs estimates

Population data (Chapters 4 and 7)	CSTDA (2003–04) and CP agency data (Chapter 6)	Archetypal cases (Chapter 8)
33,800 people with CP and like disabilities (Chapter 4) This number includes: • 16,800 people with CP • 21,200 people with CP-like disabilities—i.e. with ABI and aged under 45, whose main condition occurred before age 30, who have physical/diverse or hearing or speech disabilities, and who need personal assistance at least once a day with one or more core activities. 26,500 people with CP and like disabilities needed help with core activities (Table 7.10). 13,400 received assistance with core activities from formal services (12,900 of these also received informal help); 13,000 received informal help only. 9,400 of the 26,500 had their (core activity) needs partly met and the rest had them fully met. 4,700 of those with needs partly met received some formal assistance. These are clients. 4,600 of those with needs partly met received informal assistance only. These are 'non-clients'.	187,806 CSTDA services users in 2003–04; 79,000 community support service users. CSTDA government expenditure: $3.3 billion on all service types; $352 million for community support services (Table 6.2) This gives, on average, $4,400 per community support service user annually. This is equivalent to about 60 hours per year of therapy at $70 per hour (i.e. the archetypal cases unit cost figure); this is commensurate with WA data showing 20–90 hours per year as the average range across their cases (Table 6.12). 9,400 people received services from CP agencies; 7,300 (78%) of these received CSTDA funded community support services. Compared with all CSTDA service users, CP agency service users tended to: • have a younger age profile • have higher support needs • be more likely to have 'physical' disability as the reported main disability. Supplementary data from three states showed that the proportion of CP agency service users with a diagnosis of CP ranged from 60% to 95%; very small percentages had ABI (Table 6.8).	Averaging across all nine archetypal case categories (Section 8.5) gives: • Average annual cost per client of meeting unmet need for clients now receiving therapy equivalent to between 25% and 75% of the ideal regime: $4,630 • Average annual cost per client of meeting unmet need for clients now receiving therapy equivalent the 25% regime or less: $9,270 Average levels of unmet need for clients, based on therapists' estimates (Section 8.6): • 13 % receive equivalent to the 75% regime or more • 43% receive equivalent to between the 25% regime and 75% regime • 44 receive equivalent to the 25% regime or less. These average figures are applied to the estimated number of clients with partially met needs for help with core activities, from the population data. The more detailed estimates of cost and unmet need for each archetypal cases category are given in Tables 8.9, 8.10 and 8.11; these are applied to CSTDA service user data (Table A9.1)

Table 9.2: Assumptions employed in the three methods of estimating the cost of unmet need for therapy among clients

Assumption	Discussion of assumption	Assumptions used in:		
		Method 1: CSTDA & population data	**Method 2: population data & archetypal cases**	**Method 3: CSTDA & archetypal cases**
Unmet need for help with core activities indicates unmet need for therapy.	Support for this assumption: CP agency clients have relatively high support needs, suggesting a relationship between need for help with core activities and need for therapy; strong relationship between support needs and FIM scores (used by some CP agencies to indicate need for therapy); increased severity, characterised by higher support needs, is associated with need for more therapy (archetypal cases). See discussion of this assumption under 'method 1'.	✓	✓	
People in the population receiving some assistance with core activities from formal sources can be regarded as clients (i.e. in contact with CP agencies or similar specialist services).	Some people may receive formal assistance from sources other than specialist disability services. While some percentage of this group in the population data may strictly be non-clients as defined in this study, their unmet need for therapy may nonetheless be met by CP agencies or similar specialist disability services.	✓	✓	
People with CP and like disabilities identified in the population data are candidates for therapy services similar to those provided by CP agencies.	It is appropriate to consider the whole 'CP and CP-like' group as people with legitimate needs for therapy services similar to those provided by CP agencies. The method used to identify the CP-like group in the population data applied a series of filters to ensure maximum similarity with the CP group, in terms of indicators of therapy need.	✓	✓	
clients with partially met needs for assistance with core activities (identified in the population data) on average have their therapy needs half met.	Some assumption has to be made, but three Australian studies provide support for this approximation. See discussion under 'method 1'.	✓		
The average annual per client expenditure for therapy services for this group of clients with CP and like disabilities, whose needs are partially met, is the same as the average annual per client expenditure for CSTDA community support services overall—$4,400.	CP agency service users have higher support needs than CSTDA service users in general, so it could be expected that expenditure for CP agency service users might be higher than the average.	✓		

