4 The population: people with cerebral palsy and like disabilities

This chapter scopes and estimates the size of population under consideration in the study. The chapter discusses population data analysis and the approaches to population estimates of cerebral palsy and CP-like disabilities for the project. It begins with a summary description of the population estimates of CP and CP-like disabilities and need for therapy and equipment, followed by detailed explanations of how people with CP-like disabilities (who may need therapy and equipment) were selected for inclusion in the estimates. The chapter concludes with an analysis comparing the two groups (CP and CP-like) to confirm their similarity for the study's purposes.

The analysis in this chapter is designed to relate the 2003 SDAC concepts to the objectives of the study, in particular to provide population estimates of CP and CP-like disabilities, and statistics on disability and profiles of people with CP and CP-like disabilities. Detailed information about the 2003 SDAC and survey definitions of disability are provided in Appendix B.

4.1 Population estimates of cerebral palsy and CP-like disabilities

This study focuses on the therapy and equipment needs of people with CP and CP-like disabilities. Therefore, the population estimates consist of two subgroups: estimates relating to people with CP, and estimates relating to people with CP-like disabilities who may need therapy and equipment services similar to those for CP. This section presents key estimates of the two population subgroups, including main disability and support need profiles.

Population estimates of CP disabilities

In 2003, there were an estimated 16,800 persons who reported cerebral palsy either as their main or other long-term health condition (Table 4.8). Of these, 16,100 had a disability, including 10,700 with a severe or profound core activity limitation. These 16,100 people with CP and disability are the first subgroup of the population estimates.

Population estimates of CP-like disabilities

Population estimates for this subgroup comprise two levels: (1) a baseline estimate of the number of people with CP-like disabilities, (2) an estimate of the population with CP-like disabilities most likely to need therapy and equipment services. Sections 4.2 and 4.3 provide detailed discussions of the rationale and approaches relating to the estimation.

Broad estimate of people with CP-like disabilities

In 2003, there were 111,700 people who:

- had an ABI-related disability, and
- were aged under 45 years, and
- had acquired their main disabling condition (not necessarily ABI) before age 30, and
- also had physical/diverse or hearing or speech disabilities.

Estimate of people with CP-like disabilities: further filters to focus on candidates for therapy and equipment services

At this level, additional criteria have been applied to the broad estimate by including only those who needed personal assistance or supervision at least once per day with one or more of the core activities of self-care, mobility and communication. The resulting estimate is that, in 2003, there were 21,200 people with CP-like disabilities who may be potential candidates for therapy and equipment services (Section 4.3: Figure 4.1).

Overview of data on people with CP and CP-like disabilities

Since the scope of this study includes both people with CP and CP-like disabilities, the data analyses in following chapters are based on combined population estimates of CP and CP-like disabilities. Also, because high standard errors are associated with small estimates, combining the two subgroups allows more detailed analyses to be conducted than would be possible if the two were treated separately.

The combined population estimate of CP and CP-like disabilities is 33,800 people in 2003, which includes 16,100 people with CP disability and 21,200 people with CP-like disabilities who may need therapy and equipment services (Table 4.1).[6]

Of these 33,800 people, 59% acquired their main condition at age 0-4; 84% needed personal assistance or supervision with self-care, mobility or communication; 49% used aids for self-care, mobility or communication; and 42% needed personal help at least six times a day.

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[6] The combined population estimate (33,800) of CP and CP-like disabilities is less than the sum of CP (16,100) and CP-like (21,200). This is because there is overlap between these two groups as some people have multiple disabilities.

Table 4.1: Population estimates of people with CP or CP-like disabilities, 2003

Age	Number ('000)	%
0–4	*2.9	*8.6
5–14	*9.0	*26.5
15–19	*4.5	*13.5
20–24	*6.2	*18.4
25–29	*2.2	*6.4
30–44	*7.8	*23.2
45+	**1.2	**3.4
Age at onset of main disabling condition		
0–4	20.0	59.2
5–9	*3.2	*9.4
10–14	*2.2	*6.6
15–19	*2.3	*6.9
20–24	**1.6	**4.7
25–29	*2.5	*7.5
Not applicable	**2.0	**5.8
Need help with at least one core activity		
No	5.3	15.8
Yes	28.4	84.2
Use of aids for at least one core activity		
No	17.1	50.6
Yes	16.7	49.4
Highest frequency of need for personal assistance		
6+/day	14.3	42.3
3–5/day	*6.5	*19.2
2/day	*4.0	*11.7
1/day	*2.8	*8.2
1/week	**0.6	**1.8
1–3/month	**0.3	**1.0
Not needed	*5.3	15.8
Total	**33.8**	**100.0**

Notes

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

4.2 Scoping of CP-like disabilities for population data analysis

The scoping of CP and CP-like disabilities is a complex issue. In the population data analysis, identifying people with CP and CP-like disabilities may not simply be considered by taking a clinical perspective; the approach must relate to the scope of the study and its focus on providing estimates of need and unmet need for therapy and equipment. Our aims are to present a national picture of people with CP and CP-like disabilities who might benefit from therapy and equipment, and provide robust, useful and conservative estimates of need, unmet need and costs. Although the scoping of CP-like disabilities starts with a focus on relevant disabling conditions, the population estimates of people with CP-like disabilities who may need therapy and equipment will be conducted in the context of the broad and integrated view of disability of the ICF.

Early exploratory analyses on scoping of CP-like disabilities

The project's Advisory Committee, after detailed discussions, recommended the inclusion of ABI as a 'CP-like condition', excluding older age-related brain injury, such as stroke; it was suggested that only people who experienced a brain injury before 45 years of age should be included. The Advisory Committee also suggested the inclusion of spinal cord injury, genetic disorders and muscular dystrophy as CP-like conditions, with a focus on people with an early onset of these conditions. One of the key factors in recommending the inclusion of these types of disability as 'CP-like' was that all tend to be characterised by impairment to physical functioning and associated activity limitation.[7]

To include only people who have acquired a given CP-like condition before age 45, the data can be extracted by selecting all people aged under 45 with that condition plus those aged 45 or more with that condition if it was acquired before age 45. As the information about age at onset of a condition was collected only for a person's main condition, this would exclude people aged 45 or over with the condition if it was not reported as their main condition, even if they acquired the condition before age 45. Furthermore, the question about age at onset of main condition was asked only among people living in households, so this approach excludes all people aged 45 or more living in institutions.

In addition to the estimation of CP, some early exploratory analyses were conducted to provide preliminary estimates for three broad groups of potential CP-like conditions—'head injury/acquired brain damage', 'congenital malformations, deformations and chromosomal abnormalities' and 'other diseases of the nervous system'. For each of these condition groups, the estimates begin with including all people reporting these specific conditions, then select people with a disability, and finally, a more exclusive 'filter' is used to select people aged under 45 or aged 45 or over with main disabling condition in that group acquired before age 45.

Based on these preliminary estimates and the detailed information on coding, the Advisory Committee advised the study team to use codes 611 (cerebral palsy) and 1801 (ABI—head

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[7] Although ABI is not always associated with physical impairment, the method for identifying those people likely to be candidates for therapy services included only people with ABI and physical/diverse or hearing or speech disabilities—see Section 4.3.

injury/acquired brain damage) to estimate CP and CP-like disabilities, respectively. The other two groups ('congenital malformations, deformations and chromosomal abnormalities' and 'other diseases of the nervous system') in the data file are too diverse and broad, and it is not possible to conduct analyses that focus only on the conditions suggested by the AC—spinal cord injury, genetic disorders and muscular dystrophy. Analysis in the next section will show that the ABI group captures a substantial number of people with these conditions.

Inclusion of ABI as a CP-like disability

As well as providing services to people with cerebral palsy, CP Australia agencies also provide services to people with disabilities similar to CP who are likely to benefit from a similar range of services. The kinds of disabilities and service needs of people with ABI have important similarities to those of people with CP.

The term ABI is used as an umbrella term to describe multiple disabilities arising from damage to the brain acquired after birth. Causes of ABI include head trauma, stroke, brain tumours, infection, poisoning, lack of oxygen and degenerative neurological diseases. Effects include deterioration in cognitive, physical, emotional or independent functioning (National Community Services Data Committee 2004). The AIHW has previously published two reports with a particular focus on ABI (AIHW: Fortune & Wen 1999; AIHW 2003a). The earlier of these includes extensive material on the definition of ABI, and the nature of ABI and associated disability and service needs.

As discussed in Section 3.1, cerebral palsy is a neuro-developmental condition that is associated with physical impairments (primarily of movement and posture), often accompanied by impairments of other body functions, for example affecting sensory functions, communication and cognition. Similarly, people with ABI-related disability often have impairments in more than one domain. In 1998, 81% of people with ABI also had a physical/diverse disability, 49% had a sensory/speech disability, 47% a psychiatric disability and 36% an intellectual disability (AIHW 2003a).

Like many people with cerebral palsy, those with ABI often experience barriers to participation in employment, social activities and community life, and barriers to accessing mainstream services such as health services. Section 3.4 emphasised the holistic philosophy that today underpins the provision of therapy to people with cerebral palsy. Therapy is no longer aimed primarily at 'normalising' impairments; instead, there is a broader focus on promoting independence and meeting the person's needs within the context of their life. Therapy is of great relevance to people with ABI, both in the years following the brain injury (to minimise impairment and maximise functioning), and ongoing, to help maintain function and to facilitate participation in a range of life areas.

As descriptions of particular types of disability, neither CP nor ABI can be precisely delineated—for both, definitions leave room for debate about inclusions and exclusions at the boundary (see Section 3.1, and AIHW: Fortune & Wen 1999). Indeed, there is arguably some overlap between the two in that CP includes conditions that occur in the first few years of life, which may also fall within definitions of acquired brain injury.

As described below, the method eventually used to identify people with 'CP-like disability' in the population data employed several levels of filters to ensure maximum similarity (in terms of disability and support needs profile) between people with CP and the 'CP-like' group in the population data. Also, as illustrated in Table 4.3, the resulting ABI-based 'CP-like' group should not be considered as purely ABI, as there is overlap both with CP and with the other CP-like groups suggested by the AC that were not able to be separately identified within the population data.

This section describes how the ABI group was defined and estimated based on the SDAC data. Section 4.3 takes a broader disability perspective, using information on disability group and need for assistance with basic daily activities to focus the population estimates on people with CP-like disabilities who are likely to benefit from therapy and equipment services similar to those provided by CP agencies.

Population estimates of ABI

The AIHW method of estimation for ABI-related disabilities includes a person in the ABI group if:

- a positive response was made by or for them to the ABI-specific screening questions about whether they had 'any long-term effects as a result of a head injury that interfere with doing everyday activities', or 'any long-term effects as a result of any other kind of brain damage that interfere with doing everyday activities'
- a positive response was made by or for them to one of the 17 screening questions and one or more disabling conditions related to head injury, or acquired brain damage (code 1801) was reported.

This method (based on all reported disabling conditions) results in an estimated 438,300 people of all ages with an ABI-related disability in 2003. Survey respondents were also asked to identify the main disabling condition if they reported more than one condition. Main disabling condition was defined as the one causing the most problems to the person. Of the 438,300 people, 28,700 reported ABI as their main disabling condition.

Other conditions reported by people with ABI

The large difference between the estimate based on all disabling conditions (438,300) and that based on main disabling condition (28,700) reflects high rates of comorbidity among people with ABI and the complex causes and effects of ABI, outlined above.

Table 4.2 illustrates various types of main disabling conditions reported by people aged under 45 years with an ABI-related disability based on all reported disabling conditions. Of the total 171,400 people, 21,500 reported ABI as their main condition. It should be noted that the identification of main disabling condition is based on self-reported responses that may or may not reflect professional assessment. A person with an early onset ABI-related condition who has learnt to cope with that condition might find a different, recently acquired condition more disabling and report this as the main condition.

Table 4.3 looks at other conditions reported by people in this broad ABI group. The ABI group includes, 5,000 people with CP (33% of all people with CP), 15,700 with congenital disorders (code 1600) and 13,500 with 'other diseases of the nervous system '(code 699). This means that, although codes 699 and 1600 cannot be included in the population estimates for CP-like disabilities (they cannot be further breakdown to the lower level codes), the ABI group is likely to capture a substantial number of conditions that are covered by these two codes, possibly including spinal cord injury and muscular dystrophy.

Thus, the data in these two tables suggest that there is overlap between the ABI group and other types of disabilities, including CP and possibly others of particular interest to this study (that is included in the groups 'congenital malformations, deformations and chromosomal abnormalities' and 'other diseases of the nervous system'). This fact may, to some extent, compensate for any potential loss to the analysis of people who, while they do not have CP or ABI, do have similar therapy needs. The survey data indicate that the ABI group has broad coverage and includes people with a variety of conditions and impairments who often have multiple, inter-related disabilities similar to the CP group.

Table 4.2: People aged under 45 years with ABI-related disabilities based on all reported conditions: top 15 main disabling conditions, 2003

Main disabling condition	No. ('000)
Back problems (dorsopathies)	26.5
Head injury/acquired brain damage	21.5
Depression/mood affective disorders (excluding postnatal depression)	11.7
Other mental and behavioural disorders	10.7
Epilepsy	*7.8
Asthma	*5.1
Leg/knee/foot/hip damage from injury/accident	*4.8
Other diseases of the nervous system	*4.6
Arthritis and related disorders	*4.5
Migraine	*4.2
Congenital malformations, deformations and chromosomal abnormalities	*3.8
Intellectual and developmental disorders n.e.c.	*3.5
Cerebral palsy	*3.3
Attention deficit disorder/hyperactivity	*3.2
Other diseases of the musculoskeletal system and connective tissue	*3.1
All other conditions	52.9
Total	**171.4**

Notes

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

n.e.c. = not elsewhere classified

Table 4.3: People aged under 45 years with ABI-related disabilities, or aged 45 years or more with ABI-related main disabling condition acquired before age 45[(a)] by other reported conditions, 2003

	Number ('000)	% of ABI group
Cerebral palsy (code 611)		
No	169.3	97.0
Yes	*5.3	*3.0
Congenital malformations, deformations and chromosomal abnormalities (code 1600)		
No	158.8	91.0
Yes	15.7	9.0
Other diseases of the nervous system (code 699)		
No	161.1	92.3
Yes	13.5	7.7
Total	**174.6**	**100.0**

(a) Excludes people aged 45 years or more who did not know age at onset of main disabling condition or who lived in cared accommodation where this information was not collected.

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.

4.3 Approaches to population estimates of CP-like disabilities and therapy and equipment needs

Population estimates of CP-like disabilities and need for therapy and equipment are conducted in two main steps, using a step-by-step exclusion process (Figure 4.1). The first step—the broad estimate—selects people aged under 45 who had ABI-related disabilities, had acquired their main disabling condition (not necessarily ABI) before age 30, and had disabilities categorised as physical/diverse or hearing or speech. Thus, the broad estimate starts with all people with ABI-related long-term health conditions and then excludes people who:

- had no disability
- were aged 45 or over
- had acquired their main condition (not necessarily ABI) at age 30 or over
- had no physical/diverse or hearing or speech disabilities.

The reasons for these exclusions are explained below; in particular, decisions were guided by a desire to focus in on those people with early-onset disability, and with a disability profile similar to that typical of CP-related disability.

The second step takes the broad estimate as a starting point and focuses on the population whose profile of needs for assistance is similar to that of people with cerebral palsy. It does this by including only those people who reported a need for personal assistance or supervision at least once per day with one or more of the core activities of self-care, mobility and communication.

The detailed steps of the exclusion process are illustrated in Figure 4.1.

Step 1: Broad estimate of CP-like disabilities

In 2003, there were 816,500 people of all ages with ABI-related long-term health conditions. Of these, 378,200 did not have a disability and were excluded. This left 438,300 who had ABI-related disabilities.

About 174,600 people were either aged under 45 with ABI-related disabilities, or aged 45 or more and had acquired an ABI-related main disabling condition before age 45. This step excluded 263,700 people who were aged 45 or over and had acquired an ABI-related main condition at age 45 or more, or had not given information about age at onset of their main condition.

There were only 3,200 people aged 45 or over with an ABI-related main disabling condition that occurred before 45. A majority (69%) of them had acquired their ABI-related main disabling condition at age 35–44; of these, 52% had acquired their condition at age 40–44, a clear indicator of an onset of disability in late adulthood. No one in this age group had also reported cerebral palsy or congenital disorders, while only 500 (16%) reported conditions related to 'other disease of the nervous system' (Table 4.4). Therefore, people aged 45 and over were excluded and this left 171,400 people who were all aged under 45.

Selecting people with early onset disabilities, the baseline estimate includes only 138,200 people who were aged under 45 and had acquired their main condition (not necessarily an ABI-related condition) before age 30. Those 33,200 people who had acquired their main disabling condition at age 30 or over were excluded.

The final step in deriving the baseline estimate focuses on the 111,700 people who also had physical/diverse or hearing or speech disabilities. Some 26,500 people who had no physical/diverse, hearing or speech disabilities were excluded. This results in the exclusion of about 4,100 people and reduces the number of people with psychiatric disabilities in the CP-like group, making the disability profile of this group more similar to that of people with CP.

Step 2: Estimate of people with CP-like disabilities who may need therapy and equipment services

At the second level of estimates, the reported need for assistance and use of aids and equipment are used as a filter and applied to the broad estimate. There were 43,400 people who needed personal assistance with, or used aids for, one or more core activities. Those 68,300 people who neither needed assistance with nor used aid for core activities were excluded.

Only 21,200 people who needed personal assistance at least once a day with one or more core activities were selected in the final estimate. The remaining 22,200 people with lower frequency of need for help with core activities were excluded. This is to reflect the conservative approach being taken in focusing on people with higher support needs; it also makes the support needs profile of the CP-like group more similar to that of people with CP (Chapter 2; Section 4.5).

The resulting population estimate of people with CP-like disabilities who may need therapy and equipment is that, in 2003, there were 21,200 people aged under 45 with ABI-related disabilities who had acquired main disabling condition before age 30 and also had physical/diverse or hearing or speech disabilities, and needed personal assistance at least once a day with core activities.

In Section 4.5, these population estimates will be tested by comparing disability patterns and support needs profiles between people with CP, those with CP-like disabilities, and clients of CSTDA-funded services provided by CP Australia agencies. Section 4.4 discusses other issues relating to the population estimates of CP-like disabilities.