(continued)

191

Table 9.2 (continued): Assumptions employed in the three methods of estimating the cost of unmet need for therapy among clients

Assumption	Discussion of assumption	Method 1: CSTDA & population data	Method 2: population data & archetypal cases	Method 3: CSTDA & archetypal cases
			Assumptions used in:	
Clients receiving equivalent to the archetypal cases 75% regime or more have their needs well met.	The 75% regimes have 25% fewer hours than the 'realistic ideal' described by therapists who developed the archetypal cases therapy regimes, but CP agency data on hours received indicate that few clients actually get this level of support (Tables 6.12, 6.13).		❯	❯
Clients receiving between the archetypal cases 25% and 75% regimes are treated as receiving equivalent to 50% of the ideal regime.	The midpoint of this range seems a sensible point to use, as there is no information on whether the actual distribution of services received is skewed towards the top or bottom of this band.		❯	❯
Clients receiving the archetypal cases 25% regime or less are treated as receiving equivalent to the 25% regime.	This is likely to be conservative — some clients will be receiving less than 25%.		❯	❯
CSTDA data on CP agency service users capture all clients of specialist disability services with CP and like disabilities.	This is likely to be conservative — some people with CP and like disabilities receive disability services, including therapy, from other agencies, particularly in those jurisdictions where CP organisations do not provide services.			❯
All clients of CP agencies need therapy.	In 2003–04, 22% of CP agency clients did not use community support services; of these, some could have unmet needs for therapy, while others may not need therapy.			❯

Discussion

In terms of the concepts of need and demand, discussed in Section 2.1, all methods must strictly be considered as relating to the concept of inferred need. This is because no direct indicators of unmet demand for therapy and equipment were used. The only data on unmet demand available are the service waiting list numbers for New South Wales, reported in Chapter 6.

However, the estimates derived from methods 1 and 2, which are based on the population data estimate of clients with partially met needs, could be considered as relating to the concept of unmet demand, if it is accepted that reporting unmet need for assistance with core activities can be considered, for these clients, as indicating unmet need for therapy (see support for this assumption, summarised in Table 9.2).

Below, several considerations which affect the interpretation of these three cost estimates are briefly discussed.

Non-clients

There were an estimated 4,600 people with CP and like disabilities who received informal assistance only, and had their needs for assistance with core activities partly met; these people are regarded as non-clients, that is, not in contact with CP agencies or other similar specialist services.

The AIHW team heard somewhat conflicting evidence about the possible unmet needs of these people. On the one hand, CP Australia agencies believed that they were in touch with most people with relatively severe CP and high levels of need, with the possible exception of Aboriginal and Torres Strait Islander people, and some people of non-English speaking background. On the other hand, therapists did report hearing of people or coming into contact with people with significant needs who were not in touch with the service system (see Section 5.7).

Many people with cerebral palsy and like disabilities access privately-provided therapy, sometimes in addition to therapy provided by publicly-supported organisations. Key points when private therapy may be sought include: when the initial high-intensity input from publicly-supported therapy organisations, typical in the first 6 to 12 months after diagnosis, begins to be reduced; when a child reaches school age, to continue receiving therapy input at home in addition therapy provided through the education system; and at the transition to adulthood, when access to publicly-supported therapy is often greatly diminished.