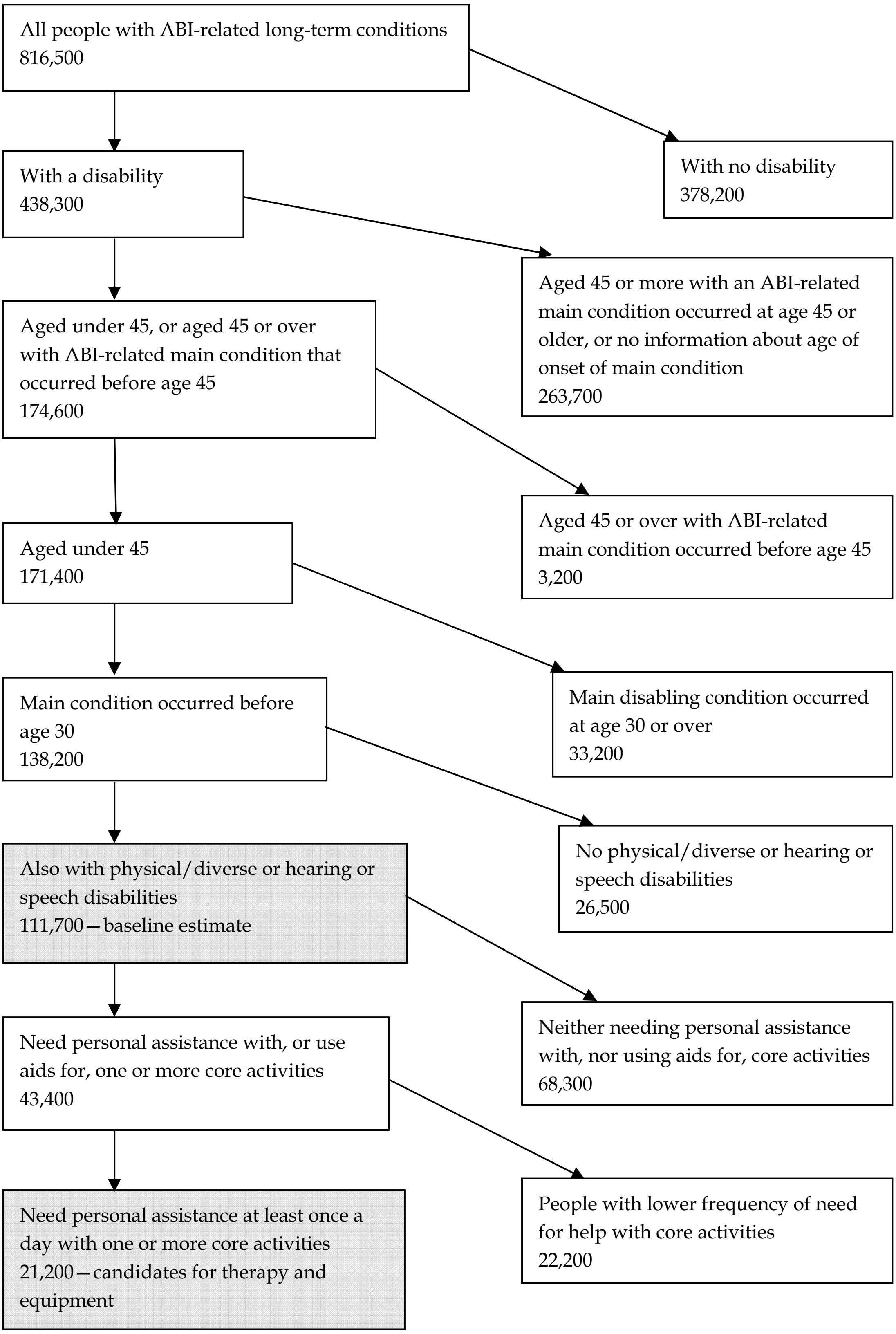

Figure 4.1: Step-by-step exclusion process for baseline estimates of cerebral palsy-like disabilities and candidates for therapy and equipment, 2003

Table 4.4: People aged 45 years or over with a disability and an ABI-related main condition acquired before age 45[(a)], by age at onset of main disabling condition, by other disabling conditions, 2003

	Number ('000)	%
Age at onset of main disabling condition		
5–9	**0.3	**10.5
25–29	**0.7	**20.8
35–39	**0.5	**16.5
40–44	**1.7	**52.3
Other disabling conditions		
Cerebral palsy		
No	*3.2	*100.0
Congenital malformations, deformations and chromosomal abnormalities		
No	*3.2	*100.0
Other diseases of the nervous system		
No	*2.7	*83.8
Yes	**0.5	**16.3
Total	***3.2**	***100.0**

(a) Excludes people aged 45 years or over who did not know age at onset of main disabling condition or who lived in cared accommodation where this information was not collected.

Notes

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

4.4 Other issues relating to the population estimates of CP-like disabilities

A lower age cut-off than age 45?

Is it reasonable and possible to impose a lower chronological age limit to the ABI disability group? Further exploratory analysis has extracted data on a selected group of people aged 25 to 44 with an ABI-related disability. The aim is to check whether it is appropriate to apply a lower age limit, for example under age 40 or 30, to the ABI group.

Table 4.5 presents various main disabling conditions reported by people in this selected group by different chronological ages. Head injury or acquired brain injury was in the top three of the list, while back problems led the list for all the four age groups.

Table 4.6 examines whether cerebral palsy, congenital disorders or 'other disease of the nervous system' were reported by the people aged 25-44 with ABI-related disability. The data do not suggest a significant difference between younger people and older people in reporting these conditions.

Table 4.5: People with a disability aged 25 to 44 who had ABI based on all reported conditions: top 15 main disabling conditions by age group, 2003

	Age group				
Main condition	**25–29**	**30–34**	**35–39**	**40–44**	**Total**
			Number ('000)		
Back problems (dorsopathies)	*4.6	*7.0	*6.0	*5.8	23.4
Head injury/acquired brain damage	*3.9	*2.3	**2.1	*3.2	11.5
Depression/mood affective disorders (excluding postnatal depression)	**1.6	*3.6	*2.4	*2.6	10.1
Arthritis and related disorders	**0.9	**0.9	**0.9	**1.8	*4.5
Stroke	**0.0	**0.4	—	**1.5	**1.9
Other mental and behavioural disorders	**1.7	**1.7	**1.5	**1.3	*6.1
Leg/knee/foot/hip damage from injury/accident	**1.0	**0.7	**1.3	**1.2	*4.2
Sight loss	—	—	—	**1.2	**1.2
Other symptoms/signs and abnormal clinical and laboratory findings n.e.c.	—	—	—	**1.2	**1.2
Epilepsy	**1.1	*1.4	**0.7	**1.2	*4.4
Other diseases of the musculoskeletal system and connective tissue	—	—	**0.6	**1.2	**1.7
Intellectual and developmental disorders n.e.c.	—	—	—	**0.9	**0.9
Migraine	**0.7	**0.9	**0.2	**0.8	*2.6
Other diseases of the nervous system	**1.2	**0.7	**0.4	**0.8	*3.0
Retinal disorders/defects	—	—	—	**0.8	**0.8
All other conditions	**7.4*	**5.9*	**9.2*	**9.8*	*32.2*
Total	**24,070**	**25,473**	**25,135**	**35,092**	**109,770**

Notes

1. Estimates marked with * have an associated relative standard error of between 25% and 50% and should be interpreted accordingly.
2. Estimates marked with ** have an associated relative standard error of greater than 50% and should be interpreted accordingly.
3. Table 4.5 is ranked by highest frequency in age 40–44.

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

Table 4.6: People with a disability aged 25 to 44 who had ABI-related conditions (based on all reported disabling conditions): CP and selected CP-like conditions,[(a)] by age group, 2003

	Age group				
	25–29	30–34	35–39	40–44	Total
Cerebral palsy			(Number ’000)		
No	23.9	25.4	24.3	34.9	108.5
Yes	**0.1	**0.1	**0.8	**0.2	**1.3
Congenital malformations, deformations and chromosomal abnormalities					
No	23.0	23.6	23.5	33.9	104.0
Yes	**1.1	**1.8	**1.6	**1.2	*5.7
Other diseases of the nervous system					
No	21.3	24.3	23.7	32.5	101.7
Yes	*2.8	**1.2	**1.5	*2.6	*8.1
Total	**24.1**	**25.5**	**25.1**	**35.1**	**109.8**

(a) Based on all reported disabling conditions.

Notes

1. Estimates marked with * have an associated relative standard error of between 25% and 50% and should be interpreted accordingly.
2. Estimates marked with ** have an associated relative standard error 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 4.7 analyses the distribution of age at onset of main disabling condition among the same selected group by different age groups. About 50% of people aged 40–44 had acquired their main disabling condition before age 30; of these people, 24% had the condition before age 20. For those aged 35–39, 60% of them had their main disabling conditions before age 30; of these, 27% had the condition at age 0–19.

In summary, the analysis results provide no clear rationale for imposing a lower chronological age cut-off to the ABI group. A large proportion of people who were aged 40-44 or 35–39 at the time of survey had acquired their main disabling condition before age 30. To exclude these people will not be consistent with our aim to include people who acquired their disability at early stage of life. However, as the baseline estimates of CP-like disabilities have excluded people who acquired their main disabling condition at age 30 or older, some 46% of people aged 40–44 and 36% of those aged 35–39 in this ABI group were excluded due to their older age at onset of main disabling condition.

Age groups relating to key transition points

The proposed age breakdown (0–4, 5–19, 20–44, 45+) can be applied to the combined population groups of CP and CP-like disabilities, with a possibility of more detailed breakdown for some age groups.

For people with cerebral palsy, only broad age groups (0–19, 20–44 and 45+) can be applied in the data analysis (Table 4.8).

Table 4.7: People aged 25 to 44 with an ABI-related disability based on all disabling conditions: age at onset of main disabling condition by current age, 2003

Age at onset of main disabling condition	Current age 25–29	30–34	35–39	40–44	Total
		(Number ’000)			
0–19	14.5	*8.6	*6.7	*8.3	38.0
20–24	*4.1	*4.7	*3.3	*5.3	17.4
25–29	*4.9	*8.1	*4.9	*3.8	21.6
30–34	—	*3.3	*6.9	*2.3	12.6
35–39	—	—	*2.2	*6.3	*8.5
40–44	—	—	—	*7.4	*7.4
Not applicable	**0.6	**0.8	**0.6	**1.1	*3.1
Not known	—	—	**0.4	**0.6	**1.1
Total	**24.1**	**25.5**	**25.1**	**35.1**	**109.8**
		Per cent (sum vertically)			
0–19	60.1	*33.7	*26.7	*23.7	34.7
20–24	*16.8	*18.6	*13.3	*15.2	15.9
25–29	*20.4	*31.6	*19.5	*10.7	19.7
30–34	—	*13.1	*27.6	*6.5	11.4
35–39	—	—	*8.8	*18.0	*7.8
40–44	—	—	—	*21.0	*6.7
Not applicable	**2.7	**3.0	**2.5	**3.1	*2.8
Not known	—	—	**1.7	**1.8	**1.0
Total	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**
		Per cent (sum horizontally)			
0–19	38.0	*22.5	*17.6	*21.8	100.0
20–24	*23.2	*27.1	*19.1	*30.5	100.0
25–29	*22.7	*37.2	*22.7	*17.4	100.0
30–34	—	*26.6	*55.2	*18.1	100.0
35–39	—	—	*25.8	*74.2	100.0
40–44	—	—	—	*100.0	100.0
Not applicable	**20.5	**24.5	**20.0	**34.9	100.0
Not known	—	—	**40.7	**59.2	100.0
Total	**21.9**	**23.2**	**22.9**	**32.0**	**100.0**

Notes

1. Estimates marked with * have an associated relative standard error of between 25% and 50% and should be interpreted accordingly.
2. Estimates marked with ** have an associated relative standard error 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 4.8: People with a disability who had cerebral palsy: age groups and type of special dwelling, 2003

Age group	Number ('000)	%
0–4	**1.2	**7.6
5–9	**1.7	**10.9
10–14	*2.7	*16.8
15–19	*2.5	*15.5
20–44	*6.7	*41.9
45–64	**0.8	**5.0
65+	**0.3	**2.2
Type of special dwelling		
Not applicable	14.1	87.8
Hospital - general	**0.3	**1.7
Hospital - other	**0.5	**3.2
Home for the aged	**0.6	**3.9
Home - other	**0.5	**3.3
Accommodation for the retired or aged	**0.0	**0.2
Total with a disability	**16.1**	**100.0**
Total with cerebral palsy conditions	**16.8**	

Notes

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

Young people in cared accommodation (institutions)

Further analysis suggests that the cell size for people with cerebral palsy living in institutions is too small for general use (Table 4.8). The possibility of looking at this group had been suggested by the Advisory Committee.

4.5 Comparisons of disability patterns and support needs

This section presents comparisons of main disability patterns and support needs among the two population groups and users of CSTDA-funded services provided by CP Australia agencies. The main purpose for these comparisons is to confirm that the main disability patterns and support needs of the CP-like population group are similar to those of the CP population group and the target group of CP services. The two population groups are the population estimates of 16,100 people with CP disabilities and 21,200 people with CP-like disabilities who may need therapy or equipment services. Data from the 2003–2004 collection of CSTDA NMDS are used to obtain information for users of CSTDA-funded services provided by CP agencies (8,138 people). The available data do not allow a match of specific disabling conditions. Although the population data have broad groups of disabling conditions, the CSTDA NMDS does not identify specific conditions.

The population group with CP-like disabilities is firstly compared with the CP population group. It is then compared with users of CSTDA-funded services provided by CP agencies.

Comparisons of people with CP and those with CP-like disabilities

Comparisons of the main disability groups of people with CP and those with CP-like disabilities are presented in Table 4.9.[8] The overall patterns suggest that both groups had a high proportion of multiple disabilities, and that physical/diverse disabilities were the dominant disabilities. All people with CP reported one or more physical/diverse disabilities and 80% of them reported a physical/diverse main disabling condition. Physical/diverse disabilities were also most prevalent among the CP-like group, based on either all disabling conditions (89%) or main disabling condition (56%). A third (37%) of people with CP also had ABI.

Based on consideration of all disabling conditions, just under 60% of people with CP and 70% of those with CP-like disabilities also reported intellectual disabilities. Sensory/speech disabilities were reported by 56% of the people with CP and 68% of people with CP-like disabilities. The proportion of psychiatric disabilities was higher for people with CP-like disabilities (59%) than that for those with CP (41%). This may be partly due to the data coding in the 2003 SDAC Confidentialised Unit Record File. Disabling conditions associated with 'Down syndrome', 'developmental learning disorders' and 'other developmental disorders' were coded into the catch-all subcategory of 'other mental and behavioural disorders' for mental and behavioural disorders instead of intellectual and learning disorders.

Comparisons of activity limitations of people with CP and those with CP-like disabilities are illustrated in Table 4.10. Corresponding to a high proportion of co-morbidities and multiple disabilities, more than half of the people with CP and over 70% of people with CP-like disabilities needed help with at least two core activities. For people with CP, more than half had a severe or profound limitation either with self-care or mobility or both, and about 40% had that limitation with communication. More than 80% of people with CP-like disabilities had a severe or profound limitation either with self-care or mobility or both, and 38% had that limitation with communication. Over 40% of people in both groups were using aids or equipment for mobility or communication activities.

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[8] Since the two population groups are estimated based on all reported disabling conditions, there are overlaps between the two groups when they are estimated separately. These overlaps will disappear when the two groups are combined in the data analysis.

Table 4.9: Comparisons of main disability groups: people with CP and CP-like disabilities, 2003

	Cerebral palsy		Cerebral palsy-like	
Disability groups	**No. (’000)**	**%**	**No. (’000)**	**%**
All disabling conditions				
Intellectual	*9.5	*59.2	14.8	69.9
Psychiatric	*6.6	*41.2	12.5	58.9
Sensory/speech	*8.9	*55.7	14.4	68.0
ABI	*5.9	*36.8	21.2	100.0
Physical/diverse	16.1	100.0	18.9	89.2
Main disabling condition				
Intellectual	**1.6	**9.8	**1.5	**10.4
Psychiatric	**0.7	**4.7	*3.3	*23.6
Sensory/speech	**0.1	**0.6	**0.4	**1.8
ABI	**0.8	**5.1	*4.1	*19.5
Physical/diverse	12.8	79.8	11.9	56.2
Total	**16.1**	**100.0**	**21.2**	**100.0**

Notes

1. Estimates marked with * have an associated relative standard error of between 25% and 50% and should be interpreted accordingly.
2. Estimates marked with ** have an associated relative standard error 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 4.10: Comparisons of activity limitations: people with CP and CP-like disabilities, 2003

	Cerebral palsy		Cerebral palsy-like	
	No. ('000)	%	No. ('000)	%
Level of self-care limitation				
Profound	*8.6	*53.2	12.8	60.6
Severe	**1.9	**11.5	*4.3	*20.5
Moderate	**1.1	**7.0	*2.3	*11.0
Mild	**0.3	**2.0	—	—
Level of mobility limitation				
Profound	*7.3	*45.4	*8.8	*41.7
Severe	**1.2	**7.3	*9.0	*42.7
Moderate	**0.5	**3.2	—	—
Mild	*5.2	*32.4	**1.3	**4.0
Level of communication limitation				
Profound	*5.3	*33.2	*7.1	*33.7
Severe	**1.1	**6.7	*2.9	*3.8
Moderate	**1.4	**8.5	**1.3	**6.3
Mild	—	—	—	—
Need assistance with core activities				
Only one of the three	*2.4	*15.2	*5.7	*26.7
Self-care and mobility	*3.7	*23.3	*7.4	*35.2
Self-care and communication	**0.2	**1.1	**0.3	**1.6
Mobility and communication	—	—	**0.7	**3.4
All three core activities	*4.4	*27.3	*7.0	*33.0
No need for help	*5.3	*33.2	—	—
The highest frequency of need for assistance (any core activities)				
6+/day	*6.5	*40.7	*9.5	*44.9
3–5/day	**1.4	**8.5	*6.1	*28.9
2/day	**1.5	**9.5	*3.2	*14.9
1/day	**0.4	**2.3	**2.4	**11.3
2–6/week	—	—	—	—
1/week	**0.6	**3.8	—	—
1–3/month	**0.3	**2.1	—	—
<1/month	—	—	—	—
Uses equipments for mobility and/or communication	*6.5	*40.5	*8.8	* 41.6
Total	**16.1**	**100.0**	**21.2**	**100.0**

Notes

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

Comparisons of the population group with CP-like disabilities and users of CSTDA-funded services provided by CP agencies

Questions relating to need for assistance with core activities in the CSTDA NMDS collection are designed to be similar to the ABS SDAC questions to allow some comparisons between the two data sources. The comparisons in this section select users of CSTDA-funded services provided by CP agencies who were aged under 45, as all people in the population group of CP-like disabilities were aged under 45 years. CSTDA NMDS data on disability groups have been aggregated to match with the five broad disability groups used in the SDAC (population) data for population groups with CP and CP like disabilities.

Based on consideration of all disabling conditions, physical/diverse and intellectual disabilities were the most prevalent disabilities among both the population group with CP-like disabilities and service users of CP agencies, followed by sensory/speech disabilities (Table 4.11).

People with CP-like disabilities had higher proportions of sensory/speech and (of course) ABI-related disabilities than service users of CP agencies. The proportion of psychiatric disability was lower for service users of CP agencies than for the CP-like population group.

Table 4.11: Comparisons of main disability groups: people with CP-like disabilities and users of CSTDA-funded services provided by CP agencies[(a)]

	People with CP-like disabilities		CSTDA service users	
Disability groups	**No. ('000)**	**%**	**No. ('000)**	**%**
All disabling conditions[(b)]				
Intellectual	14.8	69.9	5.1	62.3
Psychiatric	12.5	58.9	0.3	3.5
Sensory/speech	14.4	68.0	3.8	46.8
ABI	21.2	100.0	0.6	7.4
Physical/diverse	18.9	89.0	6.3	78.0
Not stated	n.a.	n.a.	n.a.	n.a.
Main disabling condition[(c)]				
Intellectual	**1.5	**10.4	2.4	29.7
Psychiatric	*3.3	*23.6	0.0	0.3
Sensory/speech	**0.4	**1.8	0.1	1.7
ABI	*4.1	*19.5	0.3	3.1
Physical/diverse	11.9	56.2	4.6	56.6
Not stated	n.a.	n.a.	0.7	8.5
Total	**21.2**	**100.0**	**8.1**	**100.0**

(a) Users aged under 45 years in 2003–04 financial year.

(b) Includes both primary and other significant disability groups for CSTDA service users.

(c) Corresponding to primary disability groups for CSTDA service users.

Notes

1. Estimates marked with * have an associated relative standard error of between 25% and 50% and should be interpreted accordingly.
2. Estimates marked with ** have an associated relative standard error 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 and 2003–04 CSTDA NMDS.

The overall proportion of a profound or severe core activity limitation was higher for the CP-like group (100%) than that for service users of CP agencies (74%), since one of the criteria for the estimate of CP-like group is a need for personal assistance at least once per day with one or more of the core activities.[9] The CP-like population group had higher proportions of a profound or severe limitation with self-care and mobility, compared to service users of CP agencies, while service users had a higher proportion of that limitation with communication (Table 4.12).

Among the CP-like population group, the proportions of a profound or severe core activity limitation were higher for mobility (84%) and self-care (81%) than for communication (48%). For service users of CP agencies, the highest proportion of a profound or severe limitation was with self-care (69%), followed by mobility (61%) and communication (60%).

Table 4.12: Comparisons of support need profiles: people with CP-like disabilities and users of CSTDA-funded services provided by CP agencies[(a)(b)]

	People with CP-like disabilities		**CSTDA service users**	
	No. ('000)	**%**	**No. ('000)**	**%**
Self-care				
Profound	11.8	60.6	3.8	46.4
Severe	*4.3	*20.5	1.9	23.0
Total	*17.1*	*81.1*	*5.6*	*69.4*
Mobility				
Profound	*8.8	*41.7	3.1	37.7
Severe	*9.0	*42.7	1.9	23.6
Total	*17.8*	*84.4*	*5.0*	*61.3*
Communication				
Profound	*7.1	*33.7	3.0	36.6
Severe	*2.9	*13.8	1.9	23.2
Total	*10.0*	*47.5*	*4.9*	*59.8*
All core activities				
Profound	15.7	74.2	4.2	51.8
Severe	*5.5	*25.8	1.8	22.4
Total	*21.2*	*100.0*	*6.0*	*74.2*
Total	**21.2**	**100.0**	**8.1**	**100.0**

(a) Users aged under 45 years in 2003–04 financial year.

(b) 'Profound' corresponds to 'always or unable to do' in the CSTDA data collection; 'Severe' corresponds to 'sometimes' in the CSTDA data collection.

Note: Estimates marked with * have an associated relative standard error 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 and 2003–04 CSTDA NMDS.

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[9] About 1,550 (19%) service users of CP agencies did not provide information about their support needs for self-care, mobility and communication activities.

4.6 Conclusion

In summary, the comparative analyses of Section 4.5 show that the main disability patterns of the CP-like population group were reasonably similar to those of CP population group and service users of CP agencies except that psychiatric disabilities were more commonly reported by the population with CP or CP-like disabilities. Physical/diverse and intellectual disabilities were the most prevalent disabilities for all the three groups, followed sensory/speech disabilities.

The profile of support needs of the CP-like population group was similar to that of the CP population group as well as service users of CP agencies. All these three groups had high proportions of people needing help with each of the three core activities.

The CP-like population group had a higher proportion of people with 'higher-end' (profound limitations) support needs with core activities than other groups, largely due to the criterion for the CP-like population group, which restricted to persons needing frequent personal assistance (at least daily) with one or more core activities of self-care, mobility and communication.

Overall, it was concluded that the people of 'CP-like' disabilities was a useful inclusion to the population under consideration. The available data do not allow a better match, since the population data have broad groups of disabling conditions and the CSTDA NMDS does not identify specific disabling conditions. However, the results indicate that the population data on CP and CP-like disabilities are a reasonable approximation of the clients of CP agencies.

5 Focus groups

5.1 Introduction

Focus groups of clients, parents, and professionals working with people with cerebral palsy and like disabilities were held in four Australian states. Participants volunteered to share their experiences and opinions for the groups, which were advertised throughout each jurisdiction. Each focus group consisted of between five and 18 participants. In all, 12 focus groups were held with a total of 52 clients (adults and families of children with cerebral palsy and like disabilities) and 65 professionals participating.

- Three groups were made up of adult clients and their carers or advocates.
- Four groups had families with children with cerebral palsy and like disabilities.
- Four groups comprised a multidisciplinary group of therapists, project managers, social workers, psychologists and other allied health professionals.
- One group was a mix of professionals and parents.

Clients ranged in age from pre-school to over 60 years, and had diverse residential arrangements, including cared accommodation, family homes and independent living. Participants from regional or rural areas of each state were involved, on one occasion by videoconference. Two clients who were unable to attend groups submitted written comments.

Participants were asked to discuss a number of topics related to unmet need for therapy and equipment. Participants were also asked to raise any additional issues they felt were relevant to the project. Each group was sent a record of their discussion for checking and approval of the contents.

This chapter summarises the discussion across all 12 focus groups according to the topic headings given to participants. For the purposes of this chapter, therapy and equipment are largely treated separately. However, in practice the two are intrinsically linked in supporting an individual’s functioning.

5.2 What is therapy?

The purpose of therapy

Participants described the purpose of therapy as helping them to achieve goals. For some these were physical, such as maintaining limb function and preventing or delaying need for surgery. Others expressed their long term therapy goal more holistically.

> The ultimate goals should be for every person to reach their potential and sustain this through their life.

Most people agreed that the focus of therapy should be on maximising participation in life first, ahead of arbitrary physical goals. As one person remarked,

> If we can't support the child in the broader community, are we really achieving our goals as therapists?

Provision of support and information, particularly to families of young children with CP, was also seen as an important role of therapy.

> Therapists' role is to break down the jargon and take down the barriers.

A number of clients commented on the tendency for therapy to focus on early intervention, when they considered therapy to be equally important in maintenance of functioning as an adult 'to stave off deterioration and the need for carers.' Early ageing was identified by some professionals as a significant concern that requires therapy input.

> [There is] almost no room for hands-on therapy for adults…as they age, they probably need more hands-on therapy…this will be a national issue among the ageing population.

The effect of age on therapy goals was also discussed.

> [Adults] would prefer to talk than walk. The biggest stumbling block is communication.

> It is important to consider life stages and the opportunity for the person to reach their potential at each stage.

While all participants acknowledged the value of therapy, several reflected on its place in the context of their wider life goals. Some parents had chosen to reduce therapy input as they believed it caused frustration and overemphasised their child's physical disability at the expense of their emotional needs.

> You get bombarded…and then after a few years my daughter didn't want to do it any more.

One mother described unstructured play time with her child as 'kid therapy'; another remarked:

> I have a teenager going through puberty problems. It's more important that she's happy.

Generally, it was accepted that therapy should not be an end in itself, but a means to facilitate participation.

> We are programmed to death…we are sick of programs. I need therapy and equipment that enables my life.

Types of therapy

Discussions about different therapies covered a broad range of disciplines, including traditional physiotherapy, occupational therapy and speech therapy, as well as social work and a number of alternate therapies.

Definitions of therapy provided by clients and professionals varied from structured sessions with a therapist to any beneficial activity that can be done by clients and/or carers.

> Therapy to me refers to anything that either we as parents or a family can give her or she can do herself.

Beliefs about the delivery of structured therapy differed between some parents of children with CP and professionals.

> I [as a parent] believe that a therapy session should be a proper workout session with the child.
>
> [There is an expectation] that therapy is hands-on. Intervention, however, is not primarily hands-on…there needs to be a mix of interventions. (Said by a therapist).
>
> I think we [therapists] see work towards participation as therapy but the family often don't.

Clients accessed a range of services including hydrotherapy, massage, horse riding and ballet to complement the traditional disciplines of physiotherapy, occupational therapy and speech therapy. Conductive education was viewed favourably by those families who had experienced it. Some clients independently participated in physical activities such as gym work and bike riding, described by one person as 'own therapy', to reduce or prevent problems of muscle tone.

Camps for children with CP and their families were singled out for positive comment, as they provide integrated therapy: physical strengthening activities, social interaction and family support. The exposure to new information about services and therapies was also mentioned.

> Camps offer great opportunities to test out different therapies.

Social work, respite and case management were discussed at length, with the general agreement that these fit into the broad understanding of therapy. Achievement of physical goals may be dependent on the extent to which clients and their families are supported more generally.

> Some things don't work because families are in crisis…[they] need social work and psychology.
>
> It may be liaising with other service providers…the client is not necessarily there…but it's about getting the therapy integrated into their everyday life.

Therapists commented on their role as providers of information in addition to direct physical intervention.

> The information you provide to the client and their family is part of therapy.

Expectations of therapy

A major theme to come out of the focus groups with professionals is the expectations that clients, particularly parents of young children, have of therapy. Perceptions of cures—'therapy means making people better'—puts pressure on therapists and leads to inevitable frustration for families.

> Too much hope is given and therapy is seen as the solution.
>
> Sometimes it's very painful and very cruel.

In addition to the belief that therapy can 'overcome the diagnosis', many therapists talked about parents having unrealistic goals. This creates obstacles to therapy as parents may resist alternative goals or equipment.

> Parents hang onto hope. If the child is given a wheelchair the parents think they will never walk; a communication device, the child will never speak.

Determining what is an achievable goal is in itself a difficult task, even for experienced therapists.

> We need to be very good and do a very accurate assessment because we can't undermine the kids' potential.

Education of parents with newly diagnosed children was identified as a significant role of professionals.

> Our therapy is so much about changing expectations.
>
> [The families] say 'I want my child to walk and talk.' It's about changing their expectations. Yes, your child will walk but it will look different, like with a walker.

Therapists also spoke of the need to break large goals down into smaller, achievable objectives.

> I don't think there's anything wrong with acknowledging the families' goals…You can say, yes, we want Johnny to walk but today we have to concentrate on head control.

Even so, one therapist commented on the pressure to go along with families' priorities contrary to their professional opinion.

> For some clients, for the sake of family centred practice we do their goals but they're not really realistic…And they've spent six to seven years learning how to walk and given up the opportunities to learn more important things.

Another aspect of therapy in which expectations of clients and their families often differ from practice is the mode of delivery. Parents' belief that intensive hands-on sessions are the most effective form of therapy is challenging to therapists who have to justify the reduction in direct intervention hours when a child enters school.

> Families are still largely dissatisfied…they had intensive early intervention and then [once their child grows older] they feel ripped off.

From the professionals' point of view, however, 'early intervention has not been successful if the family is not prepared for less intervention at school age.'

5.3 Efficacy of therapy

Benefits of therapy

Adult clients and parents of young children equally attributed great physical benefit to the therapy they receive. In addition, through improving confidence and functioning, therapy was seen to impart significant emotional and social benefit to clients.

Therapy as a more general form of support and assistance for families was another positive outcome mentioned. Several parents also commented on therapists as a source of information and ideas.

Finally, some people noted the benefit of therapy to the wider community. Physical improvements mean less need for carers and less hospitalisation. Enabling clients and families to participate more and contribute to the community reduces the social cost of disability.

Box 5.1: Clients and parents describe the benefits of 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 therapy I can't sleep and I can't participate in society.'*
- *'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.'*
- *'Without it I might as well be dead. I can't move without it, I can't sit up without it.'*
- *'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.'*
- *'[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.'*
- *'I see results from therapy. If I don't see results there is no point in doing it.'*

What factors influence the efficacy of therapy?

Frequency

The question of whether more therapy is always better divided clients. Several people cited a direct correlation between functioning and therapy frequency, including physical regression in between blocks of therapy.

> When [he] has physio, OT [occupational therapy] and speech 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.

> Once a week for half an hour is not worth having.

Others commented on the need for manageable amounts of therapy that don't overburden either clients or their families.

> At one stage I think we got too much therapy. I talked like a therapist, I ate like a therapist, I told everyone else how to be a therapist.
>
> I think we're getting enough of what we can handle at the moment.

Timing

A number of transition points were identified, at which therapy needs may change or intensify for a period. These may be linked to life stages such as starting school, moving from school to higher education, work or a day program, or physical experiences such as surgery.

Client focus groups expressed general satisfaction with therapy during early intervention. However, the reduction in direct intervention hours once a child starts school places stress on many families.

> I know I'll lose [physiotherapy] when I get to school so I'm trying to cram everything in now before I lose it all.

Reassessment of support needs when changing schools in some jurisdictions was also mentioned.

Participants' experience of waiting lists for therapy varied. One parent remarked,

> When we ask for something we generally get it. There's not a long waiting period.

However, in a different state, therapists identified waiting lists as a significant barrier to therapy for younger children. New clients can only be taken on when other children leave early intervention to start school. As the rate of CP increases, the waiting lists for therapy in the 0-6 year age group get longer. Families who move frequently were considered to be especially vulnerable to missing out on therapy as waiting lists for different geographical regions are managed separately. In particular, clients who move to lower socioeconomic regions to access more affordable housing often go on the end of a longer waiting list than they were on originally.

Loss of funding options upon turning 18 was raised as a major issue by therapist and client groups.

Several families commented on the lack of therapy offered postsurgery, which may reflect a poor interface between the disability and health sectors. Hospital staff are rarely allowed to train community therapists in relation to a client's postsurgical needs. The handover is usually done over the phone. Rules governing therapy can be inflexible and don't account for the realities of recovery from surgery. One child had surgery shortly before Christmas, and received no therapy afterwards because of holidays. Another received half the normal funding for postsurgery therapy after a hip operation because 'only one hip was done'.

Generally, the timing of therapy and related services was considered to be reactive rather than proactive. For instance, family support packages are often given too late and are crisis-based.

Effort required to receive therapy

Participants in the focus groups also discussed cost-benefit decisions they faced associated with therapy, and how the effort required can sometimes reduce the efficacy of therapy.

> You need to weigh up what you would get out of therapy and what you have to do to get therapy—you may end up worse off.

Examples of factors that may negate the benefits of therapy are the cost involved (often resulting in the reduction in some other benefit), transport time, the need for extensive coordination, and emotional effort.

> Therapy can only work if the participants want it to work…If we have goals in terms of equipment and therapy that professionals don't agree with then it becomes a constant fight.

Frustration and 'therapy fatigue' is especially common in children, and some parents reported taking time out of therapy to relax and live a 'de-programmed' life.

> You have to think about the time it takes out of your life, out of your child's life.

Guilt associated with therapy

Many parents described feelings of guilt associated with therapy. As therapists noted,

> Therapy should infiltrate their [clients'] daily lives, it should not be something that is separate.
>
> If you don't put it into practice the rest of the week, it's a waste of time.

However, parents feel that their own lack of time or expertise places limitations of the benefits their child may receive from therapy.

> The 'consultation' model with infrequent appointments and parents as therapist puts significant stress and guilt on parents.
>
> You feel like you're not doing enough.

One mother compared structured versus home-based therapy thus: 'help, advice, problem solving…[vs.] guilt, hard work, frustration.' Some families supplemented their home-based routine with private therapy.

> It takes away the guilt, knowing he's getting something.

On the other hand, some people are acutely conscious of the limited availability of structured therapy, and feel guilty for using a valuable resource. This is particularly the case with parents of children with mild disabilities.

> Maybe I'm taking therapy away from another child…so I find it very hard at the moment with therapy.

5.4 What is equipment?

Types of equipment

Focus group participants used a diverse range of equipment. These included common items such as manual and power wheelchairs, walkers, standing frames and ankle-foot orthoses (AFOs). A number of clients used augmentative and alternate communication (AAC) devices, ranging from relatively low-tech communication boards to speech synthesisers. Several participants referred to home and vehicle modifications and environmental controls as equipment categories. Other common items mentioned were hoists, adjustable beds, bath and shower chairs, car seats, splints and incontinence pads. A number of clients pointed out that definitions of equipment should include items that facilitate participation, even if they are not specifically designed for people with disabilities. Examples in this category include computer software to assist with writing (e.g. WordPerfect) and access to the internet.

> From a walking stick to a speech generator…anything that helps anyone improve their functioning or daily living.
>
> Anything electronic or otherwise that enables you to do any facet of your day that disability may have taken away from you. It allows me to do the things I want.

The purpose of equipment

Clients ascribed several different purposes to the equipment they use. Perhaps the most frequently mentioned objective is the maintenance or restoration of function and participation, thus improving independence and quality of life.

> Equipment allows me to do something that impairment has made me lose.
>
> Equipment allows me to do the things I want to do…it increases the number of options, for example a power wheelchair requires less energy than walking.
>
> Equipment makes it possible for people to express who they are and allows them to make lifestyle decisions.

Equipment also serves to prevent physical deterioration of clients. Appropriate seating was mentioned a number of times as an important factor in preventing back and hip problems. Equipment that prevents fatigue and injury to carers, such as hoists and adjustable beds, was additionally highlighted as being of great value.

As with therapy, professionals cautioned against having unrealistic expectations of equipment.

> Often equipment is seen as a miracle cure. It is important to give people the correct expectations and reality.

5.5 Efficacy of equipment

Impact on clients and families

Clients reported great benefit from equipment, both in terms of improved functionality and emotional impact. Examples of valuable equipment cited include wheelchairs that are comfortable and allow clients to access the community, beds, hoists and custom-built strollers that prevent back injury to carers caused by heavy lifting, and home modifications that facilitate participation in family life. One family added a new bathroom to their house equipped with hand rails, allowing their teenage daughter privacy in bathing and toileting. This gave her 'a new lease on life.' Another family built a house specifically to meet their daughter's needs, intending for her to be able to stay there after the parents had died. They hope to increasingly be able to withdraw from providing high levels of assistance to her as she becomes able to manage on her own, with services. To this end, the house is set up with ramps, track hoisting from bedroom to bathroom, an open living plan, wide doorways and angled access, and a purpose built kitchen. Their daughter can now get herself to bed, use the fridge, microwave, dishwasher and sink, get clothes off the clothesline and eat off trays stored for her—that is, she can participate in family life.

Several parents commented on the increase in their child's interaction with family members and friends due to equipment use.

> If I didn't have [a standing frame], the alternative is lying her on the floor…now she's able to interact with her sister.
>
> Before, she couldn't do anything with her hands. To sit up and not be lying down is fabulous.
>
> Equipment can be very empowering and change societal views of people with cerebral palsy. For example, an adult with cerebral palsy using a sophisticated speaking device gave a series of lectures at a university. Students commented on their change in perception of people with cerebral palsy.

Equipment that increases independence was additionally described as a form of respite for carers and reducing the social cost of disability.

> 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.

Limitations impacting on efficacy of equipment

While equipment can be of great benefit to clients, many items are under-utilised due to lack of training. Carers and school staff who are unfamiliar with particular aids and equipment may be reluctant to encourage their use, or be unaware of their possibilities. Therapists themselves have trouble keeping up with the many aids and equipment available. As one professional noted,

> Equipment is a skill area in itself where therapists need training.

The time required to train people in equipment-related issues can prevent best use of equipment.

> We have a full body jumpsuit and it restricts playing in the sandpit. It's not that they [school staff] are not open-minded to being taught, but it's a time issue.
>
> Follow up is often neglected and equipment gathers dust in a corner.
>
> Even if the family is keen, [equipment] requires a lot of support which is usually not available. We did a survey last year (of the year before) about how much each health provider had applied for AAC equipment. Most country providers never had because they didn't have speech pathologists with enough expertise to support AAC equipment.

Physical environments also placed limitations on the efficacy of equipment in some areas. The most common examples were buildings, both public and private, that are not accessible to wheelchairs. Several participants pointed out that accessibility involves more than just ramps—corridors are often too narrow, and access to many disabled toilets requires right-angle turns that are difficult to negotiate in a large chair.

> The experience of services for after school care is children get stuck in lifts, doorways, bathrooms. I haven't been to one yet that is suitable for our kids.

Appropriateness of equipment

While focus group participants spoke positively of the impact of equipment on their lives and their clients' lives, all included the caveat that items must be appropriate for the individual. Appropriate equipment is equipment that suits the client's physical environment (for example is not too wide to fit through doors at home), is not too heavy or cumbersome to be moved, suits the individual needs of the client and his/her carer(s) and enables participation. Inappropriate equipment restricts participation and in some cases is not used at all.