Some clients with highly complex needs access private therapy, although most also access therapy through publicly-supported organisations; it is more likely for clients with milder disabilities to use only private therapy. It is not appropriate to assume that use of private therapy always indicates unmet need for publicly funded therapy, although this may be the case in some instances. More information on patterns of use of private therapy, including the resulting financial impact on clients, could help to clarify the nature and quantify the extent of unmet need for publicly funded therapy.

Because of the difficulty in making defensible assumptions about levels of need or unmet need among non-clients, this group is not covered by the estimates presented here. This does not mean that unmet need is not of concern among non-clients. Rather, it is unquantifiable.

Exclusion of non-clients from the estimation of the cost of meeting unmet need for therapy is reflective of the overall conservative approach taken in this study.

Discussion of assumptions and overall effect on estimates

A review of Table 9.2 reveals that, for many of the assumptions employed in the three estimation methods, it is not possible to conclude whether their effect is to lead towards over-estimation or under-estimation. This is a reflection of the patchiness of the data available. However, reasonable evidentiary support exists for most of the assumptions, and some clearly are conservative—such as the assumption that clients receiving equivalent to the 25% regime or less all receive equivalent to the 25% regime (not less); and the assumption that CSTDA data on CP agency service users capture all clients in scope.

In addition to the assumptions outlined in Table 9.2, conservative decisions were taken at numerous points in the overall study methodology, to ensure that the final estimates could be regarded as defensible. Examples include the filters applied in the identification of people with CP-like disabilities in the population data (Section 4.3), use of 1 hour as the return trip time for all archetypal cases regimes (which was the lowest estimated time provided by the participating therapist groups) (Section 8.1), and exclusion of non-clients from the estimates.

When applying the archetypal cases data it is important to consider whether clients should receive the amount of therapy specified in the 75% regimes year on year. It is likely that this would not be seen as appropriate for all clients. Therefore, it would not be appropriate to assume that all people with CP or like disabilities who may, at certain points in their life, benefit from therapy should receive equivalent to the 75% regime every year. However, the way in which the archetypal cases data are applied to each of the national data sources adjusts for this. Both methods 2 and 3 are based on a point-in-time count of clients. This excludes people not currently in contact with specialist disability services, some of whom may have been in contact with services in the past and may be again in future.

This evaluation of the assumptions employed aids appropriate interpretation of each of the estimates. However, it is not possible on this basis to reach a conclusion about which method may produce the most accurate or realistic estimate. Also, it must be remembered that all three methods are affected by estimation errors inherent in the data sources that underpin them (see Box 9.1). For this reason, the overall findings include the full range of estimates. It is important to note, however, that the assumptions combine to exclude higher estimates that could otherwise have been arrived at.

9.4 Indications of the extent of met and unmet need for equipment

The 1993 Survey of Disability, Ageing and Carers included a question about unmet need for aids and equipment, however this was removed from subsequent surveys. Likewise, CSTDA data do not capture equipment need, met or unmet. Therefore these data sources are unable to provide indications of the extent of unmet need for equipment among people with CP and like disabilities.

Equipment was included as a factor in the archetypal cases exercise, in that the therapist groups listed aids/equipment and associated therapeutic interventions to be provided as part of each regime. However, as discussed in Section 8.7, different therapist groups appeared to take different approaches to the inclusion of equipment in regimes, and there was considerable variation between case stories, and between state replicates for each case story, in the nature and cost of items listed. Therefore, the equipment regimes can not be considered to provide a sufficiently accurate basis for costing equipment need at a population level. Further, the cost per client of equipment prescribed does not represent an average annual figure—the replacement rate of equipment items varies considerably according to many factors, such as the client's changing needs, growth, equipment type and technological advances. The often fragmented nature of equipment funding is such that it is difficult to calculate the annual expenditure on equipment across all sources (including state funding schemes, fundraising events and charities). However, several CP agencies have equipment waiting lists that record applications made by their clients, often covering multiple equipment funding sources. These waiting lists can be used as a basis for estimating unmet need for equipment at a national level, as set out below.