A good equipment scheme would be holistic, taking into account the needs of the individual rather than just counting the items they have. A number of clients mentioned the ideal of having both a manual and an electric wheelchair—perhaps one to use at home, and one to use at school or in the community. However, most funding schemes limit clients to a single item per 'equipment category', and additionally limit where it can be used (for example home, school or work only).

Box 5.2: Examples of inappropriate equipment

- *A young child received a wheelchair, but just the seat and not the tray. 'Without the tray it is not functional for her, and she will outgrow it without having used it properly.'*
- *'We are wanting to toilet our daughter. The equipment came without a footrest…She can't use what we have without the footrest as she is too scared.'*
- *Child-sized toileting equipment is too large for one 6 year old boy to use—he is so thin he falls through the hole.*

Timeliness

Waiting lists for many pieces of equipment significantly impact on their efficacy. As people's needs are dynamic, they may change in the interval between ordering and receiving a piece of equipment so that the item ordered is no longer appropriate. Several families and professionals related stories of children who outgrew equipment (such as walkers or wheelchairs) soon after receiving it.

> Your needs are always met six months after you need them.
>
> We are always playing catch-up [with equipment] because of the client's growth and life changes.

Some therapists order equipment in anticipation of a client's needs to account for the delay, but this is not always possible under the rules governing state equipment funding schemes due to limited funding.

Waiting times reported in the focus groups varied from less than six months to three years.

> You could class six months as good, but in six months [the child] changes so quickly.
>
> AFOs take way too long.

Some examples of the consequences of waiting for equipment are given in Box 5.3, below.

Several factors contribute to the length of time clients spend waiting for equipment—completing and processing applications, accumulating funds and availability of requested items. Particularly for large pieces of equipment, clients often have to rely on fundraising to cover the gap between what is granted through funding schemes and the actual cost. This adds a great deal to time delays. Administrative regulations can further complicate the process of buying equipment when multiple funding sources are used. For example, one organisation may require top up funds to be spent by the end of the financial year, but the bulk of the money may not have arrived by this time.

> People risk losing their [charity] funding because they've been on the [state equipment] waiting list too long.

The relative scarcity of equipment manufacturers can result in clients waiting for items to be produced once funding has been secured, especially items that require customisation. This is compounded by the tendency for funding to be given out in 'lumps', so manufacturers will get a lot of orders at once. Equipment frequently comes from overseas, which further adds to the delay.

Box 5.3: Examples of the consequences of lack of equipment

While a child was on a waiting list for surgery she outgrew her AFOs. New AFOs were not fitted as they would not be suitable after the surgery. The child could not stand or put weight on her legs for more than a year. As a result her osteoporosis worsened and she suffered a bad break to her leg. When she had the surgery she had been waiting for, it was more complicated and not as effective as it would have been a year earlier.

- *'A child seen 18 months ago needed a few hundred dollars of modifications made to their wheelchair. These modifications didn't occur and now the child has developed deformities, with around $12,000 now needed to provide a new wheelchair and to pay for required surgery.'*
- *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.'*
- *Several examples were cited of young children who had developed scoliosis while waiting up to two years for a wheelchair.*
- *Clients whose chairs break down and have no other seating equipment can spend days in bed while they wait for repairs.*
- *One man had to send his communication device interstate to be repaired, and had no replacement in the meantime. 'I had no voice for two weeks'.*
- *'A teenage girl needed a walking frame but while waiting had to wear a helmet and be assisted by a teacher's aide to walk in the playground'.*
- *'…Enormous stress on families…not just having to cope with emotional stress but having to deal with the bureaucracy'.*
- *'A child couldn't get a communication device until an adequate wheelchair was found, which took two years.'*

5.6 Determining need for therapy and equipment

Clients'/parents' point of view

When do people seek therapy and equipment?

Clients and families reported seeking therapy and equipment when things become difficult—such as experiencing pain or physical deterioration, or when the carer is having difficulties. People also seek therapy and equipment at times when their life changes, to learn how to adjust to new environments or new challenges. Additionally, parents of young children in particular seek advice after reaching developmental milestones, in order to decide on new goals.

> Mainly when she has aches and pains we take her up to services to be assessed.
>
> I think about equipment when…I notice she grows out of things.
>
> I think about equipment when things become difficult for me.

> [Therapy is sought] when we are having particular difficulty reaching the next milestone, or conversely when she has achieved something and we need to set her greater challenges.
>
> The need for emotional support [is a trigger to seeking therapy].

How do people decide what they need?

Deciding the best way to meet therapy and equipment needs is not always straightforward. Advice of therapists is a major driving factor, but clients can feel disempowered if they have no input into decisions. Also, a number of focus group participants commented on their therapists' resistance to some courses of action, particularly alternative therapies.

> I think in a lot of cases you really do take the advice because…you trust your therapist; they're suggesting the correct course of action for you.
>
> I find out (about equipment) through voicing my concerns and then they say how about this?
>
> A lot of therapists don't go into conductive education, chiropractics, horse riding and swimming. And parents do access these.

Networking with other people with disabilities helps clients and their families learn about therapy and equipment options and decide what may best meet their needs. Families also become more expert over time, and have greater confidence in independent decision making than they were in the early years.

> There's usually another mum who's been there and done that and can say, try this or do that.
>
> The expertise moves to yourself.

Therapists' point of view

Who is a candidate for therapy?

One group of professionals was asked to broadly describe people who are candidates for therapy—that is, people who may benefit from therapy or equipment, whether or not they currently receive any. The group agreed that they particularly focus on people with disabilities involving mobility, communication or self-care. However, people with cognitive problems, challenging behaviours or mental health issues may also be candidates for therapy.

It was noted that not all people who are candidates for therapy necessarily receive any. Due to limited time and resources, therapists have to prioritise potential clients according to their perceived needs. Similarly, multiple needs of a single client have to be prioritised as it is often not possible to meet them all.

How are needs prioritised?

Therapists explained that, in order to deal with high case loads, they have to make judgments about who will benefit the most from therapy.

> Where physiotherapy will not make much of a difference, [the client] will not be such a priority.

A number of factors were considered to be high priorities for therapy and/or equipment intervention. Priorities for school-aged children are equipment failure, vulnerable social or school arrangements and stressed family relations. A rural service provider listed their priority issues as health deterioration, then community living, then socialisation problems.

> There's always a hierarchy of needs—pressure sores, pain and discomfort first, then improve dressing and cooking.
>
> Transition times are always a priority.
>
> New clients are higher priority…as new clients need more support dealing with the process
>
> I see every request as important. It's urgent if there is an impact on a child or a family's health and safety, for example swallowing, behavioural problems, or very young children who are newly diagnosed. 'Red flag systems' are used to prioritise waiting lists.

Some therapists complained that clients' needs are often prioritised according to administrative decisions rather than clinical reasoning. This particularly applies to funding applications for equipment.

> Prioritising for equipment is beyond the therapist's control.
>
> It's often taken out of the therapist's hands…funding bodies decide. We'll often apply for everything and see what they'll get.

The necessity of ranking needs against each other means that some issues which are considered to be low priority do not get addressed. Therapists expressed concern for unmet need related to social and mental health issues. Depression in teenagers and young people was believed to be a major area that is generally poorly addressed. Greater focus on social participation goals early in life was suggested as a means to help prevent some of these problems.

> A lot of [11-14 year old] kids have social issues, but in early intervention it worries me that there's so much focus on walking and they're not getting that normal interaction.

5.7 Accessing therapy and equipment

Access to information

Access to information emerged as an important issue affecting the therapy and equipment people received.

> We need somebody to tell us what we should be after.
>
> I need somebody else there to facilitate a bit more and point me in the right direction…I feel guilty because I'm not sure.

This was acknowledged by therapists as well as clients.

> [There is] definitely an unmet need for information.

Parents commented that they became more knowledgeable with time, but especially in the first few years after their child's diagnosis they learned about services and equipment options through trial and error, or from other families.

> It seems to be by accident and talking to the right people.

While some clients and their families were happy with the information given to them, others expressed a desire for the disability service system to be more proactive about offering suggestions. One mother explained how her daughter's incontinence was solved with a simple medication, but for three years no one had thought to mention it to her and, as she didn't know it was available, she didn't ask. The acquisition of equipment in particular was believed to be heavily dependent on parents being informed and persistent.

> You have to be extremely proactive. So much work is involved.

Coordination of services

One of the issues raised by clients was their difficulty managing the many health professionals, disability services and government departments that must be dealt with in relation to disability. One group of parents, when asked who coordinates their services, unanimously agreed 'there is no coordination!'

> Everyone's giving advice and it's all helpful, but it's not coordinated. As a parent when you're given all this information it's hard for you to integrate it.

Some families had therapists attend doctor's appointments with them to ensure their child's medical and therapy goals were integrated. For many, however, this is a time luxury they can't afford and clients act at the intermediary between doctors and therapists.

> Unfortunately, because we're human we hear the things we want to hear…so we might not pass it on.

Lack of coordination is a particularly heavy burden on clients with complex needs or multiple health/disabling conditions. Several parents of children with complex needs explained that the onus of getting referrals to see specialists and arranging appointments falls on the family. The effort required to meet their child's day to day needs diminishes their ability to plan for the future and involve their child in the community. A number of parents and clients expressed concern for the future, and felt they needed more information and support to cope with this.

> There's not enough information on how she's going to cope as an adult. There's not enough information on how to be a fulfilled adult.

> Which takes priority—ageing or disability? Will I be able to access age care services as I age?

> I think it's really important to have a vision of what's going to happen in the future…because it can actually relieve some of your fears.

Some clients deal with coordination obstacles by utilising a case worker.

> A case worker who can take the pressure off you as a parent…overseeing all the different people that your child has to access…that you can bounce ideas off…would be ideal.

However, resource constraints have drastically limited their availability. Restrictions are placed on the provision of case management support—for example, only in emergencies and only for three to six months; in one jurisdiction intellectual disability is a pre-requisite for support. Some parents employ a case manager on a long term basis, at their own cost. One parent noted that 40% of her daughter's therapy funding goes towards the case manager's salary. In addition to coordinating services and providing information, case workers act as advocates for clients and their families, who are often too busy meeting basic needs to partake in lobbying and research.

> If you don't have someone to advocate for you, you need to be strong-willed.

One therapist commented, 'the death of case work is a huge issue.'

Client focus groups expressed a great deal of frustration with the lack of coordination between various government departments.

> There is a problem that legislation doesn't talk to each other. The system is very fragmented.

For example, one client explained that he signed a form at the doctor's office giving permission for relevant medical information to be accessed by government departments, but had to return to fill in forms with the doctor in order to get a disability sticker for the car renewed. Another parent who fosters a child with CP had to fill in 16 pages of forms to get a companion card, yet the department that issues the cards is also responsible for wardship, and had all the information requested internally.

> 'It would be better if everyone gave us the information and we kept the file.'

Departmental rules that do not appear to take into account the realities of CP were highlighted. In particular, the requirement for recipients of a disability allowance to demonstrate to Centrelink each year that they or their child still has a disability was described as degrading, and should be unnecessary for people with a lifelong condition like cerebral palsy. Apart from the time this involves, parents and clients described the emotional impact of having to focus on impairments in order to continue receiving support. One parent explained that years of having to repeat the minutiae of her daughter's disability has taken the emotion from her voice, so she is accused of not caring. On the other hand, if parents get emotional they are not 'holding it together.' Parents commented that children hate being spoken about negatively, and worry about the impact of continual reassessment on their child's self esteem.

Both client and professional focus groups identified a coordination problem within and between health and disability services. Staff often don't have time to read all the relevant information about each client, placing the onus of updating doctors and allied health professionals on families. Lack of coordination places particular strain on clients with complex needs. One parent explained that he had visited the children's hospital eight times in the past month to attend various clinics with his daughter, each occasion requiring extensive planning, time and financial cost. The need for a 'whole person' approach to health and disability services was emphasised, rather than each professional operating in isolation within their speciality. An example of good liaison between the different sectors is health care staff informing families and therapists of the impact of surgery on future equipment needs.

Lack of information was perceived to be a factor in the poor coordination between health and disability services. One group of participants at a special school told of how intensive care staff from the local hospital had recently visited the school, and were amazed at the fate of children once they left the intensive care unit. According to the focus group members, the hospital staff had no idea of the severity of disability experienced by children who survived neonatal health crises.

Barriers to receiving therapy and equipment

Financial considerations

Lack of money was identified by clients, families and therapists as the main barrier to accessing therapy and equipment.

> That's the key issue.
>
> The bottom line is: there are no dollars for therapies or equipment.

Some clients accessed private therapy—either to supplement what they received through public funding, or as their only form of therapy.

> I'd have to say no [our needs are not being met]. For speech we're paying a private provider at the moment because that's the only way.

Many clients and parents expressed a desire for private therapy, but said they could not afford it. Some of the benefits of private therapy described by participants are greater frequency of therapy sessions, personalised and consistent service, and more control over their treatment.

Funding restrictions impact on who receives therapy outside the private system. Many services have eligibility rules that determine whether a client will receive therapy.

> I think they create ineligibility to try to manage their case loads.

Further, financial considerations play a major role in determining the model of delivery many clients receive. While the literature supports proactive work, this is generally not put in place.

> We're all driven by the crisis situation [due to lack of funding].

One participant commented that 'learning related therapy' has been 're-badged' as personal care and is done 'to the person' in as short a time as possible, and by a lower paid worker, with efficiency the major consideration.

Clients expressed that lack of funding places severe restrictions on their freedom of choice and flexibility, particularly in regard to equipment options purchased through state equipment schemes. Several therapists remarked that they limit what they recommend to families, based on what they think may be obtainable. They don't want to 'set people up' for disappointment, or themselves for failure. But this can mean that families may not be told what the most suitable equipment is for a child.

> As a therapist I need to…determine what would benefit the child most, but I also need to weigh up the reality and cost of getting the equipment.

Equipment tends to be offered on the basis of affordability rather than suitability, and often only one item offered. One young woman was called a 'wheelchair snob' because she wasn't satisfied with the options available. However, as equipment affects an individual's ability to function and prevents deterioration, the issue is larger than simple consumer choice.

> Where funding is limited, choice is limited, which then compromises quality.

In addition to the physical impact of inappropriate equipment, lack of choice makes clients feel they have little control over their lives.

> We got knocked back for a [particular brand of] stroller…it is so frustrating. [The bureaucracy is] narrow minded. I hate the [brand offered]. The assembly, the inconvenience. It's cumbersome…it's not transportable…I wasn't shown any other or given a choice.

Participants described a number of factors that exacerbate the cost burden of equipment, for which there is no financial support available, including couriers to deliver new items, maintenance and electricity costs, and increased home and contents insurance to cover expensive items. Several people also commented on the paucity of specialised equipment suppliers in Australia, and the lack of competition necessary to ensure high quality and low prices. One parent explained that he purchased software from overseas that cost less than half the price of the local supplier, even accounting for delivery costs.

> [Suppliers are] taking advantage of people in the community who can least afford it.

A further financial consideration that frequently limits access to equipment is the time that must be devoted to obtaining and training in its use. As mentioned above equipment items are often under-utilised due to lack of training. Some items may not be prescribed at all because the necessary therapy support is unavailable, or obtaining the equipment is judged to be less critical than other interventions. An example cited by one therapist is the augmentative communication program, Minspeak®. According to research referred to by this therapist, approximately 180 hours of therapy time is required for users to become proficient in this program. Due to resource limitations, a therapist may never prescribe it, no matter how effective it is considered to be.

> It makes you select the aid quite differently.

Therapists are also constrained in terms of what they can deliver and how, as limited funding results in high caseloads. Therapists remarked that they rarely have the time to treat clients with a holistic approach, and instead are often forced to treat needs in isolation. One group commented that the profession may be more attractive if they were able to spend less time on administrative tasks and more doing what they were trained for.

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

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

Individual financial circumstances also affect access to therapy and equipment. Some state equipment schemes are means tested in an attempt to allocate funding equitably, but exclude many families who can't afford to pay for expensive items such as wheelchairs. One focus group commented that the recent relaxation of the means test in their state has benefited many families on middle incomes. However, one scheme requires clients to pay a gap before equipment can be released, even though only concession card holders qualify for any funding. The gap covers the difference between the price of the equipment and the maximum limit that applies to grants under the scheme. In one case quoted the gap was as high as $20,000.

> I think our needs are being met, but that's because we've bought most of our equipment. I can't honestly say our needs are being met through funding.

Families also commented on inequities in tax rules that grant deductions for the purchase of vans to transport people to work, but not school. There was a general belief among participants that the cost of disability isn't fully factored into administrative decisions, so clients are effectively forced to bear a large financial burden in order to receive the services they need.

> If you become a 'user pays' client you immediately get services which mean you live below the poverty line.

Clients who lack the capacity to pay experience long waits and take on much of the 'hands on' therapy themselves.

Funding limitations can place great emotional strain on clients and their families. Therapists believed that some people are deterred from seeking therapy or equipment because they find the process of applying for financial assistance to be demeaning. Participants in client focus groups agreed.

> It's hard to stay positive…you feel as if you are begging for everything.

A number of parents and therapists expressed concern that children may believe that they are a burden on society, and commented on the apparent financial priorities of the wider community.

> Fifteen million dollars on fireworks, yet they can't find dollars for essential services.

They also contrasted the large investment in neonatal intensive care services to the limited funding available to maintain functioning throughout life.

> We all think it [their survival] is great, but as a community we are not committed to their future.
>
> Equipment is their legs. There should be no question. They should have what they need to meet their needs.

Barriers of administration and regulations

Occupational health and safety (OH&S) considerations, and the failure of funding models to take these into account, were believed often to act as a barrier to therapy. Several families explained that their therapy allowance is fixed, but as children grow older and gain weight they require a second staff member for lifts and transfers. One family had to 'trade in' 2.5 hours of housework help per week to pay for the extra worker. The family was trying to preserve their daughter's right to service hours as part of their future planning. The mother commented, 'I know I'm focused on dying, but that's the big picture for me.'

Other parents carried out lifts and transfers alone, risking back injury. A therapist explained that, in her state, OH&S regulations also prevent carers from performing massage on clients, even though this has great benefit in managing pain and pressure sores. Additionally, clients' homes must meet OH&S standards before workers can enter, with the cost of modifications borne by clients. Generally, participants acknowledged the importance of a safe working environment for staff, but felt the needs of the client and their family were not also taken into consideration.

> One worker [because of OH&S issues] said to the client, 'You do the transfer. I'll stand outside the door and you transfer yourself, and if you fall I'll ring the ambulance.' The ludicrousness of it!

Liability concerns act as another barrier, especially in relation to equipment. Regulations can prevent modification, repair or recycling of many items, which instead have to be purchased new at extra cost to the individual and funding bodies. Use of equipment is often limited by the insurance of the school or public place. For instance, one family made their own walker (at a cost of $85, compared to $500 retail price), but their child is not allowed to use it at school for insurance reasons. Liability insurance also limits access to therapy in the community. Many public swimming pools won't allow people with complex needs to use the pool without a supervised, managed program. The need to pay for one or more aides puts hydrotherapy out of the financial reach of many clients.

Client, family and therapist focus groups all raised the issue of bureaucracy as a significant barrier to receiving therapy and equipment. In particular, participants felt that decisions about who is eligible to receive a service, and what type of service they may receive, are made by people who aren't living with a disability and don't understand the reality of their lives. One parent told of how her family's carer allowance had been cut off because her son could drink from a cup. Another family had therapy funding reduced because their daughter used a wheelchair—'she can get around'. An adult client commented on needing to 'prove' disability to continue to receive assistance.

> It can be a demeaning process of having to be videotaped to prove that you cannot walk.
>
> We are bogged down in bureaucracy. We work through constraints. I shudder when I go through the process [of asking for a service or for appropriate equipment] and in the end have to tell the family there is no service. There is nothing I can do to help you.
>
> Often the family have been through so many changes in the system that they don't bother to ask any more.

A number of participants identified administrative barriers at the interface between disability services and the education system. In one state, government-funded therapy is available for children in mainstream schools but not special schools, as the latter are perceived as having their needs met. 'Double dipping' is seen as a risk by a system under pressure. In a different state, therapy is provided exclusively through schools, so children can't receive assistance at home. One parent explained that she had to label her child as intellectually disabled, otherwise he would be ineligible for assistance in school. Another child was recognised as having a physical impairment but not a speech impairment, as only one disability is recognised by the education department, so the child has no access to a speech therapist at school.

Similar barriers exist in relation to the workforce. A therapist explained that employment assistance programs provide help for people with disabilities at work, but not at home. However, a person will be unable to get to work if they can't get out of bed in the morning. A client remarked on a paradox in employment support programs: to apply for workplace modifications, you need a job first. However, once you get a job, the site plan may not be appropriate.

> If the government wants us to work, the government have to enable us at their cost—mutual obligation won't work.

A number of other administrative barriers to having needs met were raised in the focus groups. One person pointed out that the effectiveness of respite is diminished when nursing staff won't do all tasks required to care for a client, such as changing incontinence pads. Another remarked on the incongruity of funding taxi transport for people with disabilities, but not allowing anyone else (including family) to travel with them.

Clearly it is important to have some rules governing therapy and equipment, and these are often driven by the need to make best use of limited financial resources. Generally, however, participants expressed a belief that the bureaucracy surrounding disability services could be cumbersome, punitive at times, and often acts as an obstacle to having their needs met.

Influence of professional expertise

All participant groups recognised the impact of professional expertise on the efficacy of therapy. The inexperience of many generalist therapists and health care workers in dealing with people with disabilities was considered to be a major issue. In particular, prescription of exercises without understanding constraints of impairments, and inability to deal with pain issues were described as limitations on the efficacy of therapy.

> One of the biggest unmet therapy needs for adults is pain.

Therapists commented that education about working with clients with disabilities was not included in their training, although some disability associations are now working with universities on this issue. Experienced therapists can spend a substantial amount of their time training junior colleagues, which is vital but reduces their availability for direct client interventions. As the efficacy of therapy is related to the expertise of the therapist, it is also important to consider the harm therapy can do when administered by an inappropriately trained professional.

Clients commented on the lack of expertise in the health sector. Many general practitioners are unfamiliar with cerebral palsy and disability more generally. Some participants highlighted the way mental health issues in clients with disabilities can be dealt with—misuse of antidepressants was seen as a big problem.

> Tired is not the same as depressed.

Expertise of staff in the education system was also raised, especially in jurisdictions where therapy is delivered through schools.

> A lot of time was spent with teachers and educational assistants who didn't get it, and I felt like I was beating my head against a brick wall.

Examples of highly effective professionals were also cited, including one who attends training workshops overseas to improve his skills with clients with disabilities.

> Therapy works when we have access to professionals willing to take a holistic approach.

Some families spoke highly of conductive education because of the integrative approach, which they find can be lacking in professionals of the traditional disciplines.

> They look at the whole thing…so much input from one person rather than three of four different people.

Physical environment

Several focus groups discussed the impact of physical environment on access to therapy and equipment. Access to therapy reported by clients in regional areas varied. Several families had moved to a capital city because of inadequate services in their home town, while others were satisfied with what they received in regional areas. Whatever the level of service in different regional areas, clients agreed that remoteness adds a financial burden as travel to larger centres is necessary for specialised treatment or assessment.

> All we get…is $46 to get us to [the city] and back home…Because the price of petrol is quite expensive at the moment, we'll have to reduce our trips to [the city].

Therapists explained that there is an uneven geographical distribution of professionals, resulting in higher workloads in regional areas. This often leads to greater rationalisation of services than in cities. Social work and speech therapy were identified as two disciplines especially under-resourced in regional areas.

> We do have speech pathologists, but they have too many people. Once [children] get to school age, it's more or less non-existent.

Difficulties finding locums when therapists take leave can result in clients going without therapy altogether, as was the case with two families. Fewer therapists also means reduced choice for clients.

A major issue raised that is related to physical environment is access to transport. Many families and clients talked about the need to buy or modify vans to transport wheelchairs, which costs a great deal and is often ineligible for financial assistance. Others relied heavily on taxis, which are expensive and may not be reliable. Clients told of waiting for up to two hours for 'wheelchair taxis' to arrive, even though they had been pre-booked. Other participants talked about difficulties using public transport. All of these factors create impediments to participation in the community and barriers to therapy. For example, one client explained that hydrotherapy at the public pool was beneficial, but requires too great an investment of time and effort to attend as often as she would like.

A number of other physical barriers were mentioned in the focus groups. These may be obstacles to therapy itself, such as swimming pools that are too cold or don't have a wide enough step to enter. Additionally, physical factors may be barriers to participation, which is the ultimate goal of therapy and equipment. For example, lack of access to the local TAFE college precluded one participant from formal education. Another person has to use an old walker when visiting her mother, as her wheelchair doesn't fit in the house.

Equipment schemes

Rules governing equipment purchase and use were the subject of vigorous discussion at several focus groups. While state funding schemes for equipment provide items that would otherwise be beyond the reach of most people, many participants felt that the rules and processes involved were more complicated than they needed to be, and failed to meet some very real equipment needs.

A number of people felt that the types of equipment funded under the various schemes are not broad enough. For example, ordinary items such as microwaves aren't covered, even though a microwave may make the difference between someone being able to cook for themselves at home and having to move into supported accommodation.

> The service system doesn't look at the person as a whole person.

This sentiment was echoed in discussion about regulations that limit the use of equipment funded through state schemes. One client explained that items granted for home use may be forbidden to be used outside the home, regardless of practicality.

> By simply going to the letterbox I am in breach of my contract.

Further, a therapist commented that the priorities in terms of items that receive the most funding do not necessarily align with priorities for maximising participation.

> [There is] little funding for communication devices. Wheelchairs are considered more important.
>
> The [scheme] prioritisation tool [is based on] perceived benefit of equipment…Assessment [is] all mobility based and so is always prioritised first. Communication needs are downplayed.

Several participants noted that rules of some schemes limit the already small pool of equipment options available in Australia. One specifies items must be Australian made where possible, even though a foreign-made item may be more suitable. A therapist suggested sharing equipment between service providers, which is not currently allowed in many jurisdictions, in order to increase the effective pool which can be drawn on.

> At X, there's equipment that may be appropriate to use for kids with CP but at the moment, it's set up to belong to X and no one else can use it…it's just sitting there.

A common criticism made about equipment schemes is that the application and ordering process can be inefficient. As a therapist commented,

> The paperwork can be incredible. Lots of repetition—[there] needs to be some process which is more streamlined.

This is especially felt by clients who need multiple items, each of which may require separate prescriptions and funding applications.

> He gets one splint from one place and another splint from another place…and then he needs shoes which aren't covered by [equipment provider].

These inefficiencies have the double effect of emotional stress and physical consequences associated with waiting for equipment. An example was relayed of a family's experience replacing a wheelchair that broke down. They were required to obtain three quotes for a new chair, specifying Australian made. At the time the story was told, the young client had been waiting five months for a replacement. During this time the family used a borrowed chair, with bad effects on the mother's back. The whole process was described as a 'major event'.

Box 5.4: Examples of waiting times

Therapy

- *One state provided a breakdown of people on waiting lists for therapy by geographical region. Waiting times vary from 3 months to 16 months, with less than 20% of clients receiving therapy within 6 months of being placed on the list.*
- *In a different state the waiting list for therapy in one region has stretched out to 2 years, with 2-3 new referrals received each week.*

Equipment

- *An on the spot audit of one disability services organisation found that 20% of their clients had waited a year or more for equipment.*
- *An adult focus group participant had been waiting 18 months for a new wheelchair, and had no indication of when he could expect it to arrive.*
- *One family waited two years for a wheelchair for their son, who has severe scoliosis.*
- *One group of therapists estimated that 6 months is a common waiting period following an urgent request for a wheelchair.*
- *'In terms of AAC [alternative and augmentative communication]…there's months and months of waiting lists. It's only the last year that we've been able to get trial devices.'*
- *The longest waiting period quoted by focus group participants was five years for a shower chair.*

As funding for more expensive items often only partially covers the cost, money needs to be sourced from a combination of government schemes, charities and fundraising. This adds a further complication, and hence more delays, to the process.

> Getting equipment is a merry-go-round…We sat there and said [the local disability services association] is happy to pay half, but we couldn't find the other $3000, and [another program] do[es]n't deal with that type of equipment.

One professional described an ideal equipment scheme as moving from 'why we can't' to 'how we can.'

Influence of personal factors

In addition to the issues described above, a number of personal factors affect individuals access to therapy and equipment. According to focus group participants, the most significant of these is a client's age. The experience of all participants was that access to therapy and equipment is dramatically reduced in adulthood. In Box 5.5, adults with cerebral palsy and like disabilities, and their therapists, describe the stark impact of age.

As discussed above, lack of information is a significant barrier to accessing therapy and equipment. While focus group participants agreed that there is a systemic problem around information provision, some individual factors serve to exacerbate this. One group of therapists talked about people with therapy and/or equipment needs who are out of touch with the service system due to lack of knowledge about services available. They believed that this is particularly common in communities that have limited contact with mainstream society due to cultural and/or language differences. In the therapists' experience, some children are first referred for disability services by schools as their parents aren't aware of the therapy their child is eligible for.

Box 5.5: Access to therapy and equipment in adulthood

- *'Before the age of 18 you have all the therapy you need. Once you turn 18 it's as though you're expected to be cured or die.'*
- *'It's not explained why they don't need it or whether they need it. It just disappears.'*
- *'Once you're an adult…you're placed on a waiting list. You only get what you pay for.'*
- *'Children have other options that [the state equipment funding scheme]; adults don't, other than government services.'*
- *'Everything is aimed at children…very little for adults with CP.'*
- *'[I was told] I was past my use-by date – I was 18 years old. I had a constant uphill fight to get the practitioner to hear I can still benefit from therapy.'*
- *'It's backwards ever since [turning 18].'*
- *'You need more therapy [as an adult] because you are ageing at a faster rate than those without CP.'*

Professionals also described how attitudes of individuals and families can influence their access to services. Some families may have beliefs about disability and therapy that prevent them from seeking assistance, perhaps feeling shame or associating having a disabled child with spiritual causes. Other families don't seek therapy and equipment because they believe these are only for people with severe disabilities. An additional barrier may come from parents who see themselves in a caring role and resist their child's move to independence.

> Sometimes the barriers are coming from the families themselves.
>
> My equipment poses problems for my family as they feel inferior and don't like me using it. Only in the last few years, I've been allowed to use a manual chair…I basically have to choose my equipment that improves my life or my family…My mum thinks that I can do the same things as I could as a child. I believe this is due to a lack of therapy input, explanation and support.

Other factors that affect people's access to therapy and equipment include past experience and levels of support both within and outside the family. Several participants spoke about becoming 'fatigued' after years of dealing with the bureaucracy. Clients may receive less therapy and equipment than they would like because they don't like asking for money or don't have the energy to navigate the system.

> Adults' past experience dictates future equipment use.
>
> If you've been doing it [advocacy] for 20 years you get tired.
>
> Who wants to keep writing begging letters?

5.8 Top three things that would change clients'/families' lives

Clients and their families were asked to specify three things that would most change their lives. Many suggestions were repeated across the focus groups. The answers to this question are summarised below.

Money/funding

- to buy equipment or make needed modifications without having to go into debt
- for transport-related costs: taxis; extra petrol; support to purchase a suitable vehicle or make modifications, perhaps in the form of interest-free loans
- for home modifications
- enough funding hours so that access to therapy doesn't impact on hours of direct care
- increase in the carer's allowance
- financial support into adulthood (providing great peace of mind to parents)
- for private therapy
- to buy personalised services
- bulk-billing of medical services
- affordable specialist therapists
- to access massage, therapy and equipment as needed
- to keep both manual and electric wheelchairs
- to provide greater independence and choice
- discretionary funding for personal care, respite and equipment
- funding with no restrictions.

Choice

- choice of equipment—the most suitable, not just the cheapest
- freedom to use equipment outside the home
- families given control of funding—what it can be spent on and when
- autonomy over what is needed rather than what is prescribed.

Therapy and other services

- improvements in the consistency of therapy
- improvements in the skills of therapists
- for therapists to listen to clients and families
- integrated services
- services closer to home

- more therapy outside school
- high quality, high frequency therapy sessions
- more social work
- therapy to improve communication
- regular, personalised physiotherapy and hydrotherapy
- access to an occupational therapist
- 3 hours of uninterrupted, unashamed, non-jumping the queue physiotherapy every week on the same day at the same time
- uninterrupted, regular, coordinated hydrotherapy
- regular massages to help with tone and pain issues
- more independence in eating and drinking
- pool or gym membership for physical fitness
- after-hours services
- access to massage, therapy and equipment when required without having it dominated by OH&S and workplace safety policies
- therapists to be informed about cerebral palsy
- getting surgery when it is needed, rather than having to wait.

Equipment and physical environment

- a hoist to lift the wheelchair into the van
- a better pool of emergency postoperative equipment
- chairs and equipment that last and don't cause pain
- getting equipment that can help in everyday life, particularly small equipment
- timely provision of equipment
- access to equipment at an early age
- equipment that works well
- access to coordinated, timely and effective equipment
- houses designed to be fully accessible
- readily accessible public transport
- more information about equipment that is available —having someone suggest equipment options that you might need rather than hearing about things too late.
- equipment, including maintenance, especially for mobility and communication
- better transport options—more reliable taxis, ramps to get on trains.

6 Clients and activities of CP agencies

6.1 Introduction

This chapter provides national data on CP agency activities and clients, and presents additional data available from some states and agencies to supplement the picture in terms of client profile and unmet needs.

After giving some background of the CSTDA, Section 6.2 presents national data on CP Australia agencies and their clients, and compares these to all other agencies receiving funding under the CSTDA in 2003–04.

Section 6.3 provides data available from some CP Australia agencies on diagnosis, severity and services received.

Section 6.4 presents information on unmet need for therapy and equipment available from some CP Australia agencies, in the form of waiting lists and waiting times.

The data presented in this chapter provide a profile of CP agency service users, highlighting how this group differs from other CSTDA service users, in terms of demographics, disability characteristics and support needs. In the context of the broader project, this information was important in informing the method used for identifying the 'CP-like' group in the population data (Chapter 4), and in providing support for some of the assumptions made in the process of estimating the cost of meeting unmet need for therapy (Chapter 9). CP agency data on hours of service received by clients provide a check for the hours of therapy specified in the archetypal case regimes, and the estimated levels of unmet need (Chapter 8). Further, data from equipment waiting lists are used as a basis for providing an indication of the possible cost of meeting unmet need for equipment nationally.

6.2 Commonwealth–State/Territory Disability Agreement National Minimum Data Set

The CSTDA NMDS contains data collected from services funded under the Commonwealth–State/Territory Disability Agreement. The agreement stipulates the responsibilities of the Australian Government for the planning, policy setting and management of employment services, and the responsibility of states and territories for all other disability services (see chapter 2 for further information on the background and scope of the collection). Within the CSTDA NMDS, information is collected about the service user (including demographics, disability, and support needs), services received, including information on type of services provided (such as accommodation or therapy), and service usage (such as start and exit dates). Additional information on the data items can be located in the CSTDA Data Guide (AIHW 2003b).

During 2003–04 there were 187,806 service users recorded as using CSTDA funded services (Table 6.1).

CSTDA funded services (with the exception of employment services) are funded primarily by their respective state/territory governments. Employment services are the responsibility of the Australian Government, who also provide additional funding to the states and territories. During 2003–04, government expenditure on CSTDA-funded services was approximately $3.3 billion (Table 6.2). Funding for community support services accounted for nearly 11% of this total—$352 million.

CP Australia agencies provide services funded under the CSTDA and contribute data regularly to the CSTDA NMDS. Several steps were required before analysis of CP-agency data could commence. These included:

1. seeking agreement from the National Disability Administrators (now Disability Policy and Research Working Group) (as the administrator of the CSTDA) for the AIHW to obtain the service type outlet and/or agency numeric identifiers of the CP agency service type outlets, and
2. obtaining written permission from CP agencies and a list of their CSTDA-funded service type outlets and/or agencies (including identifiers) who provided CSTDA NMDS data in 2003–04.

CP Australia agencies (plus a related one)[10] were then able to be identified within the broader CSTDA data set; this enabled analyses to be conducted comparing service users of CP agencies with all other CSTDA services users.

Table 6.1: Users of CSTDA-funded services, service group by state and territory, 2003–04

Service group	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Total	%
Accommodation support	6,440	12,989	4,933	3,136	4,069	1,069	334	212	33,175	17.7
Community support	18,013	28,485	8,564	11,138	9,916	2,173	188	509	78,847	42.0
Community access	6,483	18,441	5,354	10,354	4,827	1,493	419	286	47,636	25.4
Respite	4,153	8,607	3,306	2,464	1,390	238	255	155	20,547	10.9
Employment	19,003	18,283	12,036	6,217	5,911	1,667	898	410	64,281	34.2
Total service users	**43,619**	**68,238**	**26,352**	**22,896**	**19,099**	**5,197**	**1,638**	**1,258**	**187,806**	
Total per cent	**23.2**	**36.3**	**14.0**	**12.2**	**10.2**	**2.8**	**0.9**	**0.7**	**100.0**	

Notes

1. Service user data are estimates after use of a statistical linkage key to account for individuals who received services from more than one service type outlet during the 12-month period from 1 July 2003 to 30 June 2004. Totals for Australia may not be the sum of the components since individuals may have accessed services in more than one state or territory during the 12-month period. Service user data were not collected for all CSTDA service types (see Section 2.2 for details).
2. Employment totals do not include the 1,004 people categorised as 'independent workers' during 2003–04.
3. Differences in service type outlet response rates between jurisdictions should be considered when comparing jurisdictional data.
4. Victorian data are reported to be significantly understated; errors in the 'date of last service received' as well as a lower than expected response rates have led to under-counting of service users in the current year.

Source: AIHW 2005:1.

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[10] For the purpose of this chapter, these agencies will be referred to as 'CP agencies'. The 'related' agency was included as it provided specific services for adults with CP and 'CP-like' disabilities which were not available from CP Australia agencies in the same area.

Table 6.2: Expenditure on disability support services by Australian, state and territory governments, by service group and administration expenditure, 2003–04

Service group	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Aus Gov	Australia
				$ million						
Accommodation support	602.75	481.46	200.02	148.69	119.13	50.34	25.05	11.02	—	1,638.46
Community support	82.67	125.59	46.13	47.11	25.55	7.92	8.11	8.81	—	351.89
Community access	116.71	157.07	58.09	20.75	14.02	12.16	3.10	2.20	5.58(a)	389.68
Respite	65.51	41.24	34.02	19.00	10.81	5.16	4.02	1.28	4.43(a)	185.47
Employment	—	—	—	—	—	—	—	—	301.28	301.28
Advocacy, information and print disability	7.52	6.39	5.21	1.89	2.18	1.76	0.73	0.12	13.22	39.02
Other support	5.57	33.69	7.83	8.17	10.73	1.01	1.97	0.07	26.07	95.11
Subtotal	*880.73*	*845.44*	*351.30*	*245.61*	*182.42*	*78.35*	*42.98*	*23.50*	*350.58*	*3,000.91*
Administration	111.61	75.37	30.55	14.13	12.85	4.31	4.52	0.99	27.95	282.28
Total	**992.33**	**920.81**	**381.85**	**259.74**	**195.26**	**82.66**	**47.50**	**24.49**	**378.54**	**3,283.18**

(a) Australian government-funded community access and respite services are not funded under the CSTDA. They are funded under the Disability Services Act Discretionary Fund.