During the course of the focus groups it became clear that the extent of met and unmet need for equipment is influenced by rules governing funding schemes (see Section 5.7). This section therefore includes a discussion of the costs and nature of a possible ideal equipment scheme, as described by allied health professionals, clients and their families.

Estimated cost of unmet need for equipment based on waiting list data

Data provided by CP agencies in three states give the annual cost of outstanding applications for equipment (Table 9.3). For each state, the total cost of unfunded equipment requests was divided by the number of CP agency clients in that state (from CSTDA data, see Table A9.2), to give an average cost per client of additional equipment funding required. While not every client will have unmet equipment need every year, this conceptualisation of an even distribution of unmet need among all clients allows extrapolation of individual state data to the national level. The cost per client figures can be multiplied by the number of clients nationally (9,398 service users accessing CSTDA-funded services provided by CP agencies in 2003–04) to give three indications of the possible cost of meeting unmet need for equipment nationally. The resulting estimates range from $3.5m–4.4m p.a.

Table 9.3: Estimates of the cost of unmet need for equipment in three states

State	Annual unmet need for equipment	Number of CP agency clients	Cost per client	Estimated cost of national annual unmet need
NSW	$622,355	1,336	$466	$4.4 million
SA	$660,897	1,433	$461	$4.3 million
WA	$310,918	843	$369	$3.5 million

Notes

1. Annual unmet need for equipment in NSW was calculated by averaging the cost of equipment requests made in 2004–05 and 2005–06 that remained unfunded at the end of the respective financial years. WA data represent unfunded requests made in the 2005–06 financial year, as of 20 June 2006. SA data represent the cost of unfunded requests to the Independent Living Equipment Program made between June and August 2006, and therefore are likely to underestimate the cost of unmet need over a full year.

2. The estimated national annual cost of unmet need for equipment was calculated by multiplying the average 'cost per client' in each state by the number of CP agency clients nationally.

3. SA data exclude unmet need for equipment among people aged over 18 years.

Source: CPAWA; Novita Children's Services (SA); The Spastic Centre, NSW; Table A9.2

These estimates can be treated as approximate indicators only. First, they assume that client numbers have not changed significantly since 2003–04. Also, it is not possible to say how typical each of these three states is in the national context. Fluctuations in funding to equipment programs make it difficult to draw conclusions about average levels of unmet need from a single time point analysis—extra funding is often granted near the end of a financial year or an electoral cycle, but the regularity and size of such grants is unpredictable. This in itself can exacerbate unmet equipment need—during the focus group discussions, a number of participants explained that occasional large grants for equipment funding often temporarily contribute to waiting lists because there are not enough therapists to prescribe and provide training associated with new equipment, and manufacturers cannot at short notice produce the large number of items that have been funded simultaneously.

Basing an estimation of the cost of unmet need for equipment on these data further assumes that these waiting lists capture the majority of unmet need for equipment. However, there are limitations on the types of equipment that can be funded. For example, some schemes do not cover home and vehicle modifications, which are costly but necessary for many clients. Further, grants provided frequently do not cover the whole cost of purchasing an item, so clients are required to pay a gap. During the focus groups a number of therapists and clients (particularly adults) explained that charities and personal fundraising were often needed to fully cover equipment costs.

Eligibility criteria exclude some clients with equipment needs from the schemes represented by these waiting lists. For instance, the South Australian data do not provide information about unmet need for equipment among adults, so Table 9.3 is likely to underestimate the full cost of unmet need for equipment in South Australia—possibly by a significant amount, as focus group participants consistently reported higher levels of unmet need in adults than children. In Western Australia, clients must hold a valid concession card or otherwise demonstrate financial hardship to qualify for funding. As a result, Western Australian waiting list data may not capture unmet need among clients with middle to high incomes.