Notes

1. Data presented in this table are from *Report on Government Services 2005* (SCRSSP 2005), for all jurisdictions except Queensland. Queensland data are inclusive of CSTDA-funded specialist psychiatric disability services which are excluded from SCRCSSP reporting.
2. Total expenditure on services quoted from SCRCSSP 2005 includes actual payroll tax for NSW, Victoria (in part), Tasmania and the NT.

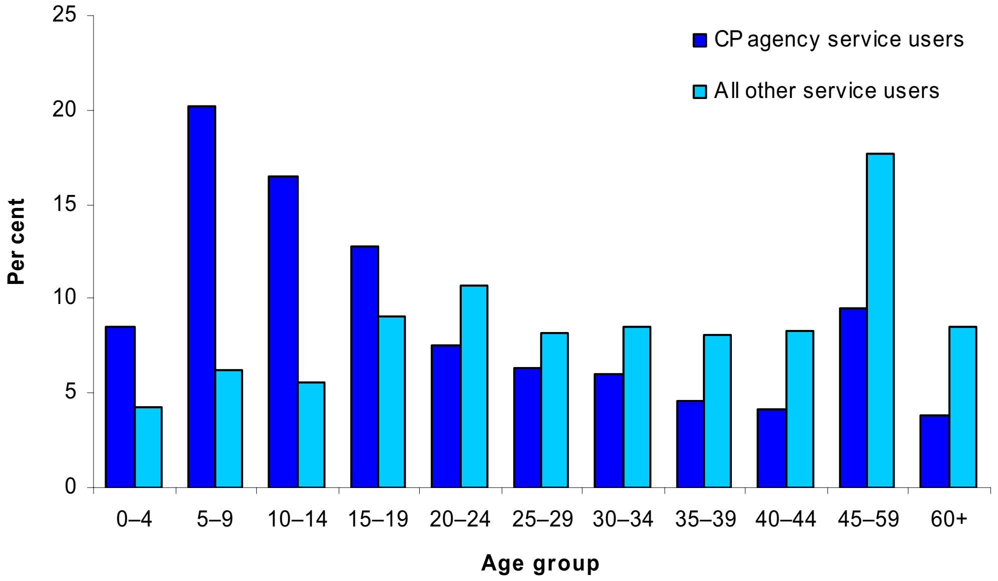
Source: AIHW 2005:6.

Comparing CP agency service users and all other users

Of the 187,806 people using services funded under the CSTDA in 2003–04, 9,398 people used services provided by CP agencies. There were 178,408 CSTDA service users who did not use a CP agency service during this period ('all other service users') (Table 6.6). There were seven CP agencies nationally. Service agencies can have multiple 'service type outlets'—there were 411 service type outlets of CP agencies.

Age and sex

The majority (58%) of CP agency service users were under the age of 20 (Figure 6.1). People aged between 5–9 years were the most common users of services (20% of all users), followed by those aged between 10–14 years (16%). Only 4% of all CP agency users were aged over 60 years. In contrast, 25% of all other agency service users were aged under 20 years, and 9% were aged 60 or over (Tables A6.1 and A6.2 provide a single year age group breakdown of users aged under 20 years). This younger age profile among CP agency service users is not surprising—there is specific targeting of therapy services towards children and younger people as early childhood and school age therapy is seen as critical in facilitating independence and participation throughout the life course.



Source: Tables A6.1 & A6.2

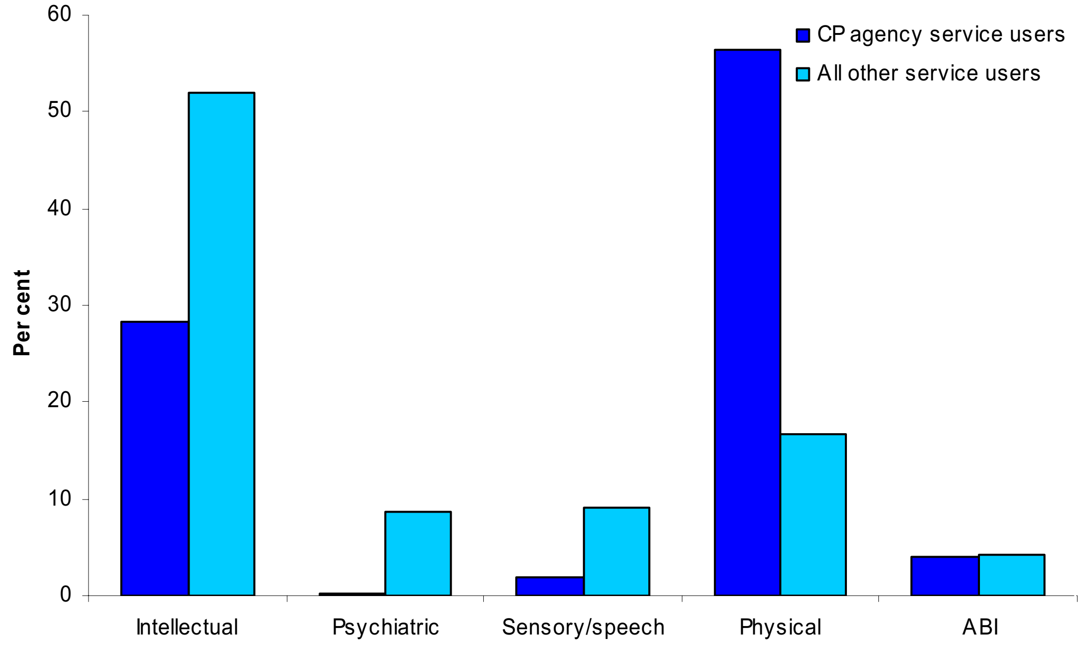
Figure 6.1: Age distribution: comparison of CP agency service users and all other service users, 1 July 2003–30 June 2004 (per cent)

Disability groups

The CSTDA NMDS collects information on primary disability group and all other significant disability groups experienced by a service user. The most commonly reported primary disability group among CP agency service users was physical (5,296 users; 56%), followed by intellectual (28%) (Figure 6.2 and Table A6.3). For all other service users, intellectual was reported as the primary disability group for 92,717 people (52%) and physical for 29,570 people (17%). In both groups, ABI was reported as the primary disability group for 4% of users.

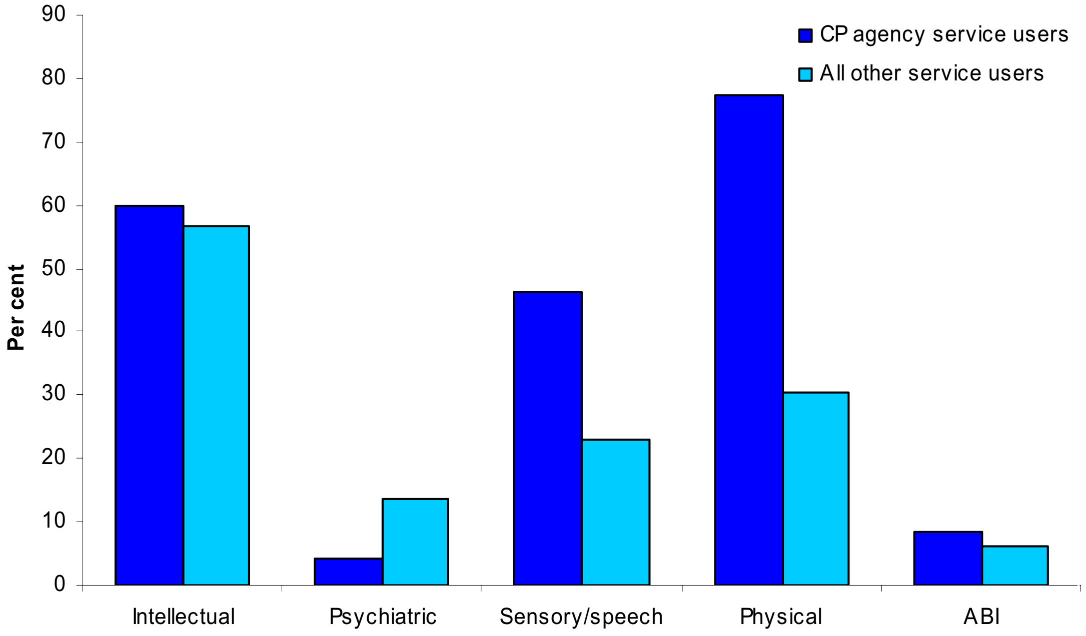
When all significant disability groups are considered, a greater proportion of CP agency service users had physical disability than all other users (77% compared to 30%); over half of both user groups had intellectual disability (60% and 57%, respectively) and 46% of CP agency service users and 23% of all other service users had sensory/speech disability (Figure 6.3). While 46% of CP agency service users had sensory/speech disability, only 2% had this as their primary disability.

A higher proportion of CP agency users had disability across every area, except psychiatric disability (Table A6.3), and CP agency service users were more likely than all other service users to have more than one disability group —68% (6,401 of 8,545 users who recorded information on disability) compared to 37% (60,466 of 161,674 users) (Table 6.3). CP agency service users had, on average, 2.8 disability groups; this was higher than the average number of 1.7 for all other service users (Figure 6.4). CP agency service users with intellectual disability had the highest average number of disability groups (3.1). For all other service users, the highest average number of disability groups was 1.9. This was among users who reported ABI as their primary disability.



Source: Table A6.3.

Figure 6.2: Primary disability group: comparison of CP agency service users and all other service users, 1 July 2003–30 June 2004 (per cent)



Source: Table A6.3.

Figure 6.3: All significant disability groups: comparison of CP agency service users and all other service users, 1 July 2003–30 June 2004 (per cent)

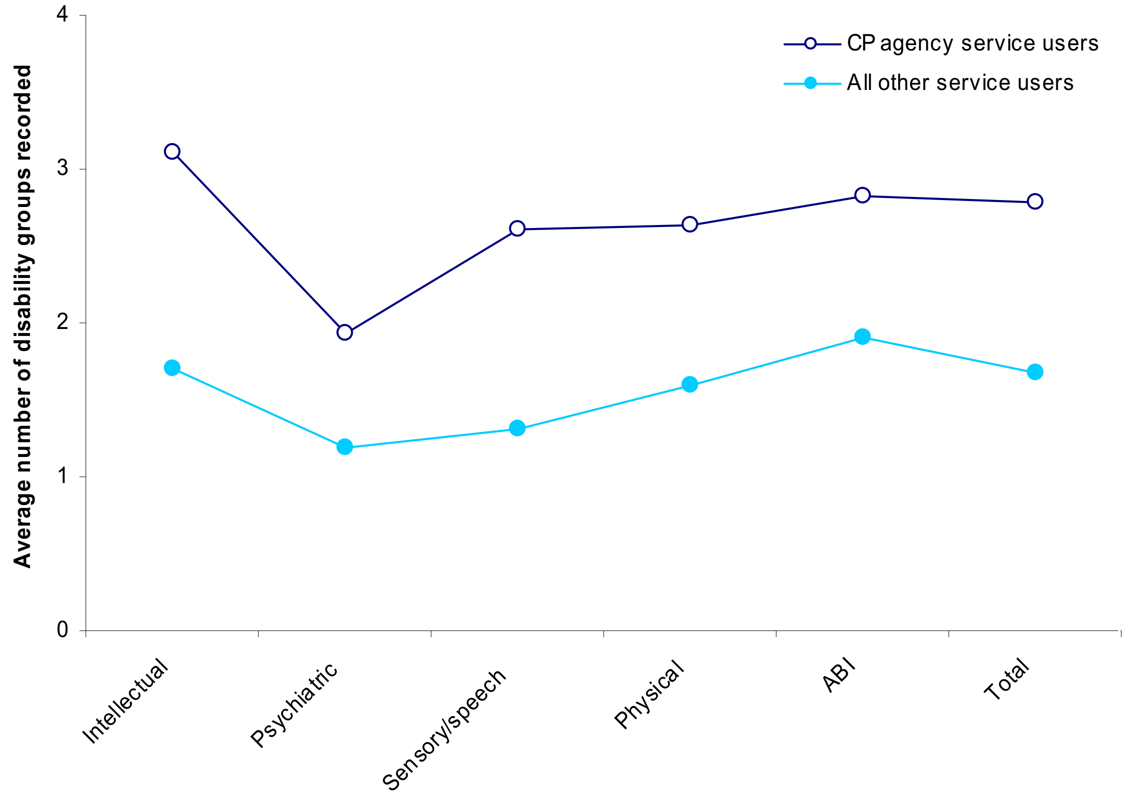


Figure 6.4: Average number of disability groups recorded by primary disability group: comparison of CP agency service users and all other service users, 1 July 2003–30 June 2004

Table 6.3: Primary disability group, with or without the presence of other significant disability groups, CP agency service users and all other service users, 2003–04

	With other significant disability groups		Without other significant disability groups		Total		Average number of disability groups recorded
Primary disability group	**No.**	**%**	**No.**	**%**	**No.**	**%**	
CP agency service users							
Intellectual	2,201	82.7	459	17.3	2,660	**100.0**	3.1
Psychiatric	15	51.7	14	48.3	29	**100.0**	1.9
Sensory/speech	126	69.2	56	30.8	182	**100.0**	2.6
Physical	3,787	71.5	1,509	28.5	5,296	**100.0**	2.6
ABI	272	72.0	106	28.0	378	**100.0**	2.8
Total	**6,401**	**68.1**	**2,144**	**22.8**	**8,545**	100.0	**2.8**
All other service users							
Intellectual	37,779	42.9	52,938	57.1	92,717	**100.0**	1.7
Psychiatric	2,475	15.9	13,055	84.1	15,530	**100.0**	1.2
Sensory/speech	3,575	21.9	12,743	78.1	16,318	**100.0**	1.3
Physical	10,669	36.1	18,901	63.9	29,570	**100.0**	1.6
ABI	3,968	52.6	3,571	47.4	7,539	**100.0**	1.9
Total	**60,466**	**37.4**	**101,208**	**62.6**	**161,674**	100.0	**1.7**

Notes

1. Service user data are estimates after use of a statistical linkage key to account for individuals who received services from more than one service type outlet during the 12-month period. Service user data were not collected for all CSTDA service types.
2. ‘Average number of disability groups’ excludes 853 CP agency service users and 16,734 other agency users for whom no disability information was available. The total also excludes these service users; hence the total does not match those in other tables.
3. The total number of all other service users ‘with other significant disability groups’ includes 2 service users whose primary disability was not stated or not collected.

Source: AIHW analysis of CSTDA NMDS 2003–04

Support needs

Data on support needs describe how often a service user needs assistance in nine life areas. There are four possible categories to describe a person’s level of need (Box 6.1).

Data on support needs across the nine life areas can be grouped into three broad areas:

- activities of daily living (ADL)—self-care, mobility and communication (this category is also commonly referred to as the core activities)
- activities of independent living (AIL)—interpersonal interactions and relationships; learning and applying knowledge and general tasks and demands; and domestic life
- activities of work, education and community living (AWEC)—education, community (civic) and economic life and working.

As there is a high rate of ‘not stated/not collected’ responses for support needs in the CSTDA NMDS, these data should be interpreted cautiously.

Box 6.1: Categories of level of personal help or supervision

1. *Unable to do or always needs help or supervision*
2. *Sometimes needs help/supervision*
3. *Does not need help or supervision but uses aids and/or equipment*
4. *Does not need help and does not use aids and/or equipment*

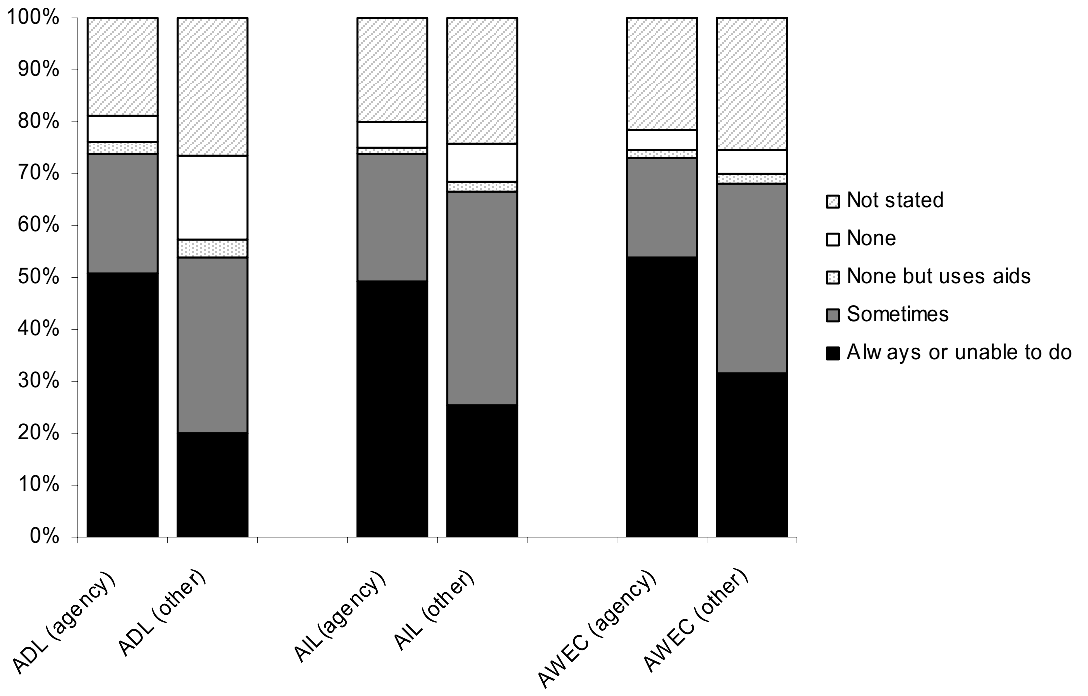


Figure 6.5: Comparison of service users' support needs, CP agency service users and all other service users, 1 July 2003 – 30 June 2004

In all three broad life areas, a higher proportion of CP agency service users than all other service users was unable to do or always needed assistance (Figure 6.5). This difference was most marked in ADL (51% of CP agency service users compared to 19% of all other service users (Table A6.4). In each of the three broad life areas around half of all CP agency service users always needed assistance. For all other users, the area of AWEC had the highest proportion of people always requiring assistance (30%). The proportion of people assisted only by aids and/or equipment across all three broad life areas was similar for the two groups (between 1% and 3 % of service users).

This pattern of support needs is similar when only service users less than 45 years of age are considered (Table A6.5). Exclusion criteria were applied in population estimates to identify people with CP-like disabilities (discussed in chapter 4) including an age limit of 45 and need for assistance at least once a day with core activities.

Over half (5,013 or 53%) of all CP agency service users required some form of assistance in every core area—self-care, mobility and communication—compared with 26% of all other users (Table 6.4). Fifteen per cent of all other users needed assistance in only one core life area compared to 5% of CP agency service users.

Table 6.4: Proportion of service users who required assistance in activities of daily living, comparison of CP agency service users and all other service users, 2003–04

	CP agency service users[(a)]		All other service users[(b)]	
Activities of daily living categories	**Number**	**%**	**Number**	**%**
Self-care only	249	2.6	5,537	3.1
Mobility only	144	1.5	5,913	3.3
Communication only	123	1.3	15,504	8.7
% of users requiring assistance in one area only	*516*	*5.4*	*26,954*	*15.1*
Self-care and mobility only	960	10.2	8,971	5.0
Self-care and communication only	344	3.6	11,471	6.4
Mobility and communication only	48	0.5	5,094	2.9
All three core life areas	*5,013*	*53.3*	*46,990*	*26.3*
Any core life areas	*6,869*	*73.1*	*99,480*	*55.8*

(a) Excludes users where information on support needs was not stated or not collected (self-care 2,059, mobility 1,795 and communication 1,792).

(b) Excludes users where information on support needs was not stated or not collected (self-care 14,253, mobility 13,868 and communication 3,518).

Source: AIHW analysis of CSTDA NMDS 2003–04

Presence of an informal carer

An informal carer is a person such as a family member, friend or neighbour who provides care and assistance on a regular and sustained basis (AIHW 2003a). Informal care of children, as it is discussed here, relates to specific care provided for children with disability rather than care provided to children in general. A total of 6,690 (71%) of CP agency service users had an informal carer compared to 71,670, or 40%, of all other users (Table 6.5). However, these data should be interpreted cautiously as there is a high proportion of 'not stated' responses (21%) in data relating to all other service users (Table A6.6).

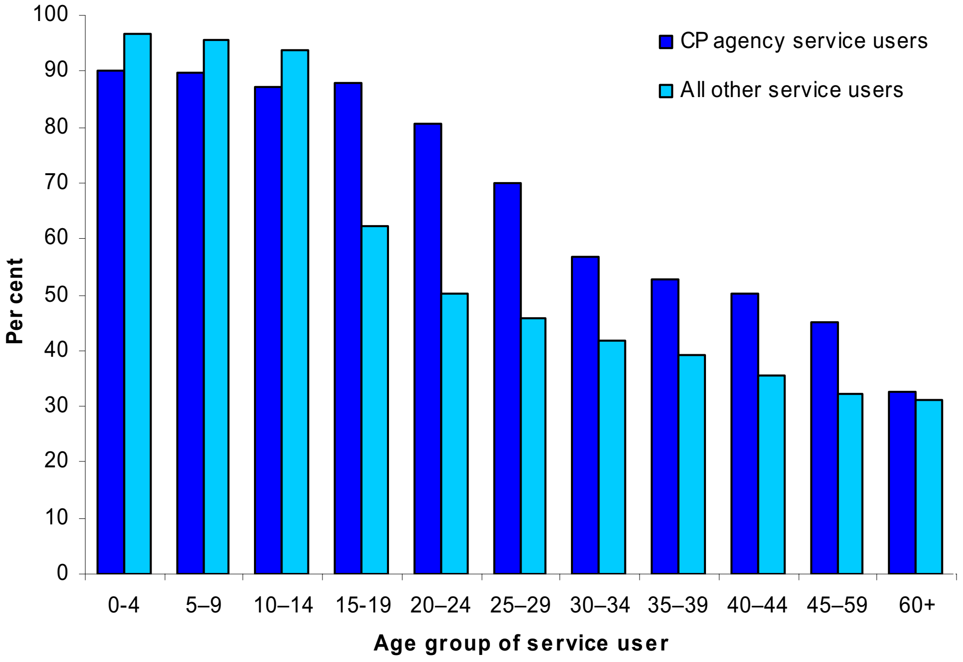
A higher proportion of CP agency service users above 14 years reported an informal carer (Figure 6.6). For service users under 14, there was relatively little difference between CP agency service users and all other service users, while the difference was most marked for users aged 15–29.

The majority of CP agency users with an informal carer reported their carer as co-resident (84%). This was the case for 67% of all other users with a carer (Table 6.5).

Table 6.5: Users with an informal carer, residency status of carer, CP agency service users and all other service users, 2003–04

	CP agency service users with an informal carer		All other service users with an informal carer	
Residency status of carer	**Number**	**%**	**Number**	**%**
Co-resident carer	5,649	84.4	47,983	66.9
Non-resident carer	337	5.0	7,104	9.9
Not stated/not collected	704	10.5	16,583	23.1
Total	**6,690**	**100.0**	**71,670**	**100.0**
% of total service users	*71.2*		*40.2*	

Source: AIHW analysis of CSTDA NMDS 2003–04



Note: Excludes 'not stated' responses.

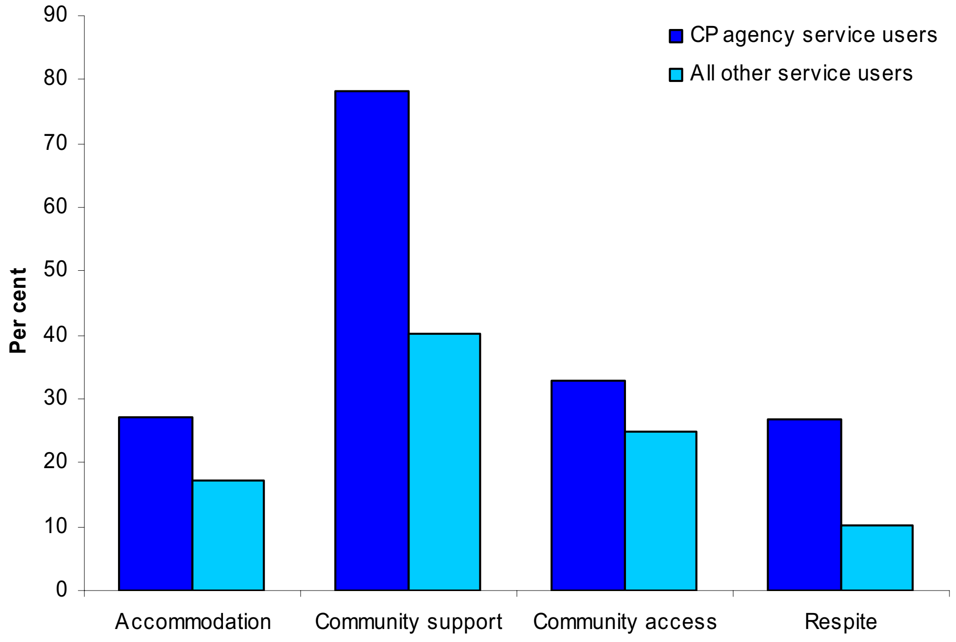
Source: Table A6.6

Figure 6.6: Presence of an informal carer by age group: comparison of CP agency service users and all other service users, 1 July 2003 – 30 June 2004 (per cent)

Service use

CSTDA-funded services are broadly grouped into five categories: accommodation support, community support, community access, respite and employment. A statistical linkage key enables the number of service users to be estimated through identification of service records which probably relate to the same person. CP agency service user data reflects usage of both CP agency services and services offered by other providers.

The most commonly used service group was community support, for both CP agency service users (78%) and all other service users (40%) (Figure 6.7). Community support services include therapy support for individuals, early childhood intervention, behaviour/specialist intervention, counselling, regional resource and support teams and case management.



Source: Table 6.6

Figure 6.7: Comparison of service group use, CP agency service users and all other service users, 1 July 2003 – 30 June 2004

Community access services were the next most commonly accessed service group, 33% of CP agency service users and 25% of all other service users. A smaller proportion of both user groups accessed accommodation services (27% of CP users and 17% of all other). As there are no CP agency services offering employment services funded under the CSTDA, employment services are not included here. However, as described above, users of CP agency services may use employment services provided by other agencies.

Focussing on users of community support services, the majority of CP agency service users were accessing therapy support for individuals (79%), compared to 22% of all other service users (Table 6.6). Interestingly, a higher proportion of all other service users accessed early childhood intervention (21%) compared to CP agency service users (8%); and 52% of all other service users accessed case management services compared to 33% of CP agency service users.

Putting these data on higher rates of use of community support services, particularly therapy, together with the data showing higher levels of need for support with self-care, mobility and communication among CP agency service users (Table 6.4), suggests a relationship between need for help with core activities and need for therapy. 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).

Group homes accounted for almost half of CP agency accommodation support users (47%) compared to 33% of all other service users accessing accommodation support. For all other users of accommodation support, 45% accessed in–home support compared with 39% of CP agency service users.

When users of respite services are considered, 66% of CP agency service users accessed centre-based respite/respite homes compared to 44% of all other service users.

Table 6.6: Service type use, CP agency service users and all other service users, 2003–04

Service type	CP agency service users	CP agency service users %	All other service users	All other service users %
Accommodation support				
Large residential/institution	247	9.7	3,692	12.0
Small residential/institution	48	1.9	916	3.0
Hostels	32	1.3	376	1.2
Group homes	1,181	46.6	10,127	33.1
Attendant care/personal care	150	5.9	1,568	5.1
In-home accommodation support	979	38.6	13,911	45.4
Alternative family placement	87	3.4	259	0.8
Other accommodation support	29	1.1	846	2.8
Total accommodation support	*2,535*	*100.0*	*30,640*	*100.0*
Per cent of all service users (within column)	*26.9*		*17.2*	
Community support				
Therapy support for individuals	5,803	79.1	15,569	21.8
Early childhood intervention	562	7.7	15,006	21.0
Behaviour/specialist intervention	587	8.0	4,391	6.1
Counselling (individual/family/group)	1,055	14.4	1,662	2.3
Regional resource and support teams	253	3.4	8,948	12.5
Case management, local coordination and development	2,447	33.3	37,229	52.1
Other community support	867	11.8	3,649	5.1
Total community support	*7,340*	*100.0*	*71,507*	*100.0*
Per cent of all service users (within column)	*78.1*		*40.1*	
Community access				
Learning and life skills development	1,931	62.4	22,890	51.4
Recreation/holiday programs	1,315	42.5	12,316	27.7
Other community access	261	8.4	11,009	24.7
Total community access	3,096	100.0	44,540	100.0
Per cent of all service users (within column)	32.9		25.0	
Respite				
Own home respite	573	22.8	1,225	6.8
Centre-based respite/respite homes	1,662	66.2	7,939	44.0
Host family respite/peer support respite	117	4.7	1,112	6.2
Flexible/combination respite	798	31.8	8,343	46.3
Other respite	43	1.7	1,479	8.2
Total respite	2,511	100.0	18,036	100.0
Per cent of all service users (within column)	26.7		10.1	
Total	**9,398**		**178,408**	

Note: Employment services are not included in this table as these services are not provided by CP agencies.

Source: AIHW analysis of CSTDA NMDS 2003–04

6.3 Diagnosis and severity: data provided by CP Australia agencies

The data for this section were provided by CP Australia agencies—the Cerebral Palsy Association WA (CPAWA), the Cerebral Palsy League of Queensland (CPLQ), Scope (Vic), Novita Children's Services (SA) and the Spastic Centre (NSW). Data from the different states are collected and recorded differently, so caution must be exercised when making comparisons between states. Nonetheless, these data supplement CSTDA data by providing information on diagnosis and measures of function for CP agency clients.

Highlights of the tables are:

- Approximately half of all people with CP in Western Australia who received CSTDA-funded services in 2000 were clients of CPAWA. Receipt of service varied with age, with 5–14 year olds most likely to receive CSTDA-funded services (Table 6.7).
- A majority of clients of CP agencies in Western Australia and Queensland in 2003–04 and South Australia in 2005–06 had cerebral palsy (as opposed to ABI and other CP-like disabilities). There was significant variation in the client population between states, as people with CP-like disabilities made up approximately 40% of the client base of CPLQ and Novita, compared to 5% in CPAWA (Table 6.8). These differences may, in part, reflect different historical influences on the client mix of CP agencies operating in different states.
- In Queensland in 2003–04, and South Australia in 2005–06, the percentage split of service users with CP and CP-like disabilities did not vary substantially, suggesting that the pattern of service usage was similar for clients with CP and CP-like disabilities. In 2003–04, CPAWA only provided individual therapy support services (Table 6.9).
- The primary disability group of CP agency clients with cerebral palsy differed substantially between states (Table 6.10). In 2003–04 all clients with CP in Western Australia and 78% of those in South Australia had physical disability recorded as their primary disability, while for clients in Queensland the most commonly recorded groups were neurological (55%) and intellectual (28%). The profile of clients with CP-like disabilities also differed between states: in Western Australia neurological was most common (52%), then autism (24%); in Queensland physical (75%) was followed by neurological (13%); in South Australia physical (57%) was followed by ABI (10%).
- Functional Independence Measure (FIM) scores are recorded for CPAWA clients and used in the process of determining therapy needs. FIM scores correlated well with CSTDA support needs data for self-care, mobility and communication (Table 6.11).
- In 2005, therapists at CPAWA delivered an average of at least 62.5 hours of services per client, including travel and indirect therapy time. The highest average service delivery was to children aged 0–4 and 5–14 (at least 125.5 hours and 75.8 hours, respectively). On average, 7.7% of time was spent on equipment-related interventions, and 13.8% on travel (Table 6.12).
- The Spastic Centre (NSW) delivered services to at least 1,292 clients in one reference week in 2003–04, with most receiving individual therapy support. Clients received an average of 0.75–1.5 hours' service in the reference week. Counselling was delivered only to clients or families of clients aged under 15 (Table 6.13).

Table 6.7: Receipt of CSTDA-funded services by all persons with a primary diagnosis of CP, WA, 2000

	CP register	CSTDA clients		CPAWA clients	
Age group	**No.**	**No.**	**% of clients on register**	**No.**	**% of clients on register**
0–4	374	101	27.0	81	21.7
5–14	725	613	84.6	322	44.4
15–24	543	283	52.1	107	19.7
25–43	803	213	26.5	100	12.5
44 and over	n.a.	99	n.a.	60	n.a.
Total	*2,445*	*1,309*		*670*	

Notes

1. The WA CP register records persons with a primary diagnosis of CP born or living in WA since 1956. Data on clients born before 1956 are not available.
2. CSTDA client data, provided to CPAWA by the Disability Services Commission, includes clients of CPAWA.

Source: CPAWA

Table 6.8: All users of CSTDA-funded services provided by CP Australia agencies (Qld, SA and WA): primary diagnosis by broad service groups, 2003–04

	Accommodation support	Community access	Respite	Community support	
				No.	**%**
CPLQ clients					
Cerebral palsy	280	109	18	735	60.8
ABI	9	7	0	15	1.7
Intellectual disability	47	49	13	86	10.4
Neurological disability	51	3	0	163	11.6
Other	7	3	0	50	3.2
Unknown	—	—	—	—	—
Missing	27	26	0	180	12.4
Total	*421*	*197*	*31*	*1,229*	*100.0*
Novita clients[(a)]					
Cerebral palsy	—	—	—	533	59.5
ABI	—	—	—	36	4.0
Other	—	—	—	327	36.5
Unknown	—	—	—	—	0.0
Missing	—	—	—	—	0.0
Total	—	—	—	*896*	*100.0*
CPAWA clients					
Cerebral palsy	—	—	—	775	94.9
ABI	—	—	—	1	0.1
Other	—	—	—	20	2.4
Unknown	—	—	—	16	2.0
Missing	—	—	—	5	0.6
Total	—	—	—	*817*	*100.0*

(a) SA data provided for the period July 2005 – April 2006.

Note: Clients may have received more than one type of service.

Source: CP League of Queensland, Novita Childrens' Services, CPAWA

Table 6.9: Community support users of CSTDA-funded services provided by CP Australia agencies (Qld, SA and WA): primary diagnosis by service type, 2003–04

	Therapy support for individuals	Early childhood intervention	Behaviour/ specialist intervention	Counselling (individual/ family/ group)	Case management, local coordination & development	Other community support
CPLQ clients						
Cerebral palsy	472	—	—	633	2	—
ABI	9	—	—	15	0	—
Intellectual disability	37	—	—	71	0	—
Neurological disability	134	—	—	139	0	—
Other	33	—	—	40	0	—
Unknown		—	—	—	—	—
Missing	108	—	—	128	0	—
Total	**793**	**—**	**—**	**1,026**	**2**	**—**
% CP	*59.5*	—	—	*61.7*	*100.0*	—
% CP-like[(a)]	*40.1*	—	—	*38.3*	—	—
Novita clients[(b)]						
Cerebral palsy	447	114	267	—	203	—
ABI	24	3	24	—	21	—
Other	247	78	147	—	126	—
Unknown	—	—	—	—	—	—
Missing	—	—	—	—	—	—
Total	**718**	**195**	**438**	**—**	**350**	**—**
% CP	*62.3*	*58.5*	*61.0*	—	*58.0*	—
% CP-like	*37.7*	*41.5*	*39.0*	—	*42.0*	—
CPAWA clients						
Cerebral palsy	775	—	—	—	—	—
ABI	1	—	—	—	—	—
Other	20	—	—	—	—	—
Unknown	16	—	—	—	—	—
Missing	5	—	—	—	—	—
Total	**817**	**—**	**—**	**—**	**—**	**—**
% CP	*94.9*	—	—	—	—	—
% CP-like	*5.1*	—	—	—	—	—

(a) CP-like includes unknown and missing diagnoses.

(b) SA data provided for the period July 2005 – April 2006.

Source: CP League of Queensland, Novita Childrens' Services, CPAWA

Table 6.10: Community support users of CSTDA-funded services provided by CP Australia agencies (Qld, SA and WA): primary diagnosis by primary disability group, 2003–04

	Cerebral palsy		CP-like disabilities[(a)]		Total[(b)]	
	No.	%	No.	%	No.	%
CPLQ clients						
Intellectual	77	27.8	42	6.9	119	13.4
Specific learning/ADD	4	1.4	—	—	4	0.5
Autism	11	4.0	9	1.5	20	2.3
Physical	—	—	459	75.2	459	51.7
ABI	13	4.7	8	1.3	21	2.4
Neurological	151	54.5	78	12.8	229	25.8
Deafblind	1	0.4	1	0.2	2	0.2
Vision	5	1.8	7	1.1	12	1.4
Hearing	5	1.8	4	0.7	9	1.0
Speech	5	1.8	1	0.2	6	0.6
Developmental delay	5	1.8	1	0.2	6	0.6
Total	*277*	*100.0*	*610*	*100.0*	*887*	*100.0*
Novita clients[(c)]						
Intellectual	13	2.4	27	7.4	40	4.5
Autism	—	—	1	0.3	1	0.1
Physical	413	77.5	206	56.7	619	69.1
ABI	13	2.4	36	9.9	49	5.5
Neurological	4	0.8	19	5.2	23	2.6
Vision	0	—	2	0.6	2	0.2
Speech	0	—	2	0.6	2	0.2
Developmental delay	1	0.2	12	3.3	13	1.5
Missing/not stated	89	16.7	58	16.0	147	16.4
Total	*533*	*100.0*	*363*	*100.0*	*896*	*100.0*
CPAWA clients						
Intellectual	—	—	1	4.8	1	0.1
Autism	—	—	5	23.8	5	0.6
Physical	775	100.0	—	—	775	94.9
ABI	—	—	1	4.8	1	0.1
Neurological	—	—	11	52.4	11	1.3
Speech	—	—	2	9.5	2	0.2
Developmental delay	—	—	1	4.8	1	0.1
Missing/not stated	—	—	—	—	21	2.6
Total	*775*	*100.0*	*21*	*100.0*	*817*	*100.0*

(a) CP-like disabilities include diagnoses classified as ABI and 'other'.

(b) Total includes unknown and missing diagnoses.

(c) SA data provided for the period July 2005 – April 2006.