In New South Wales, clients on middle to high incomes are eligible to apply to the Program of Appliance for Disabled People (PADP, the major equipment funding source for people with CP and like disabilities in New South Wales) for high cost items; however they are given lower priority than children and clients on low incomes. In a recent review of the PADP it was noted that, due to their low priority status, middle and high income clients may never reach the top of the list (PriceWaterhouseCoopers, 2005). Further, analysis of waiting list data provided by The Spastic Centre, NSW, showed that high cost items had a lower approval rate than cheaper items (Table 6.20). Given these considerations, the New South Wales waiting list may capture more of the overall unmet need for equipment than the South Australian and Western Australia lists.

Fully meeting need for equipment relies on several factors, in addition to sufficient funding for the purchase of new items. Focus group discussions with therapists raised lack of therapy support as a major contributing factor to unmet need for equipment. This was included in the archetypal cases regimes and hence is reflected in the estimates of the cost of meeting unmet need for therapy presented in Section 9.3 (methods 2 and 3). Further, regulations governing the distribution and use of equipment can have significant impact on clients' ability to purchase and effectively use equipment. The nature, as well as the extent, of equipment funding has the potential to significantly impact on met and unmet need, as was discussed in the context of an ideal equipment scheme in Section 6.5.

9.5 Conclusions

Evidence from the literature review and focus group components of this study points to the conclusion that therapy and equipment are essential to people with CP and like disabilities—crucial in supporting independence, facilitating participation and contributing to overall wellbeing. This is clear, despite the current paucity of published research evaluating the efficacy of therapy and equipment.

The focus groups revealed that both therapists and people with CP and like disabilities believe there are significant levels of unmet need for therapy. A characterisation of the nature of this unmet need is presented in Section 9.2, above.

Estimates of the annual cost of meeting unmet need for therapy using the three methods described in Section 9.3 ranged from $22.3 million to $54.8 million. These estimates can be interpreted as the additional government funding needed by CSTDA agencies to provide therapy services for clients with CP and like disabilities. CSTDA funding for community support services was $352 million in 2003–04 and $399 million in 2004–05 (2005–06 funding data are not yet available). It is recognised that therapy, as defined for the purposes of this study, may be provided by CSTDA-funded service types within the community support

services group, not only those designated therapy services. In particular, early intervention may often include a component of therapy.

It is important to recognise that CP agencies also rely on non-government funding sources to provide services—non-government funds account for roughly 30% of total CP agency funding. Provision of the additional government funding indicated by the estimates above would only fully meet need if CP agency non-government funds remain available at current levels, in real terms.

Development of the three estimation methods was guided by the principle that any assumptions employed should, on balance, be conservative so as not to over-estimate the cost of meeting unmet need. This principle also guided determination of the criteria used to identify people with CP-like disabilities in the population data (Chapter 4) and the design of the archetypal cases methodology (Chapter 8). In addition, all three estimates may be considered conservative in that they do not cover possible unmet need for therapy among people with CP and like disabilities not in contact with CP agencies and other similar specialist services.

It is considered reasonable to regard these estimates as estimates of the additional annual funding that would be required to fully meet therapy need for this client group—arguments in support of this have been provided in Sections 8.4 and 9.4. However, as mentioned in Section 9.2, it is widely recognised that lack of timely access to appropriate therapy and equipment can exacerbate problems and result in greater future need for services. Thus, some portion of current unmet need could be seen as a result of past unmet need. Arguably, then, if therapy and equipment needs were fully met in a timely manner, this may have the effect of lowering the overall level of need some years in the future.

In Section 9.4, equipment waiting list data for three states are used to produce estimates of the possible annual cost of meeting unmet need for equipment nationally. These estimates range from $3.5 million to $4.4 million. As discussed above, these should be considered only as broadly indicative of the magnitude of this cost component; it is not possible to produce a firm annual estimate that could be added to the estimated cost of meeting unmet need for therapy. It is acknowledged, however, that many people with cerebral palsy require costly specialised equipment to optimise their independence in mobility, communication and self-care; to reduce restrictions on their activities and to support their participation in community life.