Source: CP League of Queensland, Novita Childrens' Services, CPAWA

Table 6.11: Community support users of CSTDA-funded services provided by CPAWA: FIM level by life area and frequency of support or assistance needed, 2003–04 (per cent summing horizontally)

Frequency of support needed (%)	Always or unable to do	Sometimes	None but uses aids	None	Unknown	Total %	Total No.
Self-care							
FIM level 1	—	3.8	83.5	12.7	—	100.0	*79*
FIM level 2	—	60.0	40.0	—	—	100.0	*55*
FIM level 3	69.6	30.4	—	—	—	100.0	*23*
FIM level 4	96.3	3.7	—	—	—	100.0	*27*
FIM level 5	100.0	—	—	—	—	100.0	*21*
Mobility							
FIM level 1	—	1.3	41.8	57.0	—	100.0	*79*
FIM level 2	1.9	5.7	60.4	32.1	—	100.0	*53*
FIM level 3	39.1	30.4	21.7	8.7	—	100.0	*23*
FIM level 4	74.1	18.5	7.4	—	—	100.0	*27*
FIM level 5	95.2	—	—	—	4.8	100.0	*21*
Communication							
FIM level 1	—	6.3	70.9	22.8	—	100.0	*79*
FIM level 2	1.8	38.2	56.4	1.8	1.8	100.0	*55*
FIM level 3	21.7	47.8	26.1	4.3	—	100.0	*23*
FIM level 4	48.1	29.6	22.2	—	—	100.0	*27*
FIM level 5	95.2	—	—	—	4.8	100.0	*21*

Note: FIM scores were collected only for clients aged 0–19 years diagnosed with cerebral palsy and living in metropolitan areas.

Source: CPAWA

Table 6.12: Service delivery to clients of CPAWA in 2005, by age group and broad service type

	0–4	5–14	15–24	25–44	45 and over	*All ages*
Average annual service delivery per client						
			Hours			
Therapy	68.1	45.1	21.5	17.3	17.5	35.2
Equipment	3.6	4.8	3.6	6.2	6.1	4.8
Travel	19.3	11.1	3.1	3.5	5.6	8.6
Indirect therapy	34.6	14.8	11.2	4.0	7.3	13.9
Total	*125.5*	*75.8*	*39.4*	*31.1*	*36.5*	*62.5*
			Per cent			
Therapy	54.2	59.5	54.6	55.7	47.9	56.3
Equipment	2.8	6.3	9.2	20.1	16.8	7.7
Travel	15.4	14.7	7.9	11.3	15.2	13.8
Indirect therapy	27.5	19.5	28.4	12.9	20.1	22.3
Total	*100.0*	*100.0*	*100.0*	*100.0*	*100.0*	*100.0*
Total annual services delivered to all clients						
Hours	13,429	21,897	6,113	4,292	3,721	*49,452*
Per cent of total	27.2	44.3	12.4	8.7	7.5	*100.0*

Notes

1. These data underestimate the total service hours delivered to clients of CPAWA in 2005 due to incomplete recording by some therapists.
2. Equipment interventions include time spent by therapists on prescription and fitting of aids.
3. Indirect therapy includes team meetings and liaison between therapists and other professionals (e.g. teachers, health care professionals).

Source: CPAWA.

Table 6.13: Community support users of CSTDA-funded services provided by the Spastic Centre (NSW): hours received by service type and age group, 2003–04

Age group	Mean hours in reference week	Mean number of service users with hours received in reference week
Therapy support for individuals		
0–4	0.92	362
5–14	1.09	540
15–24	0.80	117
25–44	0.74	162
45 and over	0.75	111
Total		*1,292*
Counselling (individual/ family/ group)		
0–4	1.03	7
5–14	1.49	18
15–24	—	—
25–44	—	—
45 and over	—	—
Total		*25*
Other community support		
0–4	1.13	1
5–14	1.17	12
15–24	1.38	17
25–44	1.47	30
45 and over	1.50	29
Total		*89*

Notes

1. Clients may have received more than one service type during the reference week.
2. No data available for early childhood intervention, behavioural/specialist intervention, regional resource and support teams, and case management, local coordination and development service types.

Source: The Spastic Centre, NSW

6.4 Unmet need for therapy and equipment: data from some CP Australia agencies

This section contains data collected by CP Australia agencies that relate to unmet need for therapy and/or equipment among their clients. Again, caution should be exercised in comparing between states as the waiting list data relate to different time periods, different recording methods are used, and different systems for managing demand operate in each state.

Highlights of the tables are:

- Based on June 2006 data, clients of CPAWA waited an average of 2–3 months from referral to acceptance into therapy services. The maximum wait was 6 months (Table 6.14).
- In May 2005, the expected waiting time for therapy among clients of The Spastic Centre (NSW) was 5 to 16 months. The wait was longest for children in rural and remote areas (Table 6.15).
- One hundred and fifty-nine applications for equipment made by clients of CPAWA were waiting for funding from the Community Aids and Equipment Program in June 2006, with an average cost per item of $1,602. The total cost of equipment on this waiting list was approximately $255,000. An additional 21 items were waiting for funding by Equipment for Living Grants in June 2006. The cost of items on this waiting list was approximately $56,000 (Table 6.16).
- In May 2006, clients of The Spastic Centre were waiting for funding for 378 equipment items. Applications were most frequent in the 5–14 years age group (Table 6.17).
- Six hundred and fifty-two applications for equipment funding were made to the Spastic Centre in 2005–06 (to 12 May 2006); 42% had their applications approved in this period. The average waiting time for funded items was 18 weeks, with 23% of requests taking 6 months or more before funding was approved. Over 60% of items that had yet to be approved by May 2006 had been on the list for more than 6 months. The average waiting time for both funded and outstanding items was highest for clients aged 15–24. (Table 6.18).
- Funding approval rates and waiting time for equipment in NSW in 2005–06 varied according to geographical region. The southern and western area of Sydney had the lowest approval rate and highest percentage of items taking for 6 months or more for funding to be secured (Table 6.19).
- About 75% of applications for equipment recorded by the Spastic Centre, in 2005–06, were for items costing less than $5,000. Less than 30% of items costing $5,000 or more were approved for funding, compared to more than 50% of items costing less than $1,000 (Table 6.20).
- In August 2006, there were 241 outstanding requests for funding from the Independent Living Equipment Program made by clients of Novita Children's Services, SA, worth about $661,000 in total. Communication devices were the most expensive requested items, on average costing almost $10,000 each (Table 6.21).

Table 6.14: Waiting times from referral to acceptance into CPAWA therapy services by age and geographical region, June 2006

Age group	Program	No. waiting	Average waiting time (months)	Maximum waiting time (months)
Metropolitan areas				
0–4	Early Intervention Program	11	2	6
5–14	Early Intervention Program/School Age intervention Program	5	2	6
15–18	School Age intervention Program	0	2	3
19 and over	Independent Living Program	10	3	6
Rural/remote areas				
0–4	Country Resource Program	3	3	6
5–14	Country Resource Program	3	3	6
15–18	Country Resource Program	0	3	3
19 and over	n.a.[(a)]	n.a.	n.a.	n.a.

(a) CPAWA does not provide a rural/remote service to clients aged 19 and over.

Source: CPAWA

Table 6.15: Waiting times for therapy by service provider, NSW, May 2005

Region	Number on waiting list	Expected waiting time (months)
Metro North and East Sydney Children's Services	124	10
Metro South and West Sydney Children's Services	191	11
Regional Newcastle Children's Services	41	3
Rural and Remote NSW Children's Services	333	16
Metro Sydney Adult Services	64	5
Specialist state-wide technology & seating services	28	5

Source: The Spastic Centre, NSW

Table 6.16: CPAWA clients on equipment waiting lists, June 2006

Age group	No. waiting	Average cost	Total cost	Average wait (weeks)
Community Aids and Equipment Program				
0–4	28	$1,169	$32,742	9.1
5–14	43	$1,293	$55,585	5.6
15–24	29	$1,739	$50,445	6.0
25–44	29	$2,472	$71,692	3.9
45 and over	30	$1,477	$44,317	4.6
Total	**159**	**$1,602**	**$254,781**	**5.8**
Equipment for Living grants				
0–4	0	—	—	n.a.
5–14	7	$2,183	$15,279	n.a.
15–24	5	$3,135	$15,677	n.a.
25–44	3	$3,477	$10,432	n.a.
45 and over	6	$2,458	$14,749	n.a.
Total	**21**	**$2,673**	**$56,137**	n.a.

Notes

1. Waiting time was calculated as the period between the submission of an application and the date of analysis (June 2006). These figures therefore represent the minimum average waiting time, as funding had not yet been secured.
2. Equipment for Living grants are for equipment that is not funded by the Community Aids and Equipment Program.
3. Information on waiting times not available for Equipment for Living grants.

Source: CPAWA.

Table 6.17: The Spastic Centre Equipment Register, equipment applications waiting for funding by applicant age, 12 May 2006

Age group	No. waiting	Average cost per item	Total cost for group
0–4	53	$3,289	$174,341
5–14	210	$4,436	$931,455
15–24	44	$5,221	$229,709
25–44	49	$4,532	$222,082
45 and over	22	$4,023	$88,507
Total	**378**	**$4,355**	**$1,646,096**

Note: The total cost of unfunded requests includes applications outstanding from 2004–05, worth $401,933.

Source: The Spastic Centre, NSW.

Table 6.18: The Spastic Centre Equipment Register, applications and waiting time by age group, June 2004 – May 2006

			Funded items		Outstanding items	
Age group	**No. applications**	**% approvals**	**Average wait (weeks)**	**% waiting >6 months**	**Average wait (weeks)**	**% waiting >6 months**
0–4	102	48.0	13	20.4	27	49.1
5–14	389	46.0	18	22.9	33	59.0
15–24	72	38.9	29	35.7	57	79.5
25–44	59	16.9	17	10.0	50	75.5
45 and over	30	26.7	16	12.5	46	59.1
Total	**652**	**42.0**	**18**	**23.0**	**38**	**62.2**

Notes

1. The table shows the results of all applications made during the 2004–05 financial year, as well as applications in 2005–06 to 12 May 2006.
2. Waiting time was calculated as the period between the submission of an application and funding approval or, for outstanding applications, the date of analysis. The figures for outstanding items therefore represent minimum average waiting times.

Source: The Spastic Centre, NSW.

Table 6.19: The Spastic Centre Equipment Register, applications and waiting times by geographical region, June 2004 – May 2006

			Funded items		Outstanding items	
Region	**No. applications**	**% approvals**	**Average wait (weeks)**	**% waiting >6 months**	**Average wait (weeks)**	**% waiting >6 months**
ACT	3	33.3	20	0.0	28	100.0
Hunter and Central Coast	79	54.4	14	25.6	29	50.0
North and east Sydney	242	54.1	22	23.7	31	58.6
Rural NSW	139	35.3	38	20.4	38	64.4
South and west Sydney	186	26.3	16	22.4	41	67.2
TASC	3	33.3	<1	0.0	0	0.0
Total	**652**	**42.0**	**18**	**23.0**	**34**	**62.0**

Notes

1. The table shows the results of all applications made during the 2004–05 financial year, as well as applications in 2005–06 to 12 May 2006.
2. Waiting time was calculated as the period between the submission of an application and funding approval or, for outstanding applications, the date of analysis. The figures for outstanding items therefore represent minimum average waiting times.
3. TASC (Technology solutions for computer access, seating and communication) is a state-wide consultancy service dedicated to meeting the technology, mobility and communication equipment needs of people with disabilities in NSW.

Source: The Spastic Centre, NSW.

Table 6.20: The Spastic Centre Equipment Register, applications by cost group, June 2004 – May 2006

	Funded items		Outstanding items		Total	
Cost group	**No.**	**%**	**No.**	**%**	**No.**	**%**
Less than $500	72	52.2	66	47.8	138	21.1
$501–$1,000	69	59.5	47	40.5	116	17.8
$1,001–$5,000	87	36.6	151	63.4	238	36.6
$5,001–$10,000	30	28.8	74	71.2	104	15.9
$10,000–$20,000	15	28.8	37	71.2	52	8.0
> $20,000	1	25.0	3	75.0	4	0.6
Total	**274**	**42.0**	**378**	**58.0**	**652**	**100.0**

Note: The table shows the results of all applications made during the 2004–05 financial year, as well as applications in 2005–06 to 12 May 2006.

Source: The Spastic Centre, NSW.

Table 6.21: Cost of unfunded requests to the Independent Living Equipment Program (SA) by equipment category, August 2006

Equipment Category	No. unfunded requests	No. classed as urgent	Total cost	Average cost
Communication Devices	4	—	$38,293	$9,573
Wheelchairs	51	9	$304,583	$5,972
Home modifications	20	4	$93,392	$4,670
Beds & chairs	15	4	$41,180	$2,745
Hoists & slings	15	3	$40,395	$2,693
Mobility aids	34	7	$51,727	$1,521
Daily living equipment	76	8	$74,199	$976
Equipment modifications	26	3	$17,128	$659
Total	**241**	**38**	**$660,897**	**$2,742**

Notes

1. All applications made by clients aged 0–18 years.
2. Applications represented in the table were made between June 2006 and August 2006

Source: Novita Children's Services, SA.

6.5 An ideal equipment scheme?

Throughout the course of this project, professionals and clients alike commented that the extent of unmet need for equipment is not solely related to the amount of funding provided to government equipment schemes. A range of factors—related to administration, availability, expertise and the physical environment—add to clients' unmet equipment needs (discussed in detail in Section 5.7). During some of the focus groups clients were asked to describe what they would consider to be an ideal equipment scheme. Some of the common themes that emerged were greater flexibility (such as allowing clients to purchase the item that most suited their individual circumstances, rather than the least expensive), broader inclusion criteria (including funding some everyday household items that facilitate participation, not solely equipment specially designed for people with disabilities), and more opportunities to borrow and trial equipment.

The Rehabilitation Appliances Program (RAP), operated by the Department of Veterans' Affairs (DVA), is a national scheme that provides aids to eligible war veterans and their dependents. Some focus group participants pointed to this scheme as a desirable model, and expressed the view that it is one of the best schemes in the country in terms of meeting the equipment needs of people with a disability in the client group that it serves. While clients of the RAP differ considerably from the population under consideration here (for example, most RAP clients are aged over 60, compared to only 4% of CP agency clients), many of the types of equipment commonly used by people with CP and like disabilities are covered by the program, albeit to differing extents. Table 6.21 compares some broad equipment categories between the RAP and a program accessed by CP agency clients in NSW, the Program of Appliances for Disabled People.

Table 6.22: Estimated expenditure on some broad equipment categories in the Rehabilitation Appliances Program and the NSW Program of Appliances for Disabled People, 2005–06

	RAP 2005–06 expenditure		PADP 2004–05 expenditure	
Equipment category	**$ ('000)**	**% of total[c]**	**$ ('000)**	**% of total[c]**
Wheelchairs, scooters and other mobility aids	$8,780	10.5	$10,490	48.1
Continence aids	$12,100	14.5	$4,450	20.4
Beds and seating	$13,690	16.4	$1,980	9.1
Self-care aids[a]	$6,420	7.7	$1,130	5.2
Maintenance	$180	0.2	$1,070	4.9
Prostheses	$1,230	1.5	$110	0.5
Communication	—[b]	—[b]	$260	1.2
Home and vehicle modifications	$13,950	17.0	—[b]	—[b]
Personal Response System	$7,950	9.5	—[b]	—[b]
Respiratory assistance	$7,150	8.6	—[b]	—[b]
Total budget	*$83,500*	*100.0*	*$21,800*	*100.0*

(a) Self-care aids include aids to assist with toileting, bathing, grooming, dressing, cooking and eating.

(b) Not listed separately.

(c) Columns do not add to 100% as equipment categories listed are not exhaustive.

Source: PriceWaterhouseCoopers, 2005; Department of Veterans' Affairs

The total expenditure of the RAP in 2005–06 was $83.5m. While detailed service usage statistics were not available, DVA estimates that between 80,000 and 100,000 people are funded under the scheme annually (personal communication with Tim McNamara, Senior Project Officer, Rehabilitation Appliances Program, DVA). This equates to an average expenditure of $835–$1,043 per client per year. However, CP agency figures from two states show that their clients received an average of $1,800 or more in equipment expenditure in 2005–06.[11] Further, equipment waiting list data presented above suggest that the average cost of aids for which clients of CP agencies seek funding is substantially higher than $1,043 (Tables 6.16, 6.17, and 6.21). This high cost of 'average' equipment needs is not surprising, as people with CP and like disabilities have higher support needs (Figure 6.5) and use more services (Figure 6.7) than the general population of CSTDA-funded service users. These may be taken as an indicator of more severe disability, which the archetypal cases highlight as being associated with high cost equipment needs (Section 8.7).

Rather than using the RAP as a basis for estimating the cost of an equivalent ideal equipment scheme, some aspects of the nature of this program may be drawn on in considering how equipment schemes can better meet the needs of people with CP and like disabilities. Key features of such an ideal equipment scheme, reflecting the strengths of the RAP as well as issues most commonly raised in focus groups, are:

- inclusion of home and vehicle modifications
- inclusion of freight costs in funding grants
- funding to cover maintenance and repair in a timely manner
- the ability to modify, recycle and pool items between different jurisdictions
- allowance for more than one of a 'type of equipment', such as both manual and electric wheelchair to suit different needs
- a greater number of equipment options to choose from
- more funding for equipment for adults
- funding for 'everyday' items that facilitate clients' functioning and independence such as microwaves
- allocation of funding to different equipment categories to give greater consideration functioning and participation (for example, therapists commented that funding for mobility-related aids seems more readily available than for communication devices)
- greater consistency between jurisdictions in regulations governing the scheme
- efficient application process, especially for clients who need to make multiple applications over a period of time
- greater allowance for the cost of disability in determining eligibility thresholds
- the ability to make applications in anticipation of future needs.

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[11] Clients of Novita Children's Services received $2,660,000 from the ILEP, Lions, and agency funds, in addition to contributions from Variety. Averaged over the 1,433 agency clients this equates to more than $1,843 per client. Clients of CPAWA received approximately $1,475,000 from CAEP, Equipment for Living Grants, Disability Services Commission grants and agency fundraising—$1,749 per client.

6.6 Summary

As stated at the start of this chapter, CSTDA and CP agency data are used and referred to in several other chapters of this report, and are important in developing the estimates of the cost of unmet need for equipment and therapy presented in Chapter 9. The key messages from the data presented in this chapter are summarised here.

CSTDA data from 2003–04 show that, compared with all other CSTDA service users, CP agency service users were younger and had more complex disabilities and higher support needs. They were more likely to use community support services, especially therapy. In particular:

- CP agency service users had a younger age profile than all other CSTDA service users, with 58% aged under 20 years.
- Physical disability (56%) was the most commonly recorded primary disability group CP agency service users; then intellectual (28%). For all other service users intellectual disability (52%) was most common, then physical (17%). ABI was the primary disability for 4% of CP agency service users and for 4% of all other service users.
- Sensory/speech was recorded as a significant disability among 46% of CP agency service users, although only 2% had sensory/speech recorded as their primary disability group.
- Multiple disability groups were reported for 68% of CP agency service users, compared with 37% of all other service users.
- Over half of all CP agency service users needed help in all three core activity areas—self-care, mobility and communication—compared with 26% of all other service users.
- Seventy-eight per cent of CP agency service users used community support services, compared with 40% of all other service users.
- Of CP agency service users who accessed community support services, 79% used therapy, 33% case management, 14% counselling, 8% behaviour/specialist intervention and 8% early childhood intervention.

CP agency data supplement the picture provided by the CSTDA data:

- A majority of clients of CP agencies in three states had cerebral palsy, rather than ABI or other CP-like disabilities. People with CP-like disabilities made up approximately 40% of clients in Queensland and South Australia, and 5% in Western Australia.
- In Western Australia in 2000, about half of all people with CP on the Cerebral Palsy Register who received CSTDA-funded services were clients of CP agencies. In 2005, CPAWA service users received, on average, 62.5 hours of client attributable service time over the year, but some clients received much more (for instance, clients aged 0–4 years old received an average of at least 125.5 hours).

Equipment waiting list data for three states indicate that, at a given point in time, there are significant numbers of people waiting for equipment; data on average waiting times for one state suggest that waits of more than 6 months are common. Equipment waiting list data provided by CP agencies are used in Section 9.4 as a basis for providing an indication of the possible cost of meeting unmet need for equipment nationally